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Viewpoint

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Designing an Electronic Patient Management System for Multiple Sclerosis: Building a Next Generation Multiple Sclerosis Documentation System

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Abstract

Background: Technologies like electronic health records or telemedicine devices support the rapid mediation of health information and clinical data independent of time and location between patients and their physicians as well as among health care professionals. Today, every part of the treatment process from diagnosis, treatment selection, and application to patient education and long-term care may be enhanced by a quality-assured implementation of health information technology (HIT) that also takes data security standards and concerns into account. In order to increase the level of effectively realized benefits of eHealth services, a user-driven needs assessment should ensure the inclusion of health care professional perspectives into the process of technology development as we did in the development process of the Multiple Sclerosis Documentation System 3D. After analyzing the use of information technology by patients suffering from multiple sclerosis, we focused on the needs of neurological health care professionals and their handling of health information technology.

Objective: Therefore, we researched the status quo of eHealth adoption in neurological practices and clinics as well as health care professional opinions about potential benefits and requirements of eHealth services in the field of multiple sclerosis.

Methods: We conducted a paper-and-pencil–based mail survey in 2013 by sending our questionnaire to 600 randomly chosen neurological practices in Germany. The questionnaire consisted of 24 items covering characteristics of participating neurological practices (4 items), the current use of network technology and the Internet in such neurological practices (5 items), physicians' attitudes toward the general and MS-related usefulness of eHealth systems (8 items) and toward the clinical documentation via electronic health records (4 items), and physicians' knowledge about the Multiple Sclerosis Documentation System (3 items).

Results: From 600 mailed surveys, 74 completed surveys were returned. As much as 9 of the 10 practices were already connected to the Internet (67/74), but only 49% preferred a permanent access. The most common type of HIT infrastructure was a complete practice network with several access points. Considering data sharing with research registers, 43% opted for an online interface, whereas 58% decided on an offline method of data transmission. eHealth services were perceived as generally useful for physicians and nurses in neurological practices with highest capabilities for improvements in clinical documentation, data acquisition, diagnosis of specific MS symptoms, physician-patient communication, and patient education. Practices specialized in MS in comparison with other neurological practices presented an increased interest in online documentation. Among the participating centers, 91% welcomed the opportunity of a specific clinical documentation for MS and 87% showed great interest in an extended and more interconnected electronic documentation of MS patients. Clinical parameters (59/74) were most important in documentation, followed by symptomatic parameters like measures of fatigue or depression (53/74) and quality of life (47/74).

Conclusions: Physicians and nurses may significantly benefit from an electronically assisted documentation and patient management. Many aspects of patient documentation and education will be enhanced by eHealth services if the most informative measures are integrated in an easy-to-use and easily connectable approach. MS-specific eHealth services were highly appreciated, but the current level of adoption is still behind the level of interest in an extended and more interconnected electronic documentation of MS patients.

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KEYWORDS

health information technology; computers; Internet; multiple sclerosis; eHealth; disease management

Introduction

Background

Numerous promising opportunities for patients and physicians are associated with an elaborate and concerted integration of health information technology (HIT) in everyday health care of clinics and practices [1-5]. HIT commonly comprises hardware devices and software applications supporting health-related information sharing, decision making, and health behavior. Technologies like electronic health records (EHRs) and telemedicine devices facilitate the rapid mediation of health information and clinical data independent of time and location between patients and their physicians as well as among health care professionals. Today, every part of the treatment process from diagnosis, treatment selection, and application through patient education and long-term care may be enhanced by a quality-assured implementation of HIT that also takes data security standards and concerns into account [6-9].

In addition to patients and healthcare professionals, further agents in the field of health management and their particular interests must be considered when designing and maintaining a comprehensive health-related electronic application. At the level of nationwide health care systems, eHealth technologies provide a substantial potential for cost control, cost savings, and rapid responses to public health emergencies [10-14]. Furthermore, researchers and industry representatives have been showing an increased interest in data liquidity being encouraged by the prospects of widely and securely available patient data; “big data” techniques may improve the cooperation and work flow between researchers and create innovation platforms for an exchange of ideas and, of course, real world health data [15-18].

In an ideal scenario of well-connected health professionals, the EHR serves as key source of health information for physicians, patients, and other users of the health care system infrastructure comprising multimodal information from heterogeneous domains and making them accessible according to the needs of all users and the connection standards of the research network [1,19-22].

Beyond the use of EHRs for documentation and information sharing on an individual and organizational level, the perspective of long-term care and management of chronic diseases extends the concept of complex health technologies by the dimension of time. As representative of such technologies, patient-centered electronic disease management systems have gained in importance over the last few years aiming to support individual care plans and physician-patient communication by evidence-based and standardized treatment guidelines [23].

Multiple sclerosis (MS) is one of the most frequent chronic neurological diseases showing first symptoms between the second and fourth decade of life [24,25]. Due to the long duration of the disease, its early onset, and the increase in therapeutic options, physicians need to establish individualized therapeutic approaches including long-term documentation and patient management over several years [26,27]. These characteristics demonstrate the need for a well-structured health information management and an opportunity to advance health care by innovative HIT. Consequently, the amount of eHealth services for MS has been growing over the past decade. MS patients have become used to information sharing and seeking via the Internet [28-31]. Several MS-specific electronic networks and databases have been established forwarding health information between patients and toward researchers [32-38]. Furthermore, there is a growing trend to analyze data generated from EHRs [39-41]. Standardized therapy documentation provides a solid foundation for data mining from EHRs as well as for disease management. Therefore, electronic large-scale documentation systems with standardized interfaces like the Multiple Sclerosis Documentation System 3D (MSDS^{3D}, successor of the most widely used MS documentation system in Germany) constitute a promising way of aiding empirical medical research and translational health care [26,42-47].

Today, securing benefits of HIT at as many levels as possible and simultaneously precluding technology-immanent obstacles like the unfortunate exclusion of users (due to digital divide), data insecurity, and inefficient implementation (as a result of incompatibility between systems or double documentation) remain major tasks in the development of eHealth applications in general [2,48-51]. Considering this, an implementation of clinical pathways is a highly recommended strategy to realize both standardization and personalization in the treatment process [52-54]. Clinical pathways in HIT reliably comprehend data from diagnosis to treatment and enable controlling processes for quality and cost. In a multilevel approach like MSDS^{3D}, health data is shared among physicians, nurses, and patients and integrated according to clinical pathways. Beyond that, data liquidity is increased by associated data management tools and the ability to connect with research registers.

Despite the given advantages and the rising number of EHR adopters, there is still a relevant number of nonadopters of EHR systems and professionals not using the full potential of modern HIT [51,55]. In order to avoid an isolation of physicians and patients not using recommended and widespread assisting HIT and to increase the level of effectively realized benefits, a user-driven needs assessment should ensure the inclusion of health care professional and patient perspectives into the process of HIT development. After analyzing the use of information technology by MS patients and their willingness to adopt it for therapy in a previous study, we focused on the needs of neurological health care professionals and their handling of HIT, especially of electronic patient management systems and EHRs [56-58].

Objectives

With our exploratory survey among neurologists as an extension of our patient-oriented previous study, we researched the status quo of HIT adoption in neurological practices and clinics. In addition, we aimed to survey health care professionals' opinions about potential benefits and important requirements of eHealth services in the field of MS treatment and documentation in order to enhance the user-driven development of an elaborate documentation and patient management system (MSDS^{3D}). Furthermore, it had to be ascertained whether there are differences between universal neurological practices and MS-specific practices in terms of eHealth use and acceptance.

Methods

Participants

We conducted a paper-and-pencil–based mail survey at the Multiple Sclerosis Center Dresden (Dresden, Germany) in 2013 by sending our questionnaire together with a cover letter to 600 randomly chosen neurological practices in Germany. The cover letter provided information about the scope and the purpose of our survey (see Objectives). Physicians (as head of their neurological practice) were asked to anonymously fill in the 23 questions and return the survey via postal mail in an enclosed self-addressed prepaid envelope (1 questionnaire per practice). A short reminder with a download link to the survey file was also sent via postal mail 3 months after the initial mail. In doing so, we wanted to reach as many practitioners as possible without losing relevant opinions due to an unfavorable effect of technology-based preselection. Neurological practices specialized in MS and non–MS-specialized neurological practices as well as practices with small (less than 100 quarterly) and large (more than 200 quarterly) numbers of patients were included in the survey population.

Questionnaire

The questionnaire was developed in a consensus meeting with a multiprofessional expert team consisting of physicians, psychologists, and computer scientists from the Multiple Sclerosis Centre Dresden as part of the University Hospital Carl Gustav Carus Dresden in a similar manner to the development of our previous questionnaire [56]. Items were selected with respect to the target audience (physicians and nurses) and the variety of tasks in the process of daily health care. With 23 items and subitems, we aimed to describe the participating neurological practices (4 items), the current use of network technology and the Internet in such neurological practices (5 items), physicians' attitudes toward the general and MS-related usefulness of eHealth systems (8 items) and toward the clinical documentation via electronic health records (4 items), and physicians' knowledge about the MSDS (3 items). Items were structured and combined single choice, multiple choice, and free text answers. For a translated English version, see Multimedia Appendix 1.

Statistical Analysis

All statistical comparisons were two-tailed, and a *P* value of <.05 indicated statistical significance. We used SPSS version 22.0 (IBM Corp) for all statistical computations. Chi-square tests or Fisher's exact tests (in case of expected cell counts lower than 5) were used for group comparisons of nominal data. Paired dichotomous data were analyzed using the McNemar's test. For comparisons of ordinal data, the Mann–Whitney U test was applied. In case of multiple relevant predictors, binary outcomes were evaluated by a logistic regression model including MS-specialization and number of patients as predictors.

Results

Participating Practices

From 600 mailed surveys, 74 completed and returned surveys to the Multiple Sclerosis Center Dresden (12.3%). About two-thirds of the returned surveys came from neurologists with practices treating neurological and psychiatric disorders (48/74, 65%) whereas one-third were returned from purely neurological practices (26/74, 35%). As much as 32 practices (43%) featured a specialization in MS and 17 (23%) reported additional specializations like psychotherapy or epileptology. When looking at the number of patients per quarter, 32 practices (43%) stated that less than 100 patients had been treated whereas 24 (32%) treated between 100 and 200 patients and 18 (24%) medicated more than 200 patients. Practices that specialized in MS showed higher numbers of patients per quarter (median: 100-200) than other participating neurological practices (median: <100, *P*<.001).

Health Information Technology Infrastructure of Neurological Practices

Of the 10 practices, 9 were already connected to the Internet (67/74) but only 49% (36/74) preferred a permanent access. The Internet has been utilized by 82% (67/74) as a source for research, by 46% (34/74) for medical studies, by 31% (23/74) for noninterventional studies, by 19% (14/74) for clinical documentation, by 5% (4/74) for accounting, and by 4% (3/74) for email communication with patients.

Almost every practice (73/74) possessed at least one computer for documentation purposes. The most common type of HIT infrastructure was a complete practice network with several access points (65/74, 88%). The ability to access patient data network-wide was preferred (49/74, 66%). Nonetheless, some health care professionals chose documentation limited to a single device (24/74, 32%). Considering data sharing with research registers, 43% (31/73) opted for an online interface whereas 58% (42/73) decided on offline data transmission. Practices that specialized in MS in comparison with other neurological practices presented an increased interest in online documentation

(Table 1). Different numbers of patients per quarter did not result in statistically significant different answers.

Table 1. Information technology infrastructure of neurological practices.

		Practices specialized in MS, n (%)	Other neurological practices, n (%)	*P* value
Existing Internet access		31/32 (97)	36/42 (86)	.13[a]
Continuous Internet connection		20/32 (63)	16/42 (38)	.04[b]
Internet is used for...				
	Research	27/32 (84)	34/42 (81)	.70[b]
	Documentation of interventional studies	22/32 (69)	28.6% (12/42)	<.001[b]
	Documentation of noninterventional studies	15/32 (47)	8/42 (19)	.010[b]
	Clinical documentation	11/32 (34)	3/42 (7)	.003[b]
Documentation via... [c]				.44[b]
	Network	23/32 (72)	26/41 (63)	
	Single device	9/32 (28)	15/41 (37)	
Preferred method of data transmission [c]				.10[b]
	Online	17/32 (53)	14/41 (34)	
	Offline	15/32 (47)	27/41 (66)	

[a] Fisher's exact test

[b] Chi-square test

[c] Reduced sample size due to missing values

eHealth Services for Daily Care

The majority of participating practices considered eHealth services as definitely useful (doctor: 18/74, 24%; nurse: 19/74, 26%) or at least partially useful (doctor: 52/74, 70%; nurse: 49/74, 66%) for doctor's business and nurse duties whereas only a small minority doubted their usefulness (doctor: 4/74, 5%; nurse: 6/74, 8%). The highest potential for benefits of HIT were seen in clinical documentation (61/74, 82%), followed by protection against recourse (47/74, 64%), documentation of medical studies (42/74, 57%), and documentation of noninterventional studies (38/74, 51%). In this regard, physicians' assumed benefits did not differ from those of other practice staff members. When looking at specific tasks, retrieving patient data relevant for the treatment process (yes: 34/72, 47%; partially: 35/72, 49%; no: 3/72, 4%) and diagnosing specific MS symptoms and courses of disease (yes: 33/74, 45%; partially: 34/74, 46%; no: 7/74, 10%) received the highest ratings for being potentially improved by HIT. Beyond that, HIT may enhance physician-patient communication (yes: 25/73, 34%; partially: 38/73, 52%; no: 10/73, 14%) and patient education (yes: 20/72, 28%; partially: 36/72, 50%; no: 16/72, 22%). An increased precision in the assessment of MS-specific scales (1/74) and the support of practice management in general (3/74) were mentioned as additional benefits. The appreciation of eHealth services tended to be higher in practices specialized in MS than those in other neurological practices (Table 2).

Table 2. Usefulness of health information technology in neurological practices.

		Practices specialized in MS, n (%)	Other neurological practices, n (%)	*P* values
eHealth services are useful for doctors' duties				<.001[a]
	Yes	15/32 (47)	3/42 (7)	
	Partially	16/32 (50)	36/42 (86)	
	No	1/32 (3)	3/42 (7)	
eHealth services are useful for nurses' duties				.03[a]
	Yes	15/32 (47)	4/42 (10)	
	Partially	17/32 (53)	32/42 (76)	
	No	0/32	6/42 (14)	
eHealth services are useful for...				
	Recourses	23/32 (72)	24/42 (57)	.19[b]
	Clinical documentation	28/32 (88)	33/42 (79)	.32[b]
	Documentation of interventional studies	27/32 (84)	15/42 (36)	<.001[b]
	Documentation of noninterventional studies	28/32 (88)	10/42 (24)	<.001[b]
eHealth services are useful for patient education [c]				.16[a]
	Yes	11/32 (34)	9/40 (23)	
	Partially	16/32 (50)	20/40 (50)	
	No	5/32 (16)	11/40 (28)	
eHealth services are useful for physician-patient communication [c]				.23[a]
	Yes	13/32 (41)	12/41 (29)	
	Partially	16/32 (50)	22/41 (54)	
	No	3/32 (9)	7/41 (17)	
eHealth services are useful for retrieving patient data [c]				.25[a]
	Yes	17/32 (53)	17/40 (43)	
	Partially	15/32 (47)	20/40 (50)	
	No	0/32	3/40 (8)	
eHealth services are useful for diagnosing specific MS symptoms and courses of disease				.34[a]
	Yes	16/32 (50)	17/42 (41)	
	Partially	14/32 (44)	20/42 (48)	
	No	2/32 (6)	5/42 (12)	

[a] Mann-Whitney U test

[b] Chi-square test

[c] Reduced sample size due to missing values

Electronic Health Records for Multiple Sclerosis

Among the participating centers, 91% (67/74) welcomed the opportunity of a specific clinical documentation for MS and 87% (64/74) showed great interest in an extended and more interconnected electronic documentation of MS patients. Clinical parameters (59/74, 80%) were most important in documentation, followed by symptomatic parameters like measures of fatigue or depression (53/74, 72%) and quality of life (47/74, 64%). Given the chance to communicate additional desirable parameters, many options were reported: from tests for cognition and working ability to results from magnetic resonance imaging and cerebrospinal fluid, medication history, social factors (eg, family status, job status), visit structures for prominent disease modifying drugs, and a broad approach to common disabilities in MS. The request for an integration into clinical networks (53/74, 72%) significantly exceeded (*P*=.005) the request for the ability to import data from other systems (35/74, 47%), which was still considerably high. Further design tasks for EHRs were specified: the ability to support communication and data exchange with general practitioners, the integration of data management tools, an easy-to-use design, verified compatibility with other systems, data security, and possibilities to avoid double documentation in several documentation systems. Neither type of neurological practice differed in opinions about EHR systems for MS.

Recognition of the Multiple Sclerosis Documentation System

In nearly half of the participating practices (34/74, 46%), the Multiple Sclerosis Documentation System (MSDS) was already known. The level of awareness was higher among practices specialized in MS (23/32, 72%) than among other neurological practices (11/42, 26%) (*P*<.001). Fifteen practices already used one version of MSDS (MSDS Practice, Bayer Healthcare). Reasons for not using MSDS were concerns about double documentation (8/74) and the expected expenditure of time (9/74).

Discussion

Principal Findings

In the process of HIT development, a user-driven needs assessment ensures the inclusion of health care professional perspectives and, therefore, supports the realization of benefits of HIT. In order to examine this issue, we surveyed neurological health care professionals in Germany and their handling of HIT, especially of electronic patient management systems and EHRs, and included the results in the development process of the MSDS^{3D}. Looking at the results, the adoption of HIT in daily health care was quite high among neurological practices and clinics and even higher among practices specialized in MS. In general, respondents were very open-minded about eHealth services. Highest potential benefits of HIT were seen in treatment documentation and study documentation. When designing interfaces of complex eHealth services for neurological practices and clinics, options for online transmission as well as for offline transfer should be implemented, and the ability to connect with preexisting HIT structures should be assured. An MS-specific EHR system would be welcomed by the majority of participating practices.

eHealth Services for Neurological Practices

Health information technology may improve quality of care by increasing adherence to guidelines and decreasing medication errors [2]. Before this study, data on the use and acceptance of HIT by neurologists and chronic care providers in the domain of MS was lacking. Our study showed that there is a high base rate of IT adoption among neurological practices and that practices specialized in MS present an increased interest in documentation and patient management assisted by eHealth services. These results supported the assumption that the domain of MS is a promising field for upcoming eHealth trends. In addition, rates of HIT adoption did not differ by practice size measured as number of patients per quarter.

We found that eHealth services were perceived as generally useful for physicians and nurses in neurological practices with highest capabilities for improvements in clinical documentation, data acquisition, diagnosis of specific MS symptoms, physician-patient communication, and patient education. Practices specialized in MS had an increased need for eHealth services for documentation purposes of interventional and noninterventional studies. The most prominent reason for nonadoption of eHealth services was the concern about additional expenditure of time for documentation. The results were in line with other works on the benefits of HIT adoption. Mickan et al proposed four functional aspects that may be improved by mobile eHealth services: patient documentation, patient care, health information seeking, and professional work patterns [59]. Clinical pathways as representatives of such work patterns were associated with reduced in-hospital complications and improved documentation [60]. Nonetheless, mixed results were available about whether eHealth services may lead to a reduction or an increase in the time required for documentation [48,60,61].

The integration of patient data into larger systems of health data management remains an essential task to fulfill [1]. According to the responses in our survey, emphasis has to be laid on a dual-option for data transmission (online and offline mode) and on an extensive integration of standard interfaces for common research and health care networks during the development of a local EHR system.

Electronic Health Records for Multiple Sclerosis

There is a growing trend for adoption of EHRs within the past decade. Some authors reported a yearly increase of 10% [5,21,51]. In 2013, about 70% of US physicians had already implemented at least a basic version of an EHR whereas only 9% declared themselves as “persistent nonadopters” [51]. Those nonadopters were characterized as mostly elder physicians with rarely more than 2 physicians per practice. In our survey, a similar rate of physicians doubting the usefulness of HIT was found. But looking at the rate of adoption among practices specialized in MS, the rate of nonadopters tended toward zero. The vast majority of the responding practices welcomed the opportunity of electronically assisted clinical documentation for MS. Clinical parameters and scores like the Expanded

Disability Status Scale were highly appreciated for integration into an EHR for MS, followed by symptomatic parameters like measures of fatigue or depression and patient-reported outcomes like measures of health-related quality of life. Additionally, the import of data from preexisting databases and the integration into clinical networks must be secured in order to meet neurologists' needs. Likewise, Kruse et al indicated that the adoption of an EHR or a computerized physician order entry were predominantly associated with internal organizational factors that must be taken into account [21].

MSDS is the most widely used electronic documentation system for patients with MS in Germany [35]. In an evidence-based and user-driven development process, MSDS has evolved from a database to a complete patient management system [26,42,44,46,52]. In about half of the participating neurological practices, MSDS was already known, especially among practices specialized in MS (72%). Furthermore, 20% of all responders already used a version of MSDS. Results and lessons of the current survey have been integrated into the continued development of MSDS^{3D}, the current version of MSDS, which can be used by patients, nurses, and physicians to enhance data collection and facilitate an interactive analysis and interpretation of given results via touch screen devices or other devices via the Internet (by app, email, or web browser) in neurological practices.

Limitations

Only an average response rate of about 12% was achieved in this postal survey, which may have limited the variety of reported additional aspects of important EHR features and the representativeness of the given results. Despite that, no type of neurological practice (with respect to specialization and patient numbers) was underrepresented among the responding practices, and responders were clearly not restricted to the portion of practices being familiar with the system MSDS. A detailed characterization of nonresponders was not within the scope of this study. Some factors associated with the adoption of eHealth services in other studies like physician's age or the number of staff members were not included in the questionnaire. Moreover, data on the use of mobile devices could have improved the illustration of HIT usage.

Conclusions

In this study, we surveyed the use of HIT in neurological practices in Germany and the perceived usefulness of eHealth services like EHRs for the community of MS health care professionals. Both physicians and nurses may significantly benefit from electronically assisted documentation and patient management. Many aspects of patient documentation and education will be enhanced by eHealth services if the most informative measures are integrated in an easy-to-use and easily connectable approach. MS-specific eHealth services were highly appreciated, but the current level of adoption is still behind the level of interest in an extended and more interconnected electronic documentation of MS patients. A comprehensive electronic patient management system should incorporate the balanced interests and needs of all agents (physician, staff members, patients, and researchers) in the field of chronic disease management. Further research should validate the presented results and increase the knowledge about the adoption of different types of HIT and applicable devices. A comparison of the electronically assisted management of different chronic diseases and the support of a multilanguage user interface may extend the application range of existing eHealth technologies and thereby raise the cost-effectiveness of such systems.

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Conflicts of Interest

RK received personal compensation from Biogen Idec, Bayer, Novartis, Sanofi, and Teva for consulting services. Additionally, he received financial support for research activities from Bayer, Biogen Idec, Novartis, Teva, and Sanofi Aventis. JE received travel grants from Biogen, Novartis, and Teva. KT received personal compensation for oral presentations from Novartis, Bayer, and Biogen Idec. Additionally, she received financial support for research activities from Novartis. TZ received personal compensation from Biogen Idec, Bayer, Novartis, Sanofi, Teva, and Synthon for consulting services. Additionally, he received financial support for research activities from Bayer, Biogen Idec, Novartis, Teva, and Sanofi Aventis.

Multimedia Appendix 1

Questionnaire on the use of health information technology in neurological practices and on the needs of neurologists for future eHealth services.

[PDF File (Adobe PDF File), 14KB - ijmr_v5i1e2_app1.pdf]

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Abbreviations

EHR: electronic health records
HIT: health information technology
MS: multiple sclerosis
MSDS: Multiple Sclerosis Documentation System
MSDS3D: Multiple Sclerosis Documentation System 3D

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Original Paper

Accuracy, Validity, and Reliability of an Electronic Visual Analog Scale for Pain on a Touch Screen Tablet in Healthy Older Adults: A Clinical Trial

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Abstract

Background: New technology for clinical data collection is rapidly evolving and may be useful for both researchers and clinicians; however, this new technology has not been tested for accuracy, reliability, or validity.

Objective: This study aims to test the accuracy of visual analog scale (VAS) for pain on a newly designed application on the iPad (iPadVAS) and measure the reliability and validity of iPadVAS compared to a paper copy (paperVAS).

Methods: Accuracy was determined by physically measuring an iPad scale on screen and comparing it to the results from the program, with a researcher collecting 101 data points. A total of 22 healthy community dwelling older adults were then recruited to test reliability and validity. Each participant completed 8 VAS (4 using each tool) in a randomized order. Reliability was measured using interclass correlation coefficient (ICC) and validity measured using Bland-Altman graphs and correlations.

Results: Of the measurements for accuracy, 64 results were identical, 2 results were manually measured as being 1 mm higher than the program, and 35 as 1 mm lower. Reliability for the iPadVAS was excellent with individual ICC 0.90 (95% CI 0.82-0.95) and averaged ICC 0.97 (95% CI 0.95-1.0) observed. Linear regression demonstrated a strong relationship with a small negative bias towards the iPad (−2.6, SD 5.0) with limits of agreement from −12.4 to 7.1.

Conclusions: The iPadVAS provides a convenient, user-friendly, and efficient way of collecting data from participants in measuring their current pain levels. It has potential use in documentation management and may encourage participatory healthcare.

Trial Registration: Australia New Zealand Clinical Trials Registry (ANZCTR): 367297; https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=367297&isReview=true (Archived by Webcite at http://www.webcitation.org/6d9xYoUbD).

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KEYWORDS

pain; VAS; technology; scale

Introduction

The health care sector is poised at the cusp of a transformation from being reactive to disease and injury toward proactive prevention, where the ultimate goal is to maximize individual health rather than treat disease. Ready access to medical information combined with ubiquitous sensing, quantified self, mobile computing, and social networking technologies empowers individuals to participate in their own health and well-being. According to Hood and colleagues [1], active participation by individuals is a central component of the revolution in health care and wellness.

The ability to measure pain objectively forms an important part of health care, both in chronic health monitoring and in acute settings, to determine changes in patient clinical presentation and the effectiveness of interventions aimed at alleviating pain. Visual analog scales (VAS) for collecting pain data in the traditional paper-based format have been shown to be accurate, valid, reliable, and reproducible [2] across a range of settings. Using paper-based versions of VAS scales requires application of the scale in a standard manner, measurement of the value with a ruler, and then copying of the value into notes or electronic databases. This manual entry is time-consuming and has the potential for transcription or typing errors. When the researcher or clinician has to travel, paper versions of data collection are bulky and can be problematic for ensuring secure storage during transport.

Collecting the pain data electronically streamlines data measurement and management. Previously, electronic data collection using hand-held devices (eg, personal digital assistants or laptop computers) for VAS for pain has found values to be equivalent to paper-based tools; however, these electronic tools were costly [3] and differed from the paper version in the method of interacting with screen and sensations measured [4].

Costs for new technology including hand-held tablets have decreased in recent years. These devices have the benefit of a user-friendly touch screen interface. With appropriate applications, data collected on a touch screen can be automatically measured and exported to a database for secure storage within the device and can easily be emailed to the researcher or clinician when access to the Internet is available. However, this new technology has not been tested for accuracy and reliability or compared to the paper-based gold standard for validity.

We assessed the accuracy of VAS for pain on an iPad (iPadVAS), measured and compared the reliability of iPadVAS to a paper copy (paperVAS), and validated the iPadVAS against paperVAS in a healthy community group.

Methods

Accuracy Study

A single researcher drew a line across the iPadVAS line with 1 finger 100 times using all parts of the scale. After each effort, the value was measured on the 100 mm line with a ruler that had 1 mm gradations marked on it; the number corresponding to the value of the mark (ie, a number between 0 and 100) was recorded in an Excel spreadsheet (Microsoft Corp). The researcher was blinded to the results generated by the application at the time. Measures by the researcher were then compared to the data produced by the algorithm in the iPad application.

