A pre and post COVID-19 global assessment of telehealth use within the respite care industry: A quantitative study

Mohan Madisetti, Jill C Newman, Melissa C Butcher, Mary C Pittman, Suparna Qanungo, Teresa J Kelechi

Submitted to: Journal of Medical Internet Research
on: April 05, 2021

Table of Contents

A pre and post COVID-19 global assessment of telehealth use within the respite care industry: A quantitative study

Mohan Madisetti[1*] MSc; Jill C Newman[1*] MSc; Melissa C Butcher[1*] DHSc; Mary C Pittman[1*] BA; Suparna Qanungo[1*] PhD; Teresa J Kelechi[1*] PhD, RN

[1]College of Nursing Medical University Of South Carolina Charleston US
[*]these authors contributed equally

Corresponding Author:
Mohan Madisetti MSc
College of Nursing
Medical University Of South Carolina
99 Jonathan Lucas Street
Charleston
US

Abstract

Background: Deemed as non-essential businesses that were subject to disrupted services during the COVID-19 pandemic, the extent of the use of telehealth within the global respite care industry to provide for continuity of community care is unknown.

Objective: This study aimed to assess global pre and post-onset COVID-19 telehealth use among respite care providers (RCPs) and to explore adult day care (ADC) provider attitudes and opinions toward the provision of educational services via telehealth to caregivers of persons with Alzheimer's disease and related dementias (ADRD).

Methods: An online global survey was purposefully developed and electronically disseminated among 2,817 RCPs. Response data were grouped by ADC-ADRD and 'Other' respite care facility type and analyzed using descriptive statistics and a thematic framework analysis for open-ended responses. Fisher's Exact, Chi-square, or McNemar tests with logistic regression were used as appropriate for statistical analyses. Data were collected between September 1st to October 14th, 2020.

Results: Sixty-four RCPs responded to the survey, representing 5 countries across 3 continents. 32.8% (21/64) of respondents were ADC-ADRD providers and 67.2% (43/64) provided 'Other' types of respite care. Comparative pre/post-onset COVID-19 data evidence a significant increase in both the technological capacity and use of telehealth among all provider types ($P <.001$). Among ADC-ADRD providers, 71.4% expressed interested in exploring the use of telehealth to provide educational caregiver programming and 60% of those expressing no interest would change their decision if these services were reimbursable. Perceived barriers to telehealth adoption included: low clientele computer literacy (65.1%), lack of clientele internet access (63.5%), and lack of clientele interest and uptake (60.3%). Confidence in adoption was high among ADC-ADRD providers (76.2%). 85.7% of ADC-ADRD opined that telehealth would have a 'significant' or 'profound' impact in the delivery of educational support services to caregivers in the next 10 years.

Conclusions: There has been an increased use of telehealth within the respite care industry since the onset of the COVID-19 pandemic. While perceived barriers to adoption exist, there is strong interest in exploring the long-term use of this type of technology to deliver educational support services to caregivers among all provider types, including ADC-ADRD providers. With an increasingly aging global population, culturally relevant and evidence-based curricula to support provider use and interest in telehealth should be a priority focus area for international funding agencies and researchers. In non-government funded respite care delivery systems, ADC-ADRD provider reimbursement may encourage provider investment in telehealth technology and expand remote access to specialized caregiver educational support services.

(JMIR Preprints 05/04/2021:29391)
DOI: https://doi.org/10.2196/preprints.29391

Preprint Settings

1) Would you like to publish your submitted manuscript as preprint?

✓ **Please make my preprint PDF available to anyone at any time (recommended).**
Please make my preprint PDF available only to logged-in users; I understand that my title and abstract will remain visible to all users.
Only make the preprint title and abstract visible.
No, I do not wish to publish my submitted manuscript as a preprint.

2) If accepted for publication in a JMIR journal, would you like the PDF to be visible to the public?

✓ **Yes, please make my accepted manuscript PDF available to anyone at any time (Recommended).**
Yes, but please make my accepted manuscript PDF available only to logged-in users; I understand that the title and abstract will remain v
Yes, but only make the title and abstract visible (see Important note, above). I understand that if I later pay to participate in <a href="http

Original Manuscript

Original Paper

Title: A pre and post COVID-19 global assessment of telehealth use within the respite care industry: A quantitative study

Background

Declared a global pandemic in March 2020 [1] and in the absence of readily available vaccines, the international community's general response to mitigate transmission and spreading of the SARS-CoV-2 coronavirus (COVID-19) can be summarized as a collection of policies and guidelines engineered to intervene at the individual, local, and national, and international levels.[2] Measures implemented at the individual level included recommendations for frequent personal handwashing and surface sanitization, practicing social distancing when in public, mandating face mask covering, shielding or sheltering-in-place, and physically quarantining. Community-level measures employed included restrictions on social gatherings and local travel, lockdowns, and curfews under penalty of law, the installation of mass testing centers, and the use of contact tracing. National and international levels measures included the closure and/or reduced operations of publicly funded agencies and of other businesses that were viewed as either to be non-essential and/or that posed as a perceived increased risk to public health, closed borders, and foreign travel bans, respectively.

At the height of the pandemic, when considered by many nations as non-essential businesses that provided ancillary social support services in the community among vulnerable populations (predominantly the elderly) with underlying chronic medical conditions that posed increase significant risk of hospitalization and death [3], currently published literature on the effects of enacted national COVID-19 mitigation policies within the global respite care industry is limited in terms of both the number of studies that have been conducted and their immediate focus on the caregiver and/or the client rather than on the industry itself. Recent studies have reported findings of increased feelings of caregiver loneliness [4], burden, anxiety, and depression that negatively impacted their quality of life. [5-8] In these same studies, the effects of COVID-19 on the industry are anecdotal at best with generalized reports of disruptions to the provision of services due to widespread facility closures and/or the cessation/modification of operations limiting access to care.

Individuals of all ages with disabilities, chronic health issues or frailty rely on unpaid in-home caregiving from relatives or friends to perform various activities of daily living (ADL); and an accurate global estimate for the number of unpaid carers is difficult to obtain. In the US alone, there are an estimated 53.0 million unpaid family caregivers providing care to someone who is ill, disabled, or aged.[9] In Europe, derived data estimates from the European Quality of Life Survey (2016) are as high as 100 million[10]; while in Australia there are approximately 2.7 unpaid caregivers.[11] National support systems geared towards unpaid caregivers vary from country to country; they range from no support to adopted policies for financial allowances, flexible work schedules, compassionate leave, tax incentives, and the provision of government subsidized or fully funded community-based programs such as emergency, in-home, residential and short-term respite services.[10]

Under bourgeoning strain to effectively manage public health resources that were often overwhelmed by high incidence rates of COVID-19 related hospitalizations, one well described, often subsidized [12, 13], and encouraged strategy within the international community was to employ the use of telehealth to perform virtual patient medical health care visits.[14] While not new, telehealth has shown to be a readily available tool for nations to combat the pandemic while maintaining social distancing and providing access to and continuity of care across diverse patient populations and in multiple health and social settings.[15] Currently, the extent of the use of telehealth technology by respite care providers (RCP) during the pandemic while complying with national policies and providing for continuity of care to families is relatively unknown, as is the long-term role that telehealth will ultimately have in this industry.

