

Online activities among elder informal caregivers: Results from a cross-sectional study

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Abstract

Objectives: The internet can be used as a source to gain information or support during highly demanding circumstances, e.g. providing informal care. While internet use has been studied among older people, less is known about informal caregivers' online behaviour. This study aims to explore differences in internet use regarding online activities between informal caregivers and non-caregivers.

Methods: We used data of the Dutch Longitudinal Internet Studies for the Social Sciences panel (2014), including people aged 65 and older (N = 1413). To test differences with regard to 15 common internet activities; descriptive statistics and χ^2 tests were conducted.

Results: The sample included 1197 participants aged 65 and older, and 325 (27.2%) were identified as informal caregivers. It was found that informal caregivers played more online games (χ^2 (1, 1198) = 6.20, p = 0.01), while non-caregivers more often read online news (χ^2 (1, 1198) = 4.44, p = 0.04) and were more active on social network websites (χ^2 (1, 1198) = 5.07, p = 0.02) compared to their counterparts.

Conclusion: Based on a representative sample, the results show that informal caregivers do not use the internet more for information seeking, but more often for playing online games, which may indicate that the internet is used to compensate for stress. Further research is needed to identify how informal caregivers can be supported by online services.

Keywords

Informal caregiver, internet use, online activities, older people

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Introduction

In the Netherlands, approximately three million people (17.8% of the total population) are aged 65 years and older.¹ The rapidly growing number of older people is accompanied by an increase in chronic and mental diseases. Since most older people wish to stay at home, within a familiar environment, for as long as possible,² informal caregivers (ICGs) are of significant importance, and are anticipated and supported by the government.³ ICGs are generally family members or close relatives that provide unpaid support for daily living activities, such as housework or personal care, to the care recipient. In the Netherlands, roughly 12–15% of the adult population provides informal care to family members or close friends with (mental) health problems.⁴ ICGs are therefore an indispensable part of the

care system.⁵ The highest percentage of ICGs can be found in the age group 50–65 years, while people aged 65 years and older provide more hours of informal care.^{4,6} The current demographic trend indicates that the number of older ICGs is rising and will become larger in the future.

Among middle-aged to older adults, the task of informal caregiving is associated with positive and negative

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aspects. More specifically, in early stages of caregiving, ICGs report having higher levels of self-esteem, because they can care for a relative; this new task enables them to develop new skills^{7–9} and they perceive caregiving as a positive experience.¹⁰ Regardless of the positive aspects, the literature is dominated by negative aspects related to informal caregiving.¹¹ Providing informal care is often perceived as demanding, time consuming and burdensome.^{12–14} ICGs report poorer health status compared to non-caregivers.^{15,16} Furthermore, ICGs have a higher risk of developing depressive symptoms and a lower quality of life.^{17–19}

Due to these severe burdens, ICGs are also called the 'invisible second patient'.²⁰ Risk factors for perceiving informal care tasks as burdensome have been found in situations where ICGs experience high levels of stress due to experiencing a lack of coping skills and information. In contrast, social support has been found to play a protective role against perceived stress among caregivers.^{21–24} To support ICGs, several face-to-face interventions have been developed, and positive effects have been found in outcomes on caregiving confidence, increased knowledge, decreased symptoms of depression and, in some cases, even on the caregiver's quality of life.^{25–27}

Despite the positive effects of these interventions for ICGs, they are used scarcely. Only one-third of ICGs in Europe make use of support services,²⁸ and in the Netherlands, one-third of ICGs indicate having received information, advice and emotional support.²⁹ The main reasons for not using caregiving support services varied from bureaucracy, high cost and feeling no need to do so, to difficulties related to accessibility.²⁸ To overcome these barriers, the internet appears to be a promising medium for providing knowledge and supportive interventions that can potentially increase participation rates among ICGs.³⁰ This is important, because internet-based interventions have numerous advantages for participants: they can be used at home at a convenient time, are easy assessable and participants perceive more anonymity when using such interventions. Intervention content can be personalized and tailored to specific needs; furthermore, internet-based interventions are less expensive compared to face-to-face interventions.³¹⁻³³ Internet-based interventions for ICGs can have a positive impact on perceived stress, burden, coping skills, knowledge, and general mental health.³³ Moreover, they can reduce symptoms of depression and anxiety,³⁴ and more online peer interactions have been requested by ICGs.³⁵

