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Societal participation of individuals aged 55–64 years with and without chronic disease

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Background: It is unknown whether an increase in societal participation is important for individuals with a chronic disease. This study explores whether having paid work, volunteer activities or informal care giving differs for individuals with a chronic disease and those without. **Methods:** Respondents ($n = 1779$) aged 55–64 years who participated in the Longitudinal Ageing Study Amsterdam in 2002/2003 or 2012/2013 were included. We tested differences in (combinations of) performing paid work, volunteer activities or informal care giving between participants with and without a chronic disease by regression analyses, while taking into account sociodemographic confounders and effect modification by year. **Results:** Having a chronic disease was associated with having paid work in 2002/2003 (OR: 0.5; 95% CI: 0.4–0.7), but not in 2012/2013 (OR: 0.7; 95% CI: 0.4–1.1). Work participation of participants with (OR: 1.5; 95% CI: 1.0–2.2) and without a chronic disease (OR: 2.3; 95% CI: 1.3–3.9) increased in 2012/2013. Participants with a chronic disease are more likely to participate in volunteer activities than paid work. No statistically significant associations were found between having a chronic disease and informal care giving. **Conclusion:** Participation in paid work differs between individuals aged 55–64 years with a chronic disease and those without, but participation in informal care giving did not. Individuals with a chronic disease are more likely to participate in volunteer activities than paid work. Future research should focus on differences in societal participation within heterogeneous group of individuals with a chronic disease, since differences may be present in subgroups with specific chronic diseases.

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Introduction

A decline in fertility rates and an increase in longevity has led to a growth in the number and proportion of individuals aged 55 years and over in populations in Europe. Nowadays, these individuals are significantly more involved in society than in years past.¹ Work participation has increased, as well as participation in volunteer activities and informal care giving.^{2,3}

Societal participation refers to performing activities that are of benefit to individuals, groups or society as a whole.⁴ In the present study, societal participation is defined as participation in paid work, volunteer activities and informal care giving.

Previous studies provide two explanations for the increase in societal participation. First, higher education and better health have led to an increase in societal participation of individuals of 55 years and older compared to older birth cohorts.^{1,5-7} Second, due to population ageing, social security systems and health care systems need reformation to keep up with increasing costs.⁸ Therefore, governments have started to consider policies aimed at promoting participation in paid and unpaid work.⁷

Policy measures to increase labour force participation of European individuals aged 55 years and older have included an increase in official retirement age and the abolishment of early retirement schemes. Both measures have resulted in an increase in the average retirement age in Europe.⁹⁻¹¹ For example, the average retirement age in the Netherlands increased from 60.7 years in 2002 to 63.5 years in 2012.¹²

Healthcare reforms have led to an increase in informal care giving in European countries.⁸ One of these reforms was the introduction of the Social Support Act in the Netherlands in 2007.¹³ The aim of this law was to enhance home-based care delivered by significant others instead of institutionalised care,¹³ and this has led to an increase in informal care giving.¹⁴ If necessary, individuals provide informal care without respect to motivation, skills or caregiver health.¹⁵ It can be argued that when participation in paid work and informal care giving increases, participation in volunteer activities decreases due to the finite amount of time and energy an individual has available.¹⁶

The prevalence of chronic disease has increased over the last decade in Europe.¹⁷ In 2011, while 31.8% of the working age population of the European Union had a chronic disease,¹⁸ more than half the individuals aged 55 years and older had a chronic disease.² Individuals with a chronic disease may experience limitations in physical or mental functioning and find it more difficult to participate in paid work, informal care giving or volunteer activities.^{16,19,20}

The increase of the official retirement age, the abolishment of early retirement schemes and the introduction of the Social Support Act have probably increased societal participation in the Netherlands during recent years. An increase in societal participation might be beneficial for well-being, since participation gives individuals a sense of having a meaningful role in society.^{21,22}

This study aims to provide insight into the societal participation of individuals aged 55–64 years with and without a chronic disease in 2002/2003 and 2012/2013. This leads to the following research questions:

- (1) Does participation in paid work, volunteer activities and informal care giving differ between individuals with and without a chronic disease?
- (2) Are there differences in participation in paid work, volunteer activities and informal care giving between individuals with and without a chronic disease in 2002/2003 as compared to 2012/2013?
- (3) Within the group engaging in societal participation, are there differences in participation between individuals with and without a chronic disease in paid work, volunteer activities, informal care giving or combinations of having paid work, volunteer activities or informal care giving?

