Article

Not peer-reviewed version

Quality of Life and Health Determinants of Informal Caregivers Aged 65 Years and Over

Fanny Buckinx , Stéphane Adam , Mylène Aubertin-Leheudre , Marie De Saint Hubert , Alexandre Mouton , Florence Potier , Jean-Yves Reginster , Olivier Bruyère *

Posted Date: 9 October 2023

doi: 10.20944/preprints202310.0397.v1

Keywords: caregivers; survey; health determinants; physical activity; older people doi:10.20944/preprints202310.0397.v1

Article

Quality of Life and Health Determinants of Informal Caregivers Aged 65 Years and over

Fanny Buckinx [1,*], Stéphane Adam [2], Mylène Aubertin-Leheudre [3], Marie de Saint Hubert [4], Alexandre Mouton [5], Florence Potier [4], Jean-Yves Reginster [1] and Olivier Bruyere [1,5]

[1] WHO Collaborating Center for Public Health aspects of musculo-skeletal health and ageing, Division of Public Health, Epidemiology and Health Economics, University of Liège, Belgium
[2] Psychology of Aging Unit, University of Liège, Belgium
[3] Université du Québec à Montréal, Faculté des sciences, Département des sciences de l'activité physique et Centre de Recherche de l'institut Universitaire de Gériatrie de Montréal, Québec, Canada
[4] Department of Geriatric Medicine, CHU UCL Namur, Yvoir, Belgium, Institut de Recherche Santé Société, UCLouvain, Belgium
[5] Department of Sports Sciences, Research Unit for a life-Course perspective on Health & Education – RUCHE, University of Liège, Belgium
* Correspondence: fanny.buckinx@uliege.be.

Abstract: Background: Informal caregivers' own quality of life, health status, and determinants are poorly understood despite their concerns for the health of the individuals they assist. **Objectives:** To compare the quality of life and the health determinants of older informal caregivers with those of older adults without caregiving responsibilities. **Methods:** An online survey was designed to investigate the quality of life and the health determinants of people aged 65 years and over, with a focus on informal caregivers. In addition to socio-demographic data, the number of informal caregiver and the Zarit scale of caregiver burden were collected. Quality of life (SF-12) and health determinants (access to technology and level of physical activity (IPAQ)) were assessed and compared between informal caregivers and the others. **Results:** A total of 111 participants (70 ± 3.83 years, 71.2% of women). The majority of respondents (91.8%) were Belgian. One third of the respondents identified themselves as informal caregiver and declared to have severe burden (61.9±15.2/88). Socio-demographic characteristics and access to technology were similar between informal caregivers and non-caregivers (p>0.05). However, informal caregivers have a lower SF-12 score in the mental score domain (44.3±10.2 vs; 50.7±7.0; p=0.004) and a lower level of physical activity (434±312 METS/min/week vs.1126±815 METS/min/week; p=0.01) than their peers. **Conclusions:** Informal caregivers reported lower quality of life and lower level of physical activity than their peers. Given the recognized importance of physical activity for overall health, this survey highlights the need to promote physical activity among older informal caregivers.

Keywords: informal caregivers; survey; health determinants; physical activity; older people

1. Introduction

Informal care is defined as any assistance provided to a person in need of care by someone in the person's direct environment [1]. It also includes less intensive assistance, assistance to household members and assistance to institutionalised people. Informal care activities include emotional support, administrative help, advice on making appointments, transport, domestic and personal care. This informal care is unpaid, results from social rather than professional relationships and involves long-term care for sick family members or friends [1]. Informal care plays an important role in the care of people with health problems. There is therefore a considerable public interest in this type of care in Europe [2].

In Europe, around a third of the population is considered to be informal caregiver (34.3%), but variation between countries was large (from 43.6% in Finland to 8.2% in Hungary) [3]. They are mostly aged between 50 and 75 years and help their parents or partners. Informal caregivers are more ofter women, especially daughters or daughters in law [4]. The care-receiver can be older people with loss of autonomy but also sick or disabled children or young adults. The age of the care-receiver is mostly 75 years old and over [3]. The factors that encourage people to become informal caregivers are emotional ties (e.g., love and affection), a sense of duty, and a personal sense of obligation [5].

Overall, caregiving is not associated with negative health effects [6]. A systematic review of the literature even found positive effects of short-term informal care on self-reported physical health [7]. The positive impact of informal care on self-assessed health could be the result of a bias related to reference points, Di Novi and colleagues (2015) argued. Spending time with someone with poor health might raise self-rated health, because people might relate to the poor health of the care recipient when the objective health of the carer might be lower [8]. Unfortunately, being informal caregiver during a long period of time is not without constraints, as this role is recognised as a major stressor. In fact, these individuals must deal with the deteriorating health of the care-receiver, which in turn puts their own health at risk [9]. Indeed, informal caregivers are more likely to report symptoms of depression and other indicators of psychological distress than non-informal caregivers [10-12]. Furthermore, informal caregivers have poorer physical health than those who do not have this role [10,13]. Several factors increased caregiver burden, including high levels of disability and morbidity of care-receiver, number of hours of care, high variability in care tasks, care setting (home care vs. institutional care), sex and age of the informal caregiver [14,15]. Nonetheless, while informal caregivers often feel burdened by caring for a person, they can also experience positive outcomes from caring; caregiver gains. One of these relatively overlooked caregiver benefits is increased self-esteem [16] .

It is admit that providing informal care has a negative impact on caregivers' quality of life. QoL, as a multidimensional concept, combines several aspects of health, such as physical, mental, emotional and social functioning [17,18]. Comparing the QoL of informal carers with that of the general population is of great scientific importance. Such comparisons allow us to understand the unique challenges and burdens that caregivers face, shed light on potential health inequalities, and develop targeted interventions to improve their well-being. In addition, examining differences in quality of life can contribute to policy development aimed at providing adequate support and resources for this important group of people.

Otherwise, several determinants of healthy ageing have been identified. An important one is physical activity. Indeed, the health benefits of physical activity are well recognized and are related to the following outcomes: mortality, cognitive status, physical autonomy, glycaemic control, pain, disability, muscle and bone strength, depression and well-being [19-22]. According to the systematic review by Lindasay et al, previous research has shown that informal carers have low levels of physical activity and are at higher risk of being physically inactive than those who do not provide care. Whilst other research has suggested that informal carers may have higher levels of physical activity than the general population due to the physical demands of caring. [23]. Overall, in order to develop appropriate interventions and policies to promote the health and well-being of carers, there is a need to better understand their physical activity levels.

Then, the link between social network and health has received more attention in recent years [24]. In this sense, internet connectivity (i.e. access to technology) is a social determinant of health, as it can support a range of health information needs [25]. The use and access of tools such as patient portals, health trackers, health applications and remote monitoring devices is increasing. This phenomenon is related to the research findings suggesting that these tools can promote greater patient engagement, better support for patients outside of the usual care, and can improve health parameters [25]. In this sense, some authors highlighted that computers and mobile devices are practical platforms for delivering care-related information and support services to informal carers, but their reach may be more limited for carers who are older, less educated and less healthy [26]. Understanding the digital divide among older informal caregivers carers can help identify barriers and develop targeted interventions to bridge the gap, ensuring they have equal access to technological resources, information and support systems, ultimately improving their caregiving experience and overall well-being.