The primary objective of this study was to assess the global use of telehealth by RCP pre- and post-onset of the COVID-19 pandemic. A secondary exploratory aim was to explore adult day care (ADC) Alzheimer's Disease and related dementias (ADRD) provider attitudes, opinions, and perceived barriers toward the implementation and use of telehealth in providing remote individualized educational support services to caregivers in the home. This secondary aim furthers the feasibility aim of a larger parent randomized controlled trial (RCT) to assess the efficacy of a telehealth-based train-the-trainer mealtime intervention (Partners at Meals [PAM]) delivered by ADC respite center volunteers to caregivers of persons with ADRD to improve nutritional outcomes and quality of life. The PAM study protocol is more fully described elsewhere in literature.[16]

Methods

Survey Design

A 34-item survey (available as supplementary data) with six main components was designed by the researchers. These components addressed: 1) Agency/organizational and facility characteristics; 2 & 3) Pre and post COVID-19 provider capability and use of telehealth; 4 & 5) Perceived provider barriers and adoption confidence in the implementation and provision of telehealth educational support services to families; and 6) Provider interest, attitudes, and opinions towards the use of telehealth in providing educational support services to caregivers. The survey was refined by a certified gerontological respite care expert and pilot tested for face validity and clarity among two ADC-ADRD facility Directors. All recommended changes were incorporated into the final version prior to Institutional Review Board (IRB) approval and dissemination. Telehealth was defined as "any face-to-face interaction with families delivered via the internet whether by smartphone or computer". Time to complete the survey was estimated at 10-15 minutes.

Survey Participants and Distribution

The opportunity to participate in the study was globally distributed by direct RCP email survey invitation, as well as electronically disseminated through two US respite provider networks via e-newsletter and social media. Individual facility contact email addresses were compiled from publicly available online national listings of RCP agencies/organizations. Agencies/organizations could operate one or multiple type of facilities. In total, 2,817 direct survey email invitations were sent. 2,697 were from the US. In addition, and in an effort to increase geographical representation, 30 ADRD RCP agencies from each of Canada, U.K., Australia, and New Zealand were randomly selected and directly sent email invitations.

Data Collection and Management

Data were collected and managed through Research Electronic Data Capture (REDCap).[17] Emails were masked to prevent linking identifiers and to protect the respondent's privacy. Automated survey reminders were sent bi-weekly over a six-week data collection period. Individuals that contacted the researchers expressing disinterest in study participation were removed from the survey invitation process. Data were collected over a 6-week period from September 1 – October 14, 2020.

Statistical Analysis

Returned data were first grouped by ADC facility type serving ADRD clients and all 'Other' (non-ADC ADRD) respite care facility types, described by country of origin and organizational characteristic, and then analyzed using descriptive statistics. The ‘Other’ category contained persons with dementia (PWD) but that were not served in ADC settings and vice versa. Descriptive statistics are reported as means and standard deviations, medians, and interquartile ranges [Q1, Q3] or frequencies and percentage, and statistical testing for differences by group were performed using Chi Square Tests, Fisher’s Exact Tests, Student’s t-tests, and Wilcoxon Rank Sum tests as appropriate. Open-ended responses were analyzed using a thematic framework approach and assessed by group using logistic regression for repeated measures and McNemar’s Exact Tests to test for overall differences in paired pre/post COVID-19 responses. All analyses were conducted using SAS version 9.4 (SAS Institute, Cary, NC USA). *P*-values <.05 were considered statistically significant.

Results

Respite Care Organization, Facility, and Respondent Characteristics

A total of 64 surveys were returned from 2,817 survey invitations (2.3% response rate), representing organizations from 5 different countries (USA n=59, Australia n=1, New Zealand n=1, UK n=1, Canada n=1, and unknown n=1) across 3 continents (Figure 1).

Figure 1. Geographical distribution of survey respondents by continent[1]

[1] Country data was returned missing from one (1) respondent

Overall (Table 1), RCP organizational ownership types were classified as 59.4% not-for profit, 25% for-profit, 12.5% sole proprietorship, and 3.1% as Other. RCPs could self-describe operating multiple facility types serving multiple populations. Facility types and population served varied with 60.9% offering in-home care, 42.2% adult day services, 25% residential care, 10.9% emergency respite care and 17.2% other. 85.9% of RCPs served client populations with Seniors, 78.1% Adults, 45.3% Young Adults, 31.3% Adolescents, 26.6% Pediatrics, and 12.5% Infants. The top 3 conditions served were 75% Alzheimer's disease or related dementias, 60.9% chronic health conditions/aging in place, and 53.1% intellectual or developmental delay. The mean number of years in operation was 17.6 years (sd= 13.6 years), serving a median of 30 families annually [IQR 10, 80] from 30.2% urban, 27% urban cluster, 9% rural, and 33.3% in some combination of geographical areas. 76.6% of respondents self-identified as an organizational administrator, or a respite care agency director, supervisor, and/or facility program manager. Between groups comparisons revealed that 32.8% of respondents provided ADC-ADRD respite care and 67.2% provided Other types of respite care. Expected significant differences from group classification were observed, and was also noted for the receipt of funds from Donations, Charities, and Foundations, with ADC ADRDs utilizing this mechanism more than Other RCP types (*P*=.002).

