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Predictors of Digital Support Services Use by Informal Caregivers: A Cross-Sectional Survey

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Predictors of Digital Support Services Use by Informal Caregivers: A Cross-Sectional Survey

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Abstract

Objectives Digital support services may provide informal caregivers with remote access to information and training about care issues. However, there is limited specific data on how factors such as demographics, socioeconomic resources and the caregiving context may influence caregivers' use of digital support services. The aim of this study is to identify associations between informal caregiver's characteristics and the use of the Internet to access digital support services in two countries: Italy and Sweden.

Setting and Participants A sample of 663 respondents participated in a cross-sectional survey by completing the online questionnaire. Respondents were recruited by the Italian National Institute of Health and Science on Ageing and the Swedish Family Care Competence Centre.

Primary and secondary outcome measures Logistic regression analyses were performed to assess predictors of caregivers' frequent use of the Internet to access digital support services.

Results Educational attainment (odds ratio [OR] 3.649, 95%CI: 1.424-9.350, $p=0.007$), hours per week spent caring (odds ratio [OR] 2.928, 95%CI: 1.481-5.791, $p=0.002$), total household income (odds ratio [OR] 0.378, 95%CI: 0.149-0.957, $p=0.040$), care recipient relationship to the caregiver (odds ratio [OR] 2.895, 95%CI: 1.037-8.083, $p=0.042$) and gender of care recipient (odds ratio [OR] 0.575, 95%CI: 0.356-0.928, $p=0.023$) were significant predictors in the multivariate analysis for the Italian caregivers group. Hours per week spent caring (odds ratio [OR] 2.401, 95%CI: 1.105-5.218, $p=0.027$) and age of care recipient (odds ratio [OR] 2.237,

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3 95%CI: 1.150-4.352, p=0.018) were significant predictors in the multivariate
4 analysis for the Swedish caregivers group.

5 **Conclusions** Digital support services could be important tools to empower informal
6 caregivers. When it comes to policy and practice in relation to caregivers, similarly
7 to other broad vulnerable groups, there is no 'one size fits all' approach, and it is
8 therefore important to consider the specific characteristics and needs of both
9 caregivers and care recipients.
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12 **Strengths and limitations of this study**

- 14 • This study is an international comparative study investigating the important
15 factors associated with the use of digital support services among informal
16 caregivers
- 17 • Multivariate logistic regression analyses enabled the effect of confounding
18 factors to be controlled for and predictors of use of digital support services
19 among informal caregivers to be identified
- 20 • We provide evidence that there is scope for some categories of caregivers to
21 be better supported with digital support services
- 22 • Given the cross-sectional design of our study, causal relationships cannot be
23 established
- 24 • The survey was conducted using the internet, and thus our findings may not
25 be generalizable to individuals who do not use the internet
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Introduction

Informal caregivers are individuals who provide care to ill, frail or disabled relatives, friends or others, without being trained or paid, in contrast to formal caregivers who offer professional services [1]. In Europe, 80% of all care is provided by informal caregivers who are often females, either providing care to a spouse, parent or parent-in-law, and a large share is provided by individuals who are older than standard retirement age [2-4]. Estimates on the economic value of unpaid informal care in the European Union (EU) Member States range from 50% to 90% of the overall costs of formal long-term care provision [4]. The available estimates of the number of informal caregivers ranges from 10% up to 25% of the total population in Europe [5]. The number of informal caregivers over 18 years of age who provide more than 20 hours per week of informal care to older adults and relatives with disability is estimated to be more than 70 million [5]. Informal caregivers provide the bulk of long-term care, including via contributions to both activities of daily living (personal care, feeding, dressing and grooming, emotional and social support, etc.) as well as instrumental activities of daily living (transportation, care coordination, etc.)

Caregiving may prove challenging and stressful for many informal caregivers. Caregivers often experience high levels of need for information and services. Available literature points to the importance of novel technology solutions as a promising approach for empowering and supporting informal caregivers [6-8]. Digital support services for informal caregivers are services provided by any private or public organization that address caregivers and/or care recipients' needs through technological devices that are integrated or not into a wider intervention program [9]. Digital support services may provide informal caregivers with remote access to information and training about care and caring-related issues through websites, mobile applications and online training materials [10]. These solutions may contribute to a more positive caregiving experience and may help to strengthen informal caregivers' sense of social inclusion and belonging [11]. Digital support services also have macro-level benefits as these solutions may help in the integration of informal and formal care through better care coordination and a reduction in unnecessary hospitalizations and lengths of stay [8-12]. Consequently, the deployment of these solutions may generate savings and contribute to the sustainability of care systems [8-12].

Considering the substantial information needs experienced by informal caregivers, the increased availability of digital support services for caregivers as well as the potential they offer, further understanding of caregivers' use of the Internet to access digital support services is needed [13,14], in order to determine whether factors such as demographics, socioeconomic resources and the caregiving context may influence caregivers' use of digital support services [15]. Previous literature on Internet use for health information seeking showed that young age, good health status and higher education are associated with a more frequent use [16-28]. Prior

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3 studies also found that females were likely to seek health information on the
4 Internet more frequently than males [16-28]. In the literature, very few studies
5 exclusively focus on caregivers' use of the Internet to access support services. While
6 informal caregivers have been identified as a population group which could benefit
7 from the provision of digital support services, there is limited specific data on how
8 factors such as demographics, socioeconomic resources and the caregiving context
9 may influence caregivers' use of the Internet to access digital support services.
10 Mapping the sociodemographic and socioeconomic profiles of informal caregivers
11 who do use and those who not use digital support services could help improve the
12 quality of these services available to them. The aim of this study is therefore to
13 identify associations between informal caregiver's characteristics and the use of the
14 Internet to access digital support services in two countries: Italy and Sweden.
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18 Italy and Sweden represent two European extremes with respect to several
19 dimensions. These include: familistic/universalistic orientation of care system
20 (Italy: family-based, Sweden: universal); the level of overall digital skills (low in
21 Italy: 42%, high in Sweden: 72%); and that of Internet use for health information-
22 seeking (low in Italy: 35%, high in Sweden: 62%) [29-32]. The two countries share
23 however also some similarities. Both Italy and Sweden are high income countries
24 and represent two of the oldest populations in Europe [33,34], also because they
25 report an almost similar, very high life expectancy at birth, estimated at 83 and 82
26 years for Italy and Sweden, respectively [33,34]. Estimates on the prevalence of
27 informal care in Italy ranges from 14% up to 26% of the country's population [35].
28 In Sweden, it is estimated that 18% of the 18+ population provides informal care on
29 a regular basis, corresponding to over 1.3 million people overall [36]. Exploring the
30 experiences of informal caregivers in accessing digital support services in these two
31 countries could inform future reforms of the health care system, and boost
32 caregivers' access to information, services and support via new technologies in
33 accordance to their needs. Moreover, since health promotion and patient
34 empowerment via digital technologies are also on the European agenda [37],
35 exploring the commonalities and differences in informal caregivers' access to digital
36 support services in these two countries, could contribute to provide
37 recommendations useful for implementing the EU agenda on the transformation of
38 the digital health and care agenda, while responding to caregivers' needs in each
39 country.
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Methods

Study Design

This online survey study used a cross-sectional design to identify associations between informal caregiver's characteristics and the use of Internet to access digital support services in two countries: Italy and Sweden. The data presented here, aimed at evaluating technology based support services for informal caregivers, were collected through the support of a partnership of different stakeholders belonging to the Eurocarers' network (European Association Working for Carers). They represent national level caregiver organizations in mostly EU Member States as well as research centers working on these topics, such as the Centre for Socio-Economic Research on Ageing of INRCA IRCCS (Italy's National Institute of Health and Science on Ageing), the Swedish Family Care Competence Centre, the University Medical Center Groningen (Netherlands), and the Department of Economics and Social Sciences of Marche Polytechnic University (Italy).

Survey Administration

The sample was identified from the registries of the Italian National Institute of Health and Science on Ageing and the Swedish Family Care Competence Centre. The online survey link was disseminated from November 2020 till April 2021 through the different communication channels of the Italian National Institute of Health and Science on Ageing and the Swedish Family Care Competence Centre. Study participants were included provided they were:

- informal caregivers of dependent adult individuals living at home;
- 18 years old and above;
- and either resident in Italy and able to understand Italian (for participants answering the Italian version of the questionnaire), or resident in Sweden and able to understand Swedish (for participants answering the Swedish version of the questionnaire).

Exclusion criteria were as follows:

- informal caregivers of pediatric patients;
- professional or paid caregivers.

The study sample included respondents who classified themselves as informal caregivers based on the survey question: "Do you provide unpaid care at home to an adult relative, neighbor or friend to help them take care of themselves?".

Participants were asked to answer this question with "yes" or "no," and if they answered "yes," then they were asked to continue with the questionnaire. A unique identification number was provided to each participant and stored together with the survey results, in order to eliminate duplicate entries. The participants were given the option to save their responses and return to complete the survey, or they could edit or clear the replies and initiate the survey another time. Data was recorded in the system using a password-protected data extraction form.