Tools

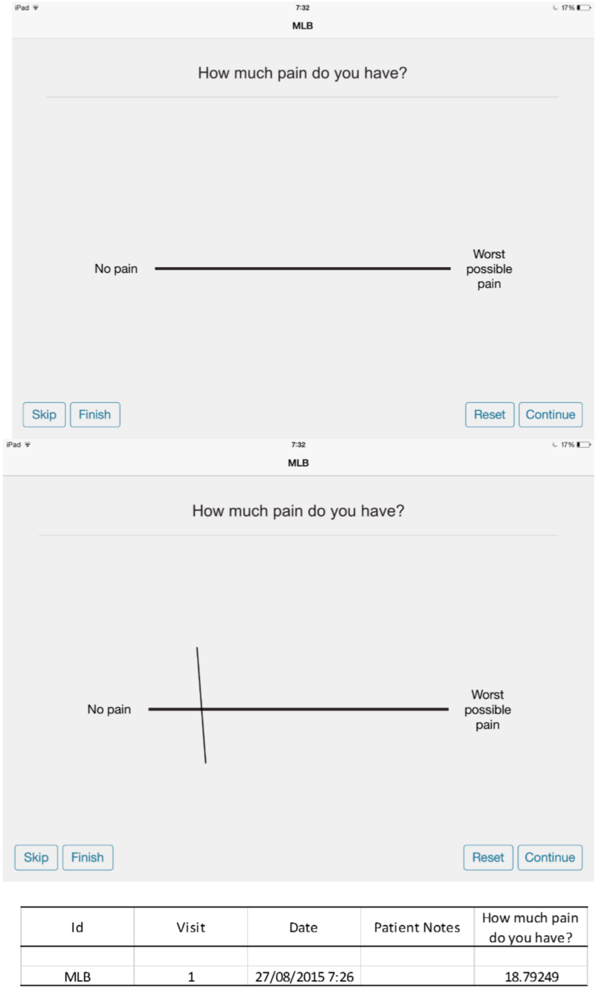
Description of paperVAS

The paperVAS was administered mounted on a clipboard and completed using a pen (0.7 mm tip width) on a line 100 mm in length and 0.75 mm high with no markings on the scale except *No pain* on the left and *Worst possible pain* on the right [2]. To preserve the dimensions of the lines, paper copies were printed and not photocopied.

Description of iPadVAS

iPadVAS was administered on an iPad 2 and completed by the participant using their finger on the screen using an application developed by the research team [5]. Similar to paperVAS, the iPadVAS was 100.06 mm long and 0.96 mm high with no markings on the scale except *No pain* on the left and *Worst possible pain* on the right end of the scale. The line that the fingertip generated on the screen was 0.38 mm wide. To preserve the dimensions of the lines, the application was locked in landscape orientation and could not be used in portrait orientation. User interface elements could not be scaled or rotated. Figure 1 shows a screen capture of a blank iPadVAS and an example of a completed iPadVAS with the data output obtained as a CSV file.

Figure 1. Screen capture of a blank iPadVAS, a completed iPadVAS, and the CSV data output file.



Id	Visit	Date	Patient Notes	How much pain do you have?
MLB	1	27/08/2015 7:26		18.79249

Comparative Study

Participants and Setting

This was a single center study conducted in healthy older adults (ages 65-85 years) at the Exercise Physiology Clinic at the University of Tasmania, Launceston, Australia. Participants who were enrolled for group Pilates classes were invited to take part in the study. The exclusion criterion was people who self-reported inadequate vision to complete the tasks. This study was approved by Human Medical Research Ethics Committee (Tasmania) Network (H0014062). The study is registered with ANZCTR (367297). Written informed consent was obtained from each participant (see Multimedia Appendix 1 for the CONSORT checklist).

Procedure

The study involved two tasks: completion of a paper-based and an electronic VAS for pain. Tests were administered in a randomized order in a single session lasting 30 minutes. Data were collected between November 2014 and April 2015. Each participant chose a token with eyes closed and the color of token selected determined the order (blue: iPadVAS first; red: paperVAS first) of the tasks. Each study participant was given instruction to draw a line through the line on the paper or iPad that corresponded to their current level of pain. They were provided with a demonstration of both tools. Each participant completed both tasks four times. After each effort, the results for the task on iPadVAS were saved and the screen reset so that the previous data were not available for comparison to the participant. Similarly, for the paperVAS, information from previous efforts was not available to the participants.

Sample Size

A change of 13 points in VAS for pain is considered as a clinically significant change [6]. A priori sample size calculation indicated that a sample size of 21 would provide a power of 90% (alpha .05; SD 18) to detect a mean difference of 13 between iPadVAS and paperVAS.

Statistical Analyses

All analyses were performed using Stata Intercooled software version 13 (StataCorp LP). The accuracy of the application algorithm to determine the value on the scale was analyzed by comparing data manually measured using a paired *t test* to determine any differences (P=.05). Linear regression was used to determine the relationship between these two methods of data collection.

Reliability was measured for both the iPadVAS and paperVAS using absolute agreement interclass correlation coefficient (ICC, 95% CI), and linear regression was used to determine the relationship between these two methods of data collection.

Reliability was reported as excellent (ICC 0.90 and higher), good (ICC between 0.80 and 0.89), moderate (ICC between 0.70 and 0.79), or low (ICC less than 0.70) [7]. Validity of the data recorded using the iPadVAS was compared to the paperVAS using Bland-Altman graphs (measuring bias and limits of agreement) and correlations to describe the relationship.

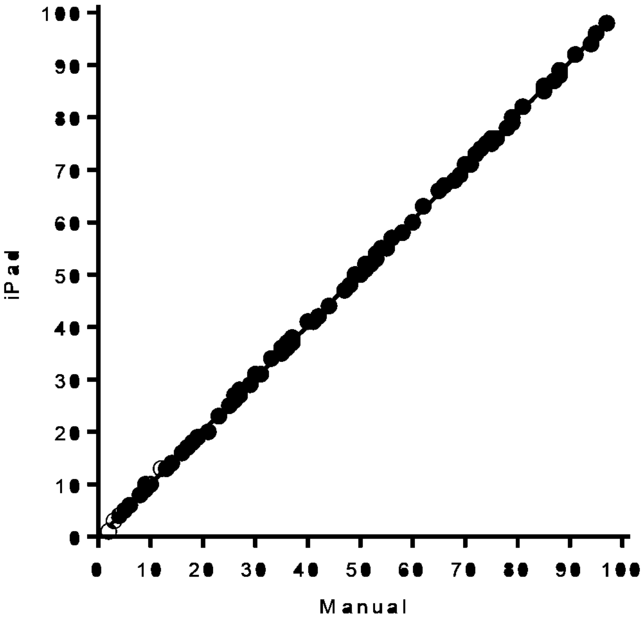
Results

Accuracy Study

A researcher compared 101 data points by examining the difference between manual measurement and the calculated measurement produced by the iPad application program. Accuracy was high with 64 identical results, 2 manually measured results 1 mm higher, and 35 lower by 1 mm than the iPad program. Student *t test* indicated a nonsignificant difference of 0.4 mm (*P*=.35).

Linear regression showed high correlation of the scores between the two measurement techniques (R^2=.9998) equation Y=1.007 × X + 0.02285 (Figure 2).

Figure 2. Correlation of VAS scores between manual and iPad application program.



Comparative Study

Reliability

A total of 22 community dwelling older adults (4 men, ages 56-86 years) were recruited to test reliability and validity. Grouped (iPad and paper) mean (SD) scores for pain values were 11.9 (10.6). Reliability for both tools was excellent (Table 1). Linear regression demonstrated a strong relationship (R^2=.904) equation Y=0.8282 × X + 4.451 (Figure 3).

Validity

There was a small negative bias (SD of bias) toward the iPad (−2.6 [5.0]) with limits of agreement between −12.42 and 7.14 (Figure 4).

Table 1. Absolute agreement ICC for the two tools.

Variable (pain)	paperVAS ICC (95%)	iPadVAS ICC (95%)
Individual	0.96 (0.92-0.98)	0.90 (0.82-0.95)
Average	0.99 (0.98-0.99)	0.97 (0.95-1.00)

Figure 3. Correlation of scores between paperVAS and iPadVAS measures of pain. Each data point is mean of 4 readings for each participant (data points 22).

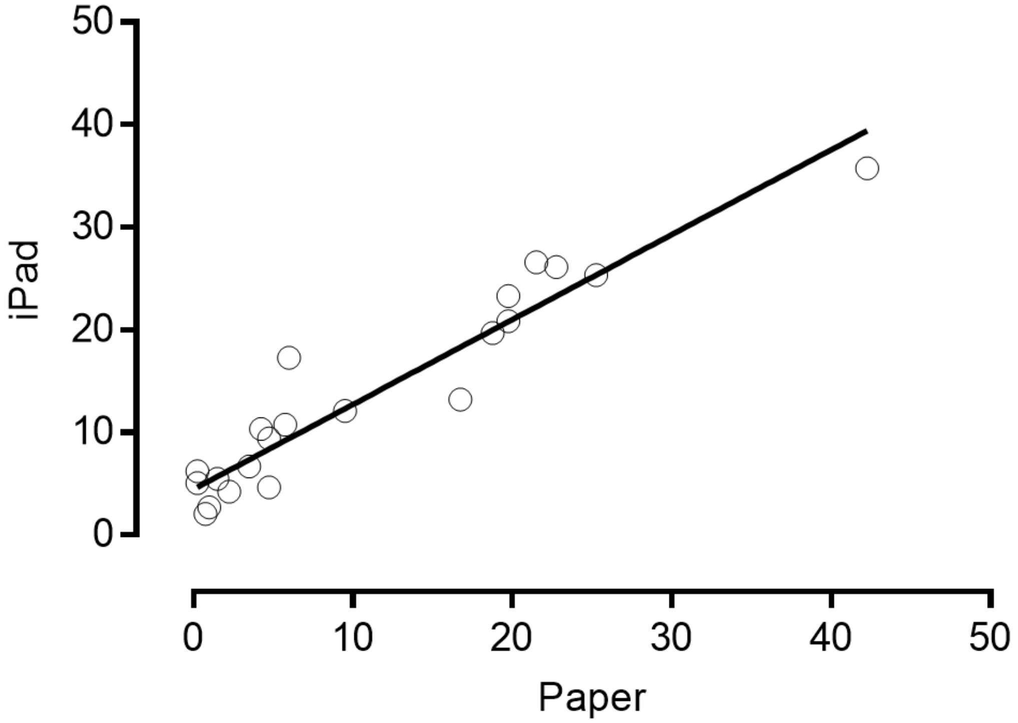
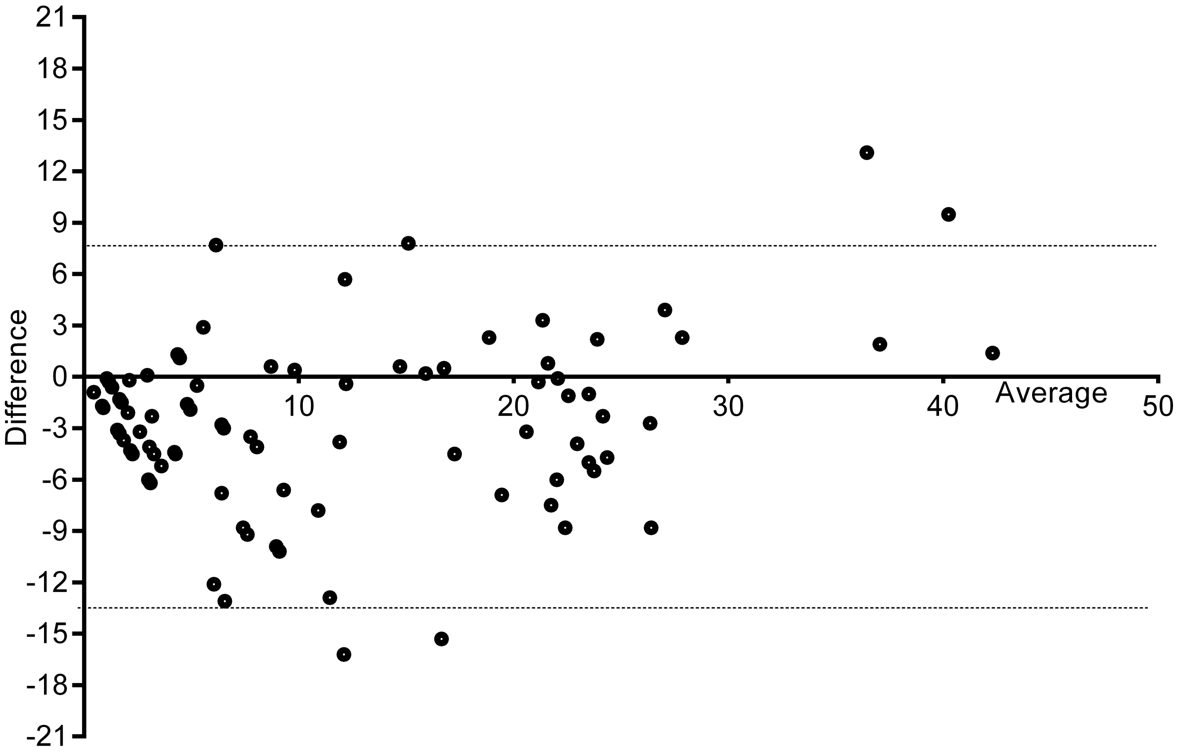


Figure 4. Bland-Altman graph with difference and average of paperVAS and iPadVAS.



Discussion

Principal Finding

This is the first study to measure accuracy, reliability, and validity of an application on a touch screen iPad for VAS. Accuracy and reliability of the iPadVAS is excellent. Validity shows a small negative bias, but the value of this is not clinically relevant. The iPad application is accurate in that the program reads the same as a manual measurement with a ruler and has a correlation coefficient of .99.

A strength of using the iPad is that it prevents people scoring a line outside the VAS line, which consequently prevents invalid results from being recorded. When using a paper-based version of the VAS, some people indicate their pain levels by drawing less than 0 or more than 100 on the paper. These results can be either interpreted as 0 or 100, respectively, or considered an invalid result. In addition, the thickness of the line drawn by the participant is not affected by finger or stylus width. The high level of similarity of results between paperVAS and iPadVAS indicates that the iPadVAS is a clinically useful tool for collecting both individual and group data.

The magnitude of bias detected in our Bland-Altman analysis is not of clinically relevant amount. A minimum of 13 mm change is required over time to suggest if pain has increased or decreased [6]. This indicates that the small degree of bias (2.6 mm) and the difference in accuracy (with one-third of the data showing 1 mm lower result when measured by the iPad program compared to measured manually) is not of a magnitude to have clinical relevance. These small difference may only be of importance if the VAS is used to determine cut-offs for clients having low-moderate (31-70 mm) or high (more than 70 mm) levels of pain, where 1 mm may make the difference in categorization of pain level.

This new tablet technology is superior to previous electronic data collection tools. The difficulty with personal digital assistants was that the full 100 mm standardized scale could not be used because of the small screen size [8-12]. In some cases, data were collected by a sliding scale or by tapping a number on the screen rather than drawing a line through a line on the screen [8,9]. As well, some studies using these tools did not measure actual perception of pain but rather intensity of different sensations, including cognitive (imagined pain) and sensory stimuli related to heaviness [9] or fatigue [13], impacting the relevance for their use with actual pain perception. Computers, including laptops and Web interfaces, have been used to collect patient data electronically on pain using a VAS [14,15], but more commonly other scales have been used [16-18].

The iPad data collection method has several strengths including portability with large data storage capacity, the ability to simply use Internet access to send data to the health care practitioner, and the potential to interface with other medical records. These features in combination with reduced costs demonstrate that this tool may have the potential to facilitate communication between clinicians and clients while enhancing participatory health care.

For clinicians and researchers, especially those involved in field work, the time, cost, and space savings of data storage are large compared to paper-based copies requiring manual measurement of values and transcription into databases or clinical notes. Hand-held electronic devices collecting questionnaire data show improved documentation completeness and fewer errors than paper-based counterparts [19]. Our study demonstrates similar benefits for VAS, which can now be used confidently for a range of health data collection. This will improve the ability of clinicians to track client health longitudinally, improving individualized clinical decision making. In the future it may be possible to integrate this client data into electronic records, enhancing continuity of care.

Reported benefits for data management [20] and a high patient satisfaction have previously been reported for electronic data collection on computers and laptops; however, the costs associated with that technology was a concern [3]. Newer style tablet devices have reduced costs, improved portability, and enhanced ability of the client to communicate objective data more closely with their healthcare professional.

One benefit of using this technology may be the ability of the devices to provide individuals with a means to objectively monitor and record their pain status without requiring them to attend physical consultation. This is especially important for geographically isolated people and those with limited mobility. The ease of frequent monitoring without the need for recall between consultations may also facilitate regular remote monitoring of chronic health conditions. Similar to other Web-based resources [21,22], this technology gives clients the ability to participate more fully in their health care and may improve the self-efficacy of pain management.

A limitation of our study is that the data were collected in a sample of people from the community who were not in high levels of pain. Replication of this study in participants with moderate to high levels of pain would establish reliability in that population, although previous research indicates that the minimally clinically significant difference in pain scales such as VAS does not differ in populations with different severities of pain [23].

Conclusion

The iPadVAS provides a convenient, user-friendly, and efficient way of collecting data from participants in measuring their current pain levels. Its use in health care documentation management has the potential to encourage participatory health care. It is accurate, reliable, and valid in healthy older adults.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

CONSORT Checklist.

[PDF File (Adobe PDF File), 137KB - ijmr_v5i1e3_app1.pdf]

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Abbreviations

ICC: interclass correlation coefficient
VAS: visual analog scales

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Viewpoint

An eHealth Platform to Manage Chronic Disease in Primary Care: An Innovative Approach

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Abstract

The number of individuals with chronic illness and multimorbidity is growing due to the rapid ageing of the population and the greater longevity of individuals. This causes an increasing workload in care, which results in a growing need for structural changes of the health care system. In recent years this led to a strong focus on promoting “self-management” in chronically ill patients. Research showed that patients who understand more about their disease, health, and lifestyle have better experiences and health outcomes, and often use less health care resources; the effect is even more when these patients are empowered to and responsible for managing their health and disease. In addition to the skills of patients, health care professionals need to shift to a role of teacher, partner, and professional supervisor of their patients. One way of supervising patients is by the use of electronic health (eHealth), which helps patients manage and control their disease. The application of eHealth solutions can provide chronically ill patients high-quality care, to the satisfaction of both patients and health care professionals, alongside a reduction in health care consumption and costs.

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KEYWORDS

eHealth; self-management; anticoagulation clinic; chronic obstructive pulmonary disease; venous thromboembolism; integrated disease management; chronically ill; telemonitoring; primary care

Introduction

The average age of the Dutch population is increasing rapidly in two distinct ways. The entire so called “baby boomer” generation, born between 1945 and 1965, will have reached the age of 65 and enter the post-active phase of their lives within the next twenty years. Following this, the population size of future generations will be smaller. By 2025, 21% of the Dutch population will consist of citizens older than 65 years, compared to approximately 10% at the turn of the millennium [1]. In addition, the life expectancy of the Dutch population has increased in recent years. Between 1980 and 2012, the life expectancy for men increased by almost seven years (from 72.4 to 79.1 years), and for women by almost four years (from 79.1 to 82.8) [2]. Technological developments in medicine and health care, as well as improved treatment methods, are the keys to the earlier detection and more adequate treatment of chronic diseases. As a result, older people are living longer despite their chronic diseases. Due to a combination of these developments, close-to-home primary health care is increasingly dominated by relatively old patients with one or more chronic diseases. On account of the resulting capacity implications for primary care, organizational health care processes will now have to be reviewed. Furthermore, new technologies will have to be tested and introduced, and it will be necessary to establish whether patients' care needs can be better managed by promoting their own sense of responsibility.

We subscribe to the new definition of health by Huber et al [3]; health is no longer defined as a static situation but as the ability to adapt and to self-manage, in the face of social, physical, and emotional challenges. In this definition, self-management is an important and irreplaceable part of health and disease management.

From this perspective, chronic diseases require lifestyle changes and an approach that is referred to as “self-management”: the ability to actively participate in the management of health with the emphasis on complete physical well-being. This involves medical management; changing, maintaining, and creating meaningful behaviors and dealing with the emotions of suffering from chronic disease(s) [4].The most important skills for self-management are problem solving, decision making, resource utilization, and taking action. The basic principle underlying self-management is that behavioral change cannot succeed without the patient taking responsibility [5].

In addition to skills of patients, another necessary ingredient for self-management is a good relationship between the patient and health care professional [4]. Until the first half of the 20th century, health care professionals were trained to diagnose and treat diseases. With the introduction of self-management, this role changed to being a teacher, partner, and professional supervisor. One way of supervising patients is by use of electronic health (eHealth), which helps patients manage and control their disease. The application of eHealth solutions can provide chronically ill patients high-quality care, to the satisfaction of both patients and care professionals, alongside a reduction in health care consumption and costs. One way of supporting self-management is the introduction of eHealth.

The pressure to implement self-management through eHealth is immense as the number of individuals with chronic illness and multimorbidity is growing fast, due to the rapid ageing and greater longevity of the population. The growing number of individuals suffering from major chronic illnesses faces many obstacles in coping with their condition, not the least of which is medical care that often does not meet their needs for effective clinical management, psychological support, and information [6]. Cumulatively, chronic diseases are the leading cause of death in many developed countries with cardiovascular and respiratory diseases dominating death statistics. Between 2005 and 2025, the number of heart failure and chronic obstructive pulmonary disease (COPD) cases in the Netherlands is expected to each rise by approximately 100,000, an increase of 45% and 33%, respectively [1].

The Case of Chronic Obstructive Pulmonary Disease

The World Health Organization (WHO) estimates that over 210 million people currently suffer from COPD. Three million people died worldwide from the disease in 2005. Although a change in smoking habits may alter this slowly, by 2020, COPD is expected to be the third most common cause of death worldwide [7]. Due to the increasing prevalence and complex treatment involved, COPD will account for a significant increase in health care costs, as well as for a growing capacity problem in care. In 2007, the number of COPD patients in the Netherlands was 276,100; between 2005 and 2025, this number is expected to increase by 38% [8].

Patients with COPD account for a higher consumption of care resources than people without COPD. On average, they visit their general practitioners (GPs) 12.7 times per year, of which 2.1 times are for COPD. In contrast, other people visit their GPs 6.1 times per year [8]. In 2005, the total cost for COPD- and asthma-related patient care was estimated at €799 million, placing COPD and asthma in the top ten of the most expensive diseases [5,8].

The two early stages of COPD, The Global Initiative for Chronic Obstructive Lung Disease (GOLD) 1 and 2 [9], represent 80% of the total COPD population in the Netherlands. These patients are mainly examined and treated within primary care. In the years to come, more and more patients with COPD will be referred back to primary care from secondary and tertiary care. Primary care has ample intervention options to offer patients with COPD that may lead to improvement of their condition. These include reactivation by support of physical therapists, smoking cessation programs, and self-management supported by bronchodilator medication. Various programs containing elements of these interventions have been implemented and tested for effectiveness in primary care [10]. A number of initial positive effects have been published so far, showing that these programs result in clinically relevant improvement in the areas of dyspnoea, exercise tolerance, and quality of life after one year [10-12].

It is well known that smoking cessation and exercise programs, as part of a multidisciplinary approach, are the most effective treatments for COPD [13]. Integrated Disease Management (IDM) programs for patients with COPD promoting self-management and exercise result in improved disease-specific quality of life and exercise capacity, and a reduction in hospital admissions and days spent in hospital [10,14]. However, this multidisciplinary approach is difficult to organize in primary care, and has, therefore, mainly been implemented and tested for effectiveness in secondary and tertiary care. Due to the organizational approach within the current health care processes, such programs have not been implemented for longer periods of time and have not produced intrinsic motivation on the part of patients to permanently switch to a healthy and active lifestyle. The main challenge within the next few years will be to strengthen the patients' own role in a responsible manner. Research has shown that self-management leads to better treatment of COPD; patients are more likely to adjust their lifestyles once they have actually acquired a sense of involvement in their disease. Fear of hospitalization and passive behavior hinder the early detection of exacerbations [15]. Effing et al demonstrated that self-management education leads to a reduction in hospital admissions and fewer sick days resulting from exacerbations [16]. Bourbeau et al showed that the application of self-management programs by patients with severe COPD results in a 40% reduction in hospital admissions [17]. Individual action plans and proper disease education for patients with moderately severe COPD improved the level of recognition and self-treatment of severe exacerbations; hence, the impact on the patients' health status due to exacerbations was reduced while promoting recovery [18]. In the bigger picture, effective self-management programs for patients with COPD may contribute to better quality of life and to a reduction in health care consumption [19], as well as health care costs [20].

An important success factor in several COPD self-management trials was that the self-management program had been effectively integrated into a disease management program, with a continuing and more remotely positioned role for health care professionals [21-23].

A few studies have been performed on eHealth interventions for patients with COPD [24-27]. While these studies mainly focused on the economic effects, they provided evidence of a decrease in the number of visits to the hospital, resulting in cost reduction. Pinnock et al examined the effectiveness of telemonitoring COPD parameters integrated into existing care programs; this intervention had no impact on the rate at which patients with COPD were admitted to the hospital. The quality of the telemonitoring process may not have sufficiently enabled patients to actually take control and the authors themselves suggest that the existing care process insufficiently improved during the study [28].

The Case of Venous Thromboembolic Disorders

Venous thromboembolism (VTE) is a common cause of potentially preventable mortality, morbidity, and high medical costs [29]. With ageing populations and persisting unhealthy lifestyles, the prevalence of VTE is rising rapidly [30]. Between 2005 and 2009, the number of patients with VTE in the Netherlands increased by 13%. In 2009, there were more than 385,000 patients with VTE in the Netherlands, more than half of whom suffered from atrial fibrillation [31]. Treatment of VTE consists of, among other interventions, anticoagulant therapy (AT) with vitamin K antagonists (VKA) to slow down the formation of blood clots [30]. AT requires frequent monitoring of the extent to which the blood clots, as well as regular visits to an anticoagulation clinic, laboratory, or physician, for venous puncture and analysis.

For this group of patients, it can be hypothesized that self-management (self-testing and self-measurement) might increase the sense of involvement in their own care. In recent years, various methods have been implemented and tested for measuring the degree of anticoagulation (international normalized ratio (INR)) in the home setting by means of self-measurement equipment. A meta-analysis by the Cochrane Collaboration in 2010 found that self-management (including self-dosing) by AT patients at home in combination with VKA treatment resulted in a decrease in thromboembolic complications and mortality at a constant frequency of bleeding complications [32]. This also applies to the Dutch situation with its extensive network of well-organized anticoagulation clinics [31].

Structured clinical trials with online self-management show a greater improvement in INR values within the therapeutic range (10%-23%) than self-management studies without online support (improved time in therapeutic range (TTR) less than 4%) [33,34]. Home measurement of INR and the reporting and dosing of weekly results online increase the TTR from 72% to 79% compared to conventional computer-assisted monitoring in an anticoagulation clinic [35]. Patient satisfaction proved to be higher using online remote monitoring of INR [36].

In anticoagulation clinics, it has been reported that fewer thromboembolic complications are reported if the self-management program is embedded in well-organized thrombosis care from a central thrombosis control center integrated in primary care [37,38].

Self-Management and eHealth

The changing and growing demand for care is causing health care costs to spiral upward in the Netherlands [5]. At the same time, there is an imminent shortage of professional health care workers, estimated to be between 280,000 and 800,000 in the Netherlands in 2025 [39]. These two aspects combined are increasing the pressure on health care, while at the same time compromising quality, accessibility, and sustainability. To ensure the provision of proper health care, a rearrangement of duties is required. “Traditional care” is reactive, mainly focused on the treatment of episodes of disease or derailment. However, changing care demands call for a more proactive policy. This can be achieved by the timely detection of diseases or complications and by continuously structured monitoring of patients for care gaps and adverse changes in their condition to ensure a faster response to changes and complications. Another element of a proactive policy consists of giving patients themselves a prominent role in coping with their illness and well-being [22,40].

The rising number of chronically ill patients and increasing workload in care bring along a growing need for structural change within the health care system. Based on this perspective, in recent years the focus has mostly been on promoting self-management in chronically ill patients. In doing so, the objective is to give patients a more prominent role in dealing with their disease and sense of well-being; self-management is not only a convenient way to organize care differently, but also offers patients significant benefit. By providing patients with more knowledge about their disease and by active involvement in the process, patients are better able to accept and maintain a healthier lifestyle [41]. The effect is even more when these patients are empowered to and responsible for managing their health and disease [42].