Methods

Study population

The study population was selected from the Longitudinal Aging Study Amsterdam (LASA). LASA is an ongoing multidisciplinary longitudinal study with a sample of participants aged 55–85 years from three nationally representative regions in the Netherlands.²³ LASA started in 1992/1993 with recruitment from municipality registries. In 2002/2003 and 2012/2013, an additional sample of respondents aged 55–65 years was recruited from the same sampling frame.^{23,24} LASA's aim is to study the determinants, trajectories and consequences of physical, cognitive, emotional and social functioning in relation to ageing.^{23,24}

Inclusion and exclusion criteria

Figure 1 shows the flowchart of the study sample. Participants aged 55–64 years in 2002/2003 or in 2012/2013 were included ($N = 1779$). To enable a comparison of the three forms of societal participation, we focused on the group eligible to participate in paid work. The age limit of 64 years was chosen because the statutory retirement age in

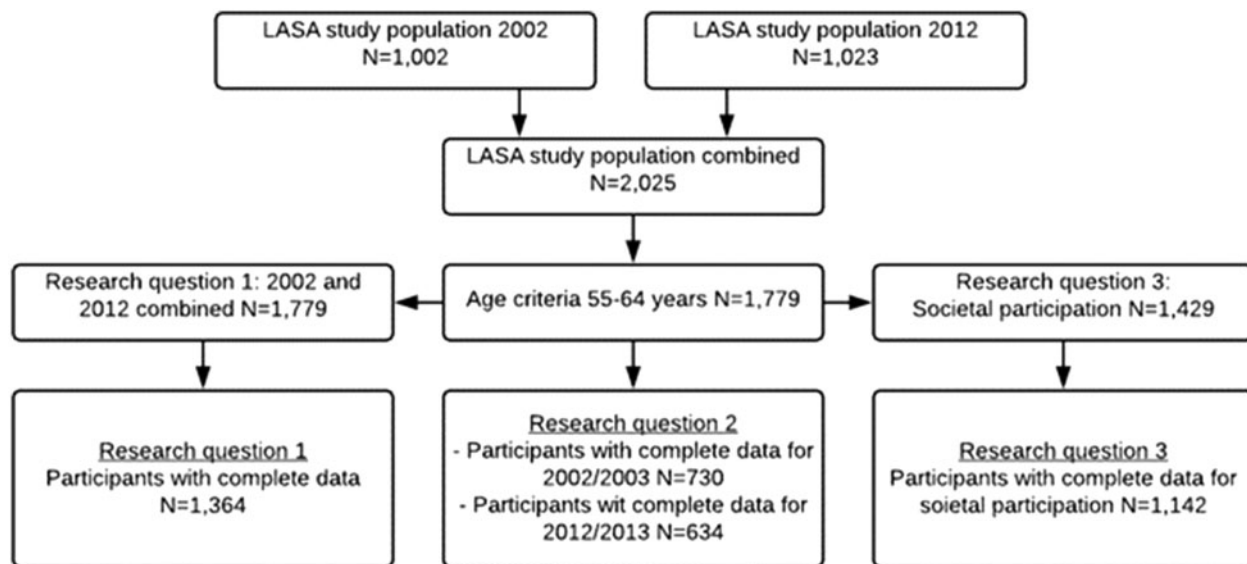


Figure 1 Flow diagram

2002/2003 in the Netherlands was 65 years. Participants with missing values were removed from analyses. The sample for the first research question consisted of 1364 participants (415 participants' data was missing). Research question two focused on the year 2002/2003 and 2012/2013 separately, meaning that 730 participants were included for 2002/2003 and 634 participants were included for 2012/2013. For the third research question, only respondents who had participated in at least one form of societal participation in 2002/2003 or 2012/2013 were selected ($n = 1429$). Only 1142 participants had complete cases (287 participants' data was missing).