Variables and Measurement

Guided by Wilson's model of information-seeking behavior [38], the previous survey on services for supporting family carers of older dependent people in Europe "EUROFAMCARE" [39], and empirical evidence in the literature [16-28], this study included the following sets of independent variables: caregiver's demographics; caregiver's socioeconomic resources; and caregiving context. The dependent variable in this study is informal caregivers' frequent use of the Internet to access digital support services. In the survey, caregivers were asked to report how frequently they were using the Internet to access digital support services. Those using the Internet at least several times per month to access digital support services were classified as "frequent users", while those accessing it less often were classified as "infrequent users". Three demographic measures were included: caregiver's age, caregiver's gender and caregiver's health status. Ages were measured in chronological years and grouped into three categories: 18 to 39, 40 to 59, and 60 or older. Gender was measured nominally and was grouped into male and female. Caregiver's health status was grouped into poor, fair and good. Measures of social and economic circumstances were the caregiver's educational attainment and their total household income. Educational attainment was grouped into primary, secondary, bachelor's degree and higher than bachelor's degree. Income was assessed by asking the caregiver about their "monthly household net income from all sources". In order to distribute the income by different income groups and enhance the cross-national comparability of results between the two countries involved in this study, Italy and Sweden, we referred to the official figures of the national median equivalized disposable annual income from the European Commission's European statistical system "Eurostat" [32]. We used these official figures in classifying the participants into three groups of household net income in each of these two countries:

- lower income group: income is less than below 50% of the national median equivalized disposable annual income. This is equivalent to an income lower than 5802 Euro in the case of Italy and an income lower than 9356 Euro in the case of Sweden;
- middle income group: income is between below 50 % of the national median equivalized disposable annual income and above 60 % of the national median equivalized disposable annual income. This is equivalent to an income between 5802 Euro and 19658 Euro in the case of Italy and an income between 9356 Euro and 26826 Euro in the case of Sweden;
- upper income group: income is higher than 19658 Euro in the case of Italy and higher than 26826 Euro in Sweden.

Caregiving context was assessed using the following variables: reported number of weekly hours of care provided to the care recipient; reported number of years spent providing care; age and gender of the care recipient; relationship between the care recipient and the caregiver; and the level of dependency of the care recipient. Responses concerning the average number of weekly hours of caregiving have been

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3 grouped into four categories: 1) 10 hours or less, 2) 11 to 20 hours, 3) 21 to 40
4 hours and 4) more than 40 hours. Care duration was measured on the basis of the
5 caregiver's reported length of care provision to the care recipient (in number of
6 years), and respondents were classified into two groups: those caring for two years
7 or less; and those caring for a longer time. The age of the care recipient was
8 reported according to two groups: 60 years or less and more than 60 years. The
9 gender of care recipients was grouped into male and female. Caregivers were
10 requested to provide information about the person whom they care for, in order to
11 assess the relationship with the care recipient (e.g. parents / parents-in-law,
12 spouse/partner, friend/neighbor, child or other relative. The level of dependency of
13 the care recipient on the caregiver was clustered in 2 groups: high dependency and
14 low dependency.
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19 **Data Analysis**

20 The data analysis was conducted in three stages. It began with univariate analyses
21 including percentages to describe the characteristics of this sample of caregivers. At
22 the second stage, the relationship between the outcome variable and the
23 independent variables was examined using Pearson's chi-squared test with Yates'
24 continuity correction. Differences between groups were considered significant at
25 the 5% level ($p \leq 0.05$). Contingency tables have been assessed, before proceeding to
26 logistic regression, to ensure there were no cells with expected frequencies of fewer
27 than 5 to prevent biased estimates [40]. At the last stage, logistic regression analysis
28 was used to establish the ability of each variable to predict caregivers' frequent use
29 of the Internet to access digital support services while controlling the effects of
30 other variables. Variables identified as statistically significant in the bivariate
31 analysis were entered into logistic regression analysis for each measure of use of the
32 Internet to access digital support services.
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36 The logistic regression analyses produced odds ratios with 95% confidence
37 intervals to identify predictors of each measure. Results are reported in odds ratios,
38 which can be interpreted as the ratio of the probability that caregivers with a
39 particular characteristic (e.g., male gender) will use the Internet frequently to access
40 digital support services, over the probability they will use the Internet frequently to
41 access digital support services, had they not this characteristic. Odds ratios that are
42 higher than 1 indicate a positive association between a given variable and using the
43 Internet frequently to access digital support services, while an odds ratio lower than
44 1 indicates a negative association. Statistical analyses were performed using SPSS
45 software version 28.0 (IBM, Armonk, NY, USA).
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49 **Research Ethics Approval**

50 Permission to conduct the study was granted by the committee of Marche
51 Polytechnic University and was approved by the executive board on November 2,
52 2020 (1026353). Informal caregivers expressing interest in participating in the
53 study were informed about the aim of the study, the expected time to complete the
54 questionnaire, and that data would be stored by the Centre for Socio-Economic
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3 Research on Ageing of the Italian National Institute of Health and Science on Ageing.
4 Informed consent was obtained from all participants.
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8 **Patient and public involvement**

9 Patients or the public were not involved in the design, or conduct, or reporting, or
10 dissemination plans of our research.
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Results

Sample Description

A total of 663 informal caregivers, 410 from Italy and 253 from Sweden, participated in the survey by completing the online questionnaire. Table 1 presents the overall characteristics of the sample. Females represented a majority of respondents in the Italian group. The median age of caregivers was 54 years while the median age of care recipients was 73 years. Most Italian participants were providing care to a parent (n = 163, 39.8%), to a female care recipient (n=223, 54.4%), spent more than 40 hours per week providing care (n=170, 41.5%) and had completed secondary school or lower (n = 254, 62%). Nearly half of the participants (n=196, 47.8%) had an annual household income of less than 19.658 Euro. The big majority of caregivers in the Italian sample (n=342, 83.4%) reported a fair or poor health status, provided care to a highly-dependent care recipient (n=329, 80.2%) and had been providing care for more than 2 years (n=287, 70%) (Table 1). When compared to their Italian counterparts, both Swedish participants and their care recipients had a higher median age of 65 and 75 years respectively. Females made up a majority of participants in the Swedish sample. Most of the Swedish respondents reported providing care to a spouse/partner (n=97, 38.3%), a male care recipient (n=136, 53.8%), spent less than 10 hours per week providing care (n=112, 44.3%) and had completed a secondary school or lower (n = 149, 58.9%). Nearly half of the participants in the Swedish group (n=109, 43.1%) had annual household incomes less than 26.826 Euro. The majority of the caregivers in the Swedish sample (n=210, 83%) had a fair or poor health status, were caring for a highly dependent care recipient (n=139, 54.9%) and had been providing care for more than 2 years (n=142, 56.1%) (Table 1).

Table 1. Characteristics of the sample (total sample N =663)

Variables	Italian sample n = 410 n (%)	Swedish sample n = 253 n (%)
Gender		
Male	93 (22.7)	57 (22.5)
Female	317 (77.3)	196 (77.5)
Age		
Median	54	65
18-39	48 (11.7)	17 (6.7)
40-59	241 (58.8)	77 (30.4)
More than 60	121 (29.5)	159 (62.8)
Health Status		
Good	68 (16.6)	43 (17.0)
Fair	171 (41.7)	155 (61.3)
Poor	171 (41.7)	55 (21.7)

Education		
Primary	29 (7.1)	35 (13.8)
Secondary	225 (54.9)	114 (45.1)
Bachelor	114 (27.8)	61 (24.1)
Higher than bachelor's degree	42 (10.2)	43 (17.0)
Income		
Lower	39 (9.5)	17 (6.7)
Middle	157 (38.3)	92 (36.4)
Upper	214 (52.2)	144 (56.9)
Care recipient relationship to caregiver		
Parents (In law)	163 (39.8)	63 (24.9)
Spouse/Partner	64 (15.6)	97 (38.3)
Child	105 (25.6)	48 (19.0)
Friend/Neighbor	30 (7.3)	26 (10.3)
Other	48 (11.7)	19 (7.5)
Gender of care recipient		
Male	187 (45.6)	136 (53.8)
Female	223 (54.4)	117 (46.2)
Age of care recipient		
Median	73	75
60 or younger	160 (39.0)	73 (28.9)
More than 60	250 (61.0)	180 (71.1)
Level of dependency of the care recipient		
High dependency	329 (80.2)	139 (54.9)
Low dependency	81 (19.8)	114 (45.1)
Hours spend caring each week		
10 hours or less	115 (28.0)	112 (44.3)
	68 (16.6)	62 (24.5)
	57 (13.9)	30 (11.9)
11-20 hours	170 (41.5)	49 (19.4)
21-40 hours		
More than 40 hours		
Number of years providing care		
2 years or less	123 (30.0)	111 (43.9)
More than 2 years	287 (70.0)	142 (56.1)

Factors associated with caregivers' frequent use of the Internet to access digital support services

Table 2 shows the factors associated with caregivers' frequent use of the Internet to access digital support services in the bivariate analysis for each of the two countries of the study. In the Italian group, two-thirds of the respondents reported using the Internet at least several times per month to access digital support services. At the bivariate level, this was associated with two demographic variables, caregiver's age and health status, and two socio-economic measures, caregiver's educational attainment and total household income. Five measures of caregiving context – care recipient relationship to the caregiver, gender of care recipient, age of care recipient, hours per week spent caring and the level of dependency of the care recipient – were also linked to the frequent use of the Internet to access digital support services.

In the Swedish sample, 54.2 % of the participants reported using the Internet at least several times per month to access digital support services. In the bivariate analysis, caregiver's age was significantly associated with the frequent use of the Internet to access digital support services. Three measures of caregiving context were also linked with the frequent use of the Internet to access digital support services: care recipient relationship to the caregiver, age of care recipient and the number of hours spent caring each week. None of the measures of socio-economic resources was significantly associated with frequent use of the Internet to access digital support services in the Swedish sample.