Offering chronically ill patients innovative self-management solutions, such as eHealth, can support or even improve their independence. Many options exist for patients to get involved through websites and platforms; the quality and content vary greatly, as do the results [43].

Several studies have shown that based on this approach, patients are better able to cope with their illness at the time and place of their choosing, allowing them to better adapt their lifestyle to their condition while taking some of the burden off the medical staff [44]. The deployment of eHealth facilitates the accessibility to health care, which in turn enhances the patients' understanding of their disease, sense of control, and willingness to engage in self-management [45,46]. By applying eHealth solutions, chronically ill patients can be provided with high-quality care, to the satisfaction of both patients and health care professionals [47,48].

The results of eHealth-supported self-management depend on the patients' expectations and level of education. Beenkens, for instance, asked 485 patients in anticoagulation clinics why they had opted for eHealth [49], and it appeared that patients mainly expect to gain benefits in their well-being, for example in the form of less travel and waiting time, and more freedom of movement. This study also showed that highly educated patients are more inclined to adopt eHealth than those with a low level of education [49].

Research into self-management in patients with COPD showed that more relevant positive effects are measured in the group of “effective self-managers”, predominantly characterized by relatively younger age, cardiac comorbidity, relatively more serious complaints, and living with others [50,51].

The Whole System Demonstrator (WSD) program is a large, randomized trial in England, in which 238 GP practices offered 6191 chronically ill patients various forms of telehealth or standard care. The telehealth systems in this study were designed to monitor vital signs, symptoms, and self-management behavior. The telehealth services were integrated within the existing GP practices and compared with a control group that was offered standard care.

An evaluation after one year showed lower mortality rates and fewer acute admissions in the group using telehealth than observed in the standard care control group [52]. It is possible that these differences were partly caused by an initial temporary increase in acute admissions in the control group. In another WSD evaluation, no differences were found between the telehealth group and the standard care group, measured by quality of life, anxiety, and depression symptoms [53].

Based on the initial results from the WSD program it can be assumed that patients receiving telehealth services are less likely to go for treatment at an accident and emergency department; further research is required to determine the underlying mechanism. Furthermore, anxiety and depression did not increase among patients using telehealth.

The randomized controlled trial (RCT) by Pinnock et al yielded the conclusion that the integration of telemonitoring within existing care had no effect on delayed hospitalization, on health-related quality of life, anxiety and depression, self-efficacy, and knowledge [28]. In their analysis, they argue that the added value generated by the WSD program can be partly explained by a general improvement in the quality of care, as a side-effect of implementation of telehealth [28].

The eVita COPD and PORTALS Studies

Based on the available knowledge described, we formulated two research questions that we wish to answer using data from our large-scale implementation projects (Textbox 1). In these projects we will record and evaluate the effects of eHealth interventions within integrated primary care in the two mentioned domains of chronic disease primary care-managed COPD (eVita COPD), and anticoagulant therapy in venous thromboembolic conditions (PORTALS).

Textbox 1. The two questions we aim to answer.

- What is the effect of the kind of eHealth implementation on use of the portals and patient outcomes?
- Does the effect depend on (1) subjectively experienced practical added value for patients, thereby making their everyday lives easier? and (2) The level of organization as an integral part of existing care?

We designed the multi-level study e-Vita to investigate different implementation methods of a self-management Web portal to support and empower patients with COPD in three different primary care settings; the level of integration of the Web portal within the care program is different in the three settings. Using a parallel cohort design, the clinical effects of the implementation of the Web portal will be assessed using an interrupted times series (ITS) study design and measured according to changes in health status with the Clinical COPD Questionnaire (CCQ). The different implementations and net benefits of self-management through eHealth on clinical outcomes with be evaluated from human, organizational, and technical perspectives. To our knowledge, eVita is the first study to combine different study designs that enable the simultaneous investigation of clinical effects (changes in health status), as well as effects of different implementation methods whilst controlling for confounding effects of the organizational characteristics.

We also used a parallel cohort design for the anticoagulation clinic patients in the PORTALS study. In this study, patient self-testing and patient self-management (including a Web portal) will be offered to patients of a thrombosis service who currently receive usual care for long-term AT. To investigate determinants of optimal implementation, we will compare two different implementation methods (1) after inclusion where participants will be randomly divided in subgroups where one group will be trained and educated by e-learning, and (2) the other group that will receive face-to-face group training. A third group, the non-self-management group consists of patients who continue to receive regular care.

In this PORTALS study, we will compare clinical outcomes and self-management skills of two different implementation methods. Second, the relationship between self-management skills, clinical outcomes, and individual characteristics will be investigated.

Hypotheses

On the basis of earlier eHealth research, we expect to see problems where patients' motivation is concerned when it comes to starting and continuing to use the patient platform [54]. If patients use the self-management platform on a regular basis, we expect to see a positive effect on quality of life, complications, and hospitalization rate in both groups.

For patients with COPD, we expect to see a relatively small improvement in their everyday lives using the digital platform. Resulting from this, we assume that the use of the platform will grow and take root less rapidly.

Patients with VTE are linked to a center that determines their INR values on a regular basis, following which the clinic determines the dose of their medication. This process has far-reaching effects on their daily lives. For these patients, a comprehensive self-management program supported by a digital platform will ease their dependence on the anticoagulation clinic and enhance their sense of self-reliance. Therefore we expect these patients to use the digital platform more frequently. As a result, we expect even better improvements in both clinical outcomes and quality of life for patients with VTE.

The Potential Added Value of eHealth

It is difficult to draw general conclusions about the impact of eHealth. The evidence of clinical and structural effects of eHealth interventions in patients with COPD and VTE is not clear-cut, partly because of the large differences in study design, interventions, and research methods. Furthermore, research methods into eHealth are a regular topic of discussion, as the focus on clinical outcomes often masks other beneficial effects. Chronic diseases require lifestyle changes and an approach that is referred to as self-management: the individual ability to properly deal with symptoms, treatment, and physical and social consequences. The basic principle underlying this approach is that behavioral change cannot succeed without the patient taking his or her responsibility [5]. eHealth is a useful method to implement self-management.

The rising number of chronically ill patients and increasing workload in care bring along a growing need for structural change within the health care system. Using eHealth as a method to implement self-management can provoke beneficial effects for both patients and caregivers.

We designed the studies eVita COPD and PORTALS, both parallel cohort designs with Web-based support for self-management, where we expect to see a positive effect on clinical outcomes and quality of life of patients through the implementation of a self-management patient platform integrated within primary care. We presume that behavioral change in both patients and caregivers is the basis for these positive effects. The implementation of eHealth will support caregivers to have a better coaching relationship with their patients and the use of eHealth will help patients take a more leading role towards their own health status and lifestyle.

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Conflicts of Interest

None declared.

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Abbreviations

AT: anticoagulant therapy
COPD: chronic obstructive pulmonary disease
eHealth: electronic health
GP: general practitioner
INR: international normalized ratio
ITS: interrupted times series
TTR: time in therapeutic range
VKA: vitamin K antagonists
VTE: venous thromboembolism
WSD: Whole System Demonstrator program

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Original Paper

Opinions and Beliefs About Telemedicine for Emergency Treatment During Ambulance Transportation and for Chronic Care at Home

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Abstract

Background: Telemedicine is a valid alternative to face-to-face patient care in many areas. However, the opinion of all stakeholders is decisive for successful adoption of this technique, especially as telemedicine expands into novel domains such as emergency teleconsultations during ambulance transportation and chronic care at home.

Objective: We evaluate the viewpoints of the broad public, patients, and professional caregivers in these situations.

Methods: A 10-question survey was developed and obtained via face-to-face interviews of visitors at the Universitair Ziekenhuis Brussel (UZB). The online questionnaire was also distributed among professional caregivers via the intranet of the UZB and among the broad public using social media.

Results: In total, 607 individuals responded to the questionnaire, expressing a positive opinion regarding telemedicine for in-ambulance emergency treatment and for chronic care at home. Privacy issues were not perceived as relevant, and most respondents were ready to participate in future teleconsultations. Lack of telecommunication knowledge (213/566, 37.6%) was the only independent factor associated with rejection of telemedicine at home and respondents via social media (250/607, 41.2%) were less concerned about privacy issues than respondents via face-to-face interviews (visitors, 234/607, 38.6%). The visitors were more positive towards in-ambulance telemedicine and more likely to agree with future participation in teleconsultations than respondents via social media.

Conclusions: The broad public, professional caregivers, and patients reported a positive attitude towards telemedicine for emergency treatment during ambulance transportation and for chronic care at home. These results support further improvement of telemedicine solutions in these domains.

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KEYWORDS

telemedicine; stroke; adoption; diagnostic techniques and procedures; emergency care; patient-centered care

Introduction

Telemedicine has been shown to be a reliable, sustainable, and cost-effective alternative for face-to-face patient care in many medical domains [1-4]. Yet, the adoption of telemedicine in routine health care has been slow and fragmented since its introduction some 50 years ago [5,6]. Key technological components for telehealth applications have come of age and are readily available at an acceptable cost, but several hurdles still need to be cleared to allow valid results. The cultural barrier, that is, the reluctance of patients and caregivers to adopt novel practices, is often perceived as a major issue [7,8] and requires more research. Opinions held by the general public, professional caregivers, and patients may differ, and a better insight into the potential role of computer illiteracy and demographics is critical for telemedicine to become a part of the everyday medical practice. Furthermore, it is unknown if all stakeholders support the expansion of telemedicine into novel domains such as hyper-acute treatment during emergency ambulance transportation [9,10] and chronic care at the patient's home [11].

This study characterizes and compares the viewpoints of the general public, health care professionals, and stroke patients on telemedicine for emergency treatment during ambulance transportation and for chronic care at home.

Methods

Survey

We designed a concise 10-question survey, which typically took less than 5 minutes to complete. The questionnaire was available in Dutch and French. In-ambulance telemedicine support for patients with suspicion of acute stroke (telestroke) was used as a showcase for emergency telemedicine [9]. The survey was available via an Internet website and contained questions related to preferred language, demographics, history of stroke, and knowledge of computer systems for telecommunication. Using 5-point Likert scales [12], we questioned the respondents' opinions about in-ambulance telestroke, telemedicine at home, protection of privacy and identity, and willingness to participate in future telemedicine consultations (see Table 1). A composite score reflecting a respondent's overall attitude towards telemedicine was computed by summation of all individual responses on the four Likert-scale questions. The answers "Strongly disagree," "Disagree," "Neutral," "Agree," and "Strongly agree" were attributed 1, 2, 3, 4, and 5 points, respectively.

Study Population

The survey was conducted via face-to-face interviews of visitors at the Universitair Ziekenhuis Brussel (UZB) on World Stroke Day (October 29, 2014) and was available online for 1 month following this day. Visitors who participated in the face-to-face interviews had access to a prototype of an in-ambulance telestroke system at the site and additional information at their request. The online questionnaire was distributed among professional caregivers via the UZB Intranet and among the general public using social media (email, Facebook). We identified the type of respondents based on Internet protocol addresses. Specific addresses correlated with the UZB Intranet, which is accessible only for UZB employees (referred to as professionals), and with the computers used for face-to-face interviews with UZB visitors on World Stroke Day (referred to as visitors). All other addresses were associated with respondents who accessed the survey via distribution through social media (referred to as social media). Only the results of respondents aged 18 years and older who provided at least one answer were taken into account. The data collection was anonymous, and no personally identifiable data related to individuals were collected.

Table 1. The 10-question survey.

Questions	Answers
Q1. Preferred language:	Dutch or French
Q2. What is your age?	Numeric input
Q3. What is your gender?	Female or Male
Q4. Did you suffer a stroke in the past?	Yes, I don't know, or No
Q5. Do you use computer systems for telecommunication, for instance, Skype?	Yes, I don't know, or No
Q6. In case of a stroke, I would like to receive support via telemedicine during transportation by ambulance to the hospital:	Strongly disagree, Disagree, Neutral, Agree, or Strongly agree
Q7. I find the use of telemedicine for patient care at home useful:	Strongly disagree, Disagree, Neutral, Agree, or Strongly agree
Q8. I am confident that my privacy and identity would be protected during telemedicine consultations:	Strongly disagree, Disagree, Neutral, Agree, or Strongly agree
Q9. I would like to participate in telemedicine consultations in the future:	Strongly disagree, Disagree, Neutral, Agree, or Strongly agree
Q10. Comments and suggestions:	Free text

Statistical Analysis

Univariate testing was performed to identify associations between possible confounding factors (language preference, age, gender, history of stroke, knowledge of computer systems for telecommunication) and the four Likert-scale questions about telemedicine. Pearson's chi-square test or Fisher's exact test were used for categorical variables, as appropriate. For continuous variables, the Spearman correlation, the Mann-Whitney U test, or the Kruskal Wallis test of variance were applied. Multivariate regression analysis by a forward stepwise method was performed with entry and removal criteria of 0.05 and 0.10, respectively, including all variables <0.05 in univariate analysis. Shift analysis of the Likert scale score was assessed by the van Elteren Cochran-Mantel-Hanszel test with adjustment for variables with significant association in univariate analysis [13]. The internal consistency of the survey was assessed by Cronbach alpha. Statistical computations were performed with the SPSS software package version 22.0, except for evaluation of the Likert-scale shift, which was carried out in Stata version 13.

Results

Study Population

In total, 642 respondents accessed the Web-based survey, of whom 607 were aged ≥18 years and provided at least one answer. We received 577 answers (95.1%) in the first 5 days after launch of the survey; 536 respondents preferred to complete the survey in Dutch (88.3%). The respondents' median age was 47 years (interquartile range [IQR] 29-57 years) and 388 respondents were female (63.9%). Nineteen respondents (3.1%) reported a previous stroke, and 8 respondents indicated that they did not know whether they had suffered from a stroke (1.3%). Patients with a (possible) history of stroke were significantly older and more often male than respondents without history of stroke (*P*<.001 for both).

Of 213 respondents (37.6%), we inferred that they lack knowledge of computer systems for telecommunication, as 209 respondents indicated that they did not have this knowledge and 4 respondents did not know whether they had this knowledge.

Of the 607 respondents, we identified 123 as professional (20.3%), 234 as visitor (38.6%), and 250 as social media (41.2%). Table 2 summarizes the characteristics of the three respondent types. Visitors less frequently preferred the Dutch language than professionals or respondents via social media (*P*<.001). Visitors were more frequently male than professionals (*P*=.001), but there was no significant gender difference between visitors and respondents via social media. Visitors were older than professionals and respondents via social media (*P*<.001 for both), and more often reported previous stroke than professionals (*P*=.018) but not more than respondents via social media (*P*=.104). Visitors more frequently had no knowledge of computer systems for telecommunication than professionals (*P*=.019) and respondents via social media (*P*<.001). There were no significant differences in baseline characteristics between professionals and respondents via social media, except for more female respondents in the subgroup of professionals (*P*=.024).

In-ambulance Telestroke

The Likert scale distribution for the question regarding in-ambulance telestroke for the total study population is illustrated by Figure 1. Very few respondents (6.0%) did not wish to receive in-ambulance telestroke (median score 4, IQR 3-5). Univariate analysis showed higher Likert scale scores for French-speaking respondents and older respondents (*P*<.001 for both). Visitors more frequently agreed and strongly agreed with in-ambulance telestroke than respondents via social media or professionals (*P*<.001 for both) (see Figure 2). Logistic regression analysis identified the respondent type as an independent predictor for acceptance (ie, "Strongly agree" or "Agree" vs "Disagree" or "Strongly disagree") of in-ambulance telestroke (OR 3.9, 95% CI 1.7-9.1; *P*=.02). Controlling for preferred language and age, the distribution of the Likert scale responses was significantly more favorable in visitors, as compared to respondents via social media (*P*=.001) (see Figure 3).

Table 2. Baseline characteristics of the three respondent types (N=607).

Parameter		Social media (n=250, 41.2%)	Visitor (n=234, 38.6%)	Professional (n=123, 20.3%)	*P* value
Dutch language (n, %)[a]		249 (99.6)	167 (71.4)	123 (97.6)	<.001
Female gender (n, %)[b]		160 (64.0)	135 (57.7)	93 (75.6)	.004
Age (median, IQR) [c]		40 (26-53)	54 (40-65)	45 (29-53)	<.001
Previous stroke (n, %) [a]					.021
	No	243 (97.2)	219 (93.6)	118 (95.9)	
	Don’t know	2 (0.8)	2 (0.9)	4 (3.3)	
	Yes	5 (2.0)	13 (5.6)	1 (0.8)	
Knowledge of telecommunication (n, %) [a]					<.001
	No	59 (25.1)	112 (49.6)	38 (36.2)	
	Don’t know	3 (1.3)	0 (0.0)	1 (1.0	
	Yes	173 (73.6)	114 (50.4)	66 (62.9)	

[a] Fisher’s test.

[b] Chi-square test.

[c] Kruskal Wallis test of variance.

Figure 1. Distribution of the Likert scale for in-ambulance telestroke in the total study population.

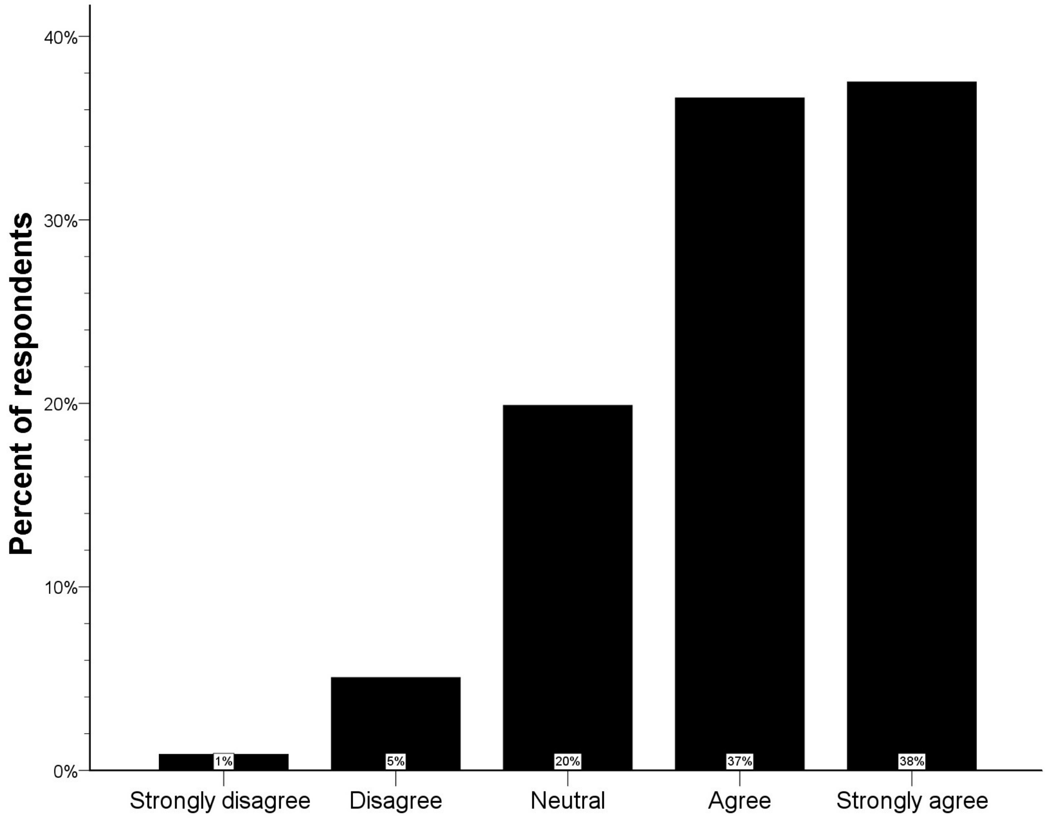


Figure 2. Distribution of the Likert scale for in-ambulance telestroke per respondent type.

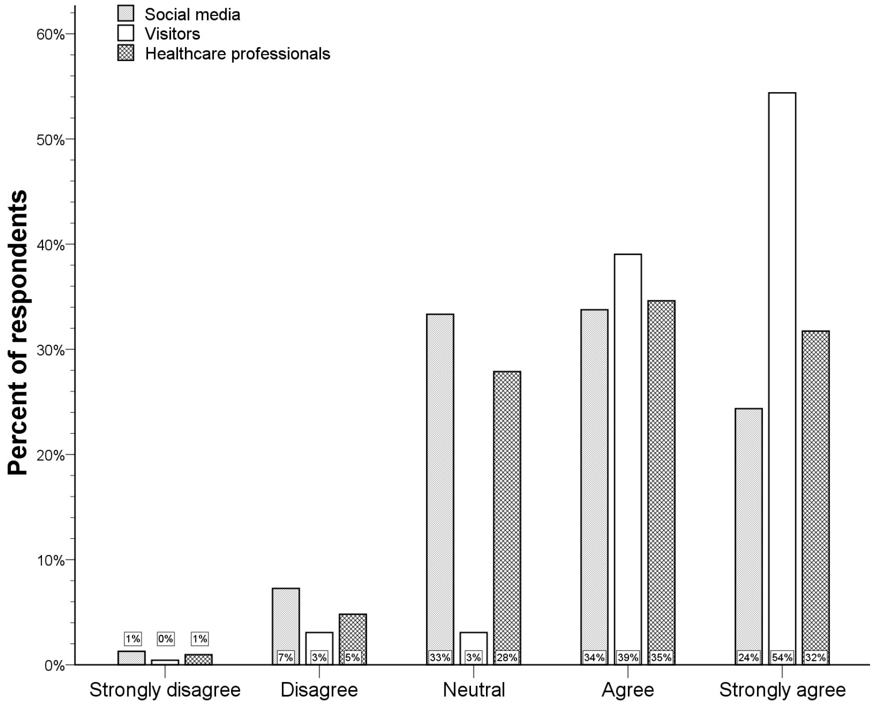
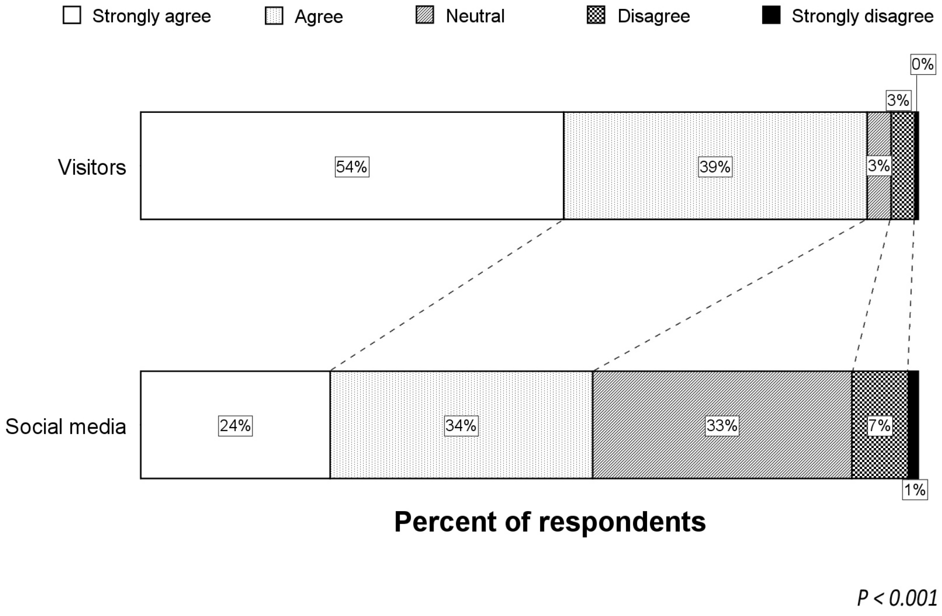


Figure 3. Shift analysis of the responses from visitors compared to social media concerning in-ambulance telestroke.



Telemedicine at Home

Figure 4 provides an overview of the opinions regarding the usefulness of telemedicine at home. Only 5% of all respondents was not convinced that telemedicine at home would be useful (median score 4, IQR 4-5). In univariate analysis, knowledge of computer systems for telecommunication was associated with more positive responses (*P*=.041), but there was no significant difference among the three respondent types (see Figure 5). Lack of telecommunication knowledge was the only independent predictor for rejection of telemedicine at home (logistic regression analysis; OR 0.36, 95% CI 0.16-0.83; *P*=.016), and there was a significant shift towards more positive answers in respondents with knowledge of telecommunication compared to those without telecommunication knowledge (*P*=.024) (see Figure 6).

Figure 4. Distribution of the Likert scale for telemedicine at home in the total study population.

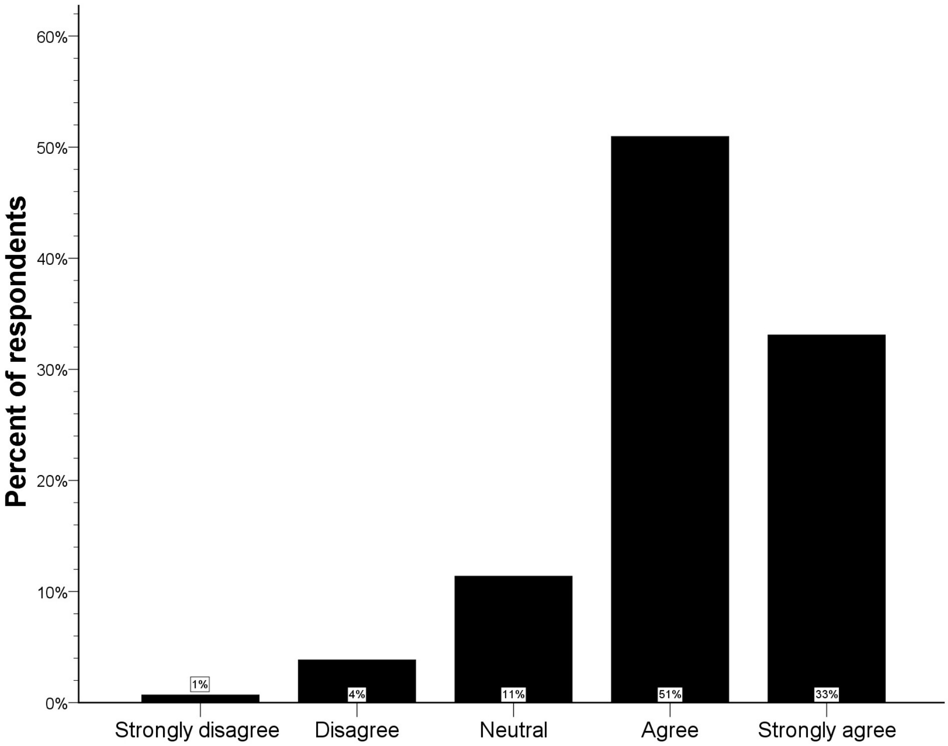


Figure 5. Distribution of the Likert scale for telemedicine at home per respondent type.