Outcome: societal participation

Paid job status was defined by a person indicating they had a paid job (full-time or part-time) at the time of the interview. Volunteer activities were measured by a binary variable specifying whether the respondent was involved in executive boards and/or conducted chores in voluntary associations. Informal care giving was defined as providing personal care or help with domestic tasks.

For the first and second research question, the reference group in the analyses consisted of participants who did not participate in paid work, volunteer activities or informal care giving. For the third research question, only participation in paid work was used as a reference group.

Main independent variable: having a chronic disease

Participants were asked to indicate whether they had the following diseases: chronic non-specific lung disease, heart disease, peripheral artery disease, diabetes mellitus, stroke, osteoarthritis, rheumatoid arthritis, cancer, incontinence or other disease. In addition, we added a group with depression based on a score of at least 16 points on the Center for Epidemiological Studies Depression scale (CES-D). This questionnaire has been shown to have good criterion validity in a general population.²⁵ A dichotomous variable specified whether a participant had one or more of these chronic diseases or had none.

Confounders

Gender (female; male), age (years), education, physical activity and household income were all included as confounders in the analyses. Education was categorized into low (elementary not completed, elementary, lower vocational), intermediate (general intermediate, intermediate vocational, general secondary) and high (higher vocational, college, university). Physical activity was addressed by asking how often and how long in the past 2 weeks the respondent engaged in the following activities: walking outdoors, bicycling, gardening, light household, heavy household and two sports activities. The amount of physical activity was measured by the intensity weighted physical activity. The Metabolic Equivalent (MET) score of each activity was multiplied by the frequency and duration of the activity. Participants' physical activity scores were summed to calculate the intensity weighted total physical activity.^{26,27} Financial situation was measured by net monthly household income. Income was dichotomized into less than or equal to and more than median income. For participants living with a partner, household income was multiplied by 0.7 to enable direct comparisons with one-person households.

Analyses

Descriptive statistics provided the percent of participants involved in paid work, volunteer activities or informal care giving for participants with and without a chronic disease. Descriptive statistics are also provided for the years 2002/2003 and 2012/2013.

First, the correlation coefficients between variables were computed. If the correlations were above 0.70, the strongest variable was selected. In the second step, logistic regressions with

performing paid work, volunteer activities or informal care giving as outcomes and with having a chronic disease as main independent variable (crude analysis) were performed. In the next step, models were adjusted for sociodemographic confounders. Finally, the models were adjusted for other forms of societal participation.

To answer the second research question, crude and adjusted logistic regression analyses were presented separately for having a chronic disease and year. A multiplicative and additive interaction term between cohort membership (2002/2003 or 2012/2013) and chronic disease (yes/no) was included in the analysis.²⁸ Multiplicative effect modification was demonstrated if the interaction term was significant at the 10% level. Additive effect modification was assessed by calculating the Relative Excess Risk due to Interaction (RERI). The RERI was calculated with Odds Ratios as estimates of relative risks, $RERI = OR(\text{chronic disease} + \text{year } 2012/2013) - OR(\text{chronic disease} + \text{year } 2002/2003) - OR(\text{no chronic disease} + \text{year } 2012/2013) + 1$. If RERI is not equal to zero, an additive effect modification is present.²⁹ The 95% confidence interval was calculated using the delta method in Excel.³⁰ Multiplicative interaction terms for gender and chronic disease were tested for informal care giving. None were significant.

For the third research question, an unordered multinomial regression analysis was performed. The years 2002/2003 and 2012/2013 were combined in case the multiplicative interaction term was not statistically significant.

Results

In 2002/2003, 71% of the participants had a chronic disease compared to 74% in 2012/2013. In 2002/2003, 45% of the participants had paid work, compared to 66% in 2012/2013. In 2002/2003, 38% of the participants engaged in volunteer activities and 36% in 2012/2013. Approximately 35% of the participants provided informal care in 2002/2003 compared to 29% in 2012/2013. Table 1 shows the characteristics of the total study population.