Table 2. Factors associated with caregivers' frequent use of the Internet to access digital support services in the bivariate analysis

Variables	Using the Internet at least several times per month to access digital support services			
	Italian sample n = 410		Swedish sample n = 253	
	n (%)	p[1]	n (%)	p
All respondents	274 (66.8)		137 (54.2)	
Gender		0.123		0.344
Male	56 (60.2) [2]		34 (59.6)	
Female	218 (68.8)		103 (52.6)	
Age		0.010		0.035
18-39	23 (47.9)		6 (35.3)	
40-59	169 (70.1)		50 (64.9)	
More than 60	82 (67.8)		81 (50.9)	
Health Status		0.042		0.268
Good	37 (54.4)		35 (63.6)	
Fair	115 (67.3)		79 (51.0)	
Poor	122 (71.3)		23 (53.5)	
Education		0.008		0.901
Primary	12 (41.4)		20 (57.1)	
Secondary	161 (71.6)		60 (52.6)	
Bachelor's degree	76 (66.7)		32 (52.5)	
Higher than bachelor's degree	25 (59.5)		25 (58.1)	
Income		0.025		0.736
Lower	32 (82.1)		10 (58.8)	
Middle	110 (70.1)		47 (51.1)	
Upper	132 (61.7)		80 (55.6)	
Care recipient relationship to caregiver		< 0.001		0.014

Parents (In law) Spouse/Partner Child Friend/Neighbor Other	95 (58.3) 49 (76.6) 88 (83.8) 16 (53.3) 26 (54.2)		23 (36.5) 55 (56.7) 33 (68.8) 15 (57.7) 11 (57.9)	
Gender of care recipient		< 0.001		0.732
Male	141 (75.4)		75 (55.1)	
Female	133 (59.6)		62 (53.0)	
Age of care recipient		0.002		0.037
60 or younger	121 (75.6)		47 (64.4)	
More than 60	153 (61.2)		90 (50.0)	
Level of dependency of the care recipient		0.032		0.853
High dependency	228 (69.3)		76 (54.7)	
Low dependency	46 (56.8)		61 (53.5)	
Hours spend caring each week		< 0.001		0.022
10 hours or less				
11-20 hours	57 (49.6)		49 (43.8)	
21-40 hours	46 (67.6)		38 (61.3)	
More than 40 hours	38 (66.7)		17 (56.7)	
	133 (78.2)		33 (67.3)	
Number of years providing care		0.464		0.213
2 years or less	79 (64.2)		65 (58.6)	
More than 2 years	195 (67.9)		72 (50.7)	
Notes: [1] Differences between groups were considered significant at the 5% level ($p \leq 0.05$) [2] Male caregivers who are frequently using the Internet as a % of the total number of male caregivers in the sample.				

Predictors of caregivers' frequent use of the Internet to access digital support services

Table 3 summarizes the results of the logistic regression analysis predicting caregivers' frequent use of the Internet to access digital support services. For the Italian sample, nine variables significantly associated with a frequent use of the Internet to access digital support services in the bivariate analysis were entered into logistic regression analysis to identify which were predictive: caregiver's age, health status, educational attainment, total household income, care recipient relationship to the caregiver, gender of care recipient, age of care recipient, number of weekly hours of care and the level of dependency of the care recipient. The multivariate analysis indicated that educational attainment, number of weekly hours of care, total household income, care recipient relationship to the caregiver and gender of care recipient remained significant predictors. The strongest predictor was the educational attainment of the caregivers. Informal caregivers who completed education equivalent to a Bachelor's degree level had 3.649 times the odds of using the Internet at least several times per month to access digital support services compared to those who completed a primary education ($p=0.007$, 95%CI: 1.424-9.350). Caregivers who spend more than 40 hours per week providing care were almost 3 times more likely to be frequent users of the Internet to access digital support services in comparison with those who spend 10 hours or less per week providing care. The odds of frequent use of the Internet to access digital support services were 2.646 times higher for caregivers belonging to the lower household income group compared to caregivers belonging to the upper household income group ($p=0.040$, 95%CI: 0.149-0.957). Regarding the relationship between the caregiver and care recipient, the caregivers of a child had 2.895 times the odds of using the Internet at least several times per month to access digital support services compared to those who provide care to another relative ($p = 0.042$, 95% CI: 1.037-8.083). The odds of frequently accessing digital support services were 1.739 times higher for caregivers who provide care to a male care recipient compared to those providing care to a female care recipient ($p = 0.023$, 95% CI: 0.356-0.928). The logistic regression analysis to predict the frequent use of the Internet to access digital support services among Swedish participants consisted of the four statistically significant factors identified in the bivariate analysis: caregiver's age, care recipient relationship to the caregiver, age of care recipient and the number of weekly hours of care (Table 3). The number of weekly hours of care remained a significant predictor in the multivariate analysis for the Swedish sample and was the strongest predictor. Swedish respondents who spend more than 40 hours per week providing care were almost 2.5 times more likely to be frequent users of the Internet to access digital support services as opposed to those who dedicate 10 hours or less per week to care provision ($p = 0.027$, 95% CI: 1.105-5.218). The age of the caregiver also remained a significant predictor in the multivariate analysis. Caregivers in the age group 40-59 years were 2.237 times more likely to use the Internet at least several times per month to access digital support services in comparison with those of the age group 60+ years ($p = 0.018$, 95% CI: 1.150-4.352).

Table 3. Multivariate logistic regressions: caregivers' frequent use of the Internet to access digital support services

	Using the Internet at least several times per month to access digital support services					
	Italian sample n = 410			Swedish sample n = 253		
Variables	p Value	OR	95% CIs	p Value	OR	95% CIs
Age (in years) (Ref.: 60+)						
18-39	0.270	0.630	0.277-1.433	0.653	0.761	0.231-2.508
40-59	0.563	1.175	0.680-2.030	0.018	2.237	1.150-4.352
Health Status (Ref.: Good)				- ¹	-	-
Fair	0.703	1.105	0.661-1.850			
Poor	0.925	1.033	0.523-2.040			
Education (Ref.: Primary)				-	-	-
Secondary	0.008	3.236	1.358-7.711			
Bachelor	0.007	3.649	1.424-9.350			
Higher than bachelor's degree	0.077	2.624	0.901-7.647			
Income (Ref.: Lower)				-	-	-
Middle	0.170	0.514	0.198-1.331			
Upper	0.040	0.378	0.149-0.957			

Care recipient relationship to caregiver (Ref.: Other)						
Parents (In law)	0.554	0.797	0.376-1.688	0.086	0.370	0.119-1.150
Spouse/Partner	0.337	1.611	0.608-4.267	0.634	0.777	0.275-2.196
Child	0.042	2.895	1.037-8.083	0.911	1.075	0.302-3.828
Friend/Neighbor	0.673	0.806	0.297-2.192	0.885	1.095	0.320-3.744
Gender of care recipient (Ref.: Male)				-	-	-
Female	0.023	0.575	0.356-0.928			
Age of care recipient (Ref.: 60 or younger)						
More than 60	0.211	1.616	0.762-3.424	0.920	1.046	0.436-2.511
Level of dependency of the care recipient (Ref.: High dependency)				-	-	-
Low dependency	0.738	1.111	0.599-2.062			
Hours spend caring each week (Ref.: 10 hours or less)						
11-20 hours	0.021	2.241	1.127-4.459	0.085	1.822	0.921-3.602
21-40 hours	0.103	1.908	0.878-4.144	0.311	1.568	0.656-3.748
More than 40 hours	0.002	2.928	1.481-5.791	0.027	2.401	1.105-5.218
Notes:						
Only variables significantly associated with using the Internet frequently to access digital support services in the bivariate analysis were entered into multivariate logistic regression analysis						

Discussion

Principal findings

The purpose of this study was to identify important factors related to caregivers' use of the Internet to access digital support services in Italy and Sweden. The findings suggest that a number of demographic, socio-economic and caring circumstances are associated with the frequency of using the Internet to access digital support services among caregivers in both countries. Multivariate regression analyses enabled the effect of confounding factors to be controlled for and predictors of use to be identified. In consistency with literature [16-28], our findings indicate that caregiver's age, health status, caregiver's educational attainment, total household income, care recipient relationship to the caregiver, gender of care recipient, age of care recipient, hours per week spent caring and the level of dependency of the care recipient are all associated with use.

The study shows that more than half of the caregivers in both countries frequently use the Internet to access digital support services. While the use of the Internet for health information has been somewhat less common in Southern European countries, in our study the Italian and the Swedish groups report a similar use of the Internet to access digital support services. This may be related to the lower median age of the Italian sample compared to the Swedish one. Caregivers from Southern European countries with a family-based care system often lack support in terms of formal services and professional training from the government [41-43]. This shortcoming of support may increase their need for information and services. Digital support services may be an alternative support source that enables remote access to information and training about care and caring-related issues. Previous studies suggested that the use of the Internet for health information in Southern European countries is increasing, and that caregivers from this region are showing an increased interest in accessing new technologies aiming to support them [48-50].

In both countries, most of the caregivers who participated in the study were females, which is consistent with the results of previous works [25-28] and with the central role played by females in the provision of informal care [2-4]. In coherence with previous literature [39,41-48], the majority of Italian participants in our study provided care to a parent (in law) and spent more than 40 weekly hours of care, compared to their Swedish counterparts who provided care to spouse/partner and spent less than 10 hours per week providing care. Previous research showed that care for someone in one's own household is more common in Southern European countries than in Northern countries. In Southern countries, caregivers are more likely to live with their care recipients who often are parents / in-laws [39,41-48]. In Northern countries, in-household care is mostly spouse care, as it is rare for old persons to live with anyone else than their spouse. Consequently, caregivers from Southern European countries spend more hours in caregiving compared to caregivers from Northern countries.