Table 1. Summary of respite care organization, facility, and survey respondent characteristics

Agency/Organizational Characteristics	**Overall n, (%)**	**ADC-ADRD Provider n, (%)**	**Other Respite Provider n, (%)**	***P*-value**
Organizational type, n, (%)				.01
Individual sole proprietor	8 (12)	0	8 (18.6)	
For profit organization	16 (25)	3 (14.3)	13 (30.2)	
Not for profit	38 (59.4)	18 (85.7)	20 (46.5)	
Other	2 (3.1)	0	2 (4.7)	
Facility type(s), n, (%)[a]				
In-home	39 (60.9)	8 (38.1)	31 (72.1)	.009
Adult Day Care	27 (42.2)	21 (100)	6 (14.0)	NA

Residential Care	16 (25.0)	6 (28.6)	10 (23.3)	0.64
Emergency Respite Care	7 (10.9)	2 (9.5)	5 (11.6)	1.0
Other	11 (17.2)	5 (23.8)	6 (14.9)	.33
Funding source(s), n, (%)[a]				
Public funds	40 (62.5)	11 (52.4)	29 (67.4)	.24
Private Insurance	14 (21.9)	5 (23.8)	9 (20.9)	.24
Private pay by families	47 (73.4)	18 (85.7)	29 (67.4)	.07
Unfunded or use of volunteers	8 (12.5)	4 (19.1)	4 (9.3)	.42
Donations, Charities, Foundations	25 (39.1)	14 (66.7)	11 (25.6)	.002
Population(s) served by age, n, (%)[a]				
Infants (<2 years)	8 (12.5)	1 (4.8)	7 (16.3)	.25
Pediatrics (2-12 years)	17 (26.6)	2 (9.5)	15 (34.9)	.03
Adolescent (13-17 years)	20 (31.3)	2 (9.5)	18 (41.9)	.01
Young Adult (18-25 years)	29 (45.3)	6 (28.6)	23 (53.5)	.06
Adults (26-64 years)	50 (78.1)	16 (76.2)	34 (79.1)	.24
Seniors (65+ years)	55 (85.9)	19 (90.5)	36 (83.7)	.25
Condition(s) served within past 12 months, n, (%)[a]				
ADD/ADHD	17 (26.6)	3 (14.3)	14 (32.6)	.14
Alzheimer's disease or related dementias	48 (75.0)	21 (100)	27 (62.8)	<.001
Autism	28 (43.8)	6 (28.6)	22 (51.2)	.09
Behavioral issues	32 (50.0)	11 (52.4)	21 (48.8)	.79
Brain injury	28 (43.8)	11 (52.4)	17 (39.5)	.33
Cerebral Palsy	24 (37.5)	8 (38.1)	16 (37.2)	.95
Chronic health conditions / aging in place	39 (60.9)	13 (61.9)	26 (60.5)	.91
Downs Syndrome	25 (39.1)	7 (33.3)	18 (41.9)	.51
Intellectual or developmental delay	34 (53.1)	11 (52.4)	23 (53.5)	.93
Mental health conditions	29 (45.3)	12 (57.1)	17 (39.5)	.18
Motor Neuron Disease	9 (14.1)	3 (14.3)	6 (14.0)	1.0
Multiple Sclerosis	13 (20.3)	2 (9.5)	11 (25.6)	.09
Muscular Dystrophy	8 (12.5)	0	8 (18.6)	.045
Spinal cord injury	12 (18.8)	2 (9.5)	10 (23.3)	.31
Other	7 (10.9)	1 (4.8)	6 (14.0)	.41
Years in operation, mean, (sd)	17.6 (13.9)	21.9 (18.2)	15.4 (10.6)	.14
Number of families served annually, median, [IQR Q1, Q3]	30.0 [10, 80]	38.5 [18, 97.5]	30.0 [10, 80]	.39
Service area, n, (%)				.65
Urbanized (areas 50,000+)	19 (30.2)	8 (38.1)	11 (26.2)	
Urban cluster (areas 2,500-50,000)	17 (27.0)	6 (28.6)	11 (26.2)	
Rural (areas <2,500)	6 (9.5)	2 (9.5)	4 (9.5)	
Combination of the above	21 (33.3)	5 (23.8)	16 (38.1)	
Respondent's job title, n, (%)				.49
Program Director or Supervisor	22 (34.4)	9 (42.9)	13 (30.2)	
Client or Family Case Manager	1 (1.6)	0	1 (2.3)	
Counselor or Social Worker	1 (1.6)	1 (4.8)	0	
Agency Director/Administrator	27 (42.2)	7 (33.3)	20 (46.5)	
Other	13 (20.3%)	4 (19.1%)	9 (20.9%)	

[a] Survey respondents may select multiple categories, % totals may not equal 100%

Comparative Pre and Post COVID-19 Telehealth RCP Capability and Use

Overall pre/post COVID-19 group comparison revealed a significant increase in the types of technology used by providers (smartphones (*P*<.001), tablets (*P*<.001), laptops (*P*<.001), and desktop computers (*P*<.001), in internet access (*P*<.001) and in use of telehealth (*P*<.001) post COVID-19 onset. In-person communications with families significantly decreased (p<0.001) over the two time points, however methods of communication by telephone, mail, text, email and through social media did not show any significant change. Among ADC-ADRD providers, 0% reported offering telehealth services before COVID-19 compared to 80% post onset (*P*<.001), which is a key finding as related to the aims of this study. The main type of telehealth services offered by ADC-ADRD providers were Caregiver support groups (47.6%), Caregiver Education (38.1%) and Other services (38.1%) post COVID-19 versus 0% for all pre-COVID-19. Of those ADC ADRD providers offering telehealth services during the pandemic, 12.5% received some form of reimbursement post COVID-19 versus none pre-COVID-19.

Table 2. Pre and post COVID-19 respite care provider telehealth capabilities and use

Provider Telehealth Capability and Use	**Before COVID-19**		**After COVID-19**		***P*-value**
	ADC-ADRD Providers (n, %)	**Other Respite Providers (n, %)**	**ADC-ADRD Providers (n, %)**	**Other Respite Providers (n, %)**	
Employee internet access					<.001
Yes, all did	21 (100)	27 (62.8)	20 (95.2)	28 (75.7)	
Yes, some did	0	10 (23.3)	1 (4.8)	8 (21.6)	
No	0	6 (14.0)	0	1 (2.7)	
Communication with families [a]					
In-person	19 (90.5)	36 (83.7)	10 (47.6)	19 (44.2)	<.001
Telephone	19 (90.5)	36 (83.7)	19 (90.5)	35 (81.4)	1.0
Mail	12 (57.1)	13 (30.2)	8 (38.1)	14 (32.6)	.55
Text	10 (47.6)	24 (55.8)	12 (57.1)	29 (67.4)	.12
Email/e-newsletters	19 (90.5)	26 (60.5)	19 (90.5)	27 (62.8)	1.0
Telehealth	0	4 (9.3)	12 (57.1)	17 (39.5)	<.001
Website/Social media	13 (61.9)	9 (20.9)	14 (66.7)	8 (18.6)	1.0
Other	0	1 (2.3)	0	1 (2.3)	NA
Provides telehealth (yes)	0	4 (9.3)	16 (80.0)	12 (30.8)	<.001
Types of telehealth programs offered [a]					
Caregiver support group	0	3 (7.0)	10 (47.6)	5 (11.6)	.004
Caregiver education	0	3 (7.0)	8 (38.1)	4 (9.3)	.02
Other services	0	0	8 (38.1)	6 (14.0)	NA
Individual caregiver support	0	4 (9.3)	5 (23.8)	8 (18.6)	.02
Medical health	0	0	2 (9.5)	0	NA
Telehealth services paid by					
Families	0	0	2 (12.5)	1 (8.3)	NA
Insurance reimbursement	0	0	0	0	NA
Telehealth technology used [a]					
Stationary telehealth unit	0	0	0	0	NA
Mobile telehealth unit	0	1 (2.3)	0	0	NA
Smartphones	0	3 (7.0)	13 (61.9)	8 (18.6)	<.001
iPods/iPads/tablets	0	3 (7.0)	14 (66.7)	5 (11.6)	<.001
Laptop/notebook	0	1 (2.3)	15 (71.4)	9 (20.9)	<.001
Desktop computer	0	1 (2.3)	12 (57.1)	6 (14.0)	<.001
Robotics	0	0	0	0	NA
Other	0	0	0	0	NA