Moreover, ageism (i.e. ageism is the umbrella term for stereotyping, prejudice and discrimination against people because of their chronological age or the perception that they are 'too old' or 'too young' to be or do something [27]) is another determinant of worse health [28]. For example, ageism reduces life expectancy, worsens physical and mental health, hinders recovery from disability and accelerates cognitive decline [28]. Ageism also increases social isolation, loneliness and reduces access to employment, education and health care [28]. However, all these aspects are also known to affect the health [28]. Based on the literature, beginning of informal care is significantly associated with a better attitude towards old age while the end of informal care is significantly associated with an increase in subjective age and an earlier onset of old age [29]. Measuring the self-perception of aging among informal caregivers is vital for understanding their attitudes and expectations regarding their caregiving role. It helps identify age-related biases, assess well-being, and develop interventions to promote positive aging experiences, enhancing overall quality of life.

Health literacy is also one of the determinants of health since low health literacy is associated with more hospitalizations, greater use of emergency care, lower use of preventive services, poorer ability to interpret labels and health messages, poorer health outcomes, higher mortality and higher health care costs [30-32]. To play their role properly, informal carers need to be able to access and understand information about the patient's health, to establish valuable communication with both the patient and the health care providers, and to manage the services offered by the health care system [32]. By measuring health literacy, we can develop targeted interventions to improve caregivers' health-related knowledge and empower them to actively engage in healthcare decision-making, ultimately enhancing their caregiving effectiveness and the well-being of care recipients.

Finally, sense of coherence is a strong determinant of positive health [33,34]. In fact, sense of coherence is associated with positive well-being, mental health, and quality of life [35] but also with reduced severity of anxiety and depression [35]. It is an important determinant of the well-being of informal caregivers and may protect them from high levels of psychological distress and caregiver burden [36]. By measuring the sense of coherence, we can identify areas for support and intervention, enhance their psychological well-being, and develop strategies to strengthen their ability to manage stress and maintain a sense of purpose in their caregiving role. This measurement is essential for promoting caregivers' overall resilience.

However, the quality of life and these health determinants have rarely been compared between older informal caregivers and the general older population. The aim of this study is therefore to fill this gap by assessing the quality of life and the health determinants of older informal caregivers and by comparing their profile with those of their peers.

2. Methods

2.1. Study design

This is an online survey carried out between August and October 2022 using the «Sondage Online» software. The protocol of this study has been approved by the hospital-faculty ethics committee of the XXXX (number XXXX).

2.2. Study population

All people aged 65 years and over were invited to participate in the survey. No exclusion criteria were defined. Participants were recruited via social networks (posting the link to the online survey on the co-authors' social media) and via neurologic and geriatric consultation at the CHU XXX. In addition, during the special week dedicated to informal caregivers (October 10 to 14th 2022) in Belgium, we went to various events dedicated to informal caregivers to invite them to participate to our survey. In fact, we participated in a discussion group (Heusy, Belgium), a “café aidant-proche” organized by the “ligue Alzheimer” (Huy, Belgium), a day of support, help and advice for informal caregivers with interactive show (Fléron, Belgium), an online information session organized by “Le Réseau Santé Bruxellois”. A convenience sample was therefore selected.

2.3. Data collected

For this study, a self-administered questionnaire was developed by our team (i.e. including experts from different fields: geriatricians, psychologists, physical activity and public health specialists). All the questions developed were closed questions with the possibility to give another open answer. This survey also included some validated questionnaires (SF-12, IPAQ, HLS-EU-Q 16and SOC-13). The survey was pre-tested with 10 community- dwelling older adults to ensure that the questions were well understood and easy to answer. The survey was designed to investigate the health determinants of people aged 65 years and over, and in particular for informal caregivers. Other variables related to caregivers were also collected as described below.

Socio-demographic data

Age, sex, body mass index (BMI), country, marital status (i.e. married, bachelor, widower, divorced/separated), place of residence (i.e. house, apartment, residence), number of people living with the respondent, highest level of education (i.e. university, higher education, upper secondary education, lower secondary education, primary education, none), monthly household income, smoker (i.e. yes or no), number of alcoholic drinks per day, number of chronic diseases, number of medicines taken per day, number of vitamins or food supplements taken per day were collected to characterize the population sample.

2.4. Informal caregivers

In order to identify informal caregivers, the following question was asked: «Do you regularly help a person with a loss of autonomy (i.e. a person who is unable to perform alone certain activities of daily living)?»

Those who answered «yes» to this question were asked to answer questions about the help provided: who is the care-receiver (i.e. the spouse, a parent/grandparent, a child, a friend, a neighbour, other); whether you live with the care-receiver or the distance between the care-receiver's home and the informal caregiver's home; age of the care-receiver; tasks performed to support the care-receiver (i.e. basic needs, meals, housekeeping, laundry, budget management, administrative management, medication management, work, hobbies, relationships, transportation, supervision); what is the care-receiver suffering from (i.e. physical difficulties, mental difficulties, both); time spent per week with the care-receiver; personal motivations to support the care-receiver (i.e. Love/ affection/ friendship, recognition, the challenge, the obligation, keeping a promise, the duty, religious beliefs, financial constraints, other); is the respondent the only one caring for this person? All these questions were closed questions. In addition, the Zarit scale which measured the caregivers Burden were also questioned [37].This questionnaire included 22 items and the total score ranged from 0 to 88 (0-21: no to mild burden; 21-40: mild to moderate burden; 41-60: moderate to severe burden; ≥ 61: severe burden) [37].

2.4.1. Quality of life

The validated «Short-Form-12» (SF-12) questionnaire was also used to assess the quality of life [38]. The SF-12 is a self-reported outcome that assesses the impact of health on an individual's daily life. The SF-12 uses the following eight domains: (1) limitations in physical activities due to health problems; (2) limitations in social activities due to physical or emotional problems; (3) limitations in usual role activities because of physical health problems; (4) bodily pain; (5) general mental health (psychological distress and well-being); (6) limitations in usual role activities due to emotional problems; (7) vitality (energy and fatigue); (8) general health perceptions. An algorithm calculates one score out of 100 for the physical score and another one for the mental score [38]. A higher score indicates a better quality of life.

2.4.2. Access to technologies

Participants were asked about their frequency of internet use, ownership of connected devices (i.e. smartphone, tablet, laptop, computer), use of messaging and video calling applications (e.g.

Messenger, WhatsApp, Skype, Facetime, …) but also about the use of physical activity applications to measure the level of physical activity (e.g. number of steps, calories burned, number of km travelled, …).

2.4.3. Level of physical activity

The validated short version (7 questions) of the «International Physical Activity Questionnaire» (IPAQ) was used [39]. This questionnaire assesses total physical activity and sedentary time over the past seven days. The questionnaire covers vigorous activity, moderate activity, walking, and sitting (sedentary time), whether during leisure activities, at work, in daily life or during transport. The questionnaire classifies the subject into 3 levels of activity: inactive, moderate, and vigorous [39]. The score is expressed as METs (Metabolic Equivalent of Task) minute/week.

2.4.4. Physical activity preferences

In order to create a specific and adapted physical activity offer, the physical activity preferences of the participants were asked using the following questions:

«How many days a week would you be willing to be physically active?», «How long do you think a physical activity session should last?» «Do you prefer to do physical activity: alone, with your partner, with a friend/family member, in group», «Do you prefer to do physical activity: outdoors, in a sports facility, at home», «what type of physical activity do you prefer?», «facilitators of physical activity» and «barriers to physical activity». All these questions were closed questions with the possibility to give another open answer.

To also assess preferences for online physical activity, participants were asked the following questions: « Would you be willing to follow an online physical activity program over the Internet?», «Would you be willing to follow an online physical activity programme using pre-recorded videos?», «Would you be willing to follow an online physical activity programme in live, with a coach?», «How many days per week would you be willing to participate in an online physical activity program?», «How long do you think an online physical activity session should last?», «What type of online physical activity program would you be willing to participate in?», «facilitators of online physical activity»,«barriers of online physical activity». All these questions were closed questions with the possibility to give another open answer.