As it is to be expected given previous research on using the Internet for general health information [19-24], the digital divide may negatively affect caregivers' use of

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3 the Internet to access digital support services [51,52]. The socioeconomic status of
4 users seems to be a significant factor that increases the digital divide in Southern
5 European countries [53-55]. This was apparent in our study, showing that the
6 divide was more significant in the case of the Italian group compared to the Swedish
7 one. While none of the measures of socio-economic resources was significantly
8 associated with a frequent use of the Internet to access digital support services in
9 the Swedish group, the strongest predictor for the frequency of Internet use in the
10 Italian group was the caregiver's educational attainment. Previous research has
11 shown that better-educated caregivers are more likely to be engaged in more
12 frequent online activities [25-28]. Income was also a predictor for the frequency of
13 Internet use to access digital support services in the Italian group, with higher odds
14 for caregivers belonging to the lower household income group. While literature
15 suggests that general Internet users in higher-income households are more likely
16 than others to go online frequently [56,57], previous studies on the Internet use for
17 health-related activities suggest that lower-income households may be more likely
18 than others to go online for support activities [16,58,59]. One possible explanation
19 is that those with higher incomes may have other means of support, while those
20 with lower incomes may turn to the Internet as an alternative source of assistance.
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26 The literature shows that age is a factor associated with Internet use [16-28]. In the
27 Swedish group of our study, age is a significant predictor of frequency of use. Age
28 remained an important predictor of use when the effects of other demographics,
29 socio-economic factors and caring circumstances had been controlled for. This
30 suggests that the relationship between age and use among Swedish caregivers
31 cannot be entirely explained by increased financial hardship in later life. Previous
32 research suggests that use of the Internet for health information is relatively
33 constant by age, until age 65 when it begins to decline [16].
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37 Patterns of use among caregivers in both countries also seem to be shaped by the
38 caring experience. The number of weekly hours of care was a significant predictor
39 for the frequency of Internet use by participants in both countries. Evidence from
40 literature suggests that high-intensity caregivers report higher levels of information
41 and service needs [60]. Given the availability and convenience of online sources,
42 high-intensity caregivers may turn to the Internet for digital support services.
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45 Limitations

46 Some limitations concerning this study need to be considered. The risk of the typical
47 sampling bias should be mentioned as higher income and more educated caregivers
48 are more likely to participate in research studies involving modern technologies,
49 which was the case in our study. Furthermore, the sample size, especially of the
50 Swedish sample, prevented us from carrying out more sophisticated statistical
51 analyses. Moreover, not all of those who provide informal caregiving and assistance
52 to others identify themselves as informal caregivers; consequently, we may have
53 failed to capture the experiences of these underrepresented groups. Although the
54 most important variables identified from empirical evidence in the literature were
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3 included in the models, residual external variables may still have influenced our
4 results. Conclusions drawn from this study results must be tempered by the fact that
5 respondents were already possessing minimal digital skills that would enable them
6 to access online services. It is possible that those who are not interested or involved
7 with technology or those with limited digital access are less likely to respond to
8 online surveys; consequently, the data collected online might be skewed and the
9 sample might be less representative for the population. These issues might have
10 influenced our findings and underline the need to interpret the findings from this
11 study and other studies on caregivers with some caution when generalizing the
12 findings.
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16 17 **Recommendations and Implications**

18 Our results indicate that digital support services may enable remote access to
19 information and training about care and caring-related issues. In this context,
20 looking for information and support services online may be considered an attempt
21 to close some knowledge gap. With the rapid technology advancement and
22 increased access to the Internet, more caregivers are expected to access these
23 services [61]. This suggests that the interaction with informal caregiver by health
24 care professionals and other parties with an interest in supporting them (e.g.
25 caregiver advocacy organizations) is an integral part of the value chain that
26 supports both communication and coordination of services. Hence, these parties
27 should all be more engaged with developing digital support services targeted at
28 informal caregivers, and carefully assess and identify their information and service
29 needs. Consequently, better targeted information could be provided to caregivers
30 through credible online sources. In this regard, an early assessment of caregivers'
31 needs and digital skills demonstrates that large-scale actions aiming to equip
32 informal caregivers with the digital skills they need to access digital support
33 services are needed. This is key to enable informal caregivers to identify the
34 available digital support services, and apply them to their own care situation. More
35 research is therefore needed to examine the extent to which existing digital support
36 services meet caregivers' information and service needs.
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38 Addressing socio-economic inequalities is likely to be key to reduce the digital
39 divide in caregivers' use of the Internet to access digital support services. As for the
40 influence of age and education on the digital divide, health care professionals,
41 service providers and social workers should pay particular attention to those
42 caregivers who are older and less educated. Access to computers and Internet
43 connections at public facilities, such as local libraries, community centers and senior
44 centers should be provided with extra support to accommodate caregivers'
45 information needs and overcome any barriers of use [15,19]. Moreover, seminars
46 and campaigns on how to access digital support services could enhance caregivers'
47 digital skills and experiences. Tailor-made campaigns and classes for older and less-
48 educated adults are needed to help address any barriers related to their use of
49 computers and new technology.
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51 The finding that caregivers who indicate higher-intensity levels of caregiving are
52 likely to engage in frequent Internet use to access digital support services may
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3 suggest that the Internet could be used to reach out to these caregivers and meet
4 their information and service needs. Online training materials, support groups,
5 social networking systems for peer support and volunteer call networks could be
6 used to reach out to caregivers [62]. Research is needed to further examine the
7 effectiveness of digital support services in helping caregivers, if we are to improve
8 these services and tailor them to the lives of those with substantial and
9 unpredictable caring responsibilities.
10

11 **Conclusions**

12 The findings from this study can provide guidance and assistance for the
13 deployment of digital support services for informal caregivers. Nevertheless, due to
14 rapid technological innovation, especially in this sector, continuous research needs
15 to be conducted and guidelines for developing digital support services should be
16 made adaptable to ongoing and future changes. The care sector is undergoing a fast
17 transformation and expansion also due to the direct and indirect effects of the
18 COVID-19 pandemic. Health and social care delivery systems experience a
19 technologically supported transition towards home care. New technologies are
20 being developed for informal caregivers and these tools may well offer benefits to
21 many of them. It is widely acknowledged that caregivers are a group with high levels
22 of unmet needs when it comes to their access to information and other services.
23 Digital support services could be important tools to empower and support informal
24 caregivers. On the other hand, it also needs to be recognized that informal
25 caregivers are a diverse population, living in a wide range of personal and social
26 circumstances. When it comes to policy and practice in relation to caregivers,
27 similarly to other broad vulnerable groups, there is no 'one size fits all' approach,
28 and it is therefore important to consider the specific characteristics and needs of
29 both caregivers and care recipients. Policy makers, health care professionals and all
30 parties with an interest in supporting informal caregivers are encouraged to identify
31 the outcomes that the latter regard as helpful, and to identify the interventions that
32 can achieve such outcomes in consultation with them. This applies as much to the
33 approach taken in relation to the development of digital support services as it does
34 to other services. While digital support services have the potential to meet some of
35 the needs of the caregivers, they cannot be seen as the only way to deliver
36 information and support. These services represent only one of many instrument in a
37 toolbox, and should therefore be tailored in a coordinated way with other existing
38 services, such as respite care, access to training, and recognition of skills and work-
39 life balance measures.
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47 **Contributorship statement**

48 AH developed the research idea and wrote the manuscript. GL and MH were
49 involved in the conceptualization of the project and provided critical evaluation and
50 approval of the final submitted manuscript
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52

53 **Competing interests**

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3 None declared

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8 **Data sharing statement**

9 Raw data cannot be made openly available as the participants provided an informed
10 consent, which indicated that the data to be collected shall not be disclosed.

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STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation	Page No
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	1-2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3-4
Objectives	3	State specific objectives, including any prespecified hypotheses	3-4
Methods			
Study design	4	Present key elements of study design early in the paper	5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants	5
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6
Bias	9	Describe any efforts to address potential sources of bias	6
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6-7
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	7-8
		(b) Describe any methods used to examine subgroups and interactions	7-8
		(c) Explain how missing data were addressed	7-8
		(d) If applicable, describe analytical methods taking account of sampling strategy	7-8
		(e) Describe any sensitivity analyses	7-8
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	9
		(b) Give reasons for non-participation at each stage	9
		(c) Consider use of a flow diagram	9
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	10-11
		(b) Indicate number of participants with missing data for each variable of interest	10-11
Outcome data	15*	Report numbers of outcome events or summary measures	12-17

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Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	12-17
		(b) Report category boundaries when continuous variables were categorized	12-17
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	12-17
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	12-17
Discussion			
Key results	18	Summarise key results with reference to study objectives	18-19
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	19-20
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	20-21
Generalisability	21	Discuss the generalisability (external validity) of the study results	20-21
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	22

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

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Predictors of Digital Support Services Use by Informal Caregivers: A Cross-Sectional Comparative Survey

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Abstract

Objectives Digital support services may provide informal caregivers with remote access to information and training about care issues. However, there is limited specific data on how factors such as demographics, socioeconomic resources and the caregiving context may influence caregivers' use of digital support services. The aim of this study is to identify associations between informal caregiver's characteristics and the use of the Internet to access digital support services in two countries: Italy and Sweden.

Setting and Participants A sample of 663 respondents who have access to the Internet participated in a cross-sectional survey by completing the online questionnaire. Respondents were recruited by the Italian National Institute of Health and Science on Ageing and the Swedish Family Care Competence Centre.

Primary and secondary outcome measures Logistic regression analyses were performed to assess predictors of caregivers' frequent use of the Internet to access digital support services.

Results Educational attainment (odds ratio [OR] 3.649, 95%CI: 1.424-9.350, $p=0.007$), hours per week spent caring (odds ratio [OR] 2.928, 95%CI: 1.481-5.791, $p=0.002$), total household income (odds ratio [OR] 0.378, 95%CI: 0.149-0.957, $p=0.040$), care recipient relationship to the caregiver (odds ratio [OR] 2.895, 95%CI: 1.037-8.083, $p=0.042$) and gender of care recipient (odds ratio [OR] 0.575, 95%CI: 0.356-0.928, $p=0.023$) were significant predictors in the multivariate analysis for the Italian caregivers group. Hours per week spent caring (odds ratio [OR] 2.401, 95%CI: 1.105-5.218, $p=0.027$) and age of care recipient (odds ratio [OR] 2.237,

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3 95%CI: 1.150-4.352, p=0.018) were significant predictors in the multivariate
4 analysis for the Swedish caregivers group.