[a] Survey respondents may select multiple categories, % totals may not equal 100%

RCP Perceptions of Barriers to the Implementation and Provision of Caregiver Educational Support Telehealth Services

Among all RCP types, the top 6 perceived barriers (Table 3) to the implementation and provision of educational support telehealth services to families were: 1) Low clientele computer literacy (65.1%);

2) Lack of clientele access to the internet (63.5%); 3) Lack of clientele interest and uptake (60.3%); 4) Need for staff and IT support (53.2%); 5) Capital costs to start-up (53.1%); and 6) Lack of reimbursement (50.0%). These barriers were consistently identified within both ADC-ADRD and Other provider groups with slight variability in order of rankings. Significant between group differences were observed for lack of evidence-based curricula (*P*=.003; differences among unsure if a barrier and not a barrier) and perceived fear of malpractice and/or liability (*P*=0.008; differences between it being a barrier and unsure if a barrier) surrounding the implementation and provision of remote educational support services via telehealth to families. The need for staff and IT was marginally significant by group (*P*=.055; differences among unsure if a barrier and not a barrier).

Table 3. Perceived barriers to the implementation and provision of caregiver educational support telehealth services

Barriers	**Overall n, (%)**	**ADC-ADRD Providers n, (%)**	**Other Respite Providers n, (%)**	***P*-value**
Low clientele computer literacy				.61
A barrier	41 (65.1)	15 (75.0)	26 (60.5)	
Unsure	14 (22.2)	3 (15.0)	11 (25.6)	
Not a barrier	8 (12.7)	2 (10.0)	6 (14.0)	
Lack of clientele access to the internet				.28
A barrier	40 (63.5)	11 (55.0)	29 (67.4)	
Unsure	14 (22.2)	4 (20.0)	10 (23.3)	
Not a barrier	9 (14.3)	5 (25.0)	4 (9.3)	
Lack of clientele interest and uptake				.51
A barrier	38 (60.3)	13 (65.0)	25 (58.1)	
Unsure	15 (23.8)	3 (15.0)	12 (27.9)	
Not a barrier	10 (15.9)	4 (20.0)	6 (14.0)	
Capital costs to start-up				.58
A barrier	33 (53.2)	9 (47.4)	24 (55.8)	
Unsure	12 (19.4)	3 (15.8)	9 (20.9)	
Not a barrier	17 (27.4)	7 (36.8)	10 (23.3)	
Need for staff and IT support				.055
A barrier	34 (53.1)	11 (52.4)	23 (53.5)	
Unsure	12 (18.8)	1 (4.8)	11 (25.6)	
Not a barrier	18 (28.1)	9 (42.9)	9 (20.9)	
Lack of reimbursement and billing				.13
A barrier	31 (50.0)	10 (47.6)	21 (51.2)	
Unsure	13 (21.1)	2 (9.5)	11 (26.8)	
Not a barrier	18 (29.0)	9 (42.9)	9 (22.0)	
Continuing costs				.17
A barrier	31 (49.2)	7 (35.0)	24 (55.8)	
Unsure	11 (17.5)	3 (15.0)	8 (18.6%	
Not a barrier	21 (33.3)	10 (50.0)	11 (25.6)	
Lack of evidence-based curricula				.003
A barrier	19 (30.2)	6 (30.0)	13 (30.2)	
Unsure	19 (30.2)	1 (5.0)	18 (41.9)	
Not a barrier	25 (39.7)	13 (65.0)	12 (27.9)	
Concerns for client privacy				.14
A barrier	16 (25.4)	2 (10.0)	14 (32.6)	
Unsure	18 (28.6)	6 (30.0)	12 (27.9)	

Not a barrier	29 (46.0)	12 (60.0)	17 (39.5)	
Lack of fit with organizational mission				.10
A barrier	15 (23.4)	3 (14.3)	12 (27.9)	
Unsure	13 (20.3)	2 (9.5)	11 (25.6)	
Not a barrier	36 (56.3)	16 (76.2)	20 (46.5)	
Fear of malpractice and/or liability				.008
A barrier	9 (14.8)	0	9 (22.0)	
Unsure	19 (31.1)	4 (20.0)	15 (36.6)	
Not a barrier	33 (54.1)	16 (80.0)	17 (41.5)	
Other				.79
A barrier	6 (30.0)	1 (25.0)	5 (31.3)	
Unsure	8 (40.0)	1 (25.0)	7 (43.7)	
Not a barrier	6 (30.0)	2 (50.0)	4 (25.0)	
Lack of leadership interest or support				.04
A barrier	5 (7.8)	0	5 (11.6)	
Unsure	14 (21.9)	2 (9.5)	12 (27.9)	
Not a barrier	45 (70.3)	19 (90.5)	26 (60.5)	
Past negative experiences with telehealth				.57
A barrier	5 (8.1)	1 (5.0)	4 (9.5)	
Unsure	17 (27.4)	4 (20.0)	13 (31.0)	
Not a barrier	40 (64.5)	15 (75.0)	25 (59.5)	

RCP Interest in the Provision of Caregiver Telehealth Educational Support Services

Among all RCP types, 60.9% were interested in exploring the provision of educational support services to caregivers via telehealth (Table 4). Interest was higher among ADC-ADRD providers (71.4%) than Other provider types (55.8%). In follow-up questioning of those providers that expressed ‘no’ interest, 58.3% indicated that they would change their initial decision if these services were reimbursable. This positive effect of reimbursement on decision making was also found among ADC-ADRD (60%) and Other (57.9%) provider types, with no difference between groups. Among providers that were interested in exploring the provision of telehealth services and those that would be interested if these services were reimbursable, 68.8% were interested in exploring Individual caregiver support services, 65.6% in Caregiver support groups, as well as Individual caregiver education programming. Overall, interest in these services was higher among the ADC-ADRD providers than the Other provider group.