Participants with a chronic disease were less likely to have paid work compared to participants without a chronic disease (OR: 0.64; 95%CI: 0.48–0.85). No statistically significant differences were found for volunteer activities or informal care giving (table 2).

In the final model, having a chronic disease was negatively associated with having paid work in 2002/2003 (OR: 0.51; 95%CI: 0.35–0.74), but not in 2012/2013 (table 3). Additional analyses showed that the association of having a chronic disease with having paid work disappeared in 2012/2013 due to an increase in educational levels (results not shown).

Compared to the group without chronic disease in 2002/2003, the odds for having paid work was higher both in the group with (OR: 1.52; 95%CI: 1.04–2.24) and without chronic disease (OR: 2.29; 95%CI: 1.35–3.87) in 2012/2013. The additive and multiplicative interaction terms were not statistically significant.

Tables 1 and 2 of the supplementary file show that no statistically significant associations were found for having a chronic disease on volunteer activities (OR: 0.81; 95%CI: 0.61–1.08 and OR: 0.87; 95%CI: 0.63–1.20) or informal care giving (OR: 0.89; 95%CI: 0.62–1.27 and OR: 1.09; 95%CI: 0.71–1.68) in both year cohorts. The interaction terms were not statistically significant.

Table 3 of the supplementary file shows the results of the combinations of the three forms of societal participation. We found a positive significant association for participants with chronic disease for volunteer activities (OR: 1.78; 95%CI: 1.08–2.94) compared to having paid work.

Discussion

This study investigated differences in societal participation between individuals aged 55–64 years with and without a chronic disease in paid work, volunteer activities and informal care giving in 2 year

Table 1 Descriptive statistics for 2002/2003 and 2012/2013 separately and descriptive statistics for paid work, informal care giving and volunteer activities for 2002/2003 and 2012/2013 combined

		Total 2002/2003 ^a N = 895		Total 2012/2013 ^a N = 884		Paid work (2002/2003 and 2012/2013) N = 986		Volunteer activities (2002/2003 and 2012/2013) N = 652		Informal care (2002/2003 and 2012/2013) N = 482	
		N (%)	Mean (SD)	N (%)	Mean (SD)	N (%)	Mean (SD)	N (%)	Mean (SD)	N (%)	Mean (SD)
Chronic disease	Yes	631 (70.5)	–	657 (74.3)	–	663 (67.4)	–	464 (71.3)	–	360 (74.7)	–
	No	260 (29.1)	–	224 (25.3)	–	321 (32.6)	–	187 (28.7)	–	122 (25.3)	–
Gender	Female	467 (52.2)	–	458 (51.8)	–	424 (43.0)	–	324 (49.7)	–	319 (66.2)	–
Age	Years	–	59.0 (2.6)	–	59.2 (2.6)	–	58.3 (2.4)	–	59.2 (2.6)	–	59.1 (2.7)
Education	Low	373 (41.7)	–	233 (26.4)	–	261 (26.5)	–	203 (31.1)	–	170 (35.3)	–
	Medium	328 (36.6)	–	372 (42.1)	–	383 (38.85)	–	256 (39.3)	–	205 (42.5)	–
	High	194 (21.7)	–	279 (31.6)	–	342 (34.7)	–	193 (29.6)	–	107 (22.2)	–
Physical activity ^b	–	–	9.0 (6.7)	–	9.1 (6.8)	–	8.4 (6.6)	–	9.6 (6.4)	–	9.7 (6.0)
Income	≥Median	319 (38.6)	–	427 (52.1)	–	559 (59.6)	–	266 (43.5)	–	173 (38.8)	–
Cohort membership	2012/2013	895 (100.0)	–	884 (100.0)	–	585 (59.3)	–	316 (48.5)	–	196 (40.7)	–
Paid work	Yes	401 (45.0)	–	585 (66.2)	–	–	–	334 (51.3)	–	229 (47.6)	–
Volunteer activities	Yes	336 (37.8)	–	316 (35.8)	–	334 (34.0)	–	–	–	223 (46.5)	–
Informal care giving	Yes	286 (34.9)	–	196 (29.2)	–	229 (27.9)	–	223 (39.5)	–	–	–

a: Total 2002/2003 and total 2012/2013 do not add up to total in paid work, informal care and volunteer activities.

b: Intensity weighted.