5 **Conclusions** Digital support services could be important tools to empower informal
6 caregivers. When it comes to policy and practice in relation to caregivers, similarly
7 to other broad vulnerable groups, there is no 'one size fits all' approach, and it is
8 therefore important to consider the specific characteristics and needs of both
9 caregivers and care recipients.
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12 **Strengths and limitations of this study**

- 14 • This study is an international comparative study investigating the important
15 factors associated with the use of digital support services among informal
16 caregivers
- 17 • Multivariate logistic regression analyses enabled the effect of confounding
18 factors to be controlled for and predictors of use of digital support services
19 among informal caregivers to be identified
- 20 • Given the cross-sectional design of our study, causal relationships cannot be
21 established
- 22 • The survey was conducted using the internet, and thus our findings may not
23 be generalizable to individuals who do not use the internet
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Introduction

Informal caregivers are individuals who provide care to ill, frail or disabled relatives, friends or others, without being trained or paid, in contrast to formal caregivers who offer professional services [1]. In Europe, 80% of all care is provided by informal caregivers who are often females, either providing care to a spouse, parent or parent-in-law, and a large share is provided by individuals who are older than standard retirement age [2-4]. Estimates on the economic value of unpaid informal care in the European Union (EU) Member States range from 50% to 90% of the overall costs of formal long-term care provision [4]. The available estimates of the number of informal caregivers ranges from 10% up to 25% of the total population in Europe [5]. The number of informal caregivers over 18 years of age who provide more than 20 hours per week of informal care to older adults and relatives with disability is estimated to be more than 70 million [5]. Informal caregivers provide the bulk of long-term care, including via contributions to both activities of daily living (personal care, feeding, dressing and grooming, emotional and social support, etc.) as well as instrumental activities of daily living (transportation, care coordination, etc.)

Caregiving may prove challenging and stressful for many informal caregivers. Caregivers often experience high levels of need for information and services. Available literature points to the importance of novel technology solutions as a promising approach for empowering and supporting informal caregivers [6-8]. Digital support services for informal caregivers are services provided by any private or public organization that address caregivers and/or care recipients' needs through technological devices that are integrated or not into a wider intervention program [9]. Digital support services may provide informal caregivers with remote access to information and training about care and caring-related issues through websites, mobile applications and online training materials [10]. These solutions may contribute to a more positive caregiving experience and may help to strengthen informal caregivers' sense of social inclusion and belonging [11]. Digital support services also have macro-level benefits as these solutions may help in the integration of informal and formal care through better care coordination and a reduction in unnecessary hospitalizations and lengths of stay [8-12]. Consequently, the deployment of these solutions may generate savings and contribute to the sustainability of care systems [8-12].

Considering the substantial information needs experienced by informal caregivers, the increased availability of digital support services for caregivers as well as the potential they offer, further understanding of caregivers' use of the Internet to access digital support services is needed [13,14], in order to determine whether factors such as demographics, socioeconomic resources and the caregiving context may influence caregivers' use of digital support services [15]. Previous literature on Internet use for health information seeking showed that young age, good health status and higher education are associated with a more frequent use [16-28]. Prior

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3 studies also found that females were likely to seek health information on the
4 Internet more frequently than males [16-28].
5 Italy and Sweden represent two European extremes with respect to several
6 dimensions. These include: familistic/universalistic orientation of care system
7 (Italy: family-based, Sweden: universal); the level of overall digital skills (low in
8 Italy: 42%, high in Sweden: 72%); and that of Internet use for health information-
9 seeking (low in Italy: 35%, high in Sweden: 62%) [29-32]. The two countries share
10 however also some similarities. Both Italy and Sweden are high income countries
11 and represent two of the oldest populations in Europe [33,34], also because they
12 report an almost similar, very high life expectancy at birth, estimated at 83 and 82
13 years for Italy and Sweden, respectively [33,34]. Estimates on the prevalence of
14 informal care in Italy ranges from 14% up to 26% of the country's population [35].
15 In Sweden, it is estimated that 18% of the 18+ population provides informal care on
16 a regular basis, corresponding to over 1.3 million people overall [36].
17 In the literature, very few studies exclusively focus on caregivers' use of the Internet
18 to access support services. While informal caregivers have been identified as a
19 population group which could benefit from the provision of digital support services,
20 there is limited specific data on how factors such as demographics, socioeconomic
21 resources and the caregiving context may influence caregivers' use of the Internet to
22 access digital support services. Mapping the sociodemographic and socioeconomic
23 profiles of informal caregivers who do use and those who not use digital support
24 services could help improve the quality of these services available to them. The aim
25 of this study is therefore to identify associations between informal caregiver's
26 characteristics and the use of the Internet to access digital support services in two
27 countries: Italy and Sweden. Exploring the experiences of informal caregivers in
28 accessing digital support services in these two countries could inform future
29 reforms of the health care system, and boost caregivers' access to information,
30 services and support via new technologies in accordance to their needs. Moreover,
31 since health promotion and patient empowerment via digital technologies are also
32 on the European agenda [37], exploring the commonalities and differences in
33 informal caregivers' access to digital support services in these two countries, could
34 contribute to provide recommendations useful for implementing the EU agenda on
35 the transformation of the digital health and care agenda, while responding to
36 caregivers' needs in each country.
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44 **Methods**

45 **Study Design**

46 This online survey study used a cross-sectional design to identify associations
47 between informal caregiver's characteristics and the use of Internet to access digital
48 support services in two countries: Italy and Sweden. The data presented here, aimed
49 at evaluating technology based support services for informal caregivers, were
50 collected through the support of a partnership of different stakeholders belonging to
51 the Eurocarers' network (European Association Working for Carers). They
52 represent national level caregiver organizations in mostly EU Member States as well
53 as research centers working on these topics, such as the Centre for Socio-Economic
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3 Research on Ageing of INRCA IRCCS (Italy's National Institute of Health and Science
4 on Ageing), the Swedish Family Care Competence Centre and the Department of
5 Economics and Social Sciences of Marche Polytechnic University (Italy).
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8 **Survey Administration**

9 The sample was identified from the registries of the Italian National Institute of
10 Health and Science on Ageing and the Swedish Family Care Competence Centre. The
11 online survey link was disseminated from November 2020 till April 2021 through
12 the different communication channels, i.e., mailing lists and official websites, of the
13 Italian National Institute of Health and Science on Ageing and the Swedish Family
14 Care Competence Centre. Study participants were included provided they were:

- 15 • informal caregivers of dependent adult individuals living at home with access
16 to the Internet;
- 17 • 18 years old and above;
- 18 • and either resident in Italy and able to understand Italian (for participants
19 answering the Italian version of the questionnaire), or resident in Sweden
20 and able to understand Swedish (for participants answering the Swedish
21 version of the questionnaire).
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25 Exclusion criteria were as follows:

- 26 • informal caregivers of pediatric patients;
- 27 • professional or paid caregivers.
- 28 • People with medical comorbidities that prevent them from completing the
29 questionnaire (e.g., cognitive impairments)
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32 The study sample included respondents who classified themselves as informal
33 caregivers based on the survey question: "Do you provide unpaid care at home to an
34 adult relative, neighbor or friend to help them take care of themselves?".

35 Participants were asked to answer this question with "yes" or "no," and if they
36 answered "yes," then they were asked to continue with the questionnaire. A unique
37 identification number was provided to each participant and stored together with the
38 survey results, in order to eliminate duplicate entries. The participants were given
39 the option to save their responses and return to complete the survey, or they could
40 edit or clear the replies and initiate the survey another time. All no respondents
41 received email reminders. The response rate is estimated to be 31%. Data was
42 recorded in the system using a password-protected data extraction form.
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47 **Variables and Measurement**

48 Guided by Wilson's model of information-seeking behavior [38], the previous survey
49 on services for supporting family carers of older dependent people in Europe
50 "EUROFAMCARE" [39], and empirical evidence in the literature [16-28], this study
51 included the following sets of independent variables: caregiver's demographics;
52 caregiver's socioeconomic resources; and caregiving context. The dependent
53 variable in this study is informal caregivers' frequent use of the Internet to access
54 digital support services. In the survey, caregivers were asked to report how
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frequently they were using the Internet to access digital support services. Those using the Internet at least several times per month to access digital support services were classified as “frequent users”, while those accessing it less often were classified as “infrequent users”. Three demographic measures were included: caregiver’s age, caregiver’s gender and caregiver’s health status. Ages were measured in chronological years and grouped into three categories: 18 to 39, 40 to 59, and 60 or older. Gender was measured nominally and was grouped into male and female. Caregiver’s health status was grouped into poor, fair and good. Measures of social and economic circumstances were the caregiver’s educational attainment and their total household income. Educational attainment was grouped into primary, secondary, bachelor’s degree and higher than bachelor’s degree. Income was assessed by asking the caregiver about their “monthly household net income from all sources”. In order to distribute the income by different income groups and enhance the cross-national comparability of results between the two countries involved in this study, Italy and Sweden, we referred to the official figures of the national median equivalized disposable annual income from the European Commission’s European statistical system “Eurostat” [32]. We used these official figures in classifying the participants into three groups of household net income in each of these two countries:

- lower income group: income is less than below 50% of the national median equivalized disposable annual income. This is equivalent to an income lower than 5802 Euro in the case of Italy and an income lower than 9356 Euro in the case of Sweden;
- middle income group: income is between below 50 % of the national median equivalized disposable annual income and above 60 % of the national median equivalized disposable annual income. This is equivalent to an income between 5802 Euro and 19658 Euro in the case of Italy and an income between 9356 Euro and 26826 Euro in the case of Sweden;
- upper income group: income is higher than 19658 Euro in the case of Italy and higher than 26826 Euro in Sweden.