2.4.5. Subjective age and age of becoming young or old

Participants were asked to report how old they felt in years. We calculated the discrepancy between subjective age and chronological age (discrepancy age = subjective age − chronological age). A positive value indicates an older subjective age and a negative value indicates a youthful subjective age. In fact, feeling older or younger is an expression of subjective age [40,41].

Moreover, in order to assess participant' views on which periods of life correspond to youth and old age, they were asked to be specific (in age): "at what age does a person stop being young" (end of youth) and "at what age does a person become old" (beginning of old age) [41,42].

2.4.6. Health literacy

Comprehensive health literacy was measured using the validated HLS-EU-Q 16questionnaire [43]. Each question of the HLS-EU-Q16 was answered by selecting one of the available options: «very difficult», «difficult», «fairly easy» and «very easy». The original version of the HLS-EU-Q16 measures health literacy in three domains: health care (seven items), disease prevention (five items) and health promotion (four items). Each of the 16 questions was coded as follow: «very difficult»/«fairly difficult» = 0, «fairly easy»/«very easy» = 1). The total score (0 to 16 points) was divided into three categories of Health Literacy: «likely inadequate» (0–8 points), «likely problematic» (9–12 points) and «likely sufficient» (13–points) [44].

2.4.7. Sense of coherence

The validated SOC-13 scale was used to assess the sense of coherence [45]; defined as a permanent and reliable feeling of confidence [34]. It consists of some items in the following subscales: Comprehensibility (understanding life event- 5 items), Manageability (feeling you can cope-4 items), and Meaningfulness (life make sense-4 items). The final score of the scale for each participant score includes a reverse score of questions 1, 2, 3, 7 and 10 (where score 7 = 1, 6 = 2, 5 = 3, 4 = 4, 3 = 5, 2 = 6 and 1 = 7). The score ranges from 13 to 91 points, with higher total scores indicating a greater sense of coherence [45].

2.5. Statistical analysis

Data were expressed as mean and standard deviation for continuous variables and as number and percentage for categorical variables. Normality of the variables was tested using the Shapiro-wilk test, comparison between means and medians and Q-plot. Analyses were performed on all data available for each question. Analyses of variance and Chi- square (or Wilcoxon for non-parametric variables) tests were used to compare variables between informal caregivers and their peers. Results were statistically significant at the 5% critical level ($p < 0.05$). All calculations were carried out using RStudio.

3. Results

3.1. Study participants

A total of 111 volunteers completed the survey. The mean age was 70.0 ± 3.8 years and 71.2% of them were women. The majority (91.8%) of respondents were Belgian. The socio-demographic characteristics of the study participants are shown in Table 1.

Table 1. socio-demographic characteristics of the participants (n=111).

Variables	**n**	**Mean ± SD OR n (%)**
Age (years)	111	70.0 ± 3.8
Sex (Ratio men: women)	111	32(28.8) : 79 (71.2)
BMI (kg/m2)	106	26.6 ± 3.6
Country:	109	
Belgium		*100 (91.7)*
Canada		*9 (8.3)*
Marital status:	110	
Married		*55 (50)*
Married Since (years)	*55*	*36.3 ± 13.5*
Bachelor		*9 (8.2)*
Widover		*26 (23.6)*
Widover Since (years)	*26*	*13 ± 10.7*
Divorced/separate		*20 (18.2)*
Divorced since (years)	*20*	*19.4 ± 10.1*
Living place:	*98*	
House		*83 (84.7)*
Apartment		*13 (13.3)*
Nursing home		*2 (2)*
Number of people living with:	*98*	
0		*27 (27.6)*
1		*53 (54.1)*

2		*16 (16.3)*
3		*2 (2)*
Highest level of education:	*97*	
University		*19 (19.6)*
Higher education		*30 (30.9)*
Upper secondary education		*31 (32)*
Lower secondary education		*14 (14.4)*
Primary education		*1 (1)*
None		*2 (2.1)*
Monthly household income:	*95*	
>3000 €		*29 (30.5)*
2000-3000 €		*19 (20)*
1000-2000€		*32 (33.7)*
<1000€		*0 (0)*
Refusal of answer		*13 (13.7)*
Do not know		*2 (2.1)*
Smoker (yes)	*97*	*4 (4.1)*
Number of cigarettes per day	*4*	*18.3 ± 7.7*
Number of alcoholic drinks:	*93*	
0 per week		*25 (26.9)*
1 or 2 per week		*35 (37.6)*
1 or 2 per day		*26 (28)*
>2 per day		*7 (7.5)*
Number of prevalent chronic diseases	*93*	*1.8 ± 1.4*
Number of drugs consumed per day	*93*	*3.1 ± 2.2*
Number of vitamins or food supplements per day	*91*	*1.6 ± 1.2*

3.2. Informal caregivers

Of the 111 respondents, 90 (81%) answered the question about informal caregivers. Among this number, 30/90 (33.3%) reported that they regularly helped a person with a loss of autonomy. The baseline characteristics of the informal caregivers (IC) were comparable to their peers (P) in terms of age (IC: 70.2 ± 3.8 y vs. P:69.6 ± 3.6 y, p=0.29), sex (ratio women : men; IC: 7 (23.3%): 23 (76.6%) vs. P: 19 (31.7%) : 42 (67.7%); p=0.45) and BMI (IC: 28.0 ± 4.9 vs. P: 26.3 ± 3.1 kg/m^2; p=0.05).

Details on the role of informal caregivers are given in Table 2. In summary, most of the time, the care-receiver is a spouse (33.3%) or a parent/grandparent (33.3%). In 40% of the cases, the informal caregiver lives with the care-receiver. Otherwise, the caregiver lives, on average, at 16km away from the care-receiver. The average age of the care-reveiver is 75.9 ± 12.7 years. The help provided mainly concerns administrative management (66.7%), medication management (55.6%) and supervision (51.9%). In addition, the care-receiver has physical difficulties (46.4% of the cases), mental difficulties (14.3% of the cases) or both physical and mental difficulties (39.3% of the cases). Almost half of the respondents (48.3%) help the person 7 days a week, for a total of 11.9 ± 9.5 hours per week on average. The respondents have been helping the person since 8.9 ± 7.2 years on average. Their personal motivation to help the care-receiver are mainly love/affection/friendship (82.1%) but 39.3% declare that it is a duty while 28.6% do it to keep their promise closed. Then, in 42.7% of cases, the respondent is the only one who warns the care-receiver. If the respondent is not the only one caring for the person, they share the task with another family member (76.5%) and/or with a health professional (47.1%). Finally, the Zarit burden is 61.9 ± 15.2 / 88, which indicates a mean score just reaching the severe burden level.

doi:10.20944/preprints202310.0397.v1

Table 2. details regarding the role of informal caregivers (n=30).