Table 2 Logistic regressions for the effect of having a chronic disease on having paid work, volunteer activities and giving informal care for the years 2002/2003 and 2012/2013 combined (N = 1364)

	Paid work		Volunteer activities		Informal care	
	OR	95% CI	OR	95% CI	OR	95% CI
Crude	0.54	0.43–0.67	0.89	0.72–1.11	1.18	0.92–1.51
Adjusted for socioeconomic factors	0.66	0.51–0.86	0.89	0.71–1.12	0.96	0.74–1.26
Final ^a	0.64	0.48–0.85	0.83	0.64–1.07	0.95	0.72–1.25

a: The models for paid work, volunteer activities and informal care were adjusted for gender, age, education, physical activity, income and societal participation.

Table 3 Modification of the associations of having a chronic disease on paid work by year (Years combined N = 1364; 2002 N = 730; 2012 N = 634)

Crude	Having no chronic disease		Having a chronic disease		Having a chronic disease within year	
	OR	95% CI	OR	95% CI	OR	95% CI
2002/2003	1.00	–	0.43	0.32–0.58	0.43	0.32–0.58
2012/2013	1.94	1.32–2.86	1.19	0.89–1.60	0.62	0.44–0.86
Final ^a						
2002/2003	1.00	–	0.52	0.36–0.75	0.51	0.35–0.74
2012/2013	2.29	1.35–3.87	1.52	1.04–2.24	0.65	0.40–1.07

Measure of effect modification on additive scale for final model: RERI (95% CI) = –0.28 (–0.37–0.81).

Measure of effect modification on multiplicative scale for final model: OR (90% CI) = 1.29 (0.78–2.14).

a: Final model was adjusted for gender, age, education, physical activity, income, volunteer activities and providing informal care.

cohorts. We found that participants with a chronic disease were less likely to participate in paid work compared to participants without a chronic disease in 2002/2003. However, the association did not remain statistically significant in 2012/2013. A second main finding was that all participants were more likely to participate in paid work in 2012/2013 compared to 2002/2003. Moreover, within the group who participated in society, individuals with a chronic disease were more likely to participate in volunteer activities than paid work. We did not find differences in informal care giving for the two groups.

Participation in paid work

Previous research has shown that individuals with a chronic disease are less often involved in paid work.²⁰ Our findings are in line with

this. The difference in participation in paid work may be due to barriers such as health problems or functional limitations.¹⁹ Furthermore, the increase in participants' educational levels between 2002/2003 and 2012/2013 may explain why having a chronic disease no longer influences having paid work in 2012/2013.

Our results indicated a time effect for participation in paid work. Both groups with and without a chronic disease in 2012/2013 were more likely to have paid work than individuals without a chronic disease in 2002/2003. This is likely due to the abolishment of early retirement schemes in Europe that has led to an increase in the average retirement age, and thus more work participation among individuals aged 55 years and older.³¹ After 2005, it has become more difficult to be granted a work disability pension.³² Therefore, individuals with a chronic disease might have continued participation in paid work more often after 2005.

Participation in volunteer activities

It was shown that having a chronic disease was not associated with participation in volunteer activities in this study. Our finding is in line with previous research that showed that individuals with a chronic disease participate less in society if they have poor self-assessed health or experience functional limitations.^{1–3,20} Since the increase of functional limitations between 2002/2003 and 2012/2013 is less than the increase in chronic diseases, this could have resulted in fewer barriers for individuals with a chronic disease to participate in society overall.^{3,20}

No time effect for participation in volunteer activities was found in this study. This might have to do with the selected age range of 55–64 years. At this age, individuals are still more likely to participate in paid work and thus have less time available for volunteer activities.