Despite these promising findings and possibilities provided by the internet, it is known that older people, aged 65 years and older, belong to a group that uses the internet the least.^{36,37} Nevertheless, 78% of Dutch people aged 65 and older have access to the

internet and, among them, 49% use the Internet on a daily basis and 14% at least once a week.³⁸

While internet usage and online behaviour among older people have been studied,³⁹ less is known about ICGs' online behaviour. The caregivers' stress process model developed by Pearlin and colleagues⁴⁰ postulates that caregivers perceive levels of stress according to the use of resources and coping strategies, such as social support. Since the internet is easily available and can provide information as well as social support, it is assumed that ICGs will make more use of the internet compared to non-ICGs. It can be expected that ICGs and non-ICGs engage in different online activities. We assume that ICGs may possibly seek more information online and may make more use of social interaction applications, such as emails or chatting, in order to receive social support.

In summary, in order to use the potential of the internet to support older people, particularly those with caregiving tasks, more in-depth insight is needed into the online behaviour of ICGs. This knowledge can be useful for adjusting online information and support services. Therefore, this study aims to provide insight into different usage patterns of the internet by ICGs.

Methods

This study uses data from the Dutch Longitudinal Internet Studies for the Social Sciences (LISS) household panel. The LISS panel is a representative sample of Dutch individuals who participate in monthly internet surveys. The panel is based on a true probability sample of households drawn from the population register. Households that are willing to participate, but have no computer and/or internet connection, are provided with both to enable them to complete the questionnaires. People who declared having participated in the panel were sent a confirmation email and a letter including login codes. With the login, participants confirmed their willingness to participate in the panel and received access to the questionnaire. In general, the panel consists of approximately 7000 individuals aged 16 and older, who complete monthly online questionnaires on different topics.

For the current study, relevant information was taken from the questionnaire on social integration and leisure, combined with the questionnaire on background variables, from 2014. The longitudinal survey about leisure time is assessed once a year.⁴¹ For this survey, 7522 household members were selected; 6643 (88.3%) responded and 6485 (86.2%) completed the questionnaire.

Participants received rewards for completing in questionnaires (€15 per hour). Data were collected and administered by CentERdata (Tilburg University, The Netherlands; www.centerdata.nl/en). For more information about the LISS panel, visit: www.lissdata.nl.

Measurements

From the background variables questionnaire, sociodemographic information about age, gender, education, income, civil status, partner, number of children, living environment, satisfaction with social contacts, amount of time spent with family, neighbors, friends and whether people provided informal care were used.

Informal caregiving was assessed with one item: 'Did you perform any informal care over the past 12 months; that is, did you regularly help someone in your environment requiring help due to a disease or other affliction?' (1 = yes, 0 = no). Accordingly, participants who responded with 'no' were classified as non-ICGs.

Gender was measured dichotomously (0 = male, 1 = female).

Education was assessed by asking for the highest obtained educational level and was categorized into three groups: lower (1 = no education, primary or lower vocational school), middle (2 = secondary vocational school or high school) and higher (3 = higher professional education or university) educational level, conforming to the guidelines of Statistics Netherlands.⁴²

On the basis of the personal net monthly income in Euros, income was categorized into three groups: low $(1 < \varepsilon 1532)$, middle $(2 = \varepsilon 1533 - \varepsilon 2481)$ and high $(3 > \varepsilon 2482)$.⁴³ If personal net monthly income had missing values, it was imputed on the basis of information regarding gross income, if available; the method used for this imputation is described elsewhere.⁴⁴

Participants were asked to describe their civil status with the following options: 'married', 'separated', 'divorced', 'widow or widower', or 'never been married'.