Variables	**N**	**Mean ±SD OR n (%)**
The care-receiver is:	30	
The spouse		10 (33.3)
A parent/grandparent		10 (33.3)
A child		2 (6.7)
A friend		5 (16.7)
A neighbour		2 (6.7)
Other		1 (3.3)
The care-receiver & the caregiver live together (yes)	30	12 (40)
Distance between the homes of the care-receiver and the caregiver (km)	18	16.3 ± 21.1
Age of the care-receiver(years)	27	75.9 ± 12.7
Tasks for which the care-receiver is helped:	27	
Basic activities of daily living (e.g. toilet, dressing, mobility)		6 (22.2)
Meals		12 (44.4)
Household		13 (48.1)
Laundry		10 (37.0)
Budget management		17 (63)
Administrative management		18 (66.7)
Drug management (e.g. preparation of the drugs)		15 (55.6)
Work		1 (3.7)
Hobbies		13 (48.1)
Social relations		11 (40.7)
Transport		20 (74)
Surveillance		14 (51.9)
What the care-receiver is suffering from?	28	
Physical difficulties		13 (46.4)
Mental difficulties		4 (14.3)
Physical and mental difficulties		11 (39.3)
Number of days per week devoted to the care-receiver:	29	
<1 day/week		5 (17.2)
1-2 days/week		5 (17.2)
3-4 days /week		5 (17.2)
5-6 days/week		0 (0)
7 days/week		14 (48.3)
Number of hours per week devoted to the care-receiver (hours)	27	11.9 ± 9.5
How long the caregiver has been caring for the person (years)	29	8.9 ± 7.2
***Personal motivations* of caregiving:**	28	
Love, affection, friendship		23 (82.1)
Acknowledgement		2 (7.1)

The challenge		0 (0)
The obligation		1 (3.6)
Keeping a promise		8 (28.6)
The duty		11 (39.3)
Religious beliefs		1 (3.6)
Financial constraints		0 (0)
Other		1 (3.6)
Is the carer the only one caring for the person? *(yes)*	29	12 (42.7)
Another person who helps him/her:	17	
Family member(s)		13 (76.5)
Friend(s)		0 (0)
Health professional(s)		8 (47.1)
Zarit burden (/88)	24	61.9 ± 15.2

3.3. Health determinants of older informal caregivers

3.3.1. Quality of life

Informal caregivers have a significantly lower mental score on the SF-12 than non-informal caregivers (IC: 44.3 ± 10.2 vs. P: 50.7 ± 7.0; p=0.004). However, the physical score (SF-12) is comparable between the two groups (IC: 61.7 ± 31.9 vs. P: 47.4 ± 7.1; p= 0.11) (*Figure 1*).

3.3.2. Access to technologies

Access to technology is similar between informal caregivers and other older adults (p-values >0.05 for all the variables). Globally, more than 80% of the informal caregivers use the internet every day and have a smartphone. Nevertheless, only a third of them have ever used an application for physical activity. According to the respondents, the most used applications for physical activity are Youtube and Strava (Table 3).

Table 3. Access to technologies.

	Informal caregivers (n=30)		**Peers (n=60)**		
Variables	**N**	**Mean±SD** **OR** **n (%)**	**N**	**Mean±SD** **OR** **n (%)**	**p-value**
Use of Internet:	27		58		0.10
Never		2 (7.4)		1 (1.7)	
Every month		1 (3.7)		2 (3.5)	
Every week		2 (7.4)		4 (6.9)	
Every day		22 (81.5)		51 (87.9)	
Use of the internet for how many years	24	19.6 ± 5.9	54	18.8 ± 6.5	0.34
Do you havethe following connected objects?	26		57		0.38
A smartphone		22 (84.6)		54 (94.7)	
A tablet		17 (65.4)		29 (50.9)	
A laptop		16 (61.5)		40 (70.2)	
A computer		12 (46.2)		22 (38.6)	

How long have you owned these connected objects?	24	17.5 ± 7.4	55	17.1 ± 6.8	0.45
Do you regularly use messaging and video calling applications (e.g. Messenger, Whatsapp, Skype, Facetime,...)? (yes)	26	21 (80.7)	58	52 (89.7)	0.14
Have you ever used an application(s) for physical activity? (yes)	26	8 (30.8)	58	22 (37.7)	0.27
Have you ever used an application(s) to measure your level of physical activity (number of steps, calories burned, number of kilometres travelled, ...)? (yes)	26	15 (57.7)	57	25 (43.9)	0.13

3.3.3. Level of physical activity

The level of physical activity, expressed in METS-minute/week is significantly lower among the informal caregivers than among their peers (IC: 434 ± 312 vs. P: 1126 ± 815; p=0.01) *(Figure 1)*. It means that informal caregivers do less physical activity. More specifically, 29.9% of the IC had done vigorous physical activity in the last 7 days compared to 49.2% of the P. The proportion of people who had done moderate physical activity in the last 7 days was comparable in the 2 groups (IC: 72% vs. P:70%). Among the IC, 81% had walked for at least 10 minutes in a row in the last 7 days, compared with 94.5% of the P. In addition, the proportion of subjects with a physical activity level below 600 METS-minute (i.e. inactive people) is higher in the informal caregivers group than in their peers (IC: 12 (75%) vs. P: 15 (35.7%); p=0.003).

3.3.4. Physical activity preferences

In face to face

Most of the informal caregivers (98.8%) say they are willing to engage in physical activity. More specifically, they are willing to do physical activity 2 (30.9%), 3-4 (38.1%) or >4 days (29.8%) per week. In addition, almost half of the informal caregivers think that a physical activity session should last 60 minutes. It is also interesting to note that 63.4% of the informal caregivers prefer to do the physical activity in groups while 41.5% prefer to do it alone. About a quarter of the respondents prefer to do physical activity with their partner or with a friend/family member. Then, 72% of the informal caregivers prefer to do physical activity outdoors, 57.3% in sports facilities and 25.6% at home. Among them, 61.3% preferred cardiovascular physical activities, 42.5% preferred mixed activities, 35% prefer body and mind activities and 16.3% preferred strengthening activities. Informal caregivers reported that 53.1% of them would be willing to participate in a paid physical activity program, while 85.2% are willing to take part in a free program. In addition, 48.1% of them reported that they would be more motivated to do physical activity if a coach is present. Barriers and facilitators to physical activity are presented in Table 4 below.

Table 4. Facilitators and barriers to physical activity according to the informal caregivers (n=25).

Barriers to physical activity: n (%)		**Facilitators to physical activity: n (%)**	
Cost of physical activities	*7 (28)*	*Health benefits*	*20 (80)*
Lack of time	*9 (36)*	*Previous sport participation*	*2 (8)*
Schedules constraints	*6 (24)*	*Free of charge*	*13 (52)*
Ageing (e.g. I am too old to exercise)	*2 (8)*	*Proximity to home*	*11 (44)*
Health condition	*3 (12)*	*Limited duration of the sessions*	*9 (36)*
Fatigue	*10 (40)*	*Atmosphere (e.g. conviviality of the group)*	*16 (64)*
Distance (e.g. far from home, access to public transport, inability to drive)	*4 (16)*	*Groups of people of the same age*	*10 (40)*
Fear of getting involved	*5 (20)*	*Supervision of the sessions by a professional*	*11 (44)*
Fear of getting injured	*0 (0)*	*Opportunities for physical activity at home*	*6 (24)*
Lack of physical activities adapted to my health condition	*2 (8)*	*The possibility of accompanying my partner during the session*	*3 (12)*
Lack of physical activities adapted to my age	*2 (8)*	*Other*	*0 (0)*
Lack of motivation	*8 (32)*		
Impossible to leave the person I am helping alone	*2 (8)*		
Other	*1 (4)*		

Online physical activity

Among the informal caregivers, 31.7% are willing to follow an online remote physical activity program. Of these, 100% are willing to participate in an online remote physical activity program using pre-recorded videos and 44.4% through live physical activity program (with a coach). The majority of them are willing to participate in an online remote physical activity program 1 or 2 days a week. For almost 90% of these respondents, online remote physical activity is expected to last 30 minutes. In addition, 55.6% of the respondents are willing to take part in mixed activities, 33.3% in cardiovascular activities, 22.2% in body and mind activities and 11.1% in strengthening activities. The main barriers to online remote physical activity identified in the present survey were (n=9): lack of space at home (33.3%), fatigue (33.3%), fear of doing exercise badly (22.2%), Lack of social interaction (22.2%), lack of motivation (22.2%), incompatibility of schedules (11.1%), ageing (11.1%), fear of injury (11.1%), Lack of physical activities adapted to my age (11.1%). Facilitators to such physical activity program were: the absence of travel (66.7%), the limited duration of the sessions (66.7%), the habit of using technologies (55.6%), health benefits (55.6%), the possibility of accompanying my partner one during the session (33.3%), groups of people of the same age (11.1%).