Participation in informal care giving

The present study did not show significant differences between individuals with and without a chronic disease in providing informal care. There may be no sufficient alternatives for informal care available, or individuals may feel obliged to provide informal care, regardless of caregiver health, motivation or skills.^{3,33} Moreover, the present study showed that there was no increase in informal care giving in 2012/2013 compared to 2002/2003. It may be the case that shrinking family sizes and increased labour force participation limits the supply of informal caregivers.^{34,35}

Participation in more than one form of societal participation

Within the group in this study that participated in society, individuals with a chronic disease were more likely to participate in volunteer activities than in paid work. For individuals with a chronic disease, participation in volunteer activities might serve as an alternative for participating in paid work given the higher flexibility in volunteer activities compared to paid work. With regard to combining roles, previous studies have shown that a high proportion of workers are able to combine their work with informal care giving and do not experience adverse effects, such as being forced to cut back on working hours or health deterioration.^{36,37} These studies did not differentiate between workers with and without chronic disease. However, the role strain theory states that combinations of societal participation increase demands placed on individuals. Individuals working full time may not have enough time or resources to adequately fulfil multiple roles.³⁷

Strengths and limitations

The strength of this study is that a relatively large group of individuals aged 55 years and older who participate in various roles was included. Furthermore, the LASA population is nationally representative of the Netherlands. In addition, this is the first study to compare various forms of societal participation between groups with and without chronic disease in 2002/2003 and 2012/2013.

Limitations of the present study include its cross-sectional design, which makes it difficult to distinguish cause and consequence. Logical reasoning supports the hypothesis that it is more likely that a chronic disease impacts societal participation than vice versa. Second, whether participants had a chronic disease was partially based on self-reports and partially on a depression symptom scale. The agreement between self-reports and medical records of the participants' general practitioners was satisfactory.³⁸ CES-D scores correlate to clinical ratings of depression, and a score above the cut-off used in this study corresponds with clinically relevant levels of depression.²⁵ Finally, the sample size might

have been too small to show statistically significant differences between the various forms of societal participation. Although, since the effect sizes for volunteer activities and informal care giving were rather small, we do not believe we missed major effects.

Implications for research and practice

Future studies should replicate our investigation with larger datasets, in particular with regard to role combinations. An important direction for future research may be to focus on specific chronic diseases. The effects of chronic diseases on some forms of societal participation may be levelled out by focussing on a group with a specific chronic disease. Specific chronic diseases may affect societal participation in disparate ways. Since we were unable to determine the intensity of participation in these three societal roles, a next step would be to focus on the number of weekly hours doing paid work, volunteer activities and informal care giving. It is already known that workers with a chronic disease work fewer hours per week compared to those without chronic disease. Similar processes may apply for volunteer activities and informal care giving. Given the increase in societal pressure in Europe to participate in paid work and informal care giving, it is expected that individuals with chronic diseases may be pushed into societal participation. This potentially vulnerable group's participation in society and how the changing societal context may change their societal participation in the future require ongoing attention. Finally, it would be valuable to gain insight into how individuals with a chronic disease experience societal participation, and how their health changes over time. We cannot rule out the possibility that the group with chronic disease does participate in society, but to a lesser extent than those without a chronic disease, or perceives limitations during societal participation that may eventually lead to withdrawing from or reducing their societal participation.

The present study showed that individuals with a chronic disease were less likely to have paid work than individuals without a chronic disease. In addition, compared to individuals without a chronic disease, those with a chronic disease are more likely to participate in volunteer activities than in paid work. Future research should focus on the type and severity of the disease and the intensity of societal participation in paid work, volunteer activities and informal care giving due to heterogeneity within the group of individuals with chronic diseases.

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Conflict of interest: None declared

Key points

- Individuals with a chronic disease were less likely to have paid work when the years 2002/2003 and 2012/2013 were combined
- In 2002/2003, having a chronic disease was inversely associated with having paid work, but this association was no longer statistically significant in 2012/2013
- Work participation of individuals with as well as without a chronic disease increased in 2012/2013 compared to 2002/2003
- Within the group that participates in society, individuals with a chronic disease were more likely to participate in volunteer activities than paid work

- Our findings imply that more research should be done and focus on specific chronic diseases since they may affect societal participation in disparate ways

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