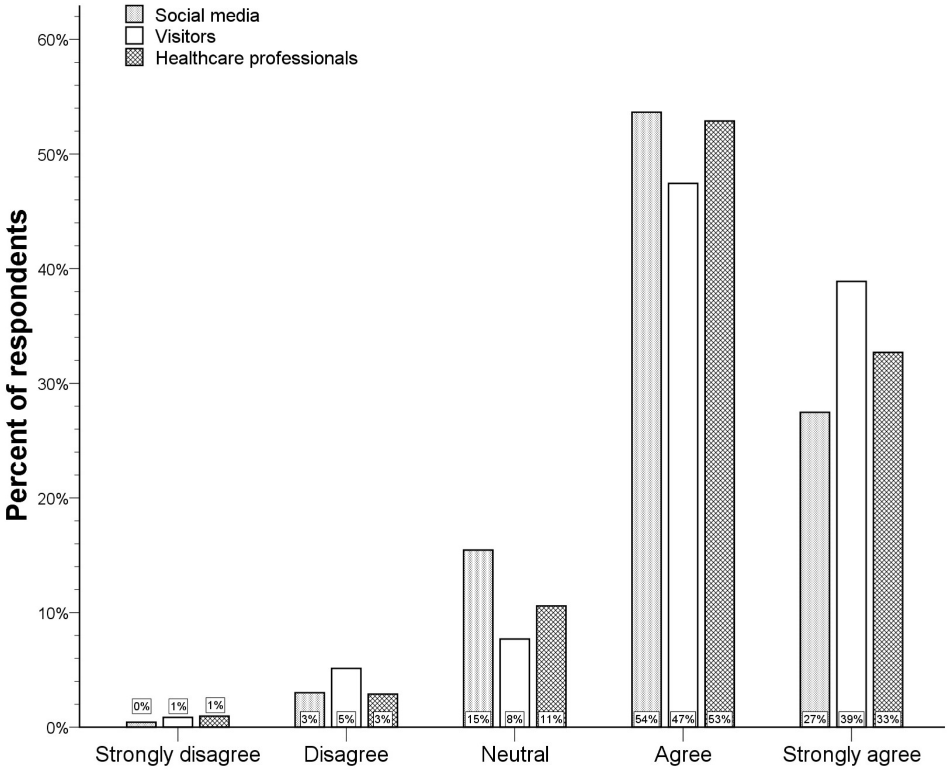
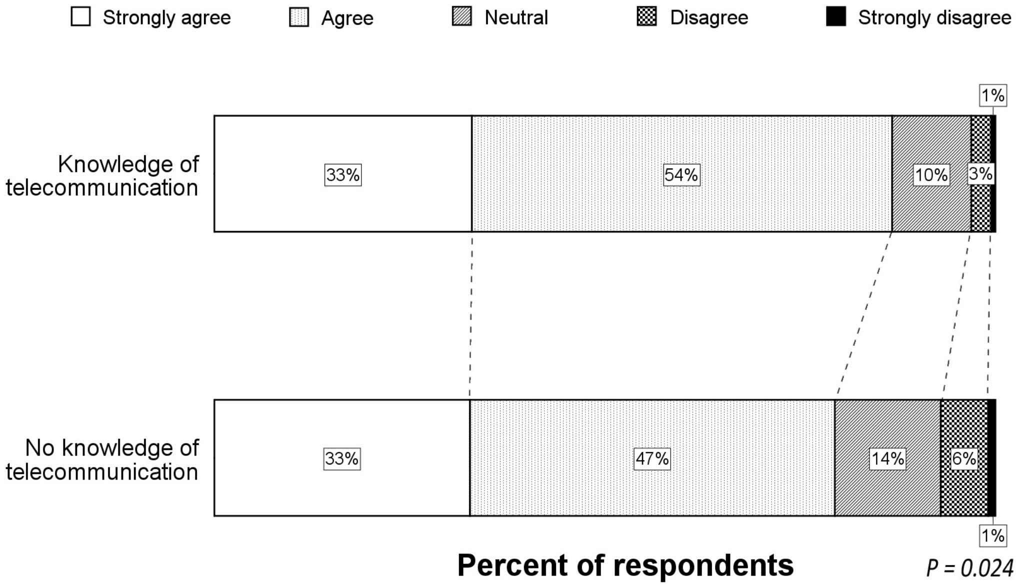


Figure 6. Shift analysis of the responses from respondents with knowledge of telecommunication compared to those without knowledge of telecommunication concerning telemedicine at home.



Protection of Privacy and Identity

As show in Figure 7, only 7% of all respondents had no confidence that their privacy and identity would be protected during telemedicine consultations (median score 4, IQR 4-5). Univariate analysis indicated that respondents via social media were more concerned about privacy issues during telemedicine consultations than visitors (*P*=.033) (see Figure 8), which is a finding that was confirmed by logistic regression analysis (OR 0.44, 95% CI 0.20-0.95; *P*=.035). Shift analysis of the Likert scale showed that respondents via social media were more frequently neutral and less frequently disagreed or strongly disagreed than visitors (see Figure 9), but the shift over the entire spectrum was not statistically significant (*P*=.550).

Figure 7. Distribution of the Likert scale for protection of privacy and identity in the total study population.

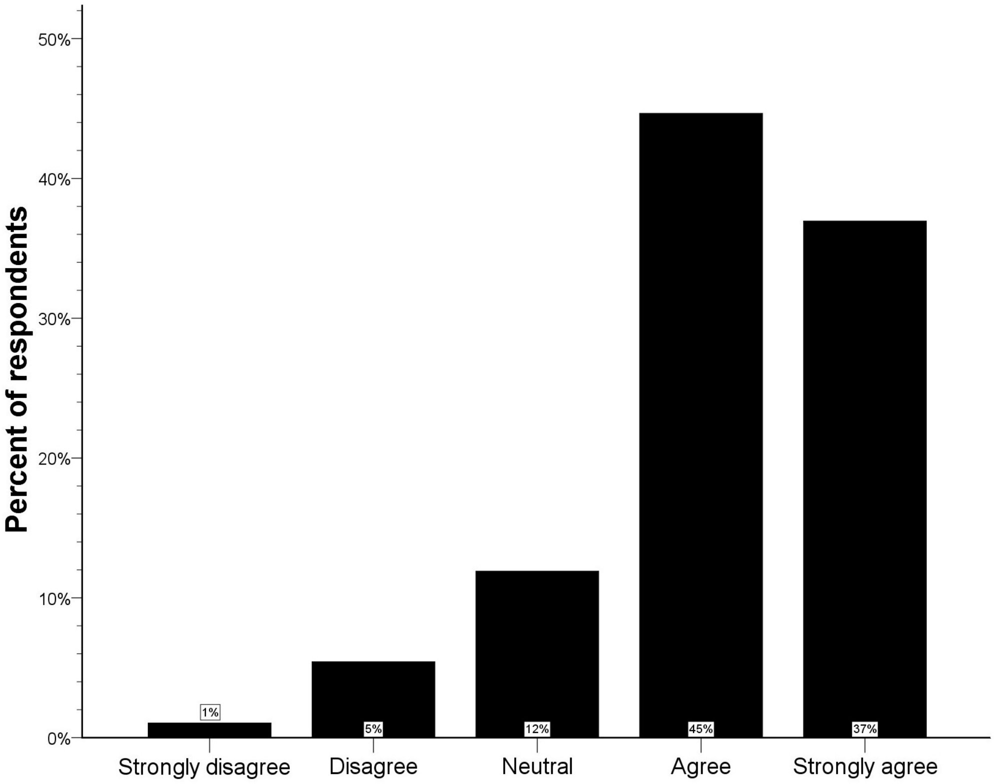


Figure 8. Distribution of the Likert scale for protection of privacy per respondent type.

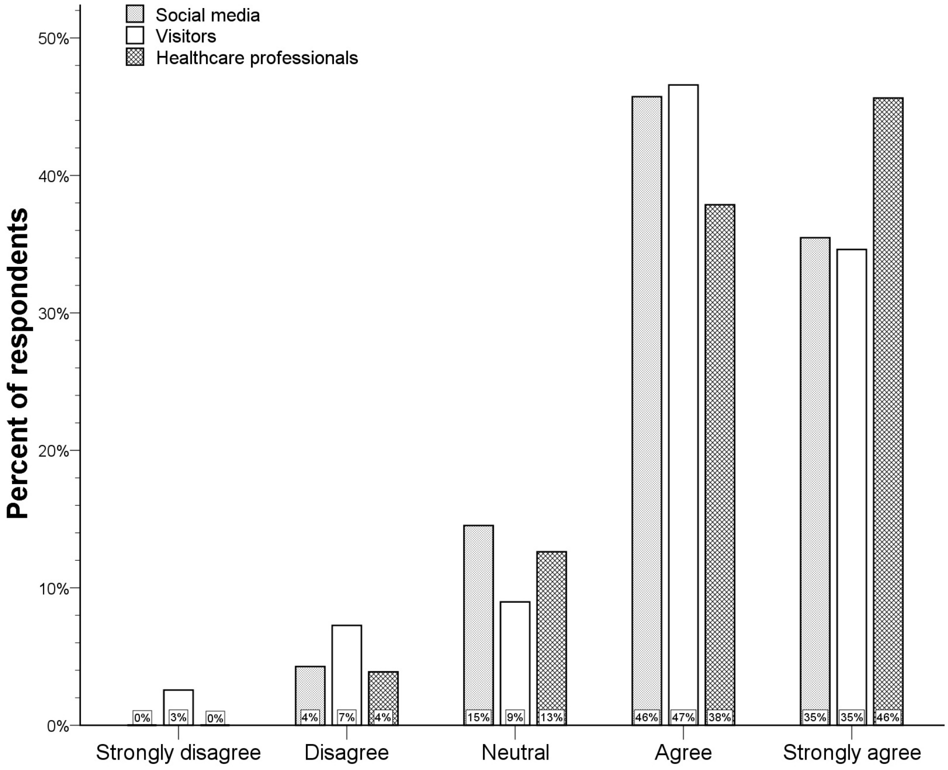
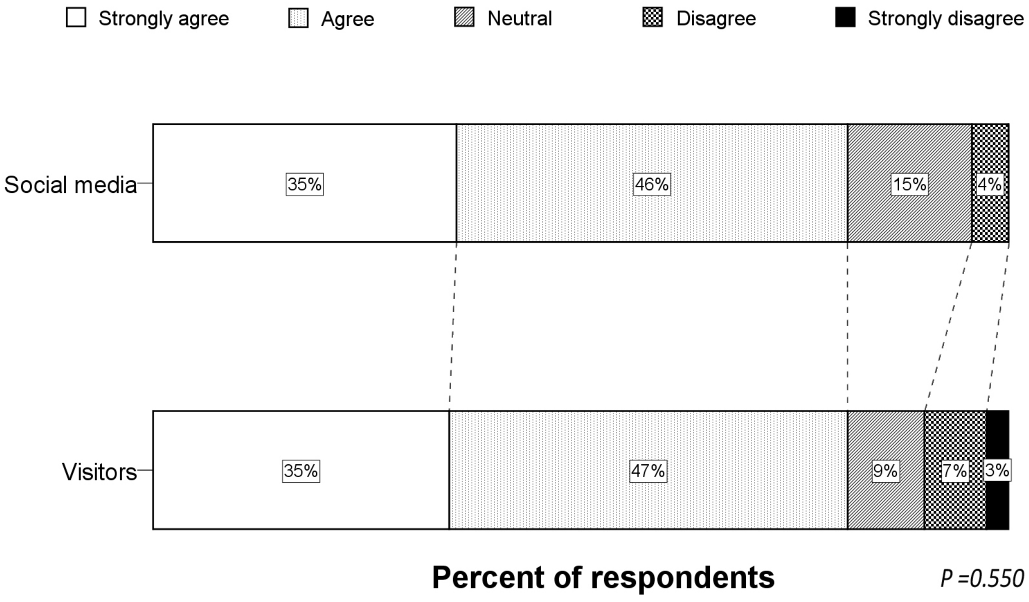


Figure 9. Shift analysis of the responses from social media compared to visitors concerning protection of privacy.



Future Participation in Telemedicine Consultations

Most respondents indicated that they would agree to participate in future telemedicine consultations, but nearly a quarter of respondents disagreed or strongly disagreed (see Figure 10) (median score 4, IQR 3-4). Visitors were more likely to agree with future participation in telemedicine consultations than respondents via social media (*P*<.001) (see Figure 11). This association was confirmed by logistic regression analysis (OR 2.5, 95% CI 1.5-4.0; *P*<.001) and by shift analysis (*P*<.001) (see Figure 12).

Figure 10. Distribution of the Likert scale for participation in future telemedicine consultations in the total study population.

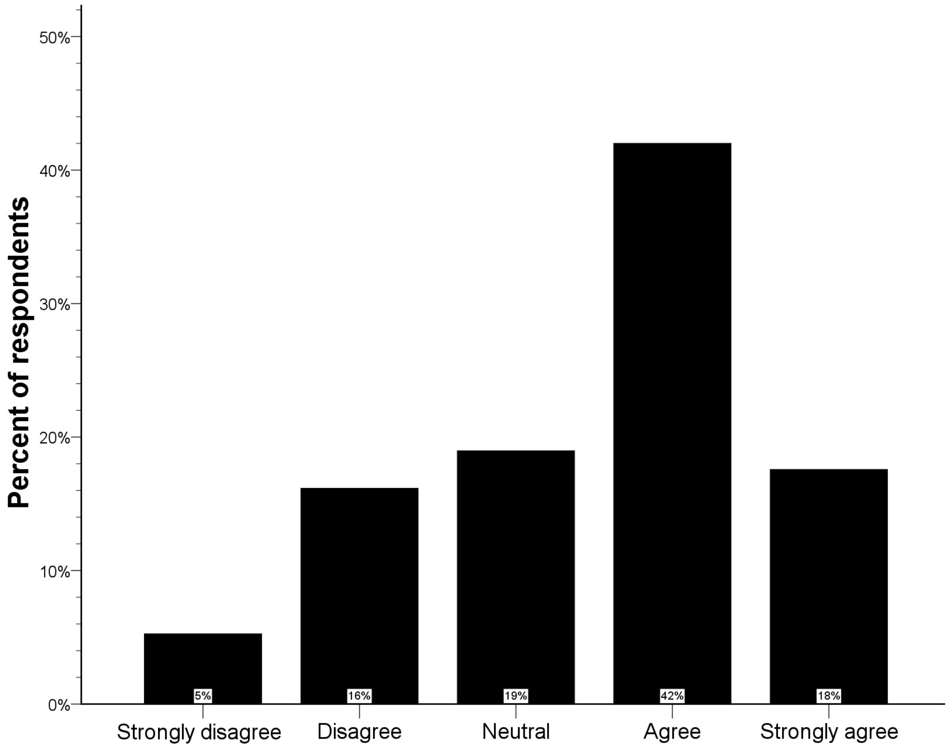


Figure 11. Distribution of the Likert scale for participation in future telemedicine consultations per respondent type.

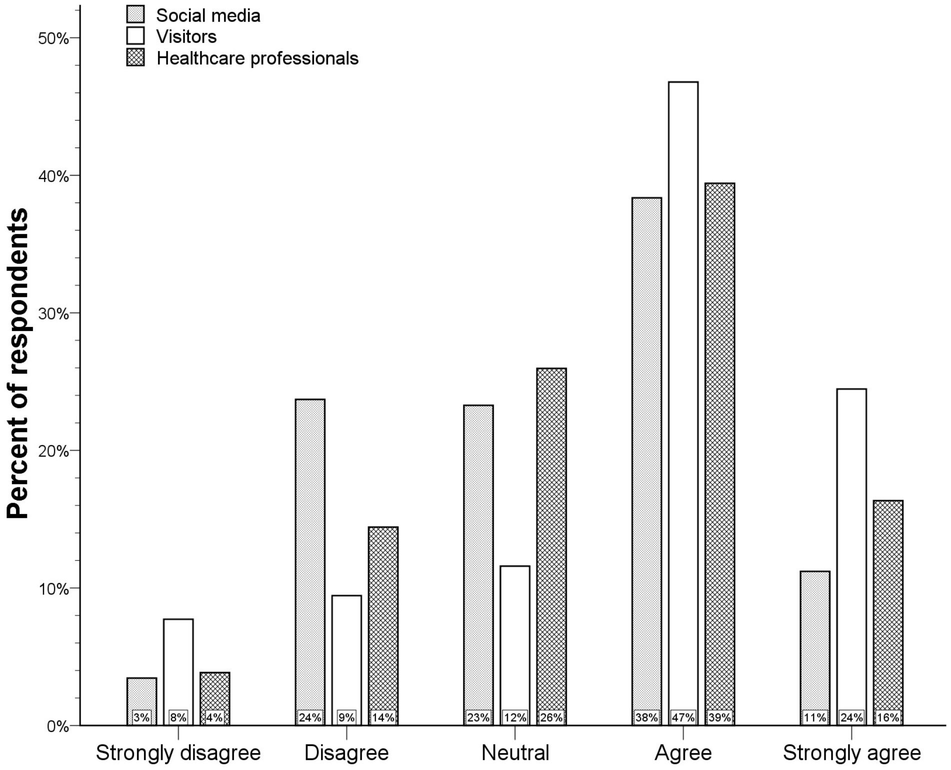
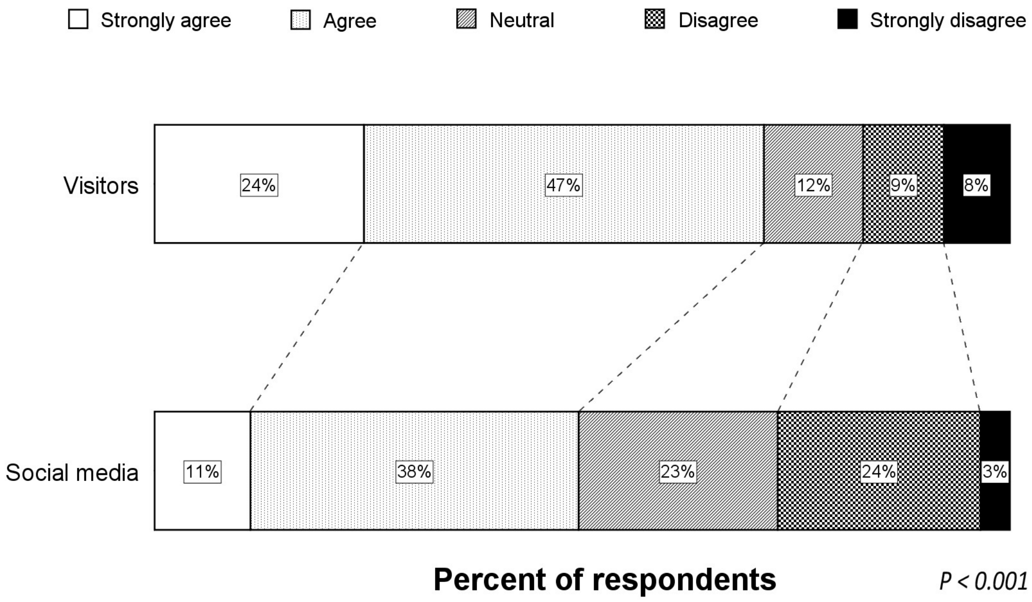


Figure 12. Shift analysis of the responses from visitors compared to social media concerning future participation in telemedicine consultations.



Composite Score

The median composite score was 16 (IQR 14-18; maximal 20), reflecting that the large majority of respondents expressed a positive overall attitude towards telemedicine. Older age was weakly correlated with higher scores (Spearman rho=.09; *P*=.038). Visitors (median 16, IQR 15-18) and professionals (median 16, IQR 14-18) provided more positive answers than respondents via social media (median 15, IQR 14-17; *P*<.001 and *P*=.025, respectively).

Respondents' Comments and Suggestions

Only 28 respondents (28/607, 4.6%) provided a comment in the last question. These comments can be categorized as (1) supportive of the further development of telemedicine (n=14), (2) additional information regarding the concept of telemedicine was needed for adequate completion of the survey (n=5), (3) telemedicine could be useful but nuances in patient-caregiver interaction may be lost (n=4), (4) concerns about technical aspects of telemedicine (n=3), and (5) telemedicine may be challenging for certain patient populations (eg, elderly, persons with autism spectrum disorder) (n=2).

Construct of the Questionnaire

The internal consistency of the four Likert-scale questions was acceptable (Cronbach alpha=.66; 95% CI 0.62-0.71). Except for the item on protection of privacy during telemedicine consultations, all items contributed to the internal consistency. All four Likert-scale questions were intercorrelated (Spearman rho; *P*<.001 for all).

Discussion

Principal Results

The main finding of this study is the positive and congruent overall attitude regarding the implementation of telemedicine, both for in-ambulance emergency therapy and for chronic care at home. Privacy issues were not perceived as problematic, and most respondents were ready to participate in future teleconsultations.

Comparison With Prior Work

Other surveys evaluating opinions about telemedicine services typically involve large cross-population inquiries [14] or report on the view of health care professionals [15] and specific patient populations [16]. To the best of our knowledge, we are the first to simultaneously present an identical questionnaire to the general public, professional caregivers, and stroke patients. This approach enables direct comparison of these key stakeholder views. It is especially noteworthy and reassuring that all three groups gave similar opinions about the application of telemedicine, the protection of privacy, and future participation in teleconsultations.

In contrast to prevailing prejudices and literature reports [17-19], older people appeared to be at least as eager to accept telemedicine in ambulances or at their homes as younger respondents. This finding is important as older patients make prime candidates for telemedicine given their increased risk of medical emergencies and higher need for long-term care.

More than one third of the study population had no knowledge of telecommunication technology. Interestingly, lack of telecommunication knowledge did not negatively impact the broad acceptance of telemedicine, except for teleconsultations at home. This may be explained by computer anxiety and the need to actively operate computer systems in the home care setting [11]. From the respondents' perspective, this differs substantially from in-ambulance teleconsultations that are initiated and managed by a physician, allowing the patient to take on a more passive role.

The fact that respondents via social media less frequently expressed concerns with privacy and identity compared to visitors is another fascinating finding. The first group represents a younger population that is more familiar with information technology and teleconferencing. Their opinion is pertinent because they represent the potential future users of telemedicine, but whether their experience with social media warrants their optimism regarding protection of privacy and identity may be matter of debate.

Strengths and Limitations

We deliberately designed a concise and user-friendly survey to limit the time needed for completion and to maximize the response rate. By doing so, we obtained a questionnaire with acceptable internal consistency that allowed us to collect the opinions of a substantial and representative study population. It should, however, be acknowledged that the small number of patients with a history of stroke hampers extrapolation of their results to the general stroke population. An inherent shortcoming of this survey is a possible selection bias as individuals with a negative or uninvolved stance towards telemedicine may have been less likely to participate, possibly resulting in overestimation of the positive general impression. Also, in contrast to respondents in face-to-face interviews, the concept of telemedicine was not clarified to those completing the survey online, nor did they have access to the prototype system for in-ambulance telemedicine. This discrepancy may be a cause of information bias and was also commented on by 5 respondents. Conversely, our study design allows the comparison of two survey data collection techniques, that is, the face-to-face interview and the use of an online questionnaire. The major strength of face-to-face surveys is the personal interaction and the possibility of providing additional clarification where needed, whereas online surveys allow inquiry of large numbers of respondents' opinions rapidly and at little cost. Contrarily, respondents in face-to-face interviews are more susceptible to social desirability bias because of the interviewer's presence, and the representativeness of online surveys may be questioned given their typical recruitment among younger individuals [20]. Specifically for this study, the availability of a prototype for in-ambulance telemedicine for participants in face-to-face interviews may have caused an additional bias [11]. For these reasons, the higher acceptance of in-ambulance telemedicine and the willingness for future participation in teleconsultations expressed by visitors participating in face-to-face interviews may not be surprising.

Conclusion

The results of this survey indicate that the general public, professional caregivers, and stroke patients welcome telemedicine as a valid part of medical care for emergency treatment during ambulance transportation and for chronic care at home. Privacy concerns, older age, or lack of telecommunication knowledge were not identified as substantive roadblocks to implementation of these services.

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Conflicts of Interest

RB and HF are co-founders of Zebra Academy cvba.

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Abbreviations

IQR: interquartile range
UZB: Universitair Ziekenhuis Brussel

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Original Paper

Can Seeding in the Clinic Reach a Wide Audience? A Proof of Concept Study on Spreading a Health Message About Juvenile Idiopathic Arthritis Using a Shareable Online Video

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Abstract

Background: Shareable online video offers the potential for spreading a health message across online and real world social networks. Seeding a message in a clinical setting may be advantageous.

Objective: To investigate the potential of an online video to spread a health message about juvenile idiopathic arthritis (JIA) when delivered or seeded in a clinical setting and investigate factors that influence sharing behavior.

Methods: Multimethod proof of concept study. Concepts for two different styles of video were developed using focus groups and interviews and reviewed by an online market research panel. We compared dissemination of the two videos from two specialist pediatric rheumatology clinics in NHS Hospitals. Participants were 15 patients, family members, and clinical staff with knowledge of JIA at concept stage; 300 market research panel members in development stage; and 38 patients and their parents or guardians in the seeding stage. Newly diagnosed patients with JIA and/or parents or guardians were invited to view and share an online video with a health message about JIA across real-life and electronic social networks. Main outcome measures were viewing statistics, sharing behavior and patterns, and participant feedback.

Results: Of 38 patients and/or their parents or guardians given links, 26 visited the video webpage and shared the link, 2 visited and did not share, and 10 did not visit. Most links were viewed and shared within a few days. A total of 3314 pageviews were recorded with a mean of 89.6 pageviews per link (range 0-1245). Links were accessed from 26 countries, with most viewers in the United Kingdom (82.5%). Mothers were the most active group of sharers.

Conclusions: Distribution of a video link in a clinical setting may be an effective way to spread a health message. Parents or guardians of children with JIA are more likely to share a link than young people. Dissemination depends on a small number of active sharers, the content of the video, and the willingness of participants to share health information about themselves.

Trial Registration: UK Clinical Research Network Study Portfolio ID (UKCRN): 13747; http://public.ukcrn.org.uk/Search/StudyDetail.aspx?StudyID=13747 (Archived by WebCite at http://www.webcitation.org/6eeXlMmM6).

(Interact J Med Res 2016;5(1):e6) doi:10.2196/ijmr.4608

KEYWORDS

juvenile arthritis; video-audio media; patient education; Internet

Introduction

Health promotion and early diagnosis are core components of the National Health Service Improving Quality program [1]. Traditional multiplatform awareness campaigns, however, can be resource intensive with a finite lifespan, and their impact and cost effectiveness may be difficult to measure [2]. In contrast, the sharing of online content may disseminate health messages at relatively low cost. The potential reach of online messages is increasing: 73% of the UK population use the Internet and of these, 71% use it to gather health information [3]. One in 20 Google searches is for health information [4]. Furthermore, improving the use of digital technologies for health is a priority for the National Health Service [5].

Viral campaigns can reach large numbers of people through active sharing, but success depends upon the willingness of individuals to share messages. Shared online health messages are not simply passed from producer to consumer but are mediated before dissemination across social and other networks (eg, email). The potential advantages of online sharing of health messages include cost-effective dissemination of bottom-up advice, greater reach than read-only information, the ability to trigger debate and generate support within networks, and encouragement for patients to "come out" as living with a chronic condition. Open discussion within social media forums can decrease stigma attached to health conditions such as mental illness [6].

We were therefore interested in finding out whether seeding a viral campaign in a clinical setting could be effective in spreading a health message. We thought this could be successful because the message came from a trusted source, and members of patients' social networks might be interested in the patients and their new diagnoses. However, we recognized this approach could fail if there was reluctance to disclose personal information (ie, participants felt vulnerable) [3] or if there was stigma associated with the condition. Furthermore, successful dissemination online depends on the tone and content: a humorous message about sexually transmitted diseases may be more widely shared than a serious one [7].

The diagnosis of musculoskeletal conditions such as juvenile idiopathic arthritis (JIA), muscular dystrophies, and bone cancer in children and young people is often delayed, which has a negative impact on clinical outcomes and experience of care [8-11]. We therefore identified JIA as an appropriate condition for this study, recognizing the approach may work for other conditions as well.

We aimed to explore in this proof of concept study whether a health message with a shareable online video would be disseminated after initial distribution in a clinical setting by newly diagnosed children and young people with JIA and their parents or guardians. We also aimed to evaluate the feasibility of this approach and factors that might influence the distribution of such a video.