3.3.5. Subjective age and age of becoming young or old

In this survey, we found that both informal caregivers and others feel younger than their chronological age (IC: -7.2 ± 4.9 vs. P: -8.6 ± 7.4 years; p=0.24). Both groups estimate that we become old at around 77 years (IC: 77.9 ± 7.5 vs. P: 77.5 ± 8.8 years; p=0.45) and stop being young at around 65 years (IC: 65.5 ± 14.2 vs. P: 64.6 ± 16.6; p=0.44).

3.3.6. Health literacy

There is no difference between the two groups in terms of health literacy as assessed by the HLS-EQ-U16 (IC: 12.5 ± 3.2 vs. P: 12.7± 2.7; p=0.23). However, the score in both groups is on the borderline between «likely problematic» and «sufficient». More specifically, health literacy was «likely inadequate» in 19% of the IC and in 13.4% of the P; «likely problematic» in 23.8+ of the IC and in 26.9% of the P and «sufficient» in 57% of the IC and in 59.6% of the P.

3.3.7. Sense of coherence

The sense of coherence is around 50 points/91 in both group (IC: 50.7 ± 5.5 vs. P: 52.8 ± 9.4; p=0.21), which is an average score.

4. Discussion

The present survey aimed to better understand the health determinants of the informal caregivers aged 65 years and over compared to those of their peers.

First, the results suggest that the mental component score of quality of life is lower among older informal caregivers than among their peers. This suggests that informal caregivers may experience more stress, concerns, and emotional difficulties related to their caregiving role, which can have a negative impact on their overall well-being. This is consistent with a recent systematic review in which quality-of-life data indicated that a large proportion of informal caregivers experienced clinical levels of anxiety (33%) or depression (12%-32%) [46]. These figures are even higher among caregivers of people with mental disorders (e.g. dementia) [47]. Another qualitative systematic review also concluded that being an informal caregiver has a significant impact on quality of life [48]. It should be noted, however, that the studies included in these systematic reviews were not specific to older informal caregivers. Our study confirms the previous findings in the population of people aged 65 years and over. However, the results of a systematic review of longitudinal studies suggest a negative association between informal care and mental health in working-age adults [49]. Moreover, the informal caregivers reported a severe burden which is associated with a risk for depressive symptoms and also associated with care cessation and nursing home admission of the care-receiver [50].

We then found that access to technology is similar between informal caregivers and other older adults. Informal caregivers have comparable accessibility to technological devices such as computers, smartphones, or tablets, compared to other older adults who are not informal caregivers. According to our results, 80% of the informal caregivers use the internet every day and have a smartphone. This percentage is comparable to the findings reported by Shaffer et al. (77.5% of Internet users among the informal caregivers) [26]. This is not surprising because Informal caregivers express a strong interest in technological innovations to support them in their caregiving role [26]. Despite this, only one third of our respondents had ever used an application for physical activity, although a recent study demonstrated the feasibility, usability and acceptability of a novel digital health apps for informal caregivers to improve physical activity levels [51].

Moreover, physical activity is also recognized as an important determinant of health [52]. Our survey shows that most informal caregivers are inactive, and their levels of physical activity are much lower than those of their peers (with very significant differences). This suggests that the responsibilities and demands of caregiving may impede informal caregivers from engaging in regular physical activity. The substantial differences in physical activity levels highlight the potential negative impact of caregiving on the ability of informal caregivers to prioritize their own physical well-being. Caregiving duties may consume a significant amount of time and energy, leaving caregivers with limited opportunities to engage in physical activities or maintain an active lifestyle.The same finding was reported by Rokicka et al., who found that informal caregivers were generally more likely to allocate less time to physical activity, hobbies, and their social life [53]. This can be explained by the fact that the role of informal caregiver is time consuming. Thus, the informal caregivers reduce the time spent on leisure and social activities, including physical activity, leading to more physical problems and reduced social well-being [54]. Therefore, it seems necessary to propose a physical activity intervention for informal caregivers to reduce the public health problem of physical inactivity behaviour in this population. A systematic review of randomised controlled trials highlighted that physical activity interventions significantly improved mental health but had inconsistent effects on physical health in informal caregivers of older adults with chronic diseases [55]. The inconsistent results can be explained, in particular, by the heterogeneity of the interventions proposed but also by the differences in the adherence rates to physical activity programs.

Our survey will help us to offer physical activity intervention that best meets the expectations of informal caregivers in an attempt to increase the adherence rate. Indeed, according to our survey, the physical activity should be delivered online using pre-recorded videos in order to address the main barriers to the practice of physical activity (i.e. lack of time, incompatibility of schedules, distance). The program should take place 2 times a week for 30 minutes and include mixed activities (i.e. cardiovascular, strengthening, body and mind activities). This kind of physical activity program has been tested in previous studies and showed encouraging results in older populations [56,57] and need to be confirmed in informal caregivers. The preferences of informal caregivers seems slightly different from those observed in other seniors (example: preference of pre-recorded videos compared to live videos in other seniors), which is explained by the time they devote to the care-receiver.

Another determinant of health in older adults examined in our study is ageism. In our study, informal caregivers, like their peers, feel younger than their chronological age. The finding indicates that informal caregivers may possess a positive self-perception of their age. This sound is important because feeling younger that one's chronological age is associated with positive outcomes, whereas feeling older than one's chronological age is associated with negative outcomes [41,58,59]. Care should be taken when interpreting these data, as some authors find that the subjective age measure is a general concept and lacks information about the person's actual experience of aging that underlies their perception [58]. Our results are in line with those observed in the general population. In a Danish sample, people older than 25 years have a younger subjective age [60]. More precisely, they feel 20% younger than their actual age (~10% in our population) [60]. The difference (20% vs. 10%) can be explained by the fact that our sample is older. Recently, the subjective age was found to be 13.8years lower than chronological age among older adults (> 65 years) in Norway [61]. This result is close to the one we obtained. It is important to note that feeling less young was associate with poorer intrinsic abilities (i.e. vitality and autonomy) in the Norwegian study [61]. More precisely, in a German study, it was highlighted that the beginning of informal care was significantly associated with a better attitude towards old age, which seems consistent with our results. However in this study, the end of informal care was significantly associated with an increase in subjective age and an earlier onset of old age [29].

Health literacy enables people to access, understand and evaluate health information. Health literacy is therefore an important determinant of health. In our population, the health literacy was borderline between «likely problematic» and «sufficient» (among informal caregivers and non-informal caregivers). Our results confirm those from a Portuguese study showing that health literacy among informal caregivers was mostly sufficient [62]. According to the literature, female sex, older age and lower education were independent predictors of low health literacy [32]. Personalised supports is needed for informal caregivers who are at high risk of low health literacy [63].

The final health determinant examined in this study is the sense of coherence, which was comparable between informal caregivers and their peers. The finding suggests that, despite the additional responsibilities and challenges associated with caregiving, informal caregivers have a similar capacity to understand and manage stressful situations as their non-caregiver counterparts. To the best of our knowledges sense of coherence of informal caregivers is poorly understood. However, it is an important determinant because a strong sense of coherence is associated with good perceived health and quality of life whereas a weak sense of coherence is associated with caregiver burden and psychological distress, particularly depression and anxiety [64].