Caregiving context was assessed using the following variables: reported number of weekly hours of care provided to the care recipient; reported number of years spent providing care; age and gender of the care recipient; relationship between the care recipient and the caregiver; and the level of dependency of the care recipient. Responses concerning the average number of weekly hours of caregiving have been grouped into four categories: 1) 10 hours or less, 2) 11 to 20 hours, 3) 21 to 40 hours and 4) more than 40 hours. Care duration was measured on the basis of the caregiver’s reported length of care provision to the care recipient (in number of years), and respondents were classified into two groups: those caring for two years or less; and those caring for a longer time. The age of the care recipient was reported according to two groups: 60 years or less and more than 60 years. The gender of care recipients was grouped into male and female. Caregivers were requested to provide information about the person whom they care for, in order to

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3 assess the relationship with the care recipient (e.g. parents / parents-in-law,
4 spouse/partner, friend/neighbor, child or other relative. The level of dependency of
5 the care recipient on the caregiver was clustered in 2 groups: high dependency and
6 low dependency.
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10 **Data Analysis**

11 The data analysis was conducted in three stages. It began with univariate analyses
12 including percentages to describe the characteristics of this sample of caregivers. At
13 the second stage, the relationship between the outcome variable and the
14 independent variables was examined using Pearson's chi-squared test with Yates'
15 continuity correction. Differences between groups were considered significant at
16 the 5% level ($p \leq 0.05$). Contingency tables have been assessed, before proceeding to
17 logistic regression, to ensure there were no cells with expected frequencies of fewer
18 than 5 to prevent biased estimates [40]. At the last stage, logistic regression analysis
19 was used to establish the ability of each variable to predict caregivers' frequent use
20 of the Internet to access digital support services while controlling the effects of
21 other variables. Variables identified as statistically significant in the bivariate
22 analysis were entered into logistic regression analysis for each measure of use of the
23 Internet to access digital support services.
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26 The logistic regression analyses produced odds ratios with 95% confidence
27 intervals to identify predictors of each measure. Results are reported in odds ratios,
28 which can be interpreted as the ratio of the probability that caregivers with a
29 particular characteristic (e.g., male gender) will use the Internet frequently to access
30 digital support services, over the probability they will use the Internet frequently to
31 access digital support services, had they not this characteristic. Odds ratios that are
32 higher than 1 indicate a positive association between a given variable and using the
33 Internet frequently to access digital support services, while an odds ratio lower than
34 1 indicates a negative association. Statistical analyses were performed using SPSS
35 software version 28.0 (IBM, Armonk, NY, USA).
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39 **Research Ethics Approval**

40 Permission to conduct the study was granted by the ethics committee of the faculty
41 of economics, Marche Polytechnic University and was approved by the executive
42 board on November 2, 2020 (1026353). Informal caregivers expressing interest in
43 participating in the study were informed about the aim of the study, the expected
44 time to complete the questionnaire, and that data would be stored by the Centre for
45 Socio-Economic Research on Ageing of the Italian National Institute of Health and
46 Science on Ageing. The technical functionality of the online questionnaire had been
47 tested before fielding the questionnaire. The estimate time for survey completion
48 was 10-15 minutes. Informed consent was obtained from all participants. No
49 personal information about the participants such as their name or their IP address
50 were collected. All the responses were anonymous.
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Patient and public involvement

Patients or the public were not involved in the design, or conduct, or reporting, or dissemination plans of our research.

Results

Sample Description

A total of 663 informal caregivers, 410 from Italy and 253 from Sweden, participated in the survey by completing the online questionnaire. Table 1 presents the overall characteristics of the sample. Females represented a majority of respondents in the Italian group. The median age of caregivers was 54 years while the median age of care recipients was 73 years. Most Italian participants were providing care to a parent (n = 163, 39.8%), to a female care recipient (n=223, 54.4%), spent more than 40 hours per week providing care (n=170, 41.5%) and had completed secondary school or lower (n = 254, 62%). Nearly half of the participants (n=196, 47.8%) had an annual household income of less than 19.658 Euro. The big majority of caregivers in the Italian sample (n=342, 83.4%) reported a fair or poor health status, provided care to a highly-dependent care recipient (n=329, 80.2%) and had been providing care for more than 2 years (n=287, 70%) (Table 1). When compared to their Italian counterparts, both Swedish participants and their care recipients had a higher median age of 65 and 75 years respectively. Females made up a majority of participants in the Swedish sample. Most of the Swedish respondents reported providing care to a spouse/partner (n=97, 38.3%), a male care recipient (n=136, 53.8%), spent less than 10 hours per week providing care (n=112, 44.3%) and had completed a secondary school or lower (n = 149, 58.9%). Nearly half of the participants in the Swedish group (n=109, 43.1%) had annual household incomes less than 26.826 Euro. The majority of the caregivers in the

Swedish sample (n=210, 83%) had a fair or poor health status, were caring for a highly dependent care recipient (n=139, 54.9%) and had been providing care for more than 2 years (n=142, 56.1%) (Table 1).

Table 1. Characteristics of the sample (total sample N =663)

Variables	Italian sample n = 410 n (%)	Swedish sample n = 253 n (%)
Gender		
Male	93 (22.7)	57 (22.5)
Female	317 (77.3)	196 (77.5)
Age		
Median	54	65
18-39	48 (11.7)	17 (6.7)
40-59	241 (58.8)	77 (30.4)
More than 60	121 (29.5)	159 (62.8)
Health Status		
Good	68 (16.6)	43 (17.0)
Fair	171 (41.7)	155 (61.3)
Poor	171 (41.7)	55 (21.7)
Education		
Primary	29 (7.1)	35 (13.8)
Secondary	225 (54.9)	114 (45.1)
Bachelor	114 (27.8)	61 (24.1)
Higher than bachelor's degree	42 (10.2)	43 (17.0)
Income		
Lower	39 (9.5)	17 (6.7)
Middle	157 (38.3)	92 (36.4)
Upper	214 (52.2)	144 (56.9)
Care recipient relationship to caregiver		
Parents (In law)	163 (39.8)	63 (24.9)
Spouse/Partner	64 (15.6)	97 (38.3)
Child	105 (25.6)	48 (19.0)
Friend/Neighbor	30 (7.3)	26 (10.3)
Other	48 (11.7)	19 (7.5)
Gender of care recipient		
Male	187 (45.6)	136 (53.8)
Female	223 (54.4)	117 (46.2)

Age of care recipient		
Median	73	75
60 or younger	160 (39.0)	73 (28.9)
More than 60	250 (61.0)	180 (71.1)
Level of dependency of the care recipient		
High dependency	329 (80.2)	139 (54.9)
Low dependency	81 (19.8)	114 (45.1)
Hours spend caring each week		
10 hours or less	115 (28.0)	112 (44.3)
11-20 hours	68 (16.6)	62 (24.5)
21-40 hours	57 (13.9)	30 (11.9)
More than 40 hours	170 (41.5)	49 (19.4)
Number of years providing care		
2 years or less	123 (30.0)	111 (43.9)
More than 2 years	287 (70.0)	142 (56.1)

Factors associated with caregivers' frequent use of the Internet to access digital support services

Table 2 shows the factors associated with caregivers' frequent use of the Internet to access digital support services in the bivariate analysis for each of the two countries of the study. In the Italian group, two-thirds of the respondents reported using the Internet at least several times per month to access digital support services. At the bivariate level, this was associated with two demographic variables, caregiver's age and health status, and two socio-economic measures, caregiver's educational attainment and total household income. Five measures of caregiving context – care recipient relationship to the caregiver, gender of care recipient, age of care recipient, hours per week spent caring and the level of dependency of the care recipient – were also linked to the frequent use of the Internet to access digital support services.

In the Swedish sample, 54.2 % of the participants reported using the Internet at least several times per month to access digital support services. In the bivariate analysis, caregiver's age was significantly associated with the frequent use of the Internet to access digital support services. Three measures of caregiving context were also linked with the frequent use of the Internet to access digital support services: care recipient relationship to the caregiver, age of care recipient and the number of hours spent caring each week. None of the measures of socio-economic

resources was significantly associated with frequent use of the Internet to access digital support services in the Swedish sample.