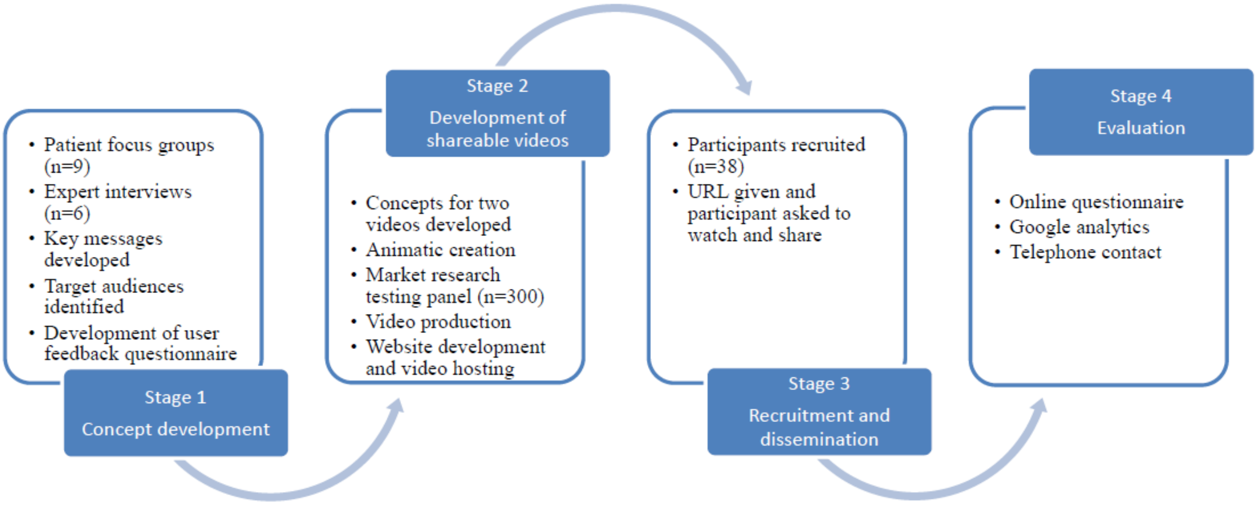
The specific objectives were

- To investigate whether an online video distributed in a clinical setting is shared
- To determine whether video style and content influence sharing
- To obtain user feedback in order to develop this approach

Methods

This was a multimethod study in 4 stages (see Figure 1). Ethical approval was obtained from the Local Regional Ethics Committee. Informed consent from parents or guardians and assent from children were obtained as appropriate and all data were anonymized before analysis.

Figure 1. Project overview.



Concept Development

In this first stage we explored ideas about online sharing and developed key concepts for video development. Focus groups were held with newly diagnosed and established children and young people with JIA (2-16 years of age) and their parents or guardians. Interviews were held with other interested parties including health care professionals caring for patients with JIA. Participants were recruited from one center (Newcastle).

A researcher (MF) led each focus group using a topic guide including the following themes: (1) awareness of JIA before diagnosis, (2) journeys to diagnosis and information seeking, (3) views about information that others should have and how to communicate that information, (4) how children and young people and parents or guardians share experiences, and (5) the reactions of others to a diagnosis of JIA. In interviews with other interested parties, themes emerging from the focus groups were further explored. Focus groups and interviews were audio recorded, and key themes were identified using grounded theory [12].

Video Development

In the second stage, a digital communications agency [13] developed 2 contrasting videos using findings from Stage 1. This process included script development, refinement, animatic (draft video storyboards) creation, market research testing, casting, filming, and editing.

To ensure videos were appropriate, informative, and likely to be shared, animatics were reviewed by an independent market research testing panel comprising 300 people without previous first-hand experience with JIA. Panel members were grouped for analysis as follows: 13- to 16-year-olds (male or female without children), 17- to 25-year-olds (male or female, including parents or guardians), and mothers of children up to 16 years of age. Panel feedback was incorporated into the final scripts. Two videos, each approximately 1 minute in duration, were cast, filmed, and edited to agreed final versions.

Recruitment and Video Dissemination

Participants were recruited using a criterion sampling method in which children and young people within 6 months of diagnosis of JIA were identified in 2 centers (Newcastle upon Tyne and Liverpool). The parent or guardian was sent an information sheet before the clinic appointment, and participants (patients or their parents/guardians) were recruited in the clinic by the researcher or a clinical staff member.

Participants were handed a postcard with a unique web link (bit.ly) and asked to access the link, view the video, and share it across their real-life and electronic social networks. Each link was associated with one of the 2 randomly assigned videos. Researchers were blinded to the allocation. Within 4 weeks, participants were interviewed by telephone for feedback about the study.

Videos were hosted on a private, purpose-built website comprising multiple pages with unique 3-digit identifiers, each of which could be tracked. Each page comprised a video and share buttons (Facebook, Twitter, LinkedIn, Google+, Blogger, Reddit, Tumblr, and email). At the end, viewers were asked to complete an online questionnaire (SurveyMonkey) including demographic details, opinion of the video, reasons for sharing or not sharing, and social network use.

Evaluation

Standard web analytic tools (Google Analytics) tracked link activity. Google Analytic algorithms count a pageview when a user loads a page. Technology platform and some other metrics are reported by session: a session starts when a user accesses a website and ends after 30 minutes of inactivity or when the user moves to another website. Data collection was terminated when activity fell to very low levels, approximately 6 weeks after recruitment of the final patient. Analysis included geographic location of viewers, viewing platform (eg, mobile or tablet), referring site, number of pageviews and sessions, and time spent on the website. Results for the 2 videos were compared. Participants were telephoned 2 weeks after recruitment. Results from the online questionnaire were compiled using standard metrics.

Results

Concept Development

Two focus groups were held, each comprising children and young people with JIA and their parents or guardians (n=9). Participants felt there was little awareness among the public and health care professionals that arthritis can affect children and treatment is often successful. Because effective treatments are available, appropriately treated JIA is an invisible albeit chronic condition. Although this means children and young people may not have to disclose their diagnosis, low visibility of physical changes may perpetuate lack of awareness and therefore delayed diagnosis. Interestingly, participants were concerned the public may have little interest in JIA because it is a manageable condition.

Participants felt that children and young people and parents or guardians are often better informed than health professionals and indeed may have suggested the possibility of JIA to their general practitioner before diagnosis. They also reported low levels of awareness in schools that arthritis affects children and young people. Therefore, support is often lacking, affected families are left to inform schools, and children and young people have to negotiate with peers. Adolescents may be reluctant to tell others about their condition to avoid being perceived as “boring” or “crippled” if unable to participate in certain activities, and this may encourage teasing or bullying.

Although fathers frequently attend hospital appointments with their child, participants felt mothers would be more engaged in information gathering, disease management, and exchange with others (eg, extended family and school). Participants identified 2 key target audiences: mothers of children and young people with arthritis and mothers of adolescents and young adults with arthritis. Videos provoking an emotional reaction were thought likely to be shared more widely than those resembling a fact sheet.

Other interested parties (n=6) were interviewed: a general practitioner with a special interest in pediatric rheumatology, a clinical nurse specialist in pediatric rheumatology, 2 consultant pediatric rheumatologists, the founder of a large parent or guardian support and awareness-raising network, and the communications officer of a relevant medical charity. Additional issues that emerged were around video style and content. Participants felt that to be widely shared, videos should be cute or humorous with key messages that children and young people can have arthritis and with timely treatment many maintain good quality of life. In addition, videos should not be heavily educational or overly alarmist while discussing symptoms (eg, persistent swelling, pain, stiffness). Participants suggested the most motivated sharers would be mothers of younger children, parents or guardians of children with more severe disease, and those who had suboptimal diagnostic experiences.

Video Development

Concepts and animatics for 2 contrasting videos were developed by the creative team. The 2 target audiences in Stage 1 were selected: parents or guardians (mothers in particular) of younger children and adolescents and young adults. Key messages were

- Anyone can get arthritis, at any age
- Early treatment is important

The video concepts were (1) “How old do you need to be…?” (Multimedia Appendix 1) and (2) “Old to young” (Multimedia Appendix 2).

Textbox 1. Video 1 concept: “How old do you need to be...?”

> A series of children approximately 4-10 years of age are shown answering “How old do you need to be...?” questions: “How old do you need to be to make a cup of tea/drive a bus/buy a house/get married/bake a cake/go on an airplane by yourself?” The answers, delivered to camera, are diverse, lighthearted, humorous, and real. Eventually we arrive at the last question—“How old do you need to be to get arthritis?”—to which children reply with high numbers (72, 65, etc). The last child we see tells us you can be any age to get arthritis. It ends with the caption “You don't have to be old to get arthritis” and a call to action to share the link.

Textbox 2. Video 2 concept: Old to young.

> An older woman is seen in a teenager's bedroom playing drum and bass on a turntable and moving to the music. Her voice is dubbed by a teenage female talking about the joy of listening to music and dancing. As her tone changes from happy and animated to sad, she talks about restricted movement, swelling, and pain, which at first she could not make sense of. The video culminates in a “big reveal” where the viewer discovers that the old woman is in fact a teenage female. The viewer sees the old woman put down her headphones, and the camera moves up to meet the face of the teenager whose voice we have been hearing. The message is that what started out as diffuse and inexplicable pains was, in fact, JIA. The video ends with the caption “You don’t have to be old to get arthritis” and a call to action to share the link.

Market research panel feedback about the animatics suggested the concepts successfully communicated key messages and would appeal to the target audiences. Concept 1 was considered more humorous and shareable and likely to appeal to mothers of young children. Concept 2 was considered more shocking and likely of greater appeal to 13- to 16-year-olds. Although the panel suggested 13- to 16-year-olds shared online video content most frequently, mothers were felt most likely to share a health message about their children online. Suggested barriers to sharing included lack of relevance, reluctance to share content about health, and self-consciousness about sharing content.

Recruitment and Dissemination

A total of 38 participants were recruited between January and May 2014 in 2 centers (23 from Newcastle upon Tyne and 15 from Liverpool). Links were distributed to the participants and/or their parents or guardians: 21 were to Video 1 (“How old do you need to be…?”) and 17 to Video 2 (“Old to young”). One participant mislaid the paper link which was replaced. Only one potential participant, a 16-year-old male, declined. In general, even when offered to children and young people considered old enough to use them, the links were accepted by a parent, guardian, or other family member instead.

The mean age of the children and young people was 7.6 years (range 2-15); 28 were female and 8 male (2 unknown). Age, gender, and video allocation did not vary significantly by center. Children and young people allocated Video 1 were not significantly different from those allocated Video 2 in terms of age or gender (Video 1, mean age 7.5 years, 18/21 female; Video 2, mean age 8.6 years, 10/17 female; P=.47 and P=.14, respectively).

Evaluation

Viewing, Sharing, and Pageviews

Of 38 distributed links, 10 were not accessed. The remaining 28 links achieved a total of 3236 pageviews (median 32 pageviews per link; range 2-1257).

Of 20 links to Video 1, 1 was not accessed. The remaining 19 links achieved a total of 2868 pageviews (median 32 pageviews per link; range 2-1257). One 12-year-old shared the link with her teacher and classmates but did not share online. Of 18 links to Video 2, 9 were not viewed. The remaining 9 links achieved a total of 368 pageviews (median 32 pageviews per link; range 2-90) (Figure 2). Visitors were recorded as *new* in 82.10% (2657/3236) of pageviews and *returning* in the remainder. The average session duration was 1:14 minutes.

Most links were viewed and shared within a few days. The lifespan of links was variable. For example, the most shared link was first shared 2 days after recruitment and generated 837 pageviews in the first week, decreasing in the subsequent 6 weeks (Figure 3). The second most shared link had a lifespan of approximately 3.5 weeks, with a peak of 469 pageviews on the second day followed by a decline in activity.

Figure 2. Box and whisker plot showing distribution of numbers of pageviews for each link grouped by the linked video.

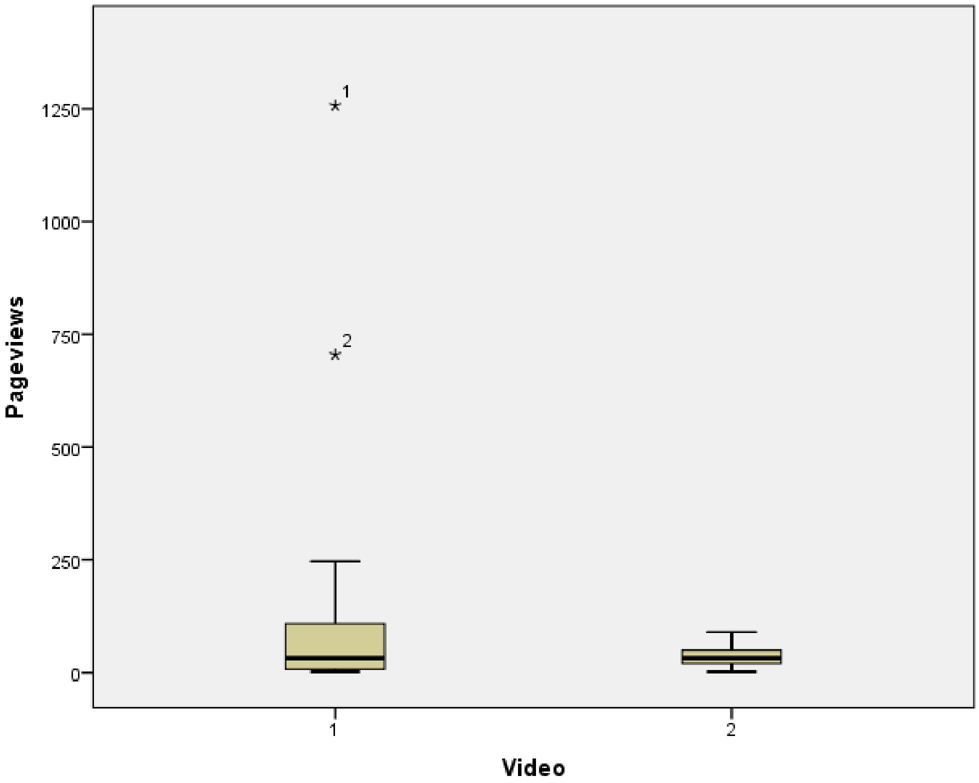
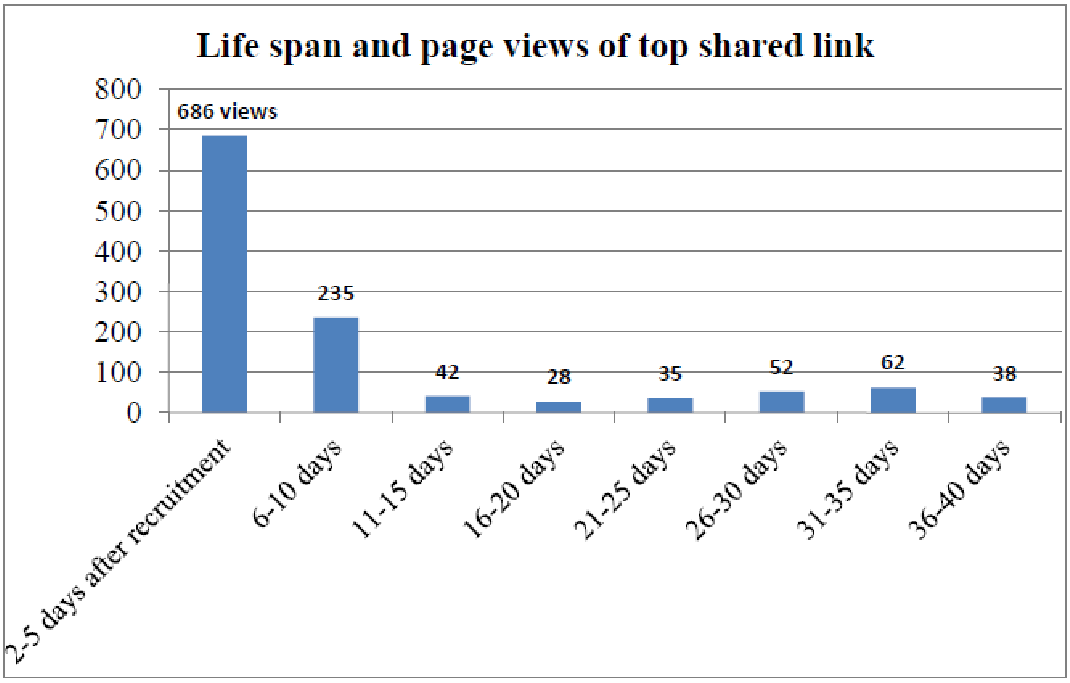


Figure 3. Life span and page views of top shared link.



Geographic Spread

Links were accessed from 26 countries (Table 1). Most viewers were in the United Kingdom (82.72%) and the United States (9.05%). Within the United Kingdom, most were in the North East and London. The 2 most shared links had the greatest geographical reach at 11 and 13 countries.

Technology Platforms

Of 3236 pageviews, 2175 (67.21%) were from social networks, 624 (19.28%) from the original bit.ly links, and 437 (13.50%) from direct links. The social networks driving viewers were Facebook (2143/2175, 98.53%), Twitter (16/2175, 0.74%), Mums in the Know (14/2175, 0.64%), and Google+ (2/2175, 0.09%). Of the 3236 pageviews, 2417 (74.69%) were on mobile or tablet devices.

Online Questionnaire Feedback

There were responses to 78 online questionnaires. All respondents either had arthritis or had a child with arthritis. The majority were female (66/72, 92%) and aged 25 to 44 years (50/72, 69%). Most (48/60, 80%) had been through or were planning to complete higher education.

Of 67 respondents to this question, 16 (24%) received the link directly from the research team, 30 (45%) via social networking sites, 5 (7%) from friends and 3 (4%) from a family member; 23 (34%) received the link from someone with JIA or whose child had JIA.

Of 72 respondents reporting their social media use, 70 (97%) used Facebook, 28 (39%) Twitter, 17 (24%) Instagram, 14 (19%) Pinterest, 6 (8%) Google+, 3 (4%) Tumblr, 2 (3%) Reddit, and 1 respondent kept a personal blog; 34 (47%) reported being logged on most of the time and 33 (46%) at least daily.

Most respondents (60/77, 78%) shared the video (Table 2). The most popular reason for sharing was that the viewer or child had JIA and wanted others to know about it. Videos were most often shared on social networking sites (48/59, 81%) with friends (24/59, 41%) or family members (17/59, 29%) and less often with work colleagues (4/59, 7%).

Table 1. Geographic distribution of viewers.

Country/Territory	Pageviews n (%)
United Kingdom	2677 (82.72)
United States	293 (9.05)
Australia	92 (2.84)
Canada	40 (1.23)
Ireland	36 (1.11)
Singapore	12 (0.37)
Italy	10 (0.31)
Netherlands	10 (0.31)
New Zealand	10 (0.31)
Germany	6 (0.18)
Spain	6 (0.18)
France	6 (0.18)
Czech Republic	4 (0.12)
Lithuania	4 (0.12)
Thailand	4 (0.12)
South Africa	4 (0.12)
Others	22 (0.68)
Total	3236 (100)

Table 2. Reasons for sharing or not sharing the video.

Response		Respondents n (%)
Shared (n=59)		
	I/my child has JIA and I want others to know about it too	48 (81)
	I know someone who has arthritis	10 (17)
	As a favor to the person/website who sent me the link	8 (14)
	It was touching	5 (8)
	It was funny	4 (7)
	It was informative	3 (5)
	It was different	2 (3)
Not shared (n=11)		
	I don't usually share things online	5 (46)
	I/my child has JIA, but I don't want to shout it from the rooftops	3 (27)
	I didn't like the look of it	3 (27)
	I don't know anybody who would be interested	2 (18)
	I didn't have time, and I forgot all about it	1 (9)

When asked what they liked about the video, responses were "It reminded me of myself/my child/someone I know who has got JIA" (31/65, 48%), "The way it talks about JIA" (24/65, 37%), "It was informative" (18/65, 28%), "It was cute" (15/65, 23%), "It made me feel quite emotional" (8/65, 12%), and "It was funny" (5/65, 8%). Comments included the following:

> *It plays on stereotypes and shows people their preconceptions are wrong.*
>
> *It's brief and to the point without being overly emotional. I don't share much about my daughter's JIA as it is personal to her but nor do I want her to feel ashamed or different—knowledge empowers and reduces prejudice. I was happy to share this.*

Some respondents (17/77, 22%) reported viewing but *not* sharing the video (Table 2). The most frequent reason for not sharing was "I don't usually share things online" (5/11, 46%). Comments included "My child is only 2 and . . . has stiff or sore joints . . . This wasn't mentioned in the video," the video was "not informative enough," and "Young people are likely to turn off as soon as the elderly person appears." Others reported it was irrelevant to their circumstances or, anticipating stigma or bullying, were not comfortable publicizing that their child had JIA.

Of 78 respondents, 18 specified what they disliked about the videos. Responses were "It reminded me of myself/my child/someone I know who has got JIA" (7/18, 39%), "It made me feel emotional" (5/18, 28%), "The way it talks about JIA" (4/18, 22%), "It was cute" (2/18, 11%), and "It was funny" (2/18, 11%). One respondent expressed concern about self-protection, vulnerability, and inviting negative attention or bullying after sharing. Two respondents specified groups they wouldn't share the video with (school friends and work colleagues) stating it would make them feel vulnerable.

In terms of content, Video 1 was considered more appealing and shareable. One respondent commented that the tone of Video 2 was "gray and depressing;" another commented that the actor did not come across as "cool" and therefore the video might not be helpful in raising awareness and engagement with the condition and that teenagers might not want to be associated with an older person's disease.

Telephone Follow-Up Interview Feedback

We were able to contact 15 participants for telephone feedback. Those contacted expressed support for the study and were positive and enthused about the video they had watched. Most felt that it was a good way to "get awareness out there." One mother described the video (Video 2) as "quite catching" and said she wished she had seen it "2-3 years ago" when she first suspected that her daughter might have a medical condition. Participants tended to share the video with friends and family (either by social media—predominantly Facebook—or directly by email). They reported receiving positive feedback about the videos as well as consistent comments like "I didn't realize that kids could get arthritis." Telephone interviews further suggested that in most cases it was the parents or guardians who shared the link via their networks, mostly with family and friends but also through JIA-specific networks such as support groups and general parenting forums. Only 1 participant mentioned explicitly that her 13-year-old daughter shared the link with family and friends on Facebook and Instagram.

Two participants had not viewed the video when contacted and were prompted to do so. Reasons for not viewing included loss of the recruitment card, having to attend to family or health-related matters, and stress following their child's recent diagnosis.

The video was also shared offline. One 13-year-old female shared the video with her teacher who then integrated it in a school lesson, although it was not widely shared online. The mother of a 9-year-old newly diagnosed female was very enthusiastic about the project but had recently stopped using social media. She suggested sharing the link through real-life networks and platforms including school notice boards and at extracurricular events.

Discussion

Principal Findings

This study has investigated the feasibility of seeding an online awareness campaign for JIA in a clinical setting and has demonstrated that this approach can work in what we believe is a unique study. We have shown that this approach is acceptable to most children and young people and their parents or guardians and that it can reach an audience which far exceeds the geographical and sociodemographic spread of other (eg, paper-based) information. Dissemination is influenced by the content and its shareability, participant engagement in social networks, and willingness to share personal or family-related health information.

The clinical motivation behind this study was to improve the diagnostic experience of patients with JIA. Our impression that awareness of JIA is low was supported by the initial group work in which children and young people and parents or guardians agreed there was little awareness of JIA in the community, schools, and primary care. Studies of delayed cancer diagnosis describe complex and varied pathways to diagnosis: delays can be patient-, family-, or doctor-related and occur between primary and secondary care or within secondary care [14]. Raising awareness in the community and within health care settings might address some of these areas and is one of the few tools available. However, although many campaigns have set out to do so [2,15,16], it is recognized that they may be ineffective or alternatively lead to increased and inappropriate demands on services [15].

Although this was a relatively small study, it demonstrated proof of concept for this technique; each link received a mean of 89.6 pageviews, and links were viewed from a wide range of geographic locations. Concentrations of views in the North East and London in the United Kingdom and within the United States likely reflect the connections of sharers locally as well as the population density and Internet usage in London and the United States.

Despite initial apparent enthusiasm from participants, links were not accessed by everyone recruited for the study. Unfortunately, we could not contact all of those concerned to understand why. The success of the project relied on a small number of enthusiastic sharers with appropriate viral dynamics or digital capital and access to and engagement with social media, factors which are crucial for successful seeding [17].

Despite the apparent social media engagement of younger digitally native patients, the most effective sharers were the parents or guardians (particularly mothers) of younger children, as predicted in the first phase. Although we had limited feedback from this population, likely factors for disengagement of JIA patients include unappealing tone and content of videos, reservations about sharing personal health-related information online, and lack of interest in the research. Other approaches like encouraging participants to make their own videos or sharing offline might be more successful.

A personal or emotional attachment to the message is important for sharing; the majority shared the video because their child or someone they knew had JIA. The engagement of patients and parents or guardians in spreading a health message represents a reconfiguration of the roles of patients and health professionals in a process which may require monitoring by public health professionals [18]. When spreading a health message online, a distinction between spreading information and awareness may be useful. We focused on the latter and tried to keep the message as simple as possible, reasoning that viewers could use the associated links to access further information. This approach, however, may reduce the effectiveness of educating the wider community.

In terms of absolute numbers of pageviews, Video 1 was more successful than Video 2 (2868 vs 368 views). However, this appeared to be driven by a couple of very successful sharers of Video 1 and not because of a significant difference in the number of pageviews. This emphasizes the impact of small numbers of highly connected and motivated individuals in online sharing. Comments about the videos appeared to favor the lighter and more humorous tone of Video 1. The online content which is shared to some extent reflects on the sharer, and it may be that sharers were happier to be associated with this than the darker tone of Video 2. Facebook was the dominant social network through which links were shared, predominantly to friends or family members. Most views were on mobile or tablet platforms.

Key to the transferability of this approach is the condition in question, and this approach may be more applicable to some conditions than others. Given the reservations about what sharers thought the messages said about themselves and their condition, messages about different conditions (eg, cancer or sexual health) are likely to be shared differently. Therefore, while there are clear elements of transferability, relevant condition-specific enablers and barriers should be taken into account when developing Web-based health messages.

Limitations

A major drawback to our study is that although we had viewing statistics, we were unable to measure whether our method had raised awareness of JIA in the population or among those who watched the videos. Testing this concept within a formal study to which patients were required to consent led to some logistical difficulties including the uneven randomization of patients across the 2 videos. Our method of sharing written links to the videos was not ideal; future studies should consider direct electronic sharing of links (either by email, text message, or QR code) to eliminate the need to manually enter the address into a browser and facilitate the sending of reminders if appropriate. We believed that up to 6 months after diagnosis patients would be more motivated to share videos but were unable to test this. Our study was heavily dependent on 2 professionally produced videos, which were relatively expensive to produce and may limit the scalability and transferability of this approach. Furthermore, the dependence on the video content itself means it is possible that different videos would have generated entirely different results. The feedback we received was predominantly from women aged 25 to 44 years, which may not reflect the majority of the viewing audience.

In developing an effective awareness campaign, it might be appropriate to target other groups (eg, health professionals). We could not tell to what extent the links had been shared with health professionals, and some research into sharing behavior might be appropriate. While awareness campaigns can improve outcomes for patients, the impact on primary and secondary care of increased numbers of referrals as a result of a campaign should be considered [19].

Conclusion

The findings of this exploratory study suggest that distributing a link to a shareable online video in a clinical setting is a feasible and potentially effective way of spreading a health message. The tone and content of the message are important factors in the success of this approach, as is an understanding of the population (patients and parents or guardians) most likely to share the resource. Other factors include the condition itself, the willingness of sharers to be identified with the condition, and preexisting awareness of the condition. The parents or guardians of affected children may be the most effective group for spreading health messages about childhood-onset conditions, and future campaigns should consider this. Further work should focus on refining this approach, delivering it at lower cost, and improving its generalizability across age groups and medical conditions.

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Authors' Contributions

The study was conceived and designed by CG, HF, and TR collaborating with CP. MF collected and analyzed the data. MF, CG, HF, and TR interpreted the data. MF drafted the paper and CG, HF, CP, and TR made revisions on subsequent drafts. All authors read and approved the final manuscript. CG is the guarantor.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Video 1. How old do you need to be . . .?

[MP4 File (MP4 Video), 54MB - ijmr_v5i1e6_app1.mp4]

Multimedia Appendix 2

Video 2. Young to Old.

[MP4 File (MP4 Video), 50MB - ijmr_v5i1e6_app2.mp4]

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Original Paper

Barriers to Managing Fertility: Findings From the Understanding Fertility Management in Contemporary Australia Facebook Discussion Group

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Abstract

Background: As part of research investigating the complexities of managing fertility in Australia, public opinions about how Australians manage their fertility were sought from women and men.

Objective: To identify public opinion about sexual and reproductive health in Australia.

Methods: To ensure access to a diverse group of people throughout Australia, an online group was advertised and convened on Facebook from October through December 2013. In a closed-group moderated discussion, participants responded to questions about how people in Australia attempt to manage three aspects of fertility: avoiding pregnancy, achieving pregnancy, and difficulties conceiving. Nonidentifiable demographic information was sought; no personal accounts of fertility management were requested. The discussion transcript was analyzed thematically.