The results of this survey should be interpreted with caution as the sample is not representative of all the older informal caregivers (lack of statistical power). In addition, the survey was conducted on a voluntary basis and mainly online. Therefore, there is a sampling bias. A recruitment bias is also acknowledged as we recruited participants during a special week dedicated to informal carers, so the study population may be healthier individuals if they could attend such events. Moreover, most of the respondents were Belgian. Then, the link of the online survey has been posted the co-authors' social media which could have led to a recruitment bias. Results may vary considerably from one country to another since the role of informal caregivers varies with culture and healthcare system (support). As only people aged 65 and over were included in our research, further studies are needed to assess the health of informal carers of working age. Then, not all health determinants were taken into account in this survey. For example, nutritional and diet status were not covered. A bias in the understanding of the questions is possible due to the online nature of the survey (absence of an investigator). Finally, this is a descriptive analysis and the relationship between health determinants has not been investigated due to the low number of informal caregivers.

5. Conclusion

In conclusion, our study highlights that informal caregivers experience a lower quality of life compared to their peers. Furthermore, we observed that older informal caregivers have similar health determinants to their counterparts, except for lower levels of physical activity. Given the potential for public health interventions to address this issue, we recommend implementing a remote mixed physical activity program for older informal caregivers. This program, consisting of 30-minute sessions twice a week, can be accessed online and tailored to meet the specific needs and constraints of this caregiving population.

Implications for policy and intervention include the need for healthcare policies to recognize and support the well-being of informal caregivers. Adequate resources should be allocated to develop and implement targeted interventions that promote physical activity among older caregivers. Additionally, public health initiatives should prioritize increasing awareness about the importance of caregiver well-being and the availability of support programs. By addressing the barriers to physical activity and providing accessible resources, policymakers and healthcare professionals can improve the overall health and quality of life of informal caregivers, ultimately benefiting both caregivers and the person they help.

Authors contribution: Fanny Buckinx: Conceptualization; Methodology; Formal analysis; investigation;Writing - Original Draft; Writing - Review & Editing; Visualization Stéphane ADAM: Methodology; Writing - Review & Editing Mylène AUBERTIN-LEHEUDRE: Methodology; Writing - Review & Editing Marie DE SAINT HUBERT: Methodology; Writing - Review & Editing Alexandre MOUTON: Methodology; Writing - Review & Editing Florence POTIER: Methodology; Writing - Review & Editing Jean-Yves REGINSTER: Conceptualization; Methodology; Writing - Review & Editing; supervision Olivier BRUYERE: Conceptualization; Methodology; Writing - Review & Editing; supervision

Funding: Fanny Buckinx is supported by the “Fonds National pour la Recherche Scientifique” (FNRS, chargée de recherches). She also received a grant from the “Fondation Léon Frédéricq”. MAL is supported by FRQS (senior salary ward).

Acknowledgments: The authors thank the “ASBL aidants-proches.be” as well as the “ligue Alzheimer” for rereading the questionnaire and sharing it on their social networks. The authors also thank prof. Eric Salmon for proofreading the questionnaire.

Conflicts of interest: The researcher claim no conflict of interest.

References

1. Lindt, N.; van Berkel, J.; Mulder, B.C. Determinants of overburdening among informal carers: a systematic review. *BMC geriatrics* **2020**, *20*, 304. https://doi.org/10.1186/s12877-020-01708-3.
2. de Klerk, M.; de Boer, A.; Plaisier, I. Determinants of informal care-giving in various social relationships in the Netherlands. *Health Soc Care Community* **2021**, *29*, 1779–1788. https://doi.org/10.1111/hsc.13286.
3. Verbakel, E.; Tamlagsrønning, S.; Winstone, L.; Fjær, E.L.; Eikemo, T.A. Informal care in Europe: findings from the European Social Survey (2014) special module on the social determinants of health. *Eur J Public Health* **2017**, *27*, 90–95. https://doi.org/10.1093/eurpub/ckw229.
4. De Koker, B. Socio-demographic determinants of informal caregiving: co-resident versus extra-resident care. *Eur J Ageing* **2009**, *6*, 3–15. https://doi.org/10.1007/s10433-008-0103-7.

5. Plöthner, M.; Schmidt, K.; de Jong, L.; Zeidler, J.; Damm, K. Needs and preferences of informal caregivers regarding outpatient care for the elderly: a systematic literature review. *BMC geriatrics* **2019**, *19*, 82. https://doi.org/10.1186/s12877-019-1068-4.
6. Burton, L.C.; Zdaniuk, B.; Schulz, R.; Jackson, S.; Hirsch, C. Transitions in spousal caregiving. *The Gerontologist* **2003**, *43*, 230–241. https://doi.org/10.1093/geront/43.2.230.
7. Bom, J.; Bakx, P.; Schut, F.; van Doorslaer, E. The Impact of Informal Caregiving for Older Adults on the Health of Various Types of Caregivers: A Systematic Review. *The Gerontologist* **2019**, *59*, e629–e642. https://doi.org/10.1093/geront/gny137.
8. Di Novi, C.; Jacobs, R.; Migheli, M. The Quality of Life of Female Informal Caregivers: From Scandinavia to the Mediterranean Sea. *European Journal of Population* **2015**, *31*, 309–333. https://doi.org/10.1007/s10680-014-9336-7.
9. Roth, D.L.; Fredman, L.; Haley, W.E. Informal caregiving and its impact on health: a reappraisal from population-based studies. *The Gerontologist* **2015**, *55*, 309–319. https://doi.org/10.1093/geront/gnu177.
10. Pinquart, M.; Sörensen, S. Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychol Aging* **2003**, *18*, 250–267. https://doi.org/10.1037/0882-7974.18.2.250.
11. Roth, D.L.; Perkins, M.; Wadley, V.G.; Temple, E.M.; Haley, W.E. Family caregiving and emotional strain: associations with quality of life in a large national sample of middle-aged and older adults. *Qual Life Res* **2009**, *18*, 679–688. https://doi.org/10.1007/s11136-009-9482-2.
12. Schulz, R.; Sherwood, P.R. Physical and mental health effects of family caregiving. *Am J Nurs* **2008**, *108*, 23–27; quiz 27. https://doi.org/10.1097/01.NAJ.0000336406.45248.4c.
13. Vitaliano, P.P.; Zhang, J.; Scanlan, J.M. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychol Bull* **2003**, *129*, 946–972. https://doi.org/10.1037/0033-2909.129.6.946.
14. Schulz, R.; Beach, S.R.; Czaja, S.J.; Martire, L.M.; Monin, J.K. Family Caregiving for Older Adults. *Annu Rev Psychol* **2020**, *71*, 635–659. https://doi.org/10.1146/annurev-psych-010419-050754.
15. Riffin, C.; Van Ness, P.H.; Wolff, J.L.; Fried, T. Multifactorial Examination of Caregiver Burden in a National Sample of Family and Unpaid Caregivers. *J Am Geriatr Soc* **2019**, *67*, 277–283. https://doi.org/10.1111/jgs.15664.
16. Jütten, L.H.; Mark, R.E.; Sitskoorn, M.M. Predicting self-esteem in informal caregivers of people with dementia: Modifiable and non-modifiable factors. *Aging Ment Health* **2020**, *24*, 221–226. https://doi.org/10.1080/13607863.2018.1531374.
17. Institute of Medicine Committee on Using Performance Monitoring to Improve Community, H. In *Improving Health in the Community: A Role for Performance Monitoring*, Durch, J.S., Bailey, L.A., Stoto, M.A., Eds. National Academies Press (US)
18. Copyright 1997 by the National Academy of Sciences. All rights reserved.: Washington (DC), 1997; 10.17226/5298.
19. Yazdanmanesh, M.; Esmaeili, R.; Nasiri, M.; Vasli, P. Relieving care burden and promoting health-related quality of life for family caregivers of elderly people with Alzheimer's disease via an empowerment program. *Aging clinical and experimental research* **2023**, *35*, 73–83. https://doi.org/10.1007/s40520-022-02277-8.
20. Posadzki, P.; Pieper, D.; Bajpai, R.; Makaruk, H.; Könsgen, N.; Neuhaus, A.L.; Semwal, M. Exercise/physical activity and health outcomes: an overview of Cochrane systematic reviews. *BMC public health* **2020**, *20*, 1724. https://doi.org/10.1186/s12889-020-09855-3.
21. Twiddy, H.M.; Wilson, P.B.; Swain, D.P.; Branch, J.D.; Morrison, S.; Reynolds, L.J. The association of moderate-to-vigorous and light-intensity physical activity on static balance in middle-aged and older-aged adults. *Aging clinical and experimental research* **2023**, 10.1007/s40520-023-02344-8. https://doi.org/10.1007/s40520-023-02344-8.
22. Jansons, P.; Fyfe, J.J.; Dalla Via, J.; Daly, R.M.; Scott, D. Barriers and enablers associated with participation in a home-based pragmatic exercise snacking program in older adults delivered and monitored by Amazon Alexa: a qualitative study. *Aging clinical and experimental research* **2023**, 10.1007/s40520-022-02327-1, 1-9. https://doi.org/10.1007/s40520-022-02327-1.
23. Harpham, C.; Gunn, H.; Marsden, J.; Connolly, L. The feasibility, safety, physiological and clinical effects of high-intensity interval training for people with Parkinson's: a systematic review and meta-analysis. *Aging clinical and experimental research* **2023**, 10.1007/s40520-022-02330-6. https://doi.org/10.1007/s40520-022-02330-6.
24. Lindsay, R.K.; Vseteckova, J.; Horne, J.; Smith, L.; Trott, M.; De Lappe, J.; Soysal, P.; Pizzol, D.; Kentzer, N. The prevalence of physical activity among informal carers: a systematic review of international literature. *Sport Sciences for Health* **2022**, *18*, 1071–1118. https://doi.org/10.1007/s11332-021-00893-x.
25. Institute of Medicine Committee on Assuring the Health of the Public in the 21st, C. In *The Future of the Public's Health in the 21st Century*, National Academies Press (US)
26. Copyright 2003 by the National Academy of Sciences. All rights reserved.: Washington (DC), 2002; 10.17226/10548.