Table 2. Factors associated with caregivers' frequent use of the Internet to access digital support services in the bivariate analysis

Variables	Using the Internet at least several times per month to access digital support services			
	Italian sample n = 410		Swedish sample n = 253	
	n (%)	p[1]	n (%)	p
All respondents	274 (66.8)		137 (54.2)	
Gender		0.123		0.344
Male	56 (60.2) [2]		34 (59.6)	
Female	218 (68.8)		103 (52.6)	
Age		0.010		0.035
18-39	23 (47.9)		6 (35.3)	
40-59	169 (70.1)		50 (64.9)	
More than 60	82 (67.8)		81 (50.9)	

Health Status		0.042		0.268
Good	37 (54.4)		35 (63.6)	
Fair	115 (67.3)		79 (51.0)	
Poor	122 (71.3)		23 (53.5)	
Education		0.008		0.901
Primary	12 (41.4)		20 (57.1)	
Secondary	161 (71.6)		60 (52.6)	
Bachelor's degree	76 (66.7)		32 (52.5)	
Higher than bachelor's degree	25 (59.5)		25 (58.1)	
Income		0.025		0.736
Lower	32 (82.1)		10 (58.8)	
Middle	110 (70.1)		47 (51.1)	
Upper	132 (61.7)		80 (55.6)	
Care recipient relationship to caregiver		< 0.001		0.014
Parents (In law)	95 (58.3)		23 (36.5)	
Spouse/Partner	49 (76.6)		55 (56.7)	
Child	88 (83.8)		33 (68.8)	
Friend/Neighbor	16 (53.3)		15 (57.7)	
Other	26 (54.2)		11 (57.9)	
Gender of care recipient		< 0.001		0.732
Male	141 (75.4)		75 (55.1)	
Female	133 (59.6)		62 (53.0)	
Age of care recipient		0.002		0.037
60 or younger	121 (75.6)		47 (64.4)	
More than 60	153 (61.2)		90 (50.0)	

Level of dependency of the care recipient		0.032		0.853
High dependency			76 (54.7)	
Low dependency	228 (69.3)		61 (53.5)	
	46 (56.8)			
Hours spend caring each week		< 0.001		0.022
10 hours or less			49 (43.8)	
11-20 hours	57 (49.6)		38 (61.3)	
21-40 hours	46 (67.6)		17 (56.7)	
More than 40 hours	38 (66.7)		33 (67.3)	
	133 (78.2)			
Number of years providing care		0.464		0.213
2 years or less			65 (58.6)	
More than 2 years	79 (64.2)		72 (50.7)	
	195 (67.9)			
Notes: [1] Differences between groups were considered significant at the 5% level ($p \leq 0.05$) [2] Male caregivers who are frequently using the Internet as a % of the total number of male caregivers in the sample.				

Predictors of caregivers' frequent use of the Internet to access digital support services

Table 3 summarizes the results of the logistic regression analysis predicting caregivers' frequent use of the Internet to access digital support services. For the Italian sample, nine variables significantly associated with a frequent use of the Internet to access digital support services in the bivariate analysis were entered into logistic regression analysis to identify which were predictive: caregiver's age, health status, educational attainment, total household income, care recipient relationship to the caregiver, gender of care recipient, age of care recipient, number of weekly hours of care and the level of dependency of the care recipient. The multivariate analysis indicated that educational attainment, number of weekly hours of care, total household income, care recipient relationship to the caregiver and gender of care recipient remained significant predictors. The strongest predictor was the educational attainment of the caregivers. Informal caregivers who completed education equivalent to a Bachelor's degree level had 3.649 times the odds of using the Internet at least several times per month to access digital support services compared to those who completed a primary education ($p=0.007$, 95%CI: 1.424-9.350). Caregivers who spend more than 40 hours per week providing care were almost 3 times more likely to be frequent users of the Internet to access digital support services in comparison with those who spend 10 hours or less per week providing care. The odds of frequent use of the Internet to access digital support

services were 2.646 times higher for caregivers belonging to the lower household income group compared to caregivers belonging to the upper household income group ($p=0.040$, 95%CI: 0.149-0.957). Regarding the relationship between the caregiver and care recipient, the caregivers of a child had 2.895 times the odds of using the Internet at least several times per month to access digital support services compared to those who provide care to another relative ($p = 0.042$, 95% CI: 1.037-8.083). The odds of frequently accessing digital support services were 1.739 times higher for caregivers who provide care to a male care recipient compared to those providing care to a female care recipient ($p = 0.023$, 95% CI: 0.356-0.928). The logistic regression analysis to predict the frequent use of the Internet to access digital support services among Swedish participants consisted of the four statistically significant factors identified in the bivariate analysis: caregiver's age, care recipient relationship to the caregiver, age of care recipient and the number of weekly hours of care (Table 3). The number of weekly hours of care remained a significant predictor in the multivariate analysis for the Swedish sample and was the strongest predictor. Swedish respondents who spend more than 40 hours per week providing care were almost 2.5 times more likely to be frequent users of the Internet to access digital support services as opposed to those who dedicate 10 hours or less per week to care provision ($p = 0.027$, 95% CI: 1.105-5.218). The age of the caregiver also remained a significant predictor in the multivariate analysis. Caregivers in the age group 40-59 years were 2.237 times more likely to use the Internet at least several times per month to access digital support services in comparison with those of the age group 60+ years ($p = 0.018$, 95% CI: 1.150-4.352).

Table 3. Multivariate logistic regressions: caregivers' frequent use of the Internet to access digital support services

Variables	Using the Internet at least several times per month to access digital support services					
	Italian sample n = 410			Swedish sample n = 253		
	p Value	OR	95% CIs	p Value	OR	95% CIs
Age (in years) (Ref.: 60+)						
18-39	0.270	0.630	0.277-1.433	0.653	0.761	0.231-2.508
40-59	0.563	1.175	0.680-2.030	0.018	2.237	1.150-4.352

Health Status (Ref.: Good)				- ¹	-	-
Fair	0.703	1.105	0.661-1.850			
Poor	0.925	1.033	0.523-2.040			
Education (Ref.: Primary)				-	-	-
Secondary	0.008	3.236	1.358-7.711			
Bachelor	0.007	3.649	1.424-9.350			
Higher than bachelor's degree	0.077	2.624	0.901-7.647			
Income (Ref.: Lower)				-	-	-
Middle	0.170	0.514	0.198-1.331			
Upper	0.040	0.378	0.149-0.957			
Care recipient relationship to caregiver (Ref.: Other)						
Parents (In law)	0.554	0.797	0.376-1.688	0.086	0.370	0.119-1.150
Spouse/Partner	0.337	1.611	0.608-4.267	0.634	0.777	0.275-2.196
Child	0.042	2.895	1.037-8.083	0.911	1.075	0.302-3.828
Friend/Neighbor	0.673	0.806	0.297-2.192	0.885	1.095	0.320-3.744
Gender of care recipient (Ref.: Male)				-	-	-
Female	0.023	0.575	0.356-0.928			

Age of care recipient (Ref.: 60 or younger)						
More than 60	0.211	1.616	0.762-3.424	0.920	1.046	0.436-2.511
Level of dependency of the care recipient (Ref.: High dependency)						
Low dependency	0.738	1.111	0.599-2.062	-	-	-
Hours spend caring each week (Ref.: 10 hours or less)						
11-20 hours	0.021	2.241	1.127-4.459	0.085	1.822	0.921-3.602
21-40 hours	0.103	1.908	0.878-4.144	0.311	1.568	0.656-3.748
More than 40 hours	0.002	2.928	1.481-5.791	0.027	2.401	1.105-5.218
Notes:	Only variables significantly associated with using the Internet frequently to access digital support services in the bivariate analysis were entered into multivariate logistic regression analysis					

Discussion

Principal findings

The purpose of this study was to identify important factors related to caregivers' use of the Internet to access digital support services in Italy and Sweden. The findings suggest that a number of demographic, socio-economic and caring circumstances are associated with the frequency of using the Internet to access digital support services among caregivers in both countries. Multivariate regression analyses enabled the effect of confounding factors to be controlled for and predictors of use to be identified. In consistency with literature on the same topic in different countries [16-28], our findings indicate that caregiver's age, health status, caregiver's educational attainment, total household income, care recipient relationship to the caregiver, gender of care recipient, age of care recipient, hours per week spent caring and the level of dependency of the care recipient are all associated with use.

The study shows that more than half of the caregivers in both countries frequently use the Internet to access digital support services. While the use of the Internet for health information has been somewhat less common in Southern European

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3 countries, in our study the Italian and the Swedish groups report a similar use of the
4 Internet to access digital support services. This may be related to the lower median
5 age of the Italian sample compared to the Swedish one. Caregivers from Southern
6 European countries with a family-based care system often lack support in terms of
7 formal services and professional training from the government [41-48]. This
8 shortcoming of support may increase their need for information and services.
9 Digital support services may be an alternative support source that enables remote
10 access to information and training about care and caring-related issues. Previous
11 studies suggested that the use of the Internet for health information in Southern
12 European countries is increasing, and that caregivers from this region are showing
13 an increased interest in accessing new technologies aiming to support them [48-50].
14 In both countries, most of the caregivers who participated in the study were
15 females, which is consistent with the results of previous works [25-28] and with the
16 central role played by females in the provision of informal care [2-4]. In coherence
17 with previous literature [39,41-48], the majority of Italian participants in our study
18 provided care to a parent (in law) and spent more than 40 weekly hours of care,
19 compared to their Swedish counterparts who provided care to spouse/partner and
20 spent less than 10 hours per week providing care. Previous research showed that
21 care for someone in one's own household is more common in Southern European
22 countries than in Northern countries. In Southern countries, caregivers are more
23 likely to live with their care recipients who often are parents / in-laws [39,41-48]. In
24 Northern countries, in-household care is mostly spouse care, as it is rare for old
25 persons to live with anyone else than their spouse. Consequently, caregivers from
26 Southern European countries spend more hours in caregiving compared to
27 caregivers from Northern countries.