It was assessed whether participants lived together with their partner (0 = no, 1 = yes).

Participants were asked how many children lived at home, which could be indicated from zero to nine, or more.

The item living area indicates the urban character of respondents based on density per km^2 ($\geq 2500 =$ extremely urban, 1500-2500 = very urban, 1000-1500 = moderately urban, 500-1000 = slightly urban and < 500 = not urban).

Satisfaction with social contacts was assessed using one item ranging from 0 (not at all) to 10 (completely satisfied).

With one item each, it was assessed how much time participants spend with (a) their family members outside their household, (b) with someone from the neighborhood and (c) with friends outside their own

In order to indicate different internet activities, we used 15 items, collected in 2014 by the Social Integration and Leisure questionnaire. Participants were asked if they ever spent time on: (a) 'email'; (b) 'searching for information on the internet (e.g. about hobbies)'; (c) 'searching for information on the internet (e.g. comparing products)'; (d) 'purchasing items via the internet': (e) 'watching movies online': (f) 'downloading software, films, music'; (g) 'internet banking'; (h) 'playing internet games'; (i) 'reading news online'; (j) 'being active on social network websites like Facebook'; (k) 'reading, writing blogs'; (l) 'posting, editing, and watching pictures, films via social media'; (m) 'chatting, video calling, sending messages'; (n) 'visiting forums, blogs'; (o) 'other activities on the internet'. Participants were asked if they ever spent time doing one of these activities by answering either 'yes' (=1) or 'no' (=0).

Statistical analysis

Data analysis was undertaken using SPSS 24 (IBM Corp, NY, USA). Only participants aged 65 years or older where included in the analyses; they were excluded if they indicated having received informal care themselves during the past 12 months (n = 152). Furthermore, 216 participants were excluded because they mentioned not using the internet except for participating in this panel (n = 74) or had missing values on this item (n = 142).

Descriptive statistics were used to describe the study sample characteristics. Differences between ICGs and non-ICGs with regard to sociodemographic characteristics were assessed using χ^2 tests for categorical variables, and a Student's *t*-test was used for continuous variables.

In order to achieve the research aim, frequency analysis was used to describe internet activities among ICGs and non-ICGs, and χ^2 tests were employed to assess the differences between these two groups. A *p*-value of 0.05 was defined as the level of significance. The Benjamini–Hochberg method was used to adjust *p*-values for multiple testing.^{45,46}

Results

Sample characteristics

As can be seen from Table 1, a total of 1197 participants aged 65 and older were included in this study. Within this sample, 872 (72.8%) participants were non-ICGs and 325 (27.2%) participants indicated having performed a wide variety of informal care,