27. Sieck, C.J.; Sheon, A.; Ancker, J.S.; Castek, J.; Callahan, B.; Siefer, A. Digital inclusion as a social determinant of health. *NPJ Digit Med* **2021**, *4*, 52. https://doi.org/10.1038/s41746-021-00413-8.
28. Shaffer, K.M.; Chow, P.I.; Cohn, W.F.; Ingersoll, K.S.; Ritterband, L.M. Informal Caregivers' Use of Internet-Based Health Resources: An Analysis of the Health Information National Trends Survey. *JMIR Aging* **2018**, *1*, e11051. https://doi.org/10.2196/11051.
29. Officer, A.; de la Fuente-Núñez, V. A global campaign to combat ageism. *Bull World Health Organ* **2018**, *96*, 295–296. https://doi.org/10.2471/blt.17.202424.
30. Mikton, C.; de la Fuente-Núñez, V.; Officer, A.; Krug, E. Ageism: a social determinant of health that has come of age. *Lancet (London, England)* **2021**, *397*, 1333–1334. https://doi.org/10.1016/s0140-6736(21)00524-9.
31. Zwar, L.; König, H.H.; Hajek, A. Can Informal Caregiving be Perceived as Rejuvenating? Changes in Perceptions of Ageing at Onset and End of Informal Caregiving during Different Stages of Life. *Gerontology* **2023**, *69*, 483–494. https://doi.org/10.1159/000527745.
32. Berkman, N.D.; Sheridan, S.L.; Donahue, K.E.; Halpern, D.J.; Crotty, K. Low health literacy and health outcomes: an updated systematic review. *Ann Intern Med* **2011**, *155*, 97–107. https://doi.org/10.7326/0003-4819-155-2-201107190-00005.
33. Coughlin, S.S.; Vernon, M.; Hatzigeorgiou, C.; George, V. Health Literacy, Social Determinants of Health, and Disease Prevention and Control. *J Environ Health Sci* **2020**, *6*.
34. Lorini, C.; Buscemi, P.; Mossello, E.; Schirripa, A.; Giammarco, B.; Rigon, L.; Albora, G.; Giorgetti, D.; Biamonte, M.A.; Fattorini, L.; et al. Health literacy of informal caregivers of older adults with dementia: results from a cross-sectional study conducted in Florence (Italy). *Aging clinical and experimental research* **2023**, *35*, 61–71. https://doi.org/10.1007/s40520-022-02271-0.
35. Drageset, J.; Nygaard, H.A.; Eide, G.E.; Bondevik, M.; Nortvedt, M.W.; Natvig, G.K. Sense of coherence as a resource in relation to health-related quality of life among mentally intact nursing home residents - a questionnaire study. *Health Qual Life Outcomes* **2008**, *6*, 85. https://doi.org/10.1186/1477-7525-6-85.
36. Potier, F.; Degryse, J.M.; Henrard, S.; Aubouy, G.; de Saint-Hubert, M. A high sense of coherence protects from the burden of caregiving in older spousal caregivers. *Archives of gerontology and geriatrics* **2018**, *75*, 76–82. https://doi.org/10.1016/j.archger.2017.11.013.
37. Dziuba, A.; Krell-Roesch, J.; Schmidt, S.C.E.; Bös, K.; Woll, A. Association Between Sense of Coherence and Health Outcomes at 10 and 20 Years Follow-Up: A Population-Based Longitudinal Study in Germany. *Front Public Health* **2021**, *9*, 739394. https://doi.org/10.3389/fpubh.2021.739394.
38. Del-Pino-Casado, R.; Espinosa-Medina, A.; López-Martínez, C.; Orgeta, V. Sense of coherence, burden and mental health in caregiving: A systematic review and meta-analysis. *J Affect Disord* **2019**, *242*, 14–21. https://doi.org/10.1016/j.jad.2018.08.002.
39. Zarit, S.H.; Reever, K.E.; Bach-Peterson, J. Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist* **1980**, *20*, 649–655. https://doi.org/10.1093/geront/20.6.649.
40. Ware, J., Jr.; Kosinski, M.; Keller, S.D. A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. *Med Care* **1996**, *34*, 220–233. https://doi.org/10.1097/00005650-199603000-00003.
41. Craig, C.L.; Marshall, A.L.; Sjöström, M.; Bauman, A.E.; Booth, M.L.; Ainsworth, B.E.; Pratt, M.; Ekelund, U.; Yngve, A.; Sallis, J.F.; et al. International physical activity questionnaire: 12-country reliability and validity. *Med Sci Sports Exerc* **2003**, *35*, 1381–1395. https://doi.org/10.1249/01.Mss.0000078924.61453.Fb.
42. Marquet, M.; Missotten, P.; Schroyen, S.; van Sambeek, I.; van den Akker, M.; Van Den Broeke, C.; Buntinx, F.; Adam, S. A Validation of the French Version of the Attitudes to Aging Questionnaire (AAQ): Factor Structure, Reliability and Validity. *Psychol Belg* **2016**, *56*, 80–100. https://doi.org/10.5334/pb.301.
43. Buckinx, F.; Charles, A.; Rygaert, X.; Reginster, J.Y.; Adam, S.; Bruyère, O. Own attitude toward aging among nursing home residents: results of the SENIOR cohort. *Aging clinical and experimental research* **2018**, *30*, 1151–1159. https://doi.org/10.1007/s40520-018-1013-y.
44. Levy, B.R.; Zonderman, A.B.; Slade, M.D.; Ferrucci, L. Memory shaped by age stereotypes over time. *J Gerontol B Psychol Sci Soc Sci* **2012**, *67*, 432–436. https://doi.org/10.1093/geronb/gbr120.
45. Sørensen, K.; Van den Broucke, S.; Pelikan, J.M.; Fullam, J.; Doyle, G.; Slonska, Z.; Kondilis, B.; Stoffels, V.; Osborne, R.H.; Brand, H. Measuring health literacy in populations: illuminating the design and development process of the European Health Literacy Survey Questionnaire (HLS-EU-Q). *BMC public health* **2013**, *13*, 948. https://doi.org/10.1186/1471-2458-13-948.
46. Mekhail, K.T.; Burström, B.; Marttila, A.; Wångdahl, J.; Lindberg, L. Psychometric qualities of the HLS-EU-Q16 instrument for parental health literacy in Swedish multicultural settings. *BMC public health* **2022**, *22*, 293. https://doi.org/10.1186/s12889-021-12346-8.
47. Antonovsky, A. The structure and properties of the sense of coherence scale. *Soc Sci Med* **1993**, *36*, 725–733. https://doi.org/10.1016/0277-9536(93)90033-z.
48. Chong, E.; Crowe, L.; Mentor, K.; Pandanaboyana, S.; Sharp, L. Systematic review of caregiver burden, unmet needs and quality-of-life among informal caregivers of patients with pancreatic cancer. *Support Care Cancer* **2022**, *31*, 74. https://doi.org/10.1007/s00520-022-07468-7.