Table 4. Provider interest in the provision of caregiver telehealth educational services

	Overall n, (%)	**ADC-ADRD Providers n, (%)**	**Other Respite Providers n, (%)**	***P*-value**
Interest in provision of caregiver telehealth educational services				.23
Yes	39 (60.9)	15 (71.4)	24 (55.8)	
No	25 (39.1)	6 (28.6)	19 (44.2)	
If ‘NOT’ interested, would your decision change if services were reimbursable?	14 (58.3)	3 (60.0)	11 (57.9)	1.0
Type of Service(s) interested in exploring more about [a]				
Individual caregiver support	44 (68.8)	17 (81.0)	27 (62.8)	.16

Caregiver support groups	42 (65.6)	17 (81.0)	25 (58.1)	.09
Individual caregiver education	42 (65.6)	14 (66.7)	28 (65.1)	.90
Individual medical health	9 (14.1)	5 (23.8)	4 (9.3)	.14
Other	4 (6.3)	3 (14.3)	1 (2.3)	.10

[a] Survey respondents may select multiple categories, % totals may not equal 100%

Confidence and Opinions Towards the Provision of Caregiver Educational Telehealth Support Support Services

Overall, 61.3% of all RCPs expressed a positive level of confidence (Table 5) that their agency/organization could successfully adapt to the implementation of remote caregiver educational support services delivered via telehealth. Confidence was higher among ADC-ADRD providers (76.2%) than Other provider types (53.7%), though the overall difference on the Likert scale was not significantly different. When asked to endorse a statement that best matched their thoughts on the future of telehealth to educate caregivers in the home in the next 10 years, 76.2% of all RCPs endorsed statements of belief that telehealth would have a ‘significant’ and/or ‘dramatic’ impact on the provision of educational support services to caregivers. Although no significant differences were observed, ADC-ADRD providers reported higher levels of belief (85.7%) than Other provider types (71.5%), respectively.

Table 5. Provider confidence, attitudes and opinions towards the provision of caregiver telehealth educational services

Confidence, Attitudes and Opinions	**Overall n, (%)**	**ADC-ADRD Providers n, (%)**	**Other Respite Providers n, (%)**	***P*-value**
Confidence that your agency/organization could successfully adapt to the implementation of remote educational support services via telehealth to caregivers in the home				.55
Very confident	17 (27.4)	8 (38.1)	9 (22.0)	
Somewhat confident	21 (33.9)	8 (38.1)	13 (31.7)	
Unsure	11 (17.7)	2 (9.5)	9 (22.0)	
Somewhat not confident	4 (6.5)	1 (4.8)	3 (7.3)	
Not confident at all	9 (14.5)	2 (9.5)	7 (17.1)	
Statement that best describes your thoughts on the future of telehealth to educate caregivers in the home in the next 10 years				.52
It is a passing trend and will have little impact on the provision of educational support services to caregivers.	2 (3.2)	0	2 (4.8)	
It is an interesting technology that will have a small impact on the provision of educational support services to caregivers.	13 (20.6)	3 (14.3)	10 (23.8)	
It is an important advance that will have a substantial impact on the provision of educational support services to caregivers.	37 (58.7)	15 (71.4)	22 (52.4)	
It is a paradigm changing development that will dramatically impact on the provision of educational support services to caregivers.	11 (17.5)	3 (14.3)	8 (19.1)	

Types of Educational Telehealth Caregiver Support Programs RCPs would Design

In free response text, when RCPs were given the opportunity to describe the type(s) of caregiver telehealth educational support program(s) they would design that they believed would be helpful (Table 6), the top 5 constructs identified among all RCP types were: 1) Self-care for caregivers (21.9%), 2) Accessing and using respite care / Community resources (12.5%), 3) Specialized education/intervention programs (10.9%), 4) Caregiving during COVID-19 (10.9%), and 5) General client care (10.9%). There was not a single type of telehealth program that a majority (>50%) of providers would design, therefore indicating a variety of needs that telehealth programs could address. Variability in the order of these themes was observed among ADC-ADRD and Other provide types, but no significant differences between groups were found.

Table 6 Type of telehealth caregiver education program(s) respite care providers would design

	Overall n, (%)	**ADC-ADRD Providers n, (%)**	**Other Respite Providers n, (%)**	***P*-value**
Type of telehealth program RCPs would design				
Self-care for Caregiver	14 (21.9)	5 (23.8)	9 (20.9)	NA
Accessing respite care / Community resources	8 (12.5)	2 (9.5)	6 (14.0)	NA
Specialized caregiver education programs	7 (10.9)	4 (19.1)	3 (7.0)	.20
Caregiving during COVID-19	7 (10.9)	4 (19.1)	3 (7.0)	.20
General client care	7 (10.9)	2 (9.5)	5 (11.6)	NA
Disease knowledge	5 (7.8)	1 (4.8)	4 (9.3)	NA
Behavior management education for caregiver	5 (7.8)	1 (4.8)	4 (9.3)	NA
Technology education for caregiver	3 (4.7)	0	3 (7.0)	NA
Social support for caregiver	3 (4.7)	1 (4.8)	2 (4.7)	NA
Medical education / Treatment planning	2 (3.1)	1 (4.8)	1 (2.3)	NA

Discussion

The aims of this study were to explore global pre- and post- onset of the COVID-19 use of telehealth services by RCPs, and to assess ADC-ADRD provider’s attitudes, opinions, and perceived barriers toward the use of telehealth to provide individual educational support services to caregivers in the home. To the best of our knowledge this is the first attempt to systematically explore these phenomena, and comparative literature in this specific field is lacking.