	Total sample N (%)	Informal caregiver N (%)	Non-informal caregiver N (%)	Tests of differences between groups
Age				t (1195) = -2.76, p = 0.004
Mean (SD)	71.2 (SD = 5.29)	70.5 (SD = 4.93)	71.5 (SD = 5.39)	
Gender				χ^2 (1, 1197) = 12.53, $p < 0.00$
Male	656 (54.8)	151 (46.5)	505 (57.9)	
Female	514 (45.2)	174 (53.5)	367 (42.1)	
Education*				χ^2 (2, 1193) = 0.07, p = 0.96
High	376 (31.5)	101 (31.2)	275 (31.6)	
Middle	281 (23.6)	78 (24.1)	203 (23.4)	
Low	536 (44.9)	145 (44.8)	391 (45.0)	
ncome*				χ^2 (2, 1142) = 2.08, p = 0.35
High	45 (3.9)	15 (4.8)	30 (3.6)	
Middle	562 (49.2)	144 (46.2)	418 (50.4)	
Low	535 (46.8)	153(49.2)	382 (46.0)	
Civil status				χ^2 (4, 1197) = 2.68, p = 0.61
Married	797 (66.6)	206 (63.4)	591 (67.8)	
Separated	8 (0.7)	2 (0.6)	6 (0.7)	
Divorced	146 (12.2)	46 (14.2)	100 (11.5)	
Widow, widower	185 (15.5)	52 (16.0)	133 (15.3)	
Never been married	61 (5.1)	19 (5.8)	42 (4.8)	
ives together with a partner				χ^2 (1, 1197) = 1.16.44, p = 0.
Yes	831 (69.4)	218 (67.1)	613 (70.3)	
Number of children living at home				χ^2 (3, 1197) = 1.47, p = 0.69
None	1155 (96.5)	311 (95.7)	844 (96.8)	
One	35 (2.9)	11 (3.4)	24 (2.8)	
Two	4 (0.3)	2 (0.6)	2 (0.2)	
Tree	3 (0.3)	1 (0.3)	2 (0.2)	
iving area*				χ^2 (4, 1195) = 5.06, $p = 0.28$
Extremely urban	126 (10.5)	42 (12.9)	84 (9.7)	
Very urban	328 (27.4)	92 (28.3)	236 (27.1)	
Moderately urban	261 (21.8)	61 (18.8)	200 (23.0)	

		characteristics,				

Table 1. Continued.

	Total sample N (%)	Informal caregiver N (%)	Non-informal caregiver N (%)	Tests of differences between groups
Slightly urban	304 (25.4)	86 (26.5)	218 (25.1)	
Not urban	176 (14.7)	44 (13.5)	132 (15.2)	

*Contains missing values.





on average 9.2 hours per week (SD = 13.80), during the past 12 months.

Regarding the sociodemographic characteristics of ICGs and non-caregivers, it was found that females were more likely to provide informal care and that ICGs were slightly younger compared to non-ICGs. There were no other significant differences between the two groups in terms of sociodemographic characteristics.

Differences in internet activities among ICGs and non-ICGs

As can be seen from Figure 1 and Table 2, 15 common internet activities were compared between ICGs and non-ICGs. It was found that significantly more ICGs used the internet for playing games online (χ^2 (1, 1198)=6.20, p=0.01) in comparison to non-ICGs. In contrast to ICGs, significantly more non-ICGs were found to use the internet for reading news online (χ^2 (1, 1198)=4.44, p=0.04) and for remaining active on social media, with posting, editing, and watching pictures or films online (χ^2 (1, 1198) = 5.07, p = 0.02). It has been found that younger people (aged 65–70 years) used 7 of the 15 online activities significantly more often than older people (Table 3).

Discussion

Given the growing number of older people, ICGs and the importance of the internet, this study focused on differences in online activities among ICGs and non-ICGs.

The results from this study have shown that ICGs and non-ICGs do not differ much from each other regarding their online activities. Only for 3 of 15 online activities could differences be found and we acknowledge that, with our large sample size, small differences can attain statistical significance even if the difference is relatively small. Nevertheless, differences were found for reading news, being active on social networking websites and playing online games.

Did you ever spend time on	χ^2 (degrees of freedom)	<i>p</i> -value
Playing internet games/online gaming	6.20 (1)	0.01 ^a
Posting, editing and watching pictures and short films via social media like Instagram, YouTube, Vimeo, Vine or others	5.07 (1)	0.02 ^a
Reading online news and magazines	4.44 (1)	0.04 ^a
Searching for information on the internet (e.g. about hobbies, work, opening hours, daytrips, etc.)	2.47 (1)	0.12
Purchasing items via the internet	1.45 (1)	0.23
Watching online films or TV programmes	0.72 (1)	0.39
Reading and/or writing blogs	0.72 (1)	0.39
Social network sites Facebook, Twitter, LinkedIn, Google+, Myspace, Tumblr, Flickr or others	0.53 (1)	0.47
Email	0.48 (1)	0.49
Visiting (discussion) forums and internet communities	0.43 (1)	0.51
Searching for and comparing products/product information on the internet	0.34 (1)	0.56
Internet banking	0.29 (1)	0.58
Downloading software, music or films	0.08 (1)	0.78
Chatting, video calling or sending messages via social media like Instagram, Skype or similar services	0.03 (1)	0.86
Other activities on the internet	0.01 (1)	0.95

Table 2. χ^2 values comparing internet activities between informal caregivers and non-informal caregivers.