Results: There were 61 female and 2 male Facebook users aged 18 to 50 years living in Australia participating in the study. Four main themes about fertility management were identified: access, geographical location, knowledge, and cost. Participants reported that young people and people from rural areas face barriers accessing contraception and fertility services. Limited knowledge about sex and reproduction and the cost of fertility services and contraception were also said to impede effective fertility management.

Conclusions: Reasons for inequalities in effective fertility management that are amenable to change were identified. Facebook is an effective method for gaining insights into public opinion about sexual and reproductive health.

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KEYWORDS

fertility management; Australia; Facebook; social media

Introduction

Avoiding pregnancy when it is not desired and achieving a desired pregnancy are matters of concern throughout the reproductive life course. Modern contraceptives and assisted reproductive technology (ART) have contributed to fertility management in what has been termed the “reproductive revolution” [1]. In contemporary high-income democracies such as Australia, these are presumed to enable all women and men to manage fertility optimally [2,3].

Australia faces the paradoxical problems of high rates of unintended pregnancy and of infertility, and many Australians do not achieve their reproductive preferences [4,5]. We know that most Australians want to have children [4,5]. Little is known about how contemporary Australians of reproductive age manage fertility [1,2].

Modern oral contraceptives first became available to married and later unmarried Australian women about 50 years ago and were thought to have initiated the era of the planned and wanted pregnancy and the end of the unplanned pregnancy. Subsequent surveys of contraceptive use, pregnancy intention, pregnancy outcome, and ideas about family formation have found that this has not been realized. For example, although the 2001-2002 Sex in Australia survey of a representative sample of 9134 people aged 16 to 59 years found that only 70% of sexually active women of reproductive age were using modern contraception [6], 22.6% reported a past induced abortion and 16.9% of women aged 20 to 29 had become pregnant during adolescence [7].

Infertility, the inability to conceive after 12 months of unprotected intercourse, occurs in 1 out of 6 Australian couples [8]. Even with ART, not all people who desire to conceive do so, even with repeated treatment cycles; success rates decline with maternal age. Financial expense, health problems, and the psychological costs of repeated experiences of hope and despair are, for some, barriers to continuing treatment [9,10], but most people appear to view these technologies as affordable, accessible, benign, and highly effective. For example, only one-third of secondary school students understand that ART does not cure infertility [11], and some adults in their mid-thirties delay conception because they believe ART is a reliable alternative if conception is difficult [12]. Most women and men who participated in the Australian Institute of Family Studies’ Fertility Decision-Making Project in 2004 believed that they were likely or very likely to succeed in having children through in vitro fertilization (IVF), and those in their late thirties were as likely as those in their twenties or early thirties to be optimistic about conceiving with IVF [13].

Social networking sites such as Facebook are extremely popular. Facebook is the largest and most widely used social networking site [14]; in January 2015, Facebook had almost 14 million users in Australia [15]. Research using social network sites is a relatively new phenomenon [16], but it has been viewed positively by research participants [17]. To date, health-related research using Facebook has mostly explored its use as a health resource or a way of recruiting study participants [18]. There has been limited use of Facebook as a platform for online discussion groups. Facebook provides valuable opportunities for researchers to engage people from diverse backgrounds and locations, including traditionally hard-to-reach groups such as younger people, in a space in which they are comfortable and open to discussing their ideas and opinions [14,19]. Social networking sites have the advantage of enabling participation in online discussion groups at times that suit participants [20], and they can be accessed via personal computers, smartphones, and tablets, removing the need for a physical venue [16].

The aim of this research was to investigate public opinion about fertility management in Australia. To ensure that participation was available as widely as possible throughout the country, an online discussion group was advertised and convened on Facebook.

Methods

Study Design

This study is part of a multimethods research project that includes a population-based survey and in-depth interviews.

Sample

English-speaking women and men aged 18 to 50 years who were Facebook users living in Australia were sought and invited to participate in the online discussion group.

Recruitment and Procedures

For the study, the researchers created a closed (private) group on Facebook. The member list of a closed group is visible to all Facebook users, but only members can read what is posted. Before the group began, researchers made decisions about reasonable expectations for privacy, ownership of any data generated, and means of moderating the discussion and removing any offensive posts. These expectations were outlined to potential participants on the project’s Facebook page.

From October through December 2013, an advertisement (see Figure 1) briefly describing the research and discussion group was placed on the Facebook pages of all users meeting the eligibility criteria. Age was identified from the user’s profile (a mandatory field on all personal Facebook accounts), and location was established from the Internet protocol address [21]. We chose the option of being charged per click rather than per thousand impressions because we were seeking people who would click through to our Facebook project page from the advertisement [22].

The project page provided further details about the research and the participation involved. A participant information statement explained that the discussion would be about their perceptions of how people in Australia manage their fertility and there would be no personal questions about participants’ own fertility management. Those who chose to participate requested to join the group by clicking on a link on the Facebook project page.

The group moderator (SH) approved requests and sent participants a “welcome to the group” message via Facebook inviting them to participate in the discussion by posting their responses to questions and to comments from other members.

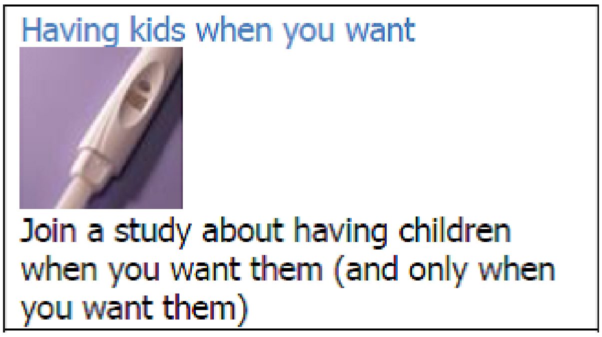
To develop a summary description of group members, a link to an online survey was included in the welcome message to new participants. The survey, which was not part of the group discussion, contained questions about demographic variables (age, sex, relationship status, country of birth, level of education, Aboriginal or Torres Strait Islander status) and fertility history (past fertility problems or accidental pregnancy, number of children).

The research team developed a guide with the following questions to initiate and prompt discussion on community views and attitudes about avoiding and achieving pregnancy.

- What do you think people do (or don’t do) when they want to avoid a pregnancy?
- What services might be available to people who want to have sex but not get pregnant?
- What do you think people do (or don’t do) when they want to get pregnant?
- What services might be available to people who want to get pregnant?

Participant responses were read daily by the moderator and discussed at least weekly by the research team. The moderator asked additional or clarifying questions as appropriate and did not censor personal anecdotes. Members of the group also commented on each other’s posts. The moderator posted a new question every few days.

Figure 1. Facebook advertisement.



Having kids when you want

Join a study about having children when you want them (and only when you want them)

Data Analysis

The transcript of the group discussion was copied from Facebook and pasted into a Word document. Participants were identified in analysis by number only. Data were analyzed using the four systematic steps appropriate for focus groups [23,24]: organizing, shaping, summarizing, and explaining. The first author systematically coded the transcript into emergent themes and subthemes. The transcript and themes were reviewed by all authors; discrepancies were discussed and agreement reached on the final themes.

Ethics

The main ethical considerations were privacy and voluntary participation. Facebook allows users to determine how much of their personal information is publicly displayed. Profile security settings can be public (ie, allowing access to the complete profile by any Facebook user) or private (ie, limiting access of some or all profile information). Before joining the discussion group, participants were asked to ensure that their Facebook privacy settings were consistent with what they wanted to reveal to the group. Participation in the group was voluntary, and participants could withdraw at any time. A request to join the group was taken as informed consent to participate.

The research project was approved by the Human Research Ethics Committees of Monash Health (Project Number 11280B, September 2011), Monash University (Project Number CF12/0302-2012000125, February 2012), the Royal Women’s Hospital (Project Number 11/44, December 2012), Family Planning Victoria (Project Number 11/3, February 2012), and Melbourne IVF (Project Number 10/12, April 2012).

Results

Participants

The Facebook advertisement was viewed 60,372 times. There were 783 clicks on the advertisement (directing respondents to the study Facebook page) and 63 requests to join the group. All requests were accepted; 61 women and 2 men joined in the group. Comments were posted by 13 (21%) members of the group. The group ran for 3 months, from October through December 2013.

Demographic data were provided by 46 (73%) participants. It was not possible to distinguish the demographic information of contributing participants from noncontributing participants or associate demographic information with individual posts. The mean age of participants who provided demographic data was 30.1 years (18-49 years). One participant identified as Aboriginal or Torres Strait Islander. Participants were mostly born in Australia (38/46, 83%); the remainder were born in Canada, Indonesia, Malaysia, New Zealand, Sri Lanka, Ukraine, and the United States. Most participants (40/46, 87%) had completed postsecondary education and were married or living in a heterosexual relationship (37/46, 80%). In this study, 2 participants were living with a partner of the same sex; 5 were not currently in a sexual relationship.

The participants had varied fertility experiences. Approximately 40% (19/46) had experienced fertility difficulties, and a similar proportion (19/46, 41%) reported an accidental pregnancy. Just over half (24/46, 52%) had had children (ranging from 1 to 4).

Key Themes

Guided by questions posted by the moderator, the discussion focused on 3 main aspects of fertility management: avoiding pregnancy, wanting to get pregnant, and difficulties getting pregnant. Analysis revealed 4 key factors identified by the participants as affecting an individual's ability to manage her/his fertility effectively: access to contraception, geographical location, level of knowledge about sex and reproduction, and the cost of fertility services and contraception.

Theme 1: Access to Contraception

Contraception was identified as the main means of avoiding an unwanted pregnancy. Participants discussed various contraceptive methods: the oral contraceptive pill, long-acting hormonal contraception for women (such as hormonal intrauterine devices), condoms, ovulation calendars, testing of cervical mucus, and herbal preparations. The oral contraceptive pill was regarded as the preferred and most commonly used contraceptive method. However, participant responses indicated that choice of contraceptive varied among age groups. Teenagers were thought to use condoms more because they are easy to access.

> *A younger teen is more likely to use condoms (if they use anything) because you don't need an appointment with a doctor to get condoms.* [Participant #1]
>
> *For the youth it also requires considerable planning to obtain a script for the pill or implant et cetera.* [Participant #2]

Younger women were thought to prefer an implant or oral contraceptive pill and use emergency contraception frequently. In contrast, older women who are in committed relationships and no longer wanted to get pregnant were viewed as preferring surgical methods because these are permanent and do not require management.

> *I live in a larger regional center and find that many women in ongoing relationships that are over 30-35 [years] prefer the male partner to have a vasectomy. Then if he won't she tends to have the tubal ligation.* [Participant #2]

Participants commented that ideally both partners in a relationship should be actively involved in making decisions about the use of contraception and avoiding unwanted pregnancies. However, participants expressed the view that, among younger people, there was a perception that women should manage contraception, and some men refuse to use contraception.

A lack of communication between partners was also perceived to influence contraceptive use, especially for younger people.

> *I think there is unfortunately still an awkwardness (particularly in young people) about actively talking with partners about contraception. The maturity to physically have sex doesn't always come with maturity to really think about the consequences that come with that responsibility or to have open conversations with partners to actively plan for and manage contraception choices. The "it won't happen to me" attitude and poor communication skills can lead to complacency and risk taking.* [Participant #3]

Participants also commented that health care professionals rarely discussed sex or sexuality with young people and recommended more education for health care professionals and parents about how to talk to young people about their sexuality and sexual health. Social media was identified as an appropriate and effective platform for facilitating discussions between health professionals and young people about contraception and fertility management

> *What would help [people manage their fertility]? GPs, MCHNs, social workers spending more time explaining contraception to young people and debunking the myths. Increased education for health professionals and the general public.* [Participant #4]

Theme 2: Geographical location

Frequent reference was made to the barriers limiting access to fertility services including more permanent contraceptive methods and abortions, particularly in rural areas.

> *It often takes 4 weeks just to get a GP appointment in the country/regional areas.* [Participant #2]
>
> *There are many options open for city people not so many for country folks however.* [Participant #5]
>
> *I live in a rural city and it is virtually impossible for a woman to get a tubal ligation here. The Ob-gyns just won't do it.* [Participant #1]
>
> *I also live in a larger regional center but not many women here get tubal ligations as there are only 2 Ob-gyns here and neither are keen on surgical intervention for contraception for women. There is one surgeon who will do vasectomies.* [Participant #2]
>
> *There is no one in my large regional center that will do a termination. Women are forced to travel at least 2 hours to access legal abortion. And being that the clinics won't allow you to leave without someone with you.* [Participant #1]

Participants also discussed the impact of location and income on access to fertility services for overcoming conception difficulties. ART was identified as a last resort after all of the other options are exhausted, but participants asserted that there should be universal access, lamenting the limited options for people living in rural areas or with inadequate financial resources.

> *We live in a rural area, though are very fortunate to have a fantastic reproductive medicine clinic for our region. I am not sure this would be so easily accessible if you didn't live in easy travel distance of such a specialist. So I guess to answer further, while getting the referral and actually accessing this clinic might be easily done, I think the reality is not so straightforward.* [Participant #3]

> *Yes of course [everyone should have access to reproductive services]!!!! Not everyone wants or can live in a big city!!!...I understand that it is cost-prohibitive to have a permanent IVF facility in country hospitals/health centers!!! But what about a traveling team!!! Surely that would be possible!* [Participant #5]

Theme 3: Level of Knowledge About Sex and Reproduction

Participants reported that although many people do not want a pregnancy, they often do not use contraception or use it incorrectly. This may reflect, at least in part, their level of knowledge about sex and reproduction. School-based sex education was identified as an inadequate and often inaccurate source of information, and sometimes it was absent altogether. Many people relied on their peers or the Internet for information about contraception.

> *I went to a girl's school and some of the...girls had no idea!! They honestly thought that if you smoked alpine [cigarettes]...you didn't get pregnant!!! We soon informed them differently!!!* [Participant #5]

> *One of the nuns told us that if we to go out with a boy—take a phone book to sit on (if we are going to sit on his lap—to prevent sperm getting to us because boys leak).* [Participant #2]

> *[School] didn't teach me anything to do with sex ed or avoiding a pregnancy. My mother had the conversation with me and I looked up information on the Internet.* [Participant #6]

> *I've found loads of things in Google.* [Participant #7]

> *I've found young people often find it the most difficult to determine whether info is reliable on the Internet. Some...then contact friends on Facebook to ask what they think or what their experience is. In comparison, someone like myself may consult government health websites or community organizations and then clarify this with a medical professional in person.* [Participant #4]

Participants thought that a lack of education about contraception and reproduction also made it difficult for disadvantaged or young people to realize their intentions and to avoid unwanted pregnancies.

> *Individuals from disadvantaged backgrounds may be more likely to opt for using condoms or the pill because they are uneducated about the other options available. Condoms are also easier to access from service stations et cetera whereas getting a script for the pill or other types of contraception involves attending a GP or clinic. Many young people were unaware they could drop in to local family planning clinics for free.* [Participant #4]

> *Young women rely on peers for information about contraception. I have worked with many young women over the past three years who had unplanned pregnancies, many who had more than one unplanned pregnancy and did not know the variety of contraception available, as well as the low cost if you have a health care card.* [Participant #4]

Participants also discussed the impact of a person's level of knowledge about sex and reproduction on achieving a wanted pregnancy. They identified the main actions to be adopted as increasing the frequency of sexual intercourse and having sex at the "right time." Participants also advocated monitoring ovulation and knowing "how our bodies work" as contributors to achieving conception.

> *A few months in, I started tracking my ovulation, having sex at the right time.* [Participant #8]

> *My husband works away for 9 days and home for 5 days. I used a period tracker phone app to monitor my cycles and get an idea when I would ovulate. Then we had sex every 2nd day as I have read that's best for trying to conceive.I also started to track cervical mucus and attempted to chart temp but wasn't accurate. I personally have looked into all the ways to determine ovulation to make it easier to conceive.* [Participant #9]

Changes to practices and behavior, including improving diet, ceasing smoking, and limiting alcohol and drug use were also recommended by the group for achieving conception.

> *Personally, trying to get pregnant was a bit of a staged process. I was so excited about starting to try that I cut down alcohol, had been taking multivitamins and folate for months before, said no to events "just in case."* [Participant #8]

Lack of recognition of men's roles and responsibilities in achieving a pregnancy were also identified.

> *I think women so often "cop the flack" for fertility issues, but it disregards the role of men's health and fertility which is equally important. You seldom hear of men quitting drinking or getting healthier in order to conceive yet they contribute half of the DNA to the process! I think definitely both partners need to be actively involved and responsible.* [Participant #3]

> *It is seen as the woman [who] needs to get healthy to carry the baby...it seems to be forgotten that first both parties have to create the baby!!!* [Participant #10]

It was claimed that men are neither very aware of or concerned about women's age-related fertility decline.

> *I don't think it's that easy to get pregnant, especially as you start to reach your thirties. This is something that I and my girlfriends are concerned about. Our husbands however don't seem to understand what all the fuss is about. There's been a lot more focus in the media in the last few years regarding the risks of having children later.* [Participant #4]

Despite participants' perception that health care professionals lacked knowledge about contraceptive options, a range of health services, such as reproductive medicine clinics and naturopaths, was identified as important sources of information about achieving pregnancy. General practitioners (GPs) and the Internet were regarded as the main sources of information.

> *If I was planning to [get pregnant] I would probably access my GP as a starting point. I'd also probably jump online to find out information before even going to the GP.* [Participant #4]

Participants commented that they had assumed it would be easy to conceive because it had been so for their friends and family but found that their own experiences challenged this assumption.

> *I am one of those that thought I would just stop the pill and instantly become pregnant, why wouldn't I, the rest of my family did!...I was super naïve...I have a number of girlfriends who literally pick a month and without understanding when ovulation occurs achieve it exactly as planned!* [Participant #10]
>
> *We expect that [pregnancy] will happen when we want it to and cease contraception.* [Participant #3]

The emphasis in sex education on avoiding pregnancy was also cited as contributing to the common belief that it is easy to get pregnant.

> *Based on my conversations with my daughter (15 year old), [people learn at school] absolutely nothing. I think in my region the myth that getting pregnant is the easiest thing in the world for everyone (and one I fell for in my younger days) is being furthered by the lack of conversation and education.* [Participant #2]

Theme 4: Cost of Fertility Services and Contraception

The cost of fertility services and contraception was also identified as a barrier to effective management of fertility.

> *We are potentially staring [down] the barrel of more IVF and it's so expensive, and last time we did it was just after funding from IVF was redirected to lap band surgery.* [Participant #10]
>
> *Many people would lack the financial capacity to actually afford to access these specialist [reproductive medical] services, and if they can to begin with, repeated treatments and the associated expenses can very quickly drain the average budget.* [Participant #3]
>
> *The costs of even condoms could be prohibitive for some people. I don't think many people are aware of the mechanisms to obtain free condoms from planning clinics or community health centers. If people are needing to prioritize food with contraception, there is likely to be that inclination to overlook it as a priority regardless of the consequences.* [Participant #3]
>
> *With the defunding of many community-based programs, no doctors [are] left that bulk bill et cetera. The reliance on condoms and the morning after pill seems to be increasing.* [Participant #2]

Discussion

Principal Findings

This study identified key themes in the understanding of fertility management in contemporary Australia. Despite the participants having a variety of views and fertility experiences, similar and consistent barriers to effective fertility management were identified: avoiding or achieving pregnancy and conceiving when faced with fertility difficulties. Younger people, people living in rural areas, and people with lower levels of knowledge about sex and reproduction were thought to have the most difficulties in managing fertility.

This study was original in its innovative use of Facebook as the platform for an online discussion group. Facebook was a cost-effective and efficient way of enabling people from diverse geographical locations to participate in the group discussion at times that were convenient for them. As a result, this study included a diverse sample of women and men living in metropolitan and regional areas of Australia with varied fertility experiences.

Limitations

The primary limitation of the study is the self-selection of the sample. The study was advertised as being about fertility management, and almost half of the participants had experienced fertility difficulties. Only 2 were male—more targeted approaches may be required to encourage men to participate in research to assess community views about sex and reproduction.

We found, as have others [25], that contraceptive practice varies by age; younger women are more likely to use oral contraceptives or condoms while older women are more likely to use permanent methods. These results may reflect childbearing patterns and sexual practices of younger people, who may be more likely to have changing sexual partners and need protection from sexually transmissible infections [26]. Participants also commented that access to long-acting and permanent methods of contraception was more difficult for people living in rural locations. Our findings from the survey component of this research indicate that lack of ready access to preferred contraceptive methods may constitute a barrier to fertility management for people living in rural areas [27]. This may reflect difficulties in rural areas of accessing health services and health professionals trained in insertion of long-acting reversible contraception.

A key finding was the perception that people's level of knowledge about sex and reproduction is inaccurate and inadequate for their needs. This confirms existing evidence of considerable knowledge gaps about avoiding and achieving pregnancy, including low awareness of when women are most fertile [28]; naivety about the likelihood of experiencing fertility difficulties [29]; and the inadequacy of school-based sex education in topics such as emergency contraception, fertility, and pregnancy [30].

Costs of fertility services and contraception were also identified as barriers to effective fertility management. Raising awareness of how and where to access affordable contraception will allow people to use effective contraceptives that suit their needs. Many effective methods (eg, oral contraceptive pills, implants, and hormonal intrauterine devices) are subsidized through the Pharmaceutical Benefits Scheme. However, Sexual Health and Family Planning Australia [31] has argued that the out-of-pocket costs of long-acting reversible contraception may be unaffordable for many women. These findings corroborate those of the survey component of this research which also showed that relative social disadvantage was associated with significantly increased odds of unintended pregnancy [27].

Policy and Practice Implications of Findings

The identified barriers to fertility management are all potentially modifiable. Education and public awareness campaigns about sex, reproduction, and available community health services should be undertaken and especially directed at young people. Knowledge gaps could also be alleviated by giving primary care providers (and others including social workers, teachers, and youth workers) adequate training for communicating about sexual and reproductive health (eg, taking time to explain contraception to young people and debunking common misconceptions). Government-sponsored public awareness campaigns were also viewed as important in educating people about the significance of men’s role in fertility management. Traveling teams of sexual and reproductive health providers could increase access to essential services in rural areas.

Conclusion

The results of this study reveal community awareness of modifiable factors that contribute to sexual and reproductive health inequalities in Australia and demonstrate the effectiveness of using social networking sites such as Facebook for sensitive health-related research.

Conflicts of Interest

None declared.

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Abbreviations

ART: assisted reproductive technology
GP: general practitioner
IVF: in vitro fertilization

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Original Paper

Surveying End-of-Life Medical Decisions in France: Evaluation of an Innovative Mixed-Mode Data Collection Strategy

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Abstract

Background: Monitoring medical decisions at the end of life has become an important issue in many societies. Built on previous European experiences, the survey and project Fin de Vie en France ("End of Life in France," or EOLF) was conducted in 2010 to provide an overview of medical end-of-life decisions in France.

Objective: To describe the methodology of EOLF and evaluate the effects of design innovations on data quality.

Methods: EOLF used a mixed-mode data collection strategy (paper and Internet) along with follow-up campaigns that employed various contact modes (paper and telephone), all of which were gathered from various institutions (research team, hospital, and medical authorities at the regional level). A telephone nonresponse survey was also used. Through descriptive statistics and multivariate logistic regressions, these innovations were assessed in terms of their effects on the response rate, quality of the sample, and differences between Web-based and paper questionnaires.

Results: The participation rate was 40.0% (n=5217). The respondent sample was very close to the sampling frame. The Web-based questionnaires represented only 26.8% of the questionnaires, and the Web-based secured procedure led to limitations in data management. The follow-up campaigns had a strong effect on participation, especially for paper questionnaires. With higher participation rates (63.21% and 63.74%), the telephone follow-up and nonresponse surveys showed that only a very low proportion of physicians refused to participate because of the topic or the absence of financial incentive. A multivariate analysis showed that physicians who answered on the Internet reported less medication to hasten death, and that they more often took no medical decisions in the end-of-life process.

Conclusions: Varying contact modes is a useful strategy. Using a mixed-mode design is interesting, but selection and measurement effects must be studied further in this sensitive field.

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KEYWORDS

end-of-life decisions; France; methodology; mixed-mode survey

Introduction

Improved living conditions, public health initiatives, and advances in medical care in most developed countries have contributed to a rise in life expectancies and a significant shift in the causes of death. Deaths from acute infectious diseases have declined, whereas deaths from chronic and degenerative diseases such as cancer and cardiovascular pathologies have increased [1,2]. More and more, people are dying at older ages, often in hospitals where they are permanently assisted by physicians and other health care workers who are directly involved in the dying process. These professionals can administer drugs to alleviate pain or other symptoms, and withhold or withdraw treatment to prolong life; however, the deliberate hastening of death is legally forbidden in France. Consequently, the quality of medical care at the end of life has become a significant concern in many societies, and it has become necessary to monitor related medical decisions reliably, to provide data to inform debates on this sensitive subject. Legislation concerning medical end-of-life decisions varies widely in Europe [3]. Over the last few decades, several European countries have performed single surveys or a series of surveys on this topic, including the Netherlands, Belgium, Denmark, Sweden, Switzerland, and Italy [4-8]. In France, major changes were introduced to the legislation in 2005 [9]. However, no nationwide representative survey has ever been undertaken, and the only available data has come from studies in hospitals and emergency wards [10-13]. Thus, there is a lack of knowledge of overall medical practices.

One of the main obstacles to conducting population-based studies is that health care professionals are recognized as a “hard-to-reach” population [14], resulting in high nonresponse rates. In combination with substantial differences between nonrespondents and respondents, this can lead to considerable nonresponse bias [15], which undermines the validity of these studies. For this reason, efforts aimed at improving participation rates must be concerned with every aspect of a protocol [16-18]. First, positive impacts have been noted using the following methods: varying contact modes and/or the form of postal contact (letters, cards, telephone, etc) [17], personalized cover letters, replacement questionnaires combined with a high number of follow-up contacts, and a long data collection period [19,20]. Second, mixing data collection modes (eg, mail and internet) may show positive results, although postal questionnaires are often favored over telephone and Web-based surveys [21,22]. Finally, surveying a sample of nonrespondents may also improve data quality, through the assessment of reasons for refusal and/or the determination of sociodemographic or professional characteristics of nonrespondents [17,23]. This latter technique was used in the 2001 end-of-life decision surveys in the Netherlands, Switzerland, and Sweden [24], as well as in the 2007 Belgium survey [25].

The survey *Fin de Vie en France* (“End of Life in France,” abbreviated as EOLF) was conducted in 2010 by the Institut national d’études démographiques (INED), with the purpose of describing end-of-life medical decisions in the French context [26]. Compared to previous surveys, EOLF comprised several innovations, including a mixed-mode procedure (internet and postal questionnaire) as well as postal and telephone follow-ups, combined with postal or email reminders sent by the medical authorities (hospitals and regional health agencies). It also comprised a nonrespondent telephone survey to assess nonresponse bias.

The aim of this paper was to describe and evaluate the methodological innovations of EOLF and to assess their impact on data collection quality. It describes response rates, representativeness of the sample, motives for nonresponse, and differences resulting from the data collection modes. Regarding the mixed-mode methodology, we assessed whether the choice of Internet over paper questionnaires was linked to the characteristics of the participating physician or of the deceased person, and whether this choice had an impact on the reporting of end-of-life medical decisions.

Methods

Retrospective Design

We chose to sample deaths and not physicians [4-8] for the same reasons given by Chambaere et al [25]. A representative sample of 14,999 deaths was selected by the CepiDc (*Centre d'épidémiologie sur les causes médicales de décès*) de l’Institut National de la Santé et de la Recherche Médicale (INSERM), and was drawn using systematic random sampling (sorted by age, gender, place of death, and region of residence of the deceased person [27]) from among 47,872 deaths of persons aged 18 and over that occurred in continental France in December 2009.

The certifying physician was identified, and a questionnaire about the selected deceased person(s) was mailed to her/him with instructions for replying. Physicians could respond either by post or by using a specially developed secure Web-based questionnaire. When physicians had more than one death in the sample, for each death, we provided an identifier and password to use in the Web-based mode and a questionnaire with a prepaid envelope to reply by post.