Deemed as non-essential businesses among many nations and subject to operational restrictions during COVID-19, the main result from this study shows an overall similar global trend as observed within the medical health care industry, namely with telehealth being embraced in the respite care industry to provide for the continuity of community care to families. Findings from this study demonstrate that prior to the onset of COVID-19, telehealth was not a standard service offered by RCPs to families. Comparative pre and post survey data shows that as in-person communications with families decreased due to COVID-19 mitigation strategies, RCP employee access to the internet and use of internet ready devices significantly increased ($P<.001$) as did the provision of telehealth services ($P<.001$). This increase was more pronounced among ADC-ADRD providers with 80% of respondents reporting the provision of telehealth services to families post COVID-19 onset compared to 0% prior. Interestingly, although the use of email by RCPs significantly increased, no significant changes in the use of telephone, mail, or social media as a mode of communication were observed during this period. These findings would appear to corroborate that the telehealth services offered by RCPs were aimed to provide remote supportive care to families during COVID-19, rather than solely being used as an adjunct mode of communication.

Across all RCP types, comparative pre-post COVID-19 results showed a 14.1% increase in the number of providers offering some form of educational support services via telehealth to caregivers in the home during the pandemic. This observed increase was from 0% to 38.1% among ADC-ADRD with 12% of these providers receiving reimbursement for services from family payment. At the individual level, the main barriers identified by ADC-ADRD respite care providers to the adoption and implementation of educational support programming via telehealth were 1) computer literacy among clientele, 2) client access to internet, and 3) lack of client interest and uptake. At the facility and/or organization level, the principal identified barriers were the need for staff ad IT support, the capital costs to start up the service, and the lack of reimbursement for the services. These findings are similar to other reports on new provider use of telehealth during COVID-19[18] and previous studies among elderly populations.[19] Despite these perceived barriers, 60.9% of all RCPs expressed an interest in exploring the provision of educational support services to caregivers via telehealth, with interest reportedly higher among ADC-ADRD providers (71.4%) than Other provider types (55.8%) and confidence in the adoption and implementation of educational support programming also comparatively higher 76.2% vs. 53.7%, respectively. Considering estimates that approximately 35.6 million individually are globally affected by dementia, a number that is expected to double by 2030 and triple by 2050 reaching 115.4 million individuals at a cost of $4 trillion, [20, 21] these findings are particularly encouraging for policy makers and funding agencies alike in planning to meet the anticipated worldwide increase in need and demand for evidence-based and specialized ADRD educational telehealth programs and services regardless of family location while reducing access to care inequalities. Although nothing can truly replace face-to-face communication, a systematic review and meta-analysis conducted by Speyer et al. in 2018 found that telehealth services can be just as effective as face-to-face encounters with several additional benefits including increased access and time and cost savings to the overall health care system.[22]

Discussion of telehealth as a standard model for care delivery has been an evolving conversation in the medical healthcare industry for many years. One notable constraining factor to its widespread adoption is reimbursement.[23] In follow up questioning of RCPs that expressed ‘no’ interest in exploring the use of telehealth, 58.3% indicated that they would change their initial decision if services were reimbursable (60% ADC-ADRD and 57.9% Other provider type). This positive effect of reimbursement on the decision-making process for RCPs to consider integrating telehealth services into daily program offerings within non-government funded respite care delivery systems can potentially influence perceived facility/organizational barriers associated with the cost for the start-up, support, and maintenance of offering telehealth services. This finding is especially relevant in the planning and development of individual national strategies to build capacity within the industry to meet the anticipated increase in worldwide demand for specialized ADRD caregiver support services while allowing PWDs to remain in their home and avoid the overwhelming expenses associated with long-term care.[24]

Over the past decade, there has been a gradual increase in international funding for ADRD caregiver and PWD telehealth research, [19, 25] and while this study supports the feasibility of telehealth use among this population by documenting real-word adoption during COVID-19, if we are to better devise global strategies moving forward to meet the challenges of an increasing aged population, it is important we understand and pay attention to the interest and needs of the consumers. RCPs, especially if the services were reimbursable, were specifically interested in: ‘Individual caregiver support services’, ‘Caregiver support groups’ and ‘Individual caregiver education’. A similar typology of interest among ADRD RCPs was identified and reported by other researchers [26] as well as reinforced here through open-ended questioning. We strongly encourage international funding agencies to prioritize and accelerate research funding for the development of evidence-based telehealth programs and provider training curricula in these content areas. In the absence of supported outcome-focused research, quality access to care cannot be ensured and despite well-meaning intentions could potentially lead to poor client outcomes and/or harm.[27]

There is no doubt that COVID-19 has acted as a global incubator for the use of telehealth in many care delivery systems among different consumer populations.[28] And, despite being readily embraced by many care delivery systems during the pandemic, the future of telehealth in these systems, including respite care, is unknown. Whether telehealth becomes a mainstay in the respite industry remains to be seen. However, when asked to endorse a statement that best matched their thoughts on the future of telehealth to educate caregivers in the home in the next 10 years, 76.2% of all RCPs endorsed statements of belief that telehealth would have a 'significant' and/or 'profound' impact on the industry. These beliefs were higher among ADC-ADRD (85.7%) than Other provider types (71.5%), respectively. In a service industry such as respite care where RCP belief in telehealth is high, we postulate that it is now better positioned to help meet the expected increasing global demand for supportive services and possibly improve consumer satisfaction through enhanced ease of remote access to specialized dementia care in the home.[29]

Limitations

The major limitations of this study are the use of an unvalidated instrument, the low survey response rate, and the limited heterogeneity in geographical representation of respondents. These all contribute to a lack of generalizability of findings to the different delivery systems within the global respite care industry. We attribute these limitations to 1) timing of survey distribution during the COVID-19 pandemic, with the closure of many respite care facilities; 2) the survey instrument was not made readily available in different native languages; and 3) limited structures and mechanisms to support cooperative international research within the respite care industry. While these concerns are legitimate and were to a certain extent anticipated, we nevertheless believe this work provides valuable insight into underlying trends within the industry and lends credible data to help guide policy makers, funding agencies and researchers in advanced planning to meet the expected increase in worldwide demand and need for the provision of specialized ADRD services to caregivers in the home.

Conclusion

Post onset of COVID-19, there was a significant increase in the use of telehealth within the respite care industry to provide continuity of care to families. This capacity building may have the potential to become a sustainable mechanism for providers to deliver remote specialized family services. While perceived barriers to the widespread adoption and provision of telehealth services exist at both the provider and client level, there is interest in exploring the long-term use of this technology to deliver caregiver educational support programs among all respite care provider types, including ADC ADRD providers. With an increasingly aging global population, culturally relevant and evidence-based curricula to support the use of telehealth by ADRD providers should be a priority focus area for international funding agencies and dementia researchers to meet the future need and anticipated growth in demand for program specific related content. Before individual nations' demand exceeds ability to supply these services, dialogue among public health policy makers should be initiated regarding the potential of funding mechanisms for telehealth services to encourage provider investment and use of telehealth to expand the provision of remote access to care for families; to reduce caregiver burden and ensure that persons with ADRD may remain longer in their preferred abode: the home and the community.