^aSignificant *p*-values after correcting for multiple comparisons according to the Benjamini—Hochberg procedure.

The finding that ICGs read news online less often compared to non-ICGs can be explained by the fact that, in our study, ICGs were more often female, who are known to make use of the internet less often to read news.⁴⁷ Other studies have shown that the internet is used by ICGs to gain (health-related) information,⁴⁸ while their preferences for news resources are often offline sources.

Interestingly, we found that ICGs were less often online on social websites, while previous studies confirmed that ICGs make use of such websites in order to receive social support and to get in touch with other ICGs.⁴⁹ It is possible that, due to the assessment of the question (do you ever spend time on: posting, editing, and watching pictures and short films via social media?), participants denied making use of social media websites for these specific purposes, but may instead use these websites offer. It seems reasonable that ICGs use these platforms to exchange information and receive support, since studies have found that ICGs who make use of such applications benefit in from it various forms, like less perceived loneliness and having better access to supportive services. 50

Furthermore, ICGs played online games more often in our sample compared to non-ICGs, which is known to be an appreciated online activity among older people.⁵¹ It may be reasonable to assume that ICGs make use of online games as a coping strategy to deal with stressful situations.⁵² Another study reports that ICGs spend more hours on the internet during emotionally stressful events.⁴⁸

Our findings concerning age are in line with previous studies showing that this personal characteristic also determines internet usage among older people.37,53,54 Being older is associated with poorer physical health and cognitive decline, which in turn can be associated with less internet use, since this behaviour requires cognitive functioning such as hand-mouse coordination.55 It may be possible that younger older people (aged 65–70 years) may have had experience of using the internet from a previous employment context.⁵⁶ Therefore, people in our sample with a higher educational level may have more internetand

Table 3. Comparison of three different age groups and online usage of 15 activities.

		General s	ample, N=:	1198	Informal	Informal caregivers, $N = 326$			
Did you ever spend time on	Age groups	N (yes)	χ ² (2)	<i>p</i> -value	N (yes)	χ² (2)	<i>p</i> -value		
Playing internet games/online gaming	65—70	172	1.55	0.46	54	1.76	0.42		
	71—76	93			35				
	77+	41			11				
Posting, editing, watching pictures and short films via social media like Instagram	65—70	115	6.73	0.03	22	0.81	0.67		
	71—76	46			13				
	77+	37			6				
Reading online news and magazines	65—70	317	3.20	0.20	79	0.18	0.92		
	71—76	168			42				
	77+	563			16				
Searching for information (e.g. about hobbies, work, opening hours, etc.)	65-70	609	20.42	<0.01 ^ª	183	2.42	0.23		
	71—76	331			89				
	77+	156			33				
Purchasing items via the internet	65—70	384	46.16	<0.01*	110	17.60	<0.01 ^a		
	71—76	164			38				
	77+	63			9				
Watching online films or TV programmes	65—70	120	2.23	0.33	39	1.69	0.43		
	71—76	55			18				
	77+	31			4				
Reading and/or writing blogs	65—70	68	3.82	0.15	21	1.05	0.59		
	71—76	32			8				
	77+	11			5				
Social network sites Facebook, Twitter, LinkedIn, Google+, Myspace, etc.	65—70	239	16.37	<0.01 ^a	68	1.84	0.40		
	71—76	102			28				
	77+	44			14				
Email	65—70	623	7.78	0.02	186	2.77	0.25		
	71—76	344			91				
	77+	171			35				
Visiting (discussion)forums and internet communities	65—70	33	12.56	<0.01 ^a	11	5.82	0.05		
							(continued)		

Table 3. Continued.