28 As it is to be expected given previous research on using the Internet for general
29 health information [19-24], the digital divide may negatively affect caregivers' use of
30 the Internet to access digital support services [51,52]. The socioeconomic status of
31 users seems to be a significant factor that increases the digital divide in Southern
32 European countries [53-55]. This was apparent in our study, showing that the
33 divide was more significant in the case of the Italian group compared to the Swedish
34 one. While none of the measures of socio-economic resources was significantly
35 associated with a frequent use of the Internet to access digital support services in
36 the Swedish group, the strongest predictor for the frequency of Internet use in the
37 Italian group was the caregiver's educational attainment. Previous research has
38 shown that better-educated caregivers are more likely to be engaged in more
39 frequent online activities [25-28]. Income was also a predictor for the frequency of
40 Internet use to access digital support services in the Italian group, with higher odds
41 for caregivers belonging to the lower household income group. While literature
42 suggests that general Internet users in higher-income households are more likely
43 than others to go online frequently [56,57], previous studies on the Internet use for
44 health-related activities suggest that lower-income households may be more likely
45 than others to go online for support activities [16,58,59]. One possible explanation
46 is that those with higher incomes may have other means of support, while those
47 with lower incomes may turn to the Internet as an alternative source of assistance.
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3 The literature shows that age is a factor associated with Internet use [16-28]. In the
4 Swedish group of our study, age is a significant predictor of frequency of use. Age
5 remained an important predictor of use when the effects of other demographics,
6 socio-economic factors and caring circumstances had been controlled for. This
7 suggests that the relationship between age and use among Swedish caregivers
8 cannot be entirely explained by increased financial hardship in later life. Previous
9 research suggests that use of the Internet for health information is relatively
10 constant by age, until age 65 when it begins to decline [16].
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14 Patterns of use among caregivers in both countries also seem to be shaped by the
15 caring experience. The number of weekly hours of care was a significant predictor
16 for the frequency of Internet use by participants in both countries. Evidence from
17 literature suggests that high-intensity caregivers report higher levels of information
18 and service needs [60]. Given the availability and convenience of online sources,
19 high-intensity caregivers may turn to the Internet for digital support services.
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21 Limitations

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23 Some limitations concerning this study need to be considered. The risk of the typical
24 sampling bias should be mentioned as higher income and more educated caregivers
25 are more likely to participate in research studies involving modern technologies,
26 which was the case in our study. Furthermore, the sample size, especially of the
27 Swedish sample, prevented us from carrying out more sophisticated statistical
28 analyses. Moreover, not all of those who provide informal caregiving and assistance
29 to others identify themselves as informal caregivers; consequently, we may have
30 failed to capture the experiences of these underrepresented groups. We may have
31 also failed to capture the concerns of the caregivers that may limit their ability in
32 using digital resources. Although the most important variables identified from
33 empirical evidence in the literature were included in the models, residual external
34 variables may still have influenced our results. Conclusions drawn from this study
35 results must be tempered by the fact that respondents were already possessing
36 minimal digital skills that would enable them to access online services. It is possible
37 that those who are not interested or involved with technology or those with limited
38 digital access are less likely to respond to online surveys; consequently, the data
39 collected online might be skewed and the sample might be less representative for
40 the population. These issues might have influenced our findings and underline the
41 need to interpret the findings from this study and other studies on caregivers with
42 some caution when generalizing the findings.
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48 Recommendations and Implications

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50 Our results indicate that digital support services may enable remote access to
51 information and training about care and caring-related issues. In this context,
52 looking for information and support services online may be considered an attempt
53 to close some knowledge gap. With the rapid technology advancement and
54 increased access to the Internet, more caregivers are expected to access these
55 services [61]. This suggests that the interaction with informal caregiver by health
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3 care professionals and other parties with an interest in supporting them (e.g.
4 caregiver advocacy organizations) is an integral part of the value chain that
5 supports both communication and coordination of services. Hence, these parties
6 should all be more engaged with developing digital support services targeted at
7 informal caregivers, and carefully assess and identify their information and service
8 needs. Consequently, better targeted information could be provided to caregivers
9 through credible online sources. In this regard, an early assessment of caregivers'
10 needs and digital skills demonstrates that large-scale actions aiming to equip
11 informal caregivers with the digital skills they need to access digital support
12 services are needed. This is key to enable informal caregivers to identify the
13 available digital support services, and apply them to their own care situation. More
14 research is therefore needed to examine the extent to which existing digital support
15 services meet caregivers' information and service needs.

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17 Addressing socio-economic inequalities is likely to be key to reduce the digital
18 divide in caregivers' use of the Internet to access digital support services. As for the
19 influence of age and education on the digital divide, health care professionals,
20 service providers and social workers should pay particular attention to those
21 caregivers who are older and less educated. Access to computers and Internet
22 connections at public facilities, such as local libraries, community centers and senior
23 centers should be provided with extra support to accommodate caregivers'
24 information needs and overcome any barriers of use [15,19]. Moreover, seminars
25 and campaigns on how to access digital support services could enhance caregivers'
26 digital skills and experiences. Tailor-made campaigns and classes for older and less-
27 educated adults are needed to help address any barriers related to their use of
28 computers and new technology.

29
30 Poor connectivity to the internet, particularly for informal caregivers in rural areas,
31 is an obstacle to the use of any support service delivered over the internet. Policy
32 makers should allocate funding for improving digital infrastructures in order to
33 facilitate the deployment of digital support services and improve informal
34 caregivers' access to these services. In this regard, an identification of sustainable
35 business models, exchange of good practices, collection of evidence, and a
36 transferability of optimal solutions among localities, regions, and countries are all
37 important to continue allocating public funding for initiatives. Moreover, informal
38 caregivers have concerns on data ownership and privacy of the data. Privacy
39 concerns may be especially relevant to older informal caregivers, who voice the
40 most concerns over the privacy and security of their information online. Digital
41 support services should be sensitive to informal caregiver privacy concerns and the
42 extent to which a technology might undermine their autonomy, control and dignity.
43 In this context, blending online support with involving health care professionals in
44 the provision of professional support leads to overcoming possible skepticism.
45 The finding that caregivers who indicate higher-intensity levels of caregiving are
46 likely to engage in frequent Internet use to access digital support services may
47 suggest that the Internet could be used to reach out to these caregivers and meet
48 their information and service needs. Online training materials, support groups,
49 social networking systems for peer support and volunteer call networks could be
50 used to reach out to caregivers [62]. Research is needed to further examine the
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effectiveness of digital support services in helping caregivers, if we are to improve these services and tailor them to the lives of those with substantial and unpredictable caring responsibilities.

Conclusions

The findings from this study can provide guidance and assistance for the deployment of digital support services for informal caregivers. Nevertheless, due to rapid technological innovation, especially in this sector, continuous research needs to be conducted and guidelines for developing digital support services should be made adaptable to ongoing and future changes. The care sector is undergoing a fast transformation and expansion also due to the direct and indirect effects of the COVID-19 pandemic. Health and social care delivery systems experience a technologically supported transition towards home care. New technologies are being developed for informal caregivers and these tools may well offer benefits to many of them. It is widely acknowledged that caregivers are a group with high levels of unmet needs when it comes to their access to information and other services. Digital support services could be important tools to empower and support informal caregivers. On the other hand, it also needs to be recognized that informal caregivers are a diverse population, living in a wide range of personal and social circumstances. When it comes to policy and practice in relation to caregivers, similarly to other broad vulnerable groups, there is no 'one size fits all' approach, and it is therefore important to consider the specific characteristics and needs of both caregivers and care recipients. Policy makers, health care professionals and all parties with an interest in supporting informal caregivers are encouraged to identify the outcomes that the latter regard as helpful, and to identify the interventions that can achieve such outcomes in consultation with them. This applies as much to the approach taken in relation to the development of digital support services as it does to other services. While digital support services have the potential to meet some of the needs of the caregivers, they cannot be seen as the only way to deliver information and support. These services represent only one of many instrument in a toolbox, and should therefore be tailored in a coordinated way with other existing services, such as respite care, access to training, and recognition of skills and work-life balance measures.

Contributorship statement

AH developed the research idea and wrote the manuscript. GL and MH were involved in the conceptualization of the project and provided critical evaluation and approval of the final submitted manuscript

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6 **Data sharing statement**

7
8 Raw data cannot be made openly available as the participants provided an informed
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CHERRIES Checklist

Item Category	Checklist item	Page no.
Target Population	Study Design	5-7
Ethics	Study Design	8
	Consent Form	8
	Data Protection	8
Development and pre-testing	Data collection	5-8
Recruitment Process and survey administration	Data Collection	5-8

Responses rate	Results	8
Preventing multiple entries from the same individual	Data collection	6
Analysis	Statistical analysis and data handling	6-8

Notes: Adapted from: Eysenbach G. Improving the quality of Web surveys: the Checklist for Reporting Results of Internet E-Surveys (CHERRIES). *J Med Internet Res.* 2004;6(3):e34. doi: 10.2196/jmir.6.3.e34. PMID: 15471760. PMCID: PMC1550605. Available from: <https://www.jmir.org/2004/3/e34/>. ©Gunther Eysenbach. Originally published in the Journal of Medical Internet Research (<http://www.jmir.org>), 29.9.2004. Creative Commons Attribution License (<http://www.creativecommons.org/licenses/by/2.0/>).

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For peer review only

STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies*

	Item No	Recommendation	Page No
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	1-2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3-4
Objectives	3	State specific objectives, including any prespecified hypotheses	3-4
Methods			
Study design	4	Present key elements of study design early in the paper	5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants	5
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6
Bias	9	Describe any efforts to address potential sources of bias	6
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6-7
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	7-8
		(b) Describe any methods used to examine subgroups and interactions	7-8
		(c) Explain how missing data were addressed	7-8
		(d) If applicable, describe analytical methods taking account of sampling strategy	7-8
		(e) Describe any sensitivity analyses	7-8
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	9
		(b) Give reasons for non-participation at each stage	9
		(c) Consider use of a flow diagram	9
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	10-11
		(b) Indicate number of participants with missing data for each variable of interest	10-11
Outcome data	15*	Report numbers of outcome events or summary measures	12-17

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2	Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included
3			12-17
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6			(b) Report category boundaries when continuous variables were categorized
7			12-17
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9			(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period
10			12-17
11	Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses
12			12-17
13			
14	Discussion		
15	Key results	18	Summarise key results with reference to study objectives
16			18-19
17			
18	Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias
19			19-20
20			
21	Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence
22			20-21
23			
24	Generalisability	21	Discuss the generalisability (external validity) of the study results
25			20-21
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28	Other information		
29	Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based
30			22
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*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.