49. D'Aoust, R.F.; Brewster, G.; Rowe, M.A. Depression in informal caregivers of persons with dementia. *International journal of older people nursing* **2015**, *10*, 14–26. https://doi.org/10.1111/opn.12043.
50. Cai, Y.; Simons, A.; Toland, S.; Zhang, J.; Zheng, K. Informal caregivers' quality of life and management strategies following the transformation of their cancer caregiving role: A qualitative systematic review. *Int J Nurs Sci* **2021**, *8*, 227–236. https://doi.org/10.1016/j.ijnss.2021.03.006.
51. Ervin, J.; Taouk, Y.; Fleitas Alfonzo, L.; Peasgood, T.; King, T. Longitudinal association between informal unpaid caregiving and mental health amongst working age adults in high-income OECD countries: A systematic review. *EClinicalMedicine* **2022**, *53*, 101711. https://doi.org/10.1016/j.eclinm.2022.101711.
52. Sheppard, K.D.; Brown, C.J.; Hearld, K.R.; Roth, D.L.; Sawyer, P.; Locher, J.L.; Allman, R.M.; Ritchie, C.S. Symptom burden predicts nursing home admissions among older adults. *J Pain Symptom Manage* **2013**, *46*, 591–597. https://doi.org/10.1016/j.jpainsymman.2012.10.228.
53. Egan, K.J.; Hodgson, W.; Imperatore, G.; Dunlop, M.D.; Maguire, R.; Kirk, A. Supporting Physical Activity for Informal Caregivers during and beyond COVID-19: Exploring the Feasibility, Usability and Acceptability of a Digital Health Smartphone Application, 'CareFit'. *Int J Environ Res Public Health* **2022**, *19*. https://doi.org/10.3390/ijerph191912506.
54. Puig-Ribera, A.; Arumí-Prat, I.; Cirera, E.; Solà, M.; Codina-Nadal, A.; Palència, L.; Biaani, B.; Pérez, K. Use of the Superblock model for promoting physical activity in Barcelona: a one-year observational comparative study. *Archives of public health = Archives belges de sante publique* **2022**, *80*, 257. https://doi.org/10.1186/s13690-022-01005-y.
55. Zajkowska, M.R.O. Informal Elderly Caregiving and Time Spent on Leisure: Evidence from Time Use Survey. *Ageing International* **2020**, *45*, pages393–410.
56. Cubukcu, M. Evaluation of quality of life in caregivers who are providing home care to cancer patients. *Support Care Cancer* **2018**, *26*, 1457–1463. https://doi.org/10.1007/s00520-017-3968-1.
57. Baik, D.; Song, J.; Tark, A.; Coats, H.; Shive, N.; Jankowski, C. Effects of Physical Activity Programs on Health Outcomes of Family Caregivers of Older Adults with Chronic Diseases: A Systematic Review. *Geriatr Nurs* **2021**, *42*, 1056–1069. https://doi.org/10.1016/j.gerinurse.2021.06.018.
58. Granet, J.; Peyrusqué, E.; Ruiz, F.; Buckinx, F.; Abdelkader, L.B.; Dang-Vu, T.T.; Sirois, M.J.; Gouin, J.P.; Pageaux, B.; Aubertin-Leheudre, M. Online physical exercise intervention in older adults during lockdown: Can we improve the recipe? *Aging clinical and experimental research* **2023**, 10.1007/s40520-022-02329-z, 1-10. https://doi.org/10.1007/s40520-022-02329-z.
59. Buckinx, F.; Aubertin-Leheudre, M.; Daoust, R.; Hegg, S.; Martel, D.; Martel-Thibault, M.; Sirois, M.J. Feasibility and Acceptability of Remote Physical Exercise Programs to Prevent Mobility Loss in Pre-Disabled Older Adults during Isolation Periods Such as the COVID-19 Pandemic. *The journal of nutrition, health & aging* **2021**, *25*, 1106–1111. https://doi.org/10.1007/s12603-021-1688-1.
60. Diehl, M.; Wahl, H.W.; Barrett, A.E.; Brothers, A.F.; Miche, M.; Montepare, J.M.; Westerhof, G.J.; Wurm, S. Awareness of Aging: Theoretical Considerations on an Emerging Concept. *Dev Rev* **2014**, *34*, 93–113. https://doi.org/10.1016/j.dr.2014.01.001.
61. Kotter-Grühn, D.; Kleinspehn-Ammerlahn, A.; Gerstorf, D.; Smith, J. Self-perceptions of aging predict mortality and change with approaching death: 16-year longitudinal results from the Berlin Aging Study. *Psychol Aging* **2009**, *24*, 654–667. https://doi.org/10.1037/a0016510.
62. Rubin, D.C.; Berntsen, D. People over forty feel 20% younger than their age: subjective age across the lifespan. *Psychon Bull Rev* **2006**, *13*, 776–780. https://doi.org/10.3758/bf03193996.
63. Langballe, E.M.; Skirbekk, V.; Strand, B.H. Subjective age and the association with intrinsic capacity, functional ability, and health among older adults in Norway. *Eur J Ageing* **2023**, *20*, 4. https://doi.org/10.1007/s10433-023-00753-2.
64. Costa, A.; Loura, D.S.; Nogueira, P.; Melo, G.; Gomes, I.; Ferraz, I.; Viegas, L.; Henriques, M.A. Informal Caregivers' Health Literacy in Lisbon, Portugal: A Profile for Health Promotion Prioritization. *Geriatrics (Basel)* **2022**, *7*. https://doi.org/10.3390/geriatrics7050092.
65. Jiang, Y.; Sereika, S.M.; Lingler, J.H.; Tamres, L.K.; Erlen, J.A. Health literacy and its correlates in informal caregivers of adults with memory loss. *Geriatr Nurs* **2018**, *39*, 285–291. https://doi.org/10.1016/j.gerinurse.2017.10.008.
66. Koelen, M.; Eriksson, M. Older People, Sense of Coherence and Community. In *The Handbook of Salutogenesis*, Mittelmark, M.B., Bauer, G.F., Vaandrager, L., Pelikan, J.M., Sagy, S., Eriksson, M., Lindström, B., Meier Magistretti, C., Eds. Springer Copyright 2022, The Author(s). Cham (CH), 2022; 10.1007/978-3-030-79515-3_19pp. 185-199.