Abbreviations

ADC:	Adult day care (short break)
ADL:	Activities of Daily Living
ADRD:	Alzheimer's Disease and related dementias
IRB:	Institutional Review Board

IT:	Information technology
PAM:	Partners at Meals
PWD:	Persons with Dementia
RCP:	Respite care provider
RCT:	Randomized controlled trial

Acknowledgements

The authors would like to thank Dr. Elaine J. Amella-Krug for assistance with survey development, and ARCH National Respite Network and Resource Center and The BREAK (Building Respite Evidence and Knowledge) Exchange for their support in survey dissemination to respite care providers, both domestically and internationally. Research reported in this publication is supported by the National Institute of Nursing Research (NINR) of the National Institutes of Health (NIH) under Award Number R01NR016466; and, by the South Carolina Clinical & Translational Research (SCTR) Institute, with an academic home at the Medical University of South Carolina, through NIH Grant Numbers UL1RR029882 and UL1TR000062. The funders did not have any input in the study design, or the collection, analysis, and interpretation of data, or in the development of this manuscript. The content of this manuscript is solely the responsibility of the authors and does not necessarily represent the official views of the NIH/NINR.

Authors’ contributions

MM, SQ and TK were primarily responsible for developing the study aims and survey design. MB, MM and MP were responsible for overseeing survey distribution and data collection procedures. JN provided statistical advice and data analysis. MM drafted the initial manuscript. All authors read, edited, and approved the final version.

Conflicts of Interest

None declared.

References

1. World Health Organization. WHO Director-General's opening remarks at the media briefing on COVID-19 - 11 March 2020. [November 11, 2020]; Available from: https://www.who.int/dg/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---11-march-2020.
2. World Health Organization. Critical preparedness, readiness and response actions for COVID-19-7 March 2020. [February 20, 2021]; Available from: https://www.who.int/publications/i/item/critical-preparedness-readiness-and-response-actions-for-covid-19.
3. Onder G, Rezza G, Brusaferro S. Case-Fatality Rate and Characteristics of Patients Dying in Relation to COVID-19 in Italy. JAMA. 2020;323(18):1775-6. doi: 10.1001/jama.2020.4683.
4. Berg-Weger M, Morley JE. Editorial: Loneliness and Social Isolation in Older Adults during the COVID-19 Pandemic: Implications for Gerontological Social Work. J Nutr Health Aging. 2020;24(5):456-8. PMID: 32346678. doi: 10.1007/s12603-020-1366-8.
5. Giebel C, Lord K, Cooper C, Shenton J, Cannon J, Pulford D, et al. A UK survey of COVID-19 related social support closures and their effects on older people, people with dementia, and carers. Int J Geriatr Psychiatry. 2020 Sep 18. PMID: 32946619. doi: 10.1002/gps.5434.
6. Colizzi M, Sironi E, Antonini F, Ciceri ML, Bovo C, Zoccante L. Psychosocial and Behavioral Impact of COVID-19 in Autism Spectrum Disorder: An Online Parent Survey. Brain Sciences. 2020;10(6):341. PMID: doi:10.3390/brainsci10060341.
7. Sheth K, Lorig K, Stewart A, Parodi JF, Ritter PL. Effects of COVID-19 on Informal Caregivers and the Development and Validation of a Scale in English and Spanish to Measure the Impact of COVID-19 on Caregivers. J Appl Gerontol. 2021 Mar;40(3):235-43. PMID: 33143545.