		General s	General sample, $N = 1198$			Informal caregivers, $N = 326$			
Did you ever spend time on	Age groups	N (yes)	χ ² (2)	<i>p</i> -value	N (yes)	χ ² (2)	<i>p</i> -value		
	71—76	4			0				
	77+	4			2				
searching for and comparing products/product information on the internet	65—70	496	23.87	<0.01 ^a	146	2.67	0.26		
	71—76	249			67				
	77+	111			24				
Internet banking	65—70	516	16.30	<0.01 ^a	154	2.27	0.32		
	71—76	275			72				
	77+	122			26				
Downloading software, music or films	65—70	88	7.29	0.03	23	1.36	0.51		
	71—76	41			12				
	77+	12			1				
Chatting, video calling or sending messages via social media like Instagram, Skype etc.	65—70	197	28.68	<0.01 ^a	58	7.55	0.02		
	71—76	76			20				
	77+	24			4				
Other activities on the internet	65—70	95	5.31	0.07	24	0.07	0.97		
	71—76	37			12				
	77+	20			5				

General sample age groups: 65–70, n = 645; 71–76, n = 368; 77+, n = 185; informal caregiver age groups: 65–70, n = 192; 71–76, n = 98; 77+, $n = 36^{\circ}$ approaches significant after correction for multiple testing due to the Benjamini–Hochberg procedure.

computer-related skills, less computer anxiety, a more positive attitude, and higher self-efficacy regarding computer and internet use, which are strong predictors of internet use among older people.^{57–59}

Limitations

There are several limitations to this study. First, the data were collected by means of a cross-sectional survey among the Dutch general population, and causal relationships between ICGs and internet use cannot be drawn based on this study.

Second, the definition of 'informal caregiving' is extremely broad in the questionnaire. A clear classification about the tasks involved in this activity was also not assessed. Due to the fact that the needs of ICGs change over time and may depend on specific caregiving situations, a more detailed description of caregiving tasks could be helpful to identify different use patterns of online activities. In early stages, ICGs may have a higher need for practical information, while in later stages, social support may be of high interest.

Third, the group of ICGs in this study was small and therefore the results should not be generalized to another population. Nevertheless, the results indicate that there are some differences regarding internet use among ICGs and non-ICGs. Further studies are necessary to identify ICGs' online information needs.

Additionally, we only assessed whether people used the internet for several activities, not the frequency or intention of use. For example, it is possible that playing online games is a pleasure for some people but could also be stressful in terms of time investment or addictions. It can be expected that there will be high heterogeneity in terms of use (e.g. some people for an average number of hours a week, others for an average number of hours a day); this was not reviewed in-depth in this study.

Furthermore, other determinants that were not included in the questionnaire may be related to internet use among older people and ICGs, e.g. perceived health situation, internet literacy and attitudes toward internet use, in order to develop strategies that can address these factors and thereby improve internet use among ICGs.

Finally, the interpretation of these results should be conducted with caution, since in the original sample, a large majority (94%) of participants were classified as internet users, which overestimates the number of internet users aged 65 years and older in the Netherlands³⁸. We excluded non-internet users from our analysis but those internet users remaining in the analysis may be more advanced users because of the nature of this online panel.

Conclusion and further implications

We found small differences between ICGs and non-ICGs with regard to online activities, which may be helpful for identifying ICGs' online behaviour preferences. This knowledge may be of use for the development of online-based information aimed at this target group. ICGs made more use of online games and used the internet less often for reading news or posting videos/pictures on social media networking websites, which may be an indication that ICGs use the internet in their spare time to cope with stressful situations. The internet may be a source of information and social support, because ICG tasks often require monitoring tasks that make it difficult for them to leave the home.

Due to the rising number of internet-based interventions for older people and ICGs, further studies are necessary to identify strategies that can help to improve and support ICGs with their burdensome tasks.

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