Anonymity and Follow-Up

While the Belgian survey procedure employed a lawyer as a third party, preliminary discussions in France concluded that any mention of a lawyer for this kind of survey would provoke reluctance rather than reassure physicians to participate. We used the services of a specialized hospital department to play the role of the trusted third party for the paper administration [28]; the members of this service also entered the paper-based questionnaire responses manually using the secure Web-based questionnaire that was developed.

The Web-based administration adapted the same approach by involving a trusted virtual party [29]. This method used more than one Web server; answers entered by the practitioner were neither sent to nor temporarily saved on the first Web server (the one to which they logged on). Instead, the responses were sent to a second server using .xml files, for which filenames included a second and different irreversible hash chain of the death identity. In addition, access to log files was not activated on this host Web server, in order to suppress information regarding Internet protocol addresses. Furthermore, no electronic acknowledgment was sent to physicians, and all .xml files received had the same date of creation on the host server. This overprotection of the practitioner’s identity contrasts with current philosophy of Web security, which consists of tracking connections to a server and forcing browser clients to dialog with a unique, well-identified server. The material sent to physicians explained how their anonymity was ensured.

No link could be established between the physician and the information in the death certificate (see *Questionnaires* and *Data Quality Check*).

Materials

Contact Material

Following the recommendations of Dillman [17], the first mailing was personalized (name and address of the physician), and the leading scientific institutions were clearly identified on the envelope. It contained: an invitation letter, which was signed by the heads of the leading scientific institutions involved and which also explained the importance of the study; a follow-up card for cases in which the physician who had only certified the death could fill in the name and address of the physician who had actually treated the patient until her/his death; a color-printed questionnaire; and a prepaid envelope for returning the questionnaire or card. A leaflet was also provided, which presented the survey and a flyer describing how the anonymity of respondents was ensured. For anonymity purposes, the completed questionnaire was placed in a sealed envelope inside the prepaid envelope (as for absentee postal voting).

The survey was also advertised by the main French medical bodies/authorities and by regional health agencies before and during data collection, as well as in a press release issued just before the survey went out to the field.

Questionnaires

The questionnaire was 20 pages long in A5 booklet form, with only closed questions and no space for writing any comments, as required by the French data protection committee (CNIL). The questionnaire of around 100 questions comprised the following sections: characteristics of the responding physician; characteristics of the deceased person; place of death; treatments (palliative care, sedation, etc); information related to the 2005 law (health-care proxy/surrogate, living will or advanced medical directives, discussion of last medical decision with patient or surrogate, and discussion with colleagues/collegiality of discussion); medical end-of-life decisions; wish of the deceased person to hasten death and/or euthanasia; medical practitioners or nursing staff involved in the end-of-life period; and visits of family/friends [30].

Although the age and sex of the deceased person, region of death, and month of death were identified on the death certificate and sent to the physician to identify the death, we asked for some of this information in the questionnaire because, in order to preserve anonymity, questionnaires were not merged with death certificates.

The questionnaires used in the phone-call campaign and in the nonresponse survey (which was also administered by phone) were shorter than the main questionnaire. Although these questionnaires focused on the motives for nonresponse, they also included several questions identical to those in the main questionnaire, for describing the physicians' characteristics.

Data Collection

Identification of the Certifying Physician

Names of physicians and their professional addresses were identified by their signatures and stamps on the death certificates and entered manually. In ambiguous or unreadable cases, names and addresses were requested from the mayor's office that recorded the certificates. The names and addresses of each physician were checked manually using the Internet and the administrative register of all physicians in France. The result of this preliminary phase is presented in Table 1.

Table 1. Identification of physicians/death certificates.[a]

Sample	n or %
Initial sample of death certificates (1)	14,999
Death certificates with directly identified physician (2)	11,412
Death certificates with unidentified physician, sent to mayor's offices (3)	3587
Physician identified by the mayor's offices (4)	2828
Impossible to identify the physician (5.1)	759
Certificate disregarded due to the cut-off of 4 certificates per physician, except in cases of heads of department (5.2)	160
Final sample, death certificates (6)=(2)+(4)−(5.2)	14,080
Number of physicians	11,828
Proportion of unused death certificates (10)=[(5.1)+(5.2)]/(1)	6.12
Proportion of used death certificates (11)=(6)/(1)	93.87

[a] The figures in parentheses are useful to compute % in this table.

Eligibility of the Physician

The major reasons for not including a physician in the study were the inability to find a professional workplace address or a late reply from the mayor's office (a cut-off point was set for the end of May, and we discarded late returns from the Mayor's office). To reduce refusal due to workload, we set a limit of four questionnaires per physician. An exception was made for department heads in institutions, because we discovered during the pilot survey that some heads of departments signed the certificate for most, if not all, deaths that occurred in their department (often treated by another physician). Thus, we anticipated that department heads would distribute questionnaires to corresponding treating physicians.

Fieldwork Stages

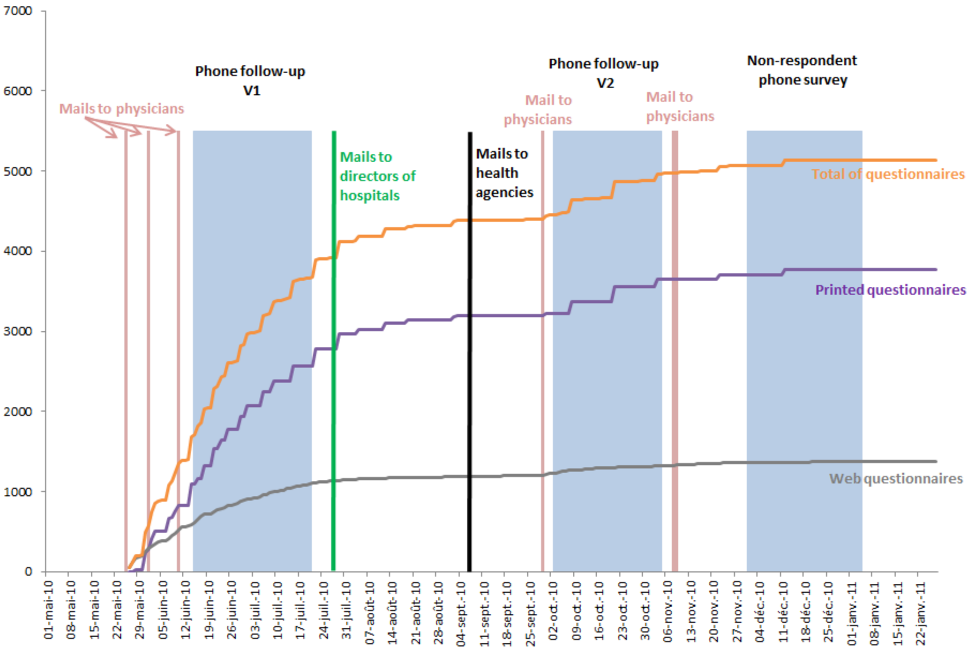
Data collection comprised three stages. The first stage was a postal phase. The initial mailing, including the questionnaire, was sent on 2010 May 25. A first postal reminder letter was sent to the nonrespondents two weeks later. Two weeks after that reminder, a third mailing was sent with the same material as the first one, but with adapted text. We avoided sending letters during the summer holiday period. A fourth and last reminder was sent to nonrespondents in September. The entire procedure was enhanced in three ways. First, there was a press release issued just before the survey. Second, we sent a letter in July to all directors of hospitals with at least one physician who had been selected for our sample, to ask him/her to convince their physicians to participate. Third, regional health agencies sent a similar motivational letter to institutions during the second half of August, asking them to communicate with physicians about the study and requesting that they pay attention to it and participate if they had been selected.

The second stage of data collection began on 17 Jun 2010 with a telephone campaign. At that time, there were 10,677 nonrespondent physicians, and a telephone number was known for 10,582 of them. The aim was to personally contact 7,000 of these physicians by phone to convince them to participate or, if they declared that they did not want to participate in the survey, to report their motives for refusal (for financial reasons, we could not contact all physicians). For this purpose, a sample of 9210 nonrespondents was drawn from among the 10,677 nonrespondents at the beginning of the telephone campaign (86.26%). This sample comprised all physicians who had signed at least two death certificates (n=1565), and others who were included randomly. Each number was to be contacted up to 16 times before being abandoned (globally, the mean number of contact attempts was 4.8). This number of call attempts was chosen based on efficiency and budgetary considerations. In parallel, a third letter, similar to the second one, was sent to 95 nonrespondent physicians whose phone number was unknown. This stage took place in two phases: 17 June-21 July, and 4 October-5 November.

The third stage was a telephone survey of 1080 final nonrespondent physicians. It began on 7 December 2010 and ended on 7 January 2011. Each phone number was to be contacted up to 20 times before being abandoned. The goal of this survey was only to collect the motives for nonresponse, along with basic characteristics of the physicians (age group, sex, and specialty). To obtain an accurate measure of these, we set a high number of call attempts because we anticipated that these physicians would be very hard to contact (Figure 1 shows the data collection modes).

During all fieldwork, a hotline (8 am-8 pm) was offered to provide information about the survey and to resend materials to physicians in case of loss.

Figure 1. Schedule of data collection fieldwork and number of questionnaires by data collection mode.



Data Quality Check

We checked that the month of death reported by physicians in the questionnaire was December 2009, to be sure that the deaths they were reporting on were those selected in the sample and not arbitrary ones (such as the most recent or a more interesting case). Previous end-of-life decision surveys in other countries did not take this precaution.

Weighting

The final respondent sample was weighted using a calibration procedure [31], considering age × sex, and region and place of death, as observed in the initial sample of deaths.

Ethical Considerations

This survey was approved by the *Comité Consultatif sur le Traitement de l'Information en matière de Recherche dans le* *domaine de la Santé* (CCTIRS) in January 2010 and authorized by CNIL (authorization number 1410166).

Statistical Analysis

Samples were described using percentages and bivariate analyses with Pearson chi-square tests. Three multivariate logistic models (providing adjusted odds ratios and 95% confidence intervals) were also computed when comparing Web-based and paper questionnaires. These models tested whether the choice of Web-based questionnaires was linked to physician characteristics (Model 1), death characteristics (Model 2), or both sets of characteristics (Model 3). All statistics were computed using SAS V9.3 and were nonweighted unless specified.

Results

Preliminary Identification of Death Certificates, Physicians, and Participation Rate

Overall, 14,080 death certificates (93.87% of the initial sample of deaths) with identified physicians were available for the survey, corresponding to 11,828 different physicians (Table 1). The final sample was reduced to 13,460 deaths because of postal address problems (changes in professional location, etc). From this sample, 5217 questionnaires were completed and returned. This led to a participation rate of 40.02% [32].

We used the standard Response Rate 2 from the American Association for Public Opinion Research (AAPOR). The formula used was 5217 questionnaires/(5217 questionnaires + 1506 refusals + 449 letters not delivered + 561 physicians who could not respond because the survey did not concern them [sudden death, not the physician in charge of the patient, could not remember the case or could not find the file] + 49 other reasons for nonresponse [eg, death of respondent, retirement, not available during data collection] + E[6287 neither responding nor refusing]) = 40.02%. E is the estimation of the proportion of eligible cases (in this case, 92.10%). E was determined by the ratio of the sum of questionnaires + refusals + others, to the sum of questionnaires + refusals + others + non-eligible persons. We counted as non-eligible those who mentioned in the follow-up survey that they did not respond because the survey did not concern them (not in charge of the patient, not a forensic scientist, could not remember or find the file of the person, etc).

An additional analysis of the follow-up file (not mentioned in the table) showed that the response rate varied with the patients' characteristics. It varied by age of the deceased (from 42.12% for deceased individuals aged 18-39 to 35.03% for those aged 90+), place of death (from 29.15% for nursing homes to 17.17% for public places and 40.20% for public hospitals), and region of residence (from 30.76% in the Mediterranean region to 40.42% in the East). It also varied with the physicians' characteristics: participation of women was higher (43.25% vs 34.14%), and type of practice exhibited variation (from 30.92% for those working in private practice—regardless of whether they were general practitioners or specialists—to 35.67% for those in emergency services and 39.12% for those working in other services at a public hospital).

Data Quality Check

During the data quality check, 311 questionnaires were discarded because either the reported month of death was not December (230) or the month of death was missing (81). Chi-square tests showed that these 311 questionnaires were slightly different for some medical decisions (treatment prolonging life: 35.37% vs 31.92%, *P*=.26; withdrawal from treatment: 16.10% vs 21.81%, *P*=.0041; treatment to alleviate pain: 44.37% vs 40.85%, *P*=.221; and medication to hasten death: 2.25% vs 0.74%, *P*=.004). Another 15 questionnaires could not be used because of computer problems encountered by the physicians. We thus decided to exclude all these deaths from the analysis: the final sample contained 4891 valid questionnaires.

Sample Structure

Table 2 exhibits the nonweighted sociodemographic structure of the initial sample drawn from the national death register and of the final death sample that was analyzed. This structure was close to the actual structure of all deaths in December, except for a small overrepresentation of deaths in public hospitals.

Telephone Campaign

The second stage of data collection was a telephone campaign: 6169 physicians/secretariats were contacted from the sample of 9220 nonrespondents at that time. Finally, 5421 physicians were spoken to personally and participated in the telephone campaign (Table 3).

Among these 5421, 505 (9.32%) felt the EOLF survey did not concern them (and thus the telephone campaign), 1106 (20.38%) reported that they were currently participating in the main survey, 2621 (48.35%) stated that they wanted to participate in the EOLF survey, while 1189 (21.93%) explicitly refused to participate. Of the physicians who wanted to participate, 1098 (41.89%) were not aware of the survey, 542 (20.67%) asked for the material to be sent again, and 981 (37.43%) promised to participate soon. The response rate to the telephone campaign was thus 63.21% (following the AAPOR standard Response Rate 2). Among the 1189 refusing physicians, 332 (27.92%) indicated that they never participate in surveys, 603 (50.71%) said that they were currently too busy, and 36 (3.03%) mentioned the absence of a financial incentive. In addition, 100 (8.41%) mentioned reasons related to the usefulness of such a survey, 29 (2.44%) reported that the subject was too personal and/or too sensitive, and another 25 (2.10%) reported other reasons related to the methodology of the survey. The other 20 refusing physicians did not specify their reasons (1.68%). Overall, the telephone campaign seemed to strongly improve the participation rate, as shown in Figure 1. The effects of the other mailings and follow-up interventions of the hospitals and health agencies were less clear, although they may also have contributed to the success of the phone campaign. The effects of the telephone campaigns on the Web-based questionnaires appeared modest compared to those on the paper questionnaires: the number of collected Web-based questionnaires was almost stable after the first phone follow-up.

Table 2. Sociodemographic characteristics of the sample of deaths: initial sample, selected sample, and returned questionnaires (%).

		Initial sample N=14,999		Selected sample (after removals) N=14,080		Final sample/analysis file[a] (nonweighted) N=4891		All deaths in December[b] N=47,986	
		n	%	n	%	n	%	n	%
Sex									
	Men	7598	50.66	7115	50.53	2454	50.17	24,370	50.79
	Women	7401	49.34	6965	49.47	2437	49.83	23,616	49.21
Age									
	18-49 years	775	5.17	712	5.06	290	5.88	2585	5.39
	50-69 years	2790	18.60	1105	18.34	946	19.34	9106	18.98
	70-79 years	3007	20.05	2835	20.13	980	20.04	9478	19.75
	80-89 years	5785	38.57	5439	38.63	1839	37.60	18,443	38.43
	≥90 years	2642	17.61	2512	17.84	836	17.09	8374	17.45
Place of patient death									
	Home	3426	22.84	3261	23.16	1013	20.71	12,797	26.67
	Public hospital	7415	49.44	6965	49.47	2705	55.31	23,460	48.89
	Private hospital	1334	8.89	1229	8.73	348	7.12	4015	8.37
	Nursing home	2310	15.40	2237	15.89	673	13.76	5625	11.72
	Public place	174	1.16	159	1.13	82	1.68	643	1.34
	Other	238	1.59	229	1.63	70	1.43	1446	3.01
	Missing	102	0.68		0.0		0.0		0.0
Region of death									
	Ile de France	2005	13.37	1847	13.12	629	12.85	6434	13.41
	Bassin Parisien	2679	17.86	2535	18.00	919	18.79	8777	18.28
	Nord	1022	6.81	935	6.64	326	6.67	3204	6.68
	Est	1337	8.91	1274	9.05	500	10.23	4178	8.70
	Ouest	2273	15.15	2144	15.23	767	15.68	7132	14.87
	Sud-Ouest	1900	11.75	1786	12.68	561	11.48	5977	12.46
	Centre-Est	1763	11.75	1657	11.77	633	12.93	5547	11.56
	Méditerranée	2020	13.47	1902	13.51	555	11.36	6737	14.04

[a] As reported on the questionnaire by the physician.

[b] Based on all coded death certificate data from December.

Table 3. Results of the telephone campaign and motives for nonresponse.[a]

Results			N	%
Contact achieved			6169	66.91
	Physician personally contacted and participated in the telephone campaign		5421	58.80
	Phone call blocked by the secretariat		296	3.21
	Contact made but physician not reachable		452	4.90
No contact achieved			3051	33.09
Personally contacted physicians who participated in the telephone campaign			5421	100.00
	Explicitly refused to participate in the main survey		1189	21.93
	Did not concern them[b]		505	9.32
	Participation in the main survey was in progress		1106	20.38
		Already sent the questionnaire	506	9.33
		Transferred the material to the right physician	600	11.07
	Wanted to participate in the main survey		2621	48.35
		Was not aware of the survey	1098	20.25
		Asked for the material to be sent again	542	10.00
		Promised to participate soon	981	18.10
Motives for explicit refusals to participate in the main survey (multiple responses)			1189	100.00
	Lack of time		603	50.71
	Never participate in surveys		332	27.92
	Too many surveys		90	7.57
	Absence of financial incentive		36	3.03
	Questionnaire too long		49	4.12
	Reason related to survey usefulness		100	8.41
	Reason related to survey topic		29	2.44
	Reason related to survey methodology		25	2.10
	Not specified		20	1.68

[a] Initial nonresponse sample (N) = 9220.

[b] Forensic scientists are the certifying physician in cases of violent or suspicious deaths.

Survey of Nonrespondents

The survey of the final nonrespondents, conducted by phone from December 2010 to January 2011 (the third stage of data collection), used a random sample of 1080 physicians with valid phone numbers who did not express explicit refusals but also did not respond during fieldwork. Contact was made in 957 cases, and 684 physicians could be contacted personally (Table 4). Finally, 547 physicians agreed to participate in the nonrespondent survey (79.97% of all personally contacted physicians); 38 reported that they had already participated in the main survey and 52 said that they would still participate, leading to a response rate of 63.74% (as above, this rate is computed following the AAPOR standard Response Rate 2).

Among respondents, the most frequent motive for nonresponse to the main survey was lack of time (53.02%). However, some survey-specific motives were frequently reported: it was impossible to remember the deceased person, or it was too difficult to find the medical file (14.26% and 9.69%). Almost 6% (5.85%) of the physicians reported having been unaware of the survey, indicating difficulties in contacting them personally.

Table 4. Results of the telephone nonrespondent survey (third stage) and motives for nonresponse (N=1080).

Result			N	%
No answer obtained			123	11.39
	Always get the answering machine		18	1.67
	No answer after 20 call-backs		38	3.52
	Number not valid		46	4.26
	Other reasons		21	1.94
Answer obtained			957	88.61
	Physician personally contacted		684	63.33
		Participation in the nonrespondent survey[a]	547	50.65
		Refusal to participate in the nonrespondent survey	47	4.35
		Already answered the main survey	38	3.52
		Not aware, will participate in the main survey	52	4.81
	Refusal from secretariat		108	10.0
	Refusal from the physician		36	3.33
	Impossible, not eligible		129	11.94
Motives for nonresponse (multiple responses) [b]			547	
	Lack of time		290	53.02
	Does not remember the case		78	14.26
	Was not in charge of the deceased person		64	11.7
	Forgot to answer/lost the questionnaire		53	9.69
	Too difficult to find the medical file		53	9.69
	Unaware of the survey		32	5.85
	Questionnaire too long		28	5.12
	Reason related to the survey topic		6	1.10
	Reason related to the survey methodology		7	1.28

[a] A total of 78 physicians who answered the nonresponse survey mentioned that they had already answered the main survey or that they would do so.

[b] The percentages do not add to 100 because this was a multiple-response question.

Differences Between Internet and Paper Responses

Overall, 73.21% of the questionnaires (n=3557) were on paper while 26.78% (n=1334) were collected through the secure Web-based questionnaire. As shown in Table 5, physicians who chose the Internet were more often male, younger, and working in large towns or institutions. Compared to general practitioners (GPs) in private practice, almost all specialists were more likely to choose the Internet, especially anesthesiologists and GPs in hospitals (but not oncologists or cardiologists). Causes of death were not exactly similar in both modes (*P*=.033): cancer was more frequent for the paper questionnaire (28.45% vs 25.19%, *P*=.019) and infectious diseases more frequent for the Web-based questionnaire (8.80% vs 6.28%, *P*=.003). Medical decisions were similarly distributed in the two samples (*P*=.114), although medications to hasten death were more frequent for the paper questionnaire (0.96% vs 0.33%, *P*=.036, crude odds ratio [OR] 0.35, 95% CI 0.13-0.96).

To test whether these bivariate differences could be explained by patient or physician characteristics, we ran three logistic models. Controlling for physician characteristics, Model 1 shows that physician differences between the Web-based and paper questionnaires remained, and that reporting “no decision” was more frequent for Web-based questionnaires (OR 1.44, 95% CI 1.08-1.71).

Table 5. Comparison of questionnaires completed on the Internet versus on paper: percentages, adjusted odds ratios (OR), and 95% confidence intervals (95% CI).

Characteristics		Internet sample n[a]=1334	Paper sample n[a]=3557		Physician characteristic (Model 1)		Patients characteristic (Model 2)		Physician and patient characteristics (Model 3)	
		%	%	*P* [b]	OR	95% CI	OR	95% CI	OR	95% CI
Physician gender				.001						
	Men	73.45	65.27		1		1			
	Women[c]	26.55	34.73		0.61	0.52-0.72			0.60	0.51-0.70
Physician age				.001						
	18-39 years old	29.20	21.40		1				1	
	40-49	32.16	28.23		0.87	0.72-1.04			0.86	0.72-1.04
	50-59	27.96	35.81		0.56	0.46-0.68			0.55	0.45-0.67
	60+	10.68	14.56		0.54	0.42-0.70			0.52	0.40-0.68
Physician medical specialty				.001						
	GPs in private practice	11.21	20.69		1				1	
	Oncologists	3.24	4.00		1.05	0.68-1.63			1.02	0.62-1.67
	Cardiologists	2.89	3.04		1.16	0.73-1.84			1.15	0.69-1.91
	Geriatrists in hospitals	6.57	7.56		1.54	1.10-2.16			1.51	1.04-2.17
	Geriatrists elsewhere	10.92	11.91		1.44	1.05-1.96			1.42	0.99-2.04
	Emergency physicians	17.78	13.54		1.55	1.14-2.11			1.41	1.02-1.95
	Anesthesiologists	18.72	9.25		2.39	1.76-3.25			2.18	1.50-3.16
	Other specialist in hospital	3.74	3.80		1.29	0.86-1.94			1.24	0.79-1.94
	Other specialist outside hospital	11.87	12.50		1.20	0.89-1.64			1.18	0.82-1.71
	Other GPs	7.36	8.32		1.46	1.07-2.01			1.44	1.03-2.02
	GPs in hospitals	5.71	5.40		1.75	1.21-2.54			1.69	1.12-2.57
Physician town size				.001						
	>200,000	25.59	15.26		1				1	
	<10,000	17.90	30.19		0.58	0.45-0.75			0.59	0.45-0.76
	10,000-20,000	11.02	12.44		0.84	0.66-1.07			0.81	0.63-1.05
	20,000-100,000	32.66	32.64		0.62	0.51-0.75			0.61	0.50-0.74
	100,000-200,000	12.83	9.47		0.50	0.39-0.63			0.49	0.39-0.63
Death certificates (3 months)				.001						
	0	3.42	6.15		1				1	
	1-2	18.40	22.01		1.26	0.87-1.83			1.28	0.88-1.85
	3-4	27.96	28.53		1.29	0.87-1.92			1.34	0.90-2.00
	5-9	27.91	25.66		1.27	0.81-1.98			1.27	0.81-2.01
	10-19	15.73	12.60		1.23	0.85-1.78			1.27	0.88-1.85
	20+	6.57	5.06		1.19	0.81-1.73			1.20	0.82-1.76

Characteristics		Internet sample n[a]=1334	Paper sample n[a]=3557		Physician characteristic (Model 1)		Patients characteristic (Model 2)		Physician and patient characteristics (Model 3)	
		%	%	P [b]	OR	95% CI	OR	95% CI	OR	95% CI
Physician medical decision				.0242						
	Sudden death	17.53	16.68		1		1		1	
	Life-prolonging treatment	12.62	12.04		1.05	0.80-1.36	0.90	0.69-1.16	1.02	0.77-1.35
	Treatment withheld	13.12	15.10		1.02	0.79-1.32	0.88	0.68-1.14	1.05	0.80-1.39
	Treatment withdrawn	4.94	3.96		1.15	0.80-1.67	1.17	0.82-1.67	1.18	0.81-1.73
	Intensity of pain alleviation	27.46	28.31		1.11	0.88-1.40	0.97	0.77-1.22	1.13	0.88-1.47
	Medication to hasten death	0.33	0.96		0.44	0.15-1.28	0.35	0.12-0.99	0.43	0.15-1.27
	None of the above	24.00	22.95		1.44	1.08-1.71	1.09	0.87-1.36	1.39	1.09-1.78
Patient gender				.134						
	Men	52.43	50.01				1		1	
	Women	47.57	49.99				1.00	0.87-1.15	1.03	0.89-1.19
Patient age				.001						
	18-49	5.43	5.06				1		1	
	50-69	21.93	17.43				1.21	0.86-1.15	1.23	0.87-1.75
	70-79	21.86	19.24				1.08	0.77-1.52	1.19	0.84-1.70
	80-89	37.00	39.22				0.86	0.62-1.19	1.06	0.75-1.50
	90+	13.78	19.05				0.67	0.46-0.96	0.90	0.61-1.33
Place of death				.001						
	Hospital	64.10	56.52				1		1	
	Home	21.07	24.00				0.76	0.64-0.92	1.04	0.81-1.36
	Nursing/retirement home	12.03	16.69				0.73	0.58-0.90	1.02	0.78-1.32
	Other	2.80	2.79				0.87	0.56-1.32	1.20	0.75-1.91
Cause of patient death				.033						
	Cancer	25.19	28.45	.019			1		1	
	Cardiovascular disease	24.49	24.32	.900			1.41	1.14-1.74	1.11	0.88-1.39
	Neurological disease	13.91	14.90	.362			1.31	1.04-1.65	1.08	0.84-1.38
	Infectious disease	8.80	6.28	.003			1.78	1.35-2.34	1.32	0.98-1.77
	Respiratory disease	6.76	6.52	.729			1.39	1.04-1.86	1.12	0.82-1.53
	Digestive disease	5.00	4.03	.113			1.42	1.00-2.00	1.18	0.82-1.71
	Mental health	3.01	3.12	.819			1.46	0.96-2.22	1.35	0.87-2.09
	Violent death	3.07	3.59	.417			1.03	0.67-1.58	0.80	0.51-1.27
	Other	9.77	8.78	.300			1.56	1.19-2.06	1.35	0.87-2.09

Controlling for patient characteristics, Model 2 shows that deaths of people aged 90 and over were less often reported using the Web-based questionnaire, as were deaths outside the hospital. Furthermore, compared to cancer, most other causes of death (except violent or sudden death) were reported more often in the Web-based questionnaire. The administration of medication to hasten death was reported less in the Web-based questionnaire (OR 0.35, 95% CI 0.12-0.99).

When both physician and patient characteristics were controlled (Model 3), only physician characteristics were significantly associated with response mode. Regarding end-of-life decisions, reporting "no decision" was more prevalent for the Web-based questionnaire (OR 1.39, 95% CI 1.09-1.78), as in Model 1.