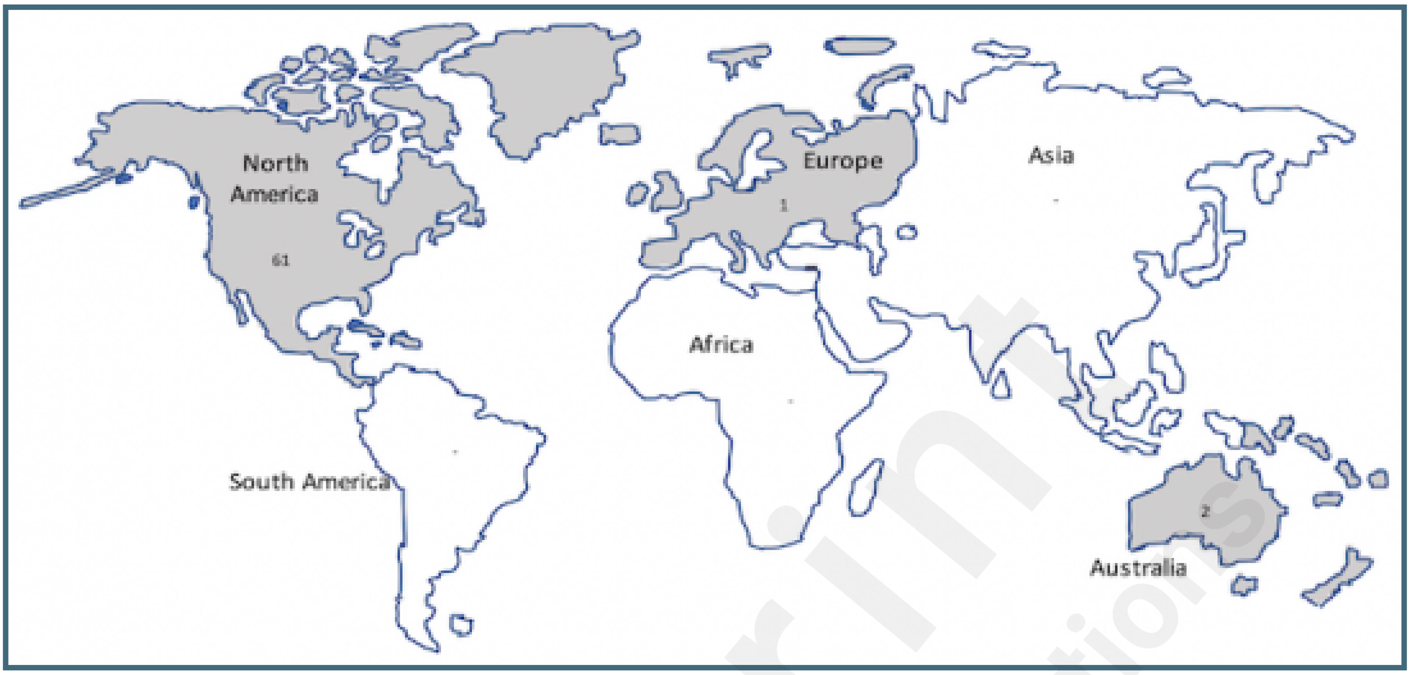
doi: 10.1177/0733464820971511.
8. Altieri M, Santangelo G. The Psychological Impact of COVID-19 Pandemic and Lockdown on Caregivers of People With Dementia. Am J Geriatr Psychiatry. 2020 Oct 22. PMID: 33153872. doi: 10.1016/j.jagp.2020.10.009.
9. The National Alliance for Caregiving & the AARP Public Policy Institute. Caregiving in the U.S. 2020. [January 13, 2021]; Available from: https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf.
10. International Alliance of Carer Organizatons (IACO). Global State of Care Report 2018. [January 13, 2021]; Available from: https://internationalcarers.org/wp-content/uploads/2018/11/IACO-EC-GSoC-Report-FINAL-10-20-18-.pdf.
11. Australian Government Department of Social Services. Supporting Carers (2018). [January 13, 2021]; Available from: https://www.dss.gov.au/disability-and-carers/carers.
12. Prime Minister of Australia. $2.4 billion health plan to fight COVID-19. March 11, 2020. 2020; Available from: https://www.pm.gov.au/media/24-billion-health-plan-fight-covid-19.
13. Center for Medicare and Medicaid Services. Billing for Professional Telehealth Distant Site Services During the Public Health Emergency. March 31, 2020. [Jan 13, 2021]; Available from: https://www.cms.gov/outreach-and-educationoutreachffsprovpartprogprovider-partnership-email-archive/2020-04-03-mlnc-se#_Toc36815181.
14. Bhaskar S, Bradley S, Chattu VK, Adisesh A, Nurtazina A, Kyrykbayeva S, et al. Telemedicine Across the Globe-Position Paper From the COVID-19 Pandemic Health System Resilience PROGRAM (REPROGRAM) International Consortium (Part 1). Front Public Health. 2020;8:556720. PMID: 33178656. doi: 10.3389/fpubh.2020.556720.
15. Doraiswamy S, Abraham A, Mamtani R, Cheema S. Use of Telehealth During the COVID-19 Pandemic: Scoping Review. J Med Internet Res. 2020 Dec 1;22(12):e24087. PMID: 33147166. doi: 10.2196/24087.
16. Amella Krug EJ, Qanungo S, Martin KL, Mueller M, Madisetti M, Kelechi TJ. A cluster randomized controlled trial to assess the efficacy of a telehealth-based train-the-trainer mealtime intervention delivered by respite care center volunteers to caregivers of persons with dementia to improve nutritional outcomes and quality of life. BMC Nutrition. 2020 2020/06/24;6(1):24. doi: 10.1186/s40795-020-00350-x.
17. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)--a metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform. 2009 Apr;42(2):377-81. PMID: 18929686. doi: 10.1016/j.jbi.2008.08.010.
18. Saliba-Gustafsson EA, Miller-Kuhlmann R, Kling SMR, Garvert DW, Brown-Johnson CG, Lestoquoy AS, et al. Rapid Implementation of Video Visits in Neurology During COVID-19: Mixed Methods Evaluation. J Med Internet Res. 2020 2020/12/9;22(12):e24328. doi: 10.2196/24328.
19. Adams JL, Myers TL, Waddell EM, Spear KL, Schneider RB. Telemedicine: A valuable tool in neurodegenerative diseases. Curr Geriatr Rep. 2020 Jun;9(2):72-81. PMID: 32509504. doi: 10.1007/s13670-020-00311-z.
20. World Health Organization. Global action plan on the public health response to dementia 2017-2025. [January 14, 2021]; Available from: https://apps.who.int/iris/bitstream/handle/10665/259615/9789241513487-eng.pdf.
21. World Health Organization. Dementia: a public health priority. Geneva [November 24, 2020]; Available from: https://apps.who.int/iris/handle/10665/75263.
22. Temesgen ZM, DeSimone DC, Mahmood M, Libertin CR, Varatharaj Palraj BR, Berbari EF. Health Care After the COVID-19 Pandemic and the Influence of Telemedicine. Mayo Clin Proc. 2020 Sep;95(9S):S66-S8. PMID: 32948262. doi: 10.1016/j.mayocp.2020.06.052.

23. Dorsey ER, Topol EJ. State of Telehealth. N Engl J Med. 2016 Jul 14;375(2):154-61. PMID: 27410924. doi: 10.1056/NEJMra1601705.
24. Peek ST, Wouters EJ, van Hoof J, Luijkx KG, Boeije HR, Vrijhoef HJ. Factors influencing acceptance of technology for aging in place: a systematic review. Int J Med Inform. 2014 Apr;83(4):235-48. PMID: 24529817. doi: 10.1016/j.ijmedinf.2014.01.004.
25. Waller A, Dilworth S, Mansfield E, Sanson-Fisher R. Computer and telephone delivered interventions to support caregivers of people with dementia: a systematic review of research output and quality. BMC Geriatrics. 2017 2017/11/16;17(1):265. doi: 10.1186/s12877-017-0654-6.
26. Kim S, Shaw C, Williams KN, Hein M. Typology of Technology-Supported Dementia Care Interventions From an In-Home Telehealth Trial. West J Nurs Res. 2019 Dec;41(12):1724-46. PMID: 30688175. doi: 10.1177/0193945919825861.
27. Martinez-Martin N, Dasgupta I, Carter A, Chandler JA, Kellmeyer P, Kreitmair K, et al. Ethics of Digital Mental Health During COVID-19: Crisis and Opportunities. JMIR Ment Health. 2020 2020/12/22;7(12):e23776. doi: 10.2196/23776.
28. Bashshur RL, Doarn CR, Frenk JM, Kvedar JC, Shannon GW, Woolliscroft JO. Beyond the COVID Pandemic, Telemedicine, and Health Care. Telemedicine journal and e-health : the official journal of the American Telemedicine Association. 2020;26(11):1310-3. PMID: 32809913. doi: 10.1089/tmj.2020.0328.
29. Williams K, Blyler D, Vidoni ED, Shaw C, Wurth J, Seabold D, et al. A randomized trial using telehealth technology to link caregivers with dementia care experts for in-home caregiving support: FamTechCare protocol. Res Nurs Health. 2018 Jun;41(3):219-27. PMID: 29504666. doi: 10.1002/nur.21869.

Supplementary Files

Figures

Geographical distribution of survey respondents by continent1.



Multimedia Appendixes

Respite care provider telehealth survey instrument.
URL: http://asset.jmir.pub/assets/4825dace69c0dce5991420227405bce1.pdf