In all three models, medication to hasten death tended to be reported less through the Web-based questionnaire (although, significantly, only in two models). Thus, choosing the Web-based questionnaire was associated mainly with physician characteristics, but Web-based questionnaires still presented specificities compared to paper questionnaires: reports of medications to hasten death were rarer, whereas those of "no medical decision" were more frequent.

Discussion

Principal Findings

This is the first mixed-mode survey on end-of-life medical decisions. It followed most of the methodological recommendations in the literature for improving response rates [17-19]. Phone calls and postal reminders had a strong impact on participation (Figure 1), and all of these efforts contributed to a robust sample of respondents, despite a modest response rate (40.02%).

Female physicians were more likely to respond than males, as were physicians working in hospitals compared to those in private practice, while paper questionnaires were favored over Web-based questionnaires. Nevertheless, Web-based questionnaires were favored by physicians with certain characteristics: males, specialists, those who were younger, those working in neurology, emergency, and geriatrics, and those in large towns and institutions. Reports of medication to hasten death were also rarer for Web-based questionnaires (0.33% vs 0.96%), while the multivariate results suggested that there might have been fewer reports of illegal decisions through Web-based questionnaires, even when adjusting for physician characteristics.

The following paragraphs focus on the interpretation of these results and provide comments on the efficacy and drawbacks of our survey protocol.

Mixed-Mode Methodology

As our mixed-mode protocol used only self-administered questionnaires, the effect of the data collection mode on results may have been limited. In the case in which the selection of the data collection mode is controlled, data quality may be slightly higher by Internet [33] due to higher internal consistency. We wondered if this was the case and concluded first that the paper questionnaire was favored over the Web-based questionnaire, as found in previous studies in Australia, the United States, and Canada [21,22,34]. Secondly, the fact that some types of physicians favored the Web-based questionnaire was in line with the literature about mixed-mode surveys in the general population (young males living in large cities are more likely to respond by Internet); however, others were specific to the working conditions of the physicians (working in an institution instead of private practice), while others merit further investigation, such as medical specialty (neurology and emergency). Multivariate regressions showed that answering on the Internet was mainly associated with physicians' characteristics, but Web-based questionnaires still presented some specificities: medication to hasten death was more rarely reported and the absence of a medical decision was more frequently reported. Thus, Web-based responses seem to concern less problematic (controversial or illegal) decisions. The choice of the Internet may reflect a selection effect related to the medical practice and typical type of medical decision made by the physician or a deliberate choice of the Internet for less problematic deaths. On the other hand, it may be a true data collection mode effect; for example, a physician who responds on the Internet may be more reluctant to declare controversial or illegal decisions, regardless of the type of death or medical decision. With the absence of randomization and nonresponse, disentangling the two is impossible. Because of the specificity of the respondents and the topics covered in the most sensitive questions, we cannot determine the direction and magnitude of the bias that occurred for each data collection.

We also noticed that the effects of the follow-up interventions (phone calls and postal reminders) were lower for Web-based questionnaires than for postal questionnaires. This is also in line with the literature on Web-based surveys, which shows that if people do not participate immediately, they tend to feel less concerned about a survey within a short time after they have been contacted. It may also be due to the absence of any email reminders.

According to Scott et al [35], using a simultaneous mixed mode may not be the most efficient protocol for surveying physicians: it is better than using only a Web-based survey, but it is costlier. Furthermore, it provides no further benefits than using a sequential mixed-mode that begins on the Internet. Unfortunately, the opposite sequence was not compared. It is likely that the mixed-mode increased the participation rate compared to either a Web-based or paper only survey, but we cannot measure to what extent. In our protocol, the reduction in costs was not substantial compared to a pure paper survey, because all contacts were made by post and only a small number chose to answer by the Internet.

Identification of the Deceased Person

We found that 311 questionnaires were related to a different month of death than the one expected. The reasons for this may be: (1) physicians reported on the month they participated in the survey rather than the month the person died; (2) they did not understand or see that the questions were about a specific case; (3) they did not have access to the person's file but still wanted to participate, so they chose another case; (4) they wanted to respond about a specific case that—from their point of view—was more interesting. The significant differences between retained and discarded questionnaires suggest that, in some cases, these physicians may indeed have purposely chosen what they believed to be a "more interesting case."

Comparison With Other Studies

The methodology of our survey was similar to the one applied by earlier nationwide epidemiological postal surveys in Europe [4,25]; however, it used a mixed-mode strategy with telephone call backs and postal reminders from different medical authorities. The trusted party was not allowed or able to link the characteristics of the deceased to the questionnaire sent by the physician, but we showed that asking for some characteristics of the deceased person allowed us to check for possible errors in their identity, which contrasts with previous Belgian surveys [8,36]. We did not use a lawyer as a third party: a preliminary discussion in France concluded that this choice would cause physicians to be reluctant and thus undermine the confidentiality and anonymity that we sought. The use of a specialized hospital department was well received (did not provoke any comment).

Our response rate was modest but comparable to what has been commonly found in other surveys among physicians in France [37]. Furthermore, we attained almost twice the response rate that was recently reported in a representative survey of all practitioners in Australia [35]. However, ours was lower than those of previous surveys of the same topic in other countries [4,8,36]. One reason for this low rate may be the fact that a large proportion of the physicians felt unconcerned, because they thought the deaths they were in charge of were rather ordinary (sudden death or death without any particular end-of-life decision).

Limitations and Recommendations for Future Surveys (in France and in Other Countries)

An apparent weakness is that we did not provide any incentive to improve our response rate. Prior research has demonstrated that prepaid monetary incentives (rather than nonmonetary) were effective in promoting survey participation [38-40]. In France, monetary incentives for surveys conducted by public institutions are uncommon, as opposed to studies sponsored by the pharmaceutical industry. As a consequence, no methodological evaluation study has been published on this topic. However, the success of financial incentive is not guaranteed: in a recent national telephone survey of GPs carried out by the National Institute of Health Education and Prevention in France, many participants refused the €30 incentive (equivalent to 1.5 times the consultation fee) to participate [41], arguing that this proved the survey may have had a commercial purpose. In the context of the EOLF survey, it might have been perceived as inappropriate. Nonmonetary incentives [39,40] may also improve participation, but it is not guaranteed, as demonstrated by a randomized, controlled experiment conducted among physicians in France [37]. In EOLF, 3.03% of refusals were explicitly linked to the absence of financial incentive; even if underreported, the effect on the participation rate was most likely marginal.

The fact that 19% of the contacted physicians in the call-back phase and 4.81% of the physicians in the nonrespondent survey were not aware of the original survey suggests that a phone call is necessary to overcome postal mailing problems, and we strongly recommend it for future surveys. For the same reason, although we could not assess the performance of this procedure, we recommend implementing public campaigns and reminders by medical authorities.

For data protection purposes, we made sure that no linkage was possible. This has three important consequences. (1) Due to the anonymity process, we were unable to eliminate potential paper and Internet questionnaires related to the same deceased person (if any). Some of the physicians used the same logins and passwords for all of their questionnaires and therefore generated tedious work for reconstituting each case. (2) The weighting process of the survey had to be simple, as no detailed information merging the initial sample and the respondent sample could be used, except when using aggregated data. (3) It is impossible to compute an accurate response rate by physician characteristics, because we could not merge the information in the sampling frame to that in the contact files and questionnaires. Future surveys must take these constraints into account. Our results nevertheless show that a good option for ensuring consistency in the questionnaire is to ask for broad characteristics of the deceased instead of linking them from the death certificate.

With a clear preference for the paper questionnaire and differences in reporting some important medical decisions, it seems too early to consider only an Internet-based survey in France. As precluding the internet does not appear to be an option currently—especially among young physicians—and as the topic and respondents of surveys on end-of-life medical decisions are very specific, we recommend conducting a mixed mode survey. Nevertheless, future research is needed for defining the best protocol (simultaneous vs sequential paper and Web-based), as well as for controlling selection and measurement effects in the data collection mode.

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Authors' Contributions

SL created the first draft and participated in the survey design. SP defined the survey design, analyzed the data, and made critical revisions to the manuscript. NB defined the pilot survey design. AS participated in the survey management and computed statistics. JB and JC made critical revisions to the manuscript. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

AAPOR: American Association for Public Opinion Research
CCTIRS: Comité Consultatif sur le Traitement de l’Information en matière de Recherche dans le domaine de la Santé
EOLF: End of Life in France
GP: general practitioners
INED: Institut National d’Études Démographiques
INSERM: de l’Institut National de la Santé et de la Recherche Médicale
OR: odds ratio

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Original Paper

Large Controlled Observational Study on Remote Monitoring of Pacemakers and Implantable Cardiac Defibrillators: A Clinical, Economic, and Organizational Evaluation

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Abstract

Background: Patients with implantable devices such as pacemakers (PMs) and implantable cardiac defibrillators (ICDs) should be followed up every 3–12 months, which traditionally required in-clinic visits. Innovative devices allow data transmission and technical or medical alerts to be sent from the patient's home to the physician (remote monitoring). A number of studies have shown its effectiveness in timely detection and management of both clinical and technical events, and endorsed its adoption. Unfortunately, in daily practice, remote monitoring has been implemented in uncoordinated and rather fragmented ways, calling for a more strategic approach.

Objective: The objective of the study was to analyze the impact of remote monitoring for PM and ICD in a “real world” context compared with in-clinic follow-up. The evaluation focuses on how this service is carried out by Local Health Authorities, the impact on the cardiology unit and the health system, and organizational features promoting or hindering its effectiveness and efficiency.

Methods: A multi-center, multi-vendor, controlled, observational, prospective study was conducted to analyze the impact of remote monitoring implementation. A total of 2101 patients were enrolled in the study: 1871 patients were followed through remote monitoring of PM/ICD (I-group) and 230 through in-clinic visits (U-group). The follow-up period was 12 months.

Results: In-clinic device follow-ups and cardiac visits were significantly lower in the I-group compared with the U-group, respectively: PM, I-group = 0.43, U-group = 1.07, *P*<.001; ICD, I-group = 0.98, U-group = 2.14, *P*<.001. PM, I-group = 0.37, U-group = 0.85, *P*<.001; ICD, I-group = 1.58, U-group = 1.69, *P*=.01. Hospitalizations for any cause were significantly lower in the I-group for PM patients only (I-group = 0.37, U-group = 0.50, *P*=.005). There were no significant differences regarding use of the emergency department for both PM and ICD patients. In the I-group, 0.30 (PM) and 0.37 (ICD) real clinical events per patient per year were detected within a mean (SD) time of 1.18 (2.08) days. Mean time spent by physicians to treat a patient was lower in the I-group compared to the U-group (-4.1 minutes PM; -13.7 minutes ICD). Organizational analysis showed that remote monitoring implementation was rather haphazard and fragmented. From a health care system perspective, the economic analysis showed statistically significant gains (*P*<.001) for the I-group using PM.

Conclusions: This study contributes to build solid evidence regarding the usefulness of RM in detecting and managing clinical and technical events with limited use of manpower and other health care resources. To fully gain the benefits of RM of PM/ICD, it is vital that organizational processes be streamlined and standardized within an overarching strategy.

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KEYWORDS

healthcare economics and organization; telehealth and telemonitoring; implantable cardiac defibrillator; cardiac pacemaker

Introduction

Patients with implantable devices such as pacemakers (PM) and implantable cardiac defibrillators (ICD) should be followed up every 3–12 months, which traditionally required in-clinic visits. Innovative devices allow data transmission and technical or medical alerts to be sent from the patient's home to the physician. This is known as remote monitoring (RM). Recent studies have shown the clinical benefits of remote monitoring of cardiac implantable electronic devices (CIEDs) [1-9]. As a consequence, a number of scientific societies [10,11] have integrated the RM of CIED within their guidelines. However, the adoption of RM of CIED by several European health care services is still somewhat patchy [12,13]. Hurdles must be overcome before large scale RM can become routine [13,14]. Above all, scaling up remote patient monitoring requires effective strategies to address clinical, technological, organizational, economic, and ethical dimensions. Within the framework of the European RENEWING HEALTH project [15], an observational, prospective study, unfunded by device vendors, was implemented. The study adopted a rigorous assessment approach (model for assessment of telemedicine, MAST) [16], as an overall framework.

Methods

Study Objectives

The study analyzed the effectiveness and efficiency of RM for pacemakers (PM) and implantable cardiac defibrillators (ICD) in a “real world” context compared with in-clinic follow-up. The following outcomes were considered: specialist visits (in-clinic PM/ICD follow-ups, cardiology visits), hospital admissions for any cause, accesses to the emergency department, timeliness of detection of acute episodes recorded by the device, workload, and direct costs.

Study Protocol

This study is a multi-center, multi-vendor, controlled, observational, prospective study. Patients were enrolled by six cardiology departments located within six different local health authorities (LHAs). Currently, each cardiology unit follows more than 1900 patients with an implanted device. We assumed both cardiology units and communities, which reside within different LHAs, but belong to the same northern Italian region (Veneto), to be similar.

There were five LHAs that assigned patients to the I-group and followed them up with a RM system. These patients were enrolled during in-clinic follow-up, either after device implantation or directly invited to participate in the study. In the I-group, patients with a PM were not monitored through in-clinic follow-ups, unless necessary from a clinical or technological point of view. Patients with an ICD were offered at least one in-clinic follow-up. A sixth LHA registered consecutive patients as a control group (U-group) during routine follow-ups. This LHA had no experience with CIED RM. U-group patients were followed up through regularly scheduled in-clinic visits. Follow-ups were performed every 12 months for PM and every 6 months for ICD, and any variation in visits’ frequency was related to CIED functioning.

Inclusion criteria were: patients with implanted PM and ICD devices; patients who had given written consent to participate in the study; age > 18; not pregnant; and absence of comorbidities with a life expectancy < 12 months. Both patient groups were followed up for 12 months. Local Ethics Committees have approved the study protocol in accordance with the Declaration of Helsinki.

Remote Monitoring Service

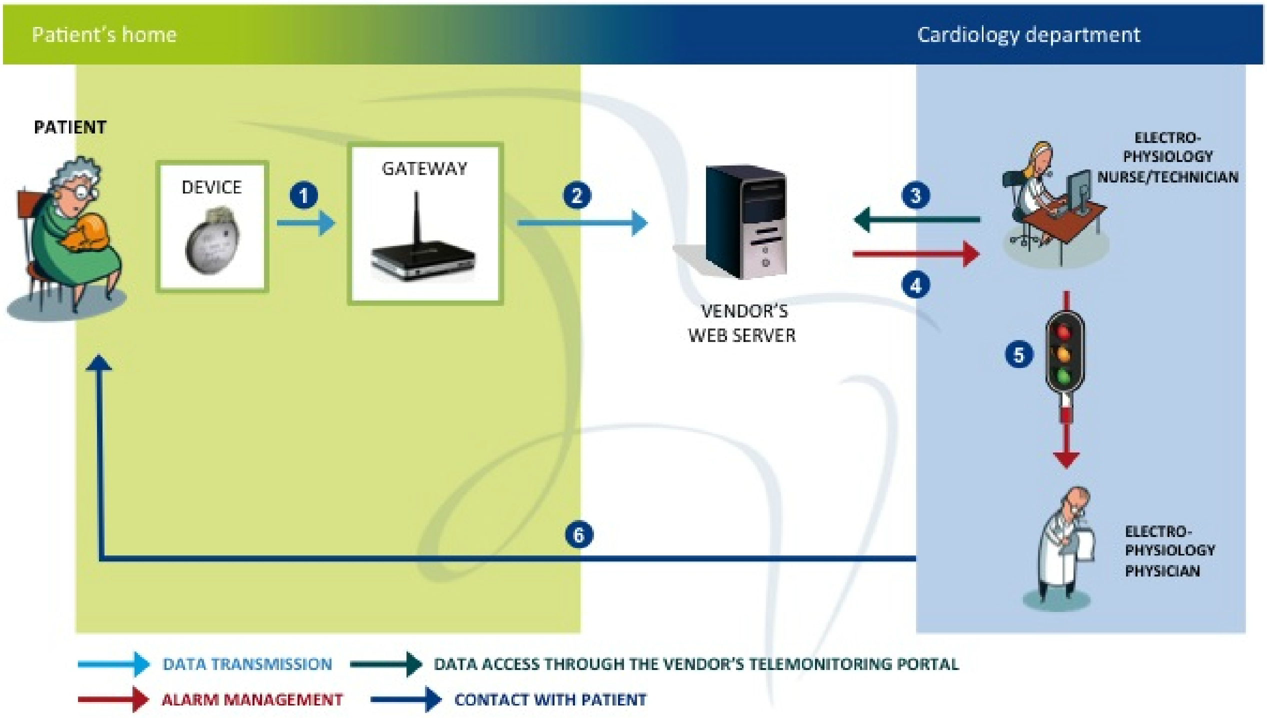
RM systems included both wireless RM (WRM) and manual RM devices. WRM devices enable the automatic transmissions of daily or weekly alerts, whereas manual RM devices require that patients manually interrogate the PM/ICD with the handle of the gateway. Centers involved in the study used a similar organizational model to provide telemedicine services. Figure 1 shows the workflow for managing RM of PM/ICD patients.

The process consists of the following six steps:

1. PMs and ICDs periodically relay remote programmed transmissions (RPTs), and daily or weekly transmit serious recorded events to a home gateway;
2. The gateway automatically sends data to the vendor’s Web server;
3. The nurse checks RPTs’ data daily during regular working time, accessing them through the different vendors’ Web-portals;
4. In case of an alert, the nurse receives a notification via email, fax, or short message service, and, still during regular working time, reviews data;
5. In case of a serious event, the nurse submits data to the physician. The physician evaluates data, and decides if the patient needs a specialist visit, in-clinic device follow-up, therapy modification, or other actions; and
6. When appropriate, the nurse contacts the patient to offer recommendations and care instructions.

All involved nurses and physicians had specific competence in cardiac electrophysiology and electro-stimulation. They were also exposed to a specific training offered by vendors’ specialists regarding the use of RM technology and portals. The training consisted of a face-to-face session lasting one hour. RM systems [17] were supplied by one of the five following Companies: (1) HM of Biotronik Gmbh, Berlin, German; (2) CareLink Network by Medtronic Inc, Minneapolis, MN, USA; (3) Latitude Patient Management System by Boston Scientific, St Paul, MN, USA; (4) Merlin.Net system by St Jude Medical, Sylmar, CA, USA; and (5) SmartView system by Sorin Group, Italy.

Figure 1. Workflow of remote monitoring service [15].



Data Collection and Evaluation

At enrollment, patient sociodemographic and clinical data at the time of the implant were collected through a case report form (CRF). Data concerning health care services' use (exams, outpatient visits, visits to the emergency department, hospitalizations, medications supplied by hospitals and pharmacies) were extracted from the Veneto region data-warehouse. For WRM systems, data on type of event, reaction time, and clinical decisions were collected. Events generated by devices were separated into real and false positive events, for example, not useful for patients' management. Clinical events included: ventricular tachycardia, supraventricular tachycardia, thoracic impedance out of range suggesting pulmonary edema, effects of therapy delivered by the device, and others. Technical events consisted of: low battery, malfunctioning of leads (sensing, threshold, impedance and disabling of auto-capture), low percentage of left ventricular pacing, high percentage of right ventricular pacing, inappropriate shock, and others. Events related to flawed communication between device and vendors' servers were also collected.

As an overall framework, this study adopted the MAST [16] model. However, due to limitations of data concerning the patient perspective, our economic analysis was limited to the health care system's perspective. Theoretically, the value of the resources to be considered is their opportunity cost, but since this is often difficult to estimate, a pragmatic approach recommends the use of market prices. Staff costs were bases on the average "total employee cost" of health professionals involved in the study, including their gross compensation, severance indemnity and Social Security allowances, and health insurance. Diagnosis related group (DRG) payment rates were used to quantify the costs of health care services delivery. Such costs are listed in the Veneto Regional Health Service Register of Tariffs, together with costs incurred by the Regional Pharmaceutical Health care system. Remote follow-ups generate extra costs related to the additional services provided by the device manufacturers and to the involvement of health care professionals who monitor patients' data. Currently, the former does not represent a marginal cost, since in Italy vendors do not require a fee for implementing RM service. This is why in our study, similarly to other recent analyses [18], the cost of the RM service was not considered. Given that remote follow-up is not covered by official reimbursement, its cost was estimated on the basis of time consumed by RM management. The vendors did not charge for the gateway and server acquisition. There were no other hardware investment costs.

Data concerning organizational aspects were collected through the following tools: semistructured interviews of clinicians, CRF of alerts, and regional data-warehouse. Total time spent caring for patients in the I-group was estimated by adding the time needed to deliver in-clinic follow-ups and to manage telemedicine services. For both groups, time spent to provide in-clinic follow-ups was collected, differentiating between nurses and physicians.

Statistical Analysis

The analysis of the cost items revealed some outliers. Therefore, the interquartile range (IQR) was used to sort the data. Costs below the lower fence (1° quartile - 1.5 IQR) and above the upper fence (3° quartile + 1.5 IQR) were considered as outliers and excluded from the analysis. Cost variables were considered normally distributed [19]. Normality of outcomes data was assessed using the Shapiro-Wilk W test. When variables were not normally distributed, groups were compared using the Mann-Whitney's U test. Differences between groups are displayed as difference of means, medians with 95% confidence intervals, and IQR. For categorical clinical outcomes, we used chi-square test of goodness of fit or the Fisher test. Differences between groups are calculated as risk ratios with 95% confidence intervals. The analysis was carried out using R software 3.0.1.

Standard data quality control tools, such as data entry controls including tolerance limits, ranges for applicable data fields, and data sequence checks, were used. Clinicians involved in the study had adequate competence and followed the study protocol. Controlled access to survey results and data-warehouse, including password protection and locking formulas, and documented processes ensuring appropriate timing and frequency of data back-up, were used.

Results

Patient Population

On the whole, 1871 (979 PM, 892 ICD) patients were enrolled in the I-group and 230 (192 PM, 38 ICD) in the U-group, from October 2011 to November 2012. There were no important differences between the two groups (Table 1). The population resembled the expected characteristics of CIED patients, being comparable to the largest and most recent Italian CIED registry [7]. There were (2.03%) 38/1871 patients allocated to the I-group that were lost to follow-up. In the PM group, loss to follow-up was (2.0%) 20/979, due to: choice of patients or relatives (7); technical difficulties in the use of RM systems (7); moving to another LHA (4); and other (2). In the ICD group, loss to follow-up was (2.0%) 18/892, due to: choice of patients or relatives (5); technical difficulties in the use of RM systems (8); moving to another LHA (2); and other (3). There was no significant difference in mortality between the I-group and the U-group PM: I-group (6.6%) 63/959 deaths, U-group (4.4%) 8/184 deaths, and *P*=.27; and ICD: I-group (5.4%) 47/874 deaths, and U-group (5%) 2/38 deaths, and *P*=.99. Patients who completed the study comprised: 896 PMs (419 with WRM function) and 827 ICDs (811 with WRM function) in the I-group, and 184 PMs and 36 ICDs in the U-group.

Clinical Evaluation

In the PM group, the mean (IQR) of hospitalizations per patient-year was 0.37 (0-0) in the I-group versus 0.50 (0-1) in the U-group (*P*=.005). The mean (IQR) of in-clinic follow-ups per patient-year was 0.43 (0-1) in the I-group versus 1.07 (1-1) in the U-group (*P*<.001). The mean (IQR) number of cardiology visits per patient-year was 0.37 (0-1) in the I-group versus 0.85 (1-1) in the U-group (*P*<.001). There were no significant differences regarding the number of visits to the emergency department in the I-group, 0.64 (0-1), compared to the U-group, 0.67 (0-1).

In the ICD group, there were significant differences in the in-clinic follow-ups and cardiology visits. The mean (IQR) number of in-clinic follow-ups per patient-year was statistically different (*P*<.001): the I-group 0.98 (0-2) versus the U-group 2.14 (2-2.25). The mean (IQR) number of cardiology visits per patient per year was also statistically significant (*P*=.01): the I-group 1.58 (0-2) versus the U-group 1.69 (1-2.25). However, there were no significant differences regarding the number of hospitalizations per patient per year between the I-group 0.60 (0-1) and the U-group 0.67 (0-1) and in the number of visits to the emergency department 0.80 (0-1) in the I-group versus the U-group 0.64 (0-1).

In the PM group, a total of 125 real clinical events (0.30 events per patient per year) were detected within a mean (SD) time of 1.18 (2.08) days. In the ICD group, a total of 300 real clinical events (0.37 events per patient per year) were found within a median (SD) time of 1.03 (1.68) days. There were 21.9% and 21.7% of patients that presented at least one real clinical event in both the PM (92 of 419) and the ICD (176 out of 811) group. Among patients, without history of atrial fibrillation (AF), enrolled at implant or within the first days after implant, the percentage of first detected episodes of AF was 17% (13 out of 75) in the PM group, and 10.7% (13 out of 122) in the ICD group.

Economic Evaluation

Tables 2 (PM) and 3 (ICD) show the mean direct costs per patient per year. Economic results are statistically significant only for the PM-group (*P*<.001).

Table 1. Baseline data.

Measurements		I-group PM	U-group PM	I-group ICD	U-group ICD
Sample size (n)		979	192	892	38
Age at enrollment (years), mean (SD)		76.93 (10.75)	77.85 (8.49)	67.45 (13.46)	66.66 (11.24)
Age at implant (years), mean (SD)		75.36 (10.78)	76.34 (8.54)	65.83 (13.28)	64.80 (11.6)
Men, n (%)		588 (60.1)	100 (52.1)	708 (79.4)	30 (79)
New implant, n (%)		700 (71.5)	153 (79.7)	573 (64.1)	30 (79)
Replacement, n (%)		279 (28.5)	39 (20.3)	320 (35.9)	8 (21)
Type of device, n (%)					
	Single-chamber	248 (25.3)	86 (44.8)	342 (38.3)	15 (40)
	Dual-chamber	679 (69.4)	103 (53.6)	193 (21.6)	7 (18)
	Biventricular	52 (5.3)	3 (1.6)	358 (40.1)	16 (42)
Implant indication, n (%)					
	Atrium-ventricular block	493 (50.3)	79 (41.1)	n/a	n/a
	Sick sinus syndrome	136 (13.9)	43 (22.4)	n/a	n/a
	Syncope	122 (12.5)	20 (10.4)	n/a	n/a
	Heart failure	39 (4.0)	2 (1.0)	n/a	n/a
	Bradicardia atrial fibrillation	121 (12.4)	40 (20.8)	n/a	n/a
	Other	13 (1.3)	6 (3.1)	n/a	n/a
	Data missed	55 (5.6)	2 (1.0)	2 (0.2)	n/a
	Primary prevention	n/a	n/a	666 (74.7)	25 (66)
	Secondary prevention	n/a	n/a	224 (25.1)	13 (34)
Ejection fraction, % (SD)		55.4 (11.0)	60 .1(9.7)	35.4 (11.5)	37.1 (11.3)
New York Heart Association class, n (%)					
	I	636 (65.0)	126 (65.6)	247 (27.6)	16 (42)
	II	258 (26.4)	55 (28.7)	431 (48.3)	16 (42)
	III	67 (6.8)	10 (5.2)	197 (22.1)	5 (13)
	IV	8 (0.8)	0 (0.0)	14 (1.6)	0 (0)
	Data missed	10 (1.0)	1 (0.5)	3 (0.4)	1 (3)
Cardiovascular disease, n (%)					
	AMI	103 (10.5)	25 (13.0)	375 (42.0)	17 (45)
	Hypertension	539 (55.1)	117 (60.9)	378 (42.3)	7 (18)
	Heart failure	91 (9.3)	16 (8.3)	350 (39.2)	14 (37)
	Ventricular arrhythmia	13 (1.3)	1 (0.5)	298 (33.4)	11 (29)
	Atrial arrhythmia	340 (34.7)	70 (36.5)	235 (26.3)	10 (26)
	Atrial fibrillation	302 (30.8)	62 (32.3)	222 (24.9)	9 (24)
	Other atrial arrhythmias	38 (3.9)	8 (4.2)	14 (1.5)	1 (3)
	Dilated cardiomyopathy	n/a	n/a	157 (17.6)	3 (8)
		n/a	n/a	29 (3.2)	1 (3)
	Brugada syndrome	n/a	n/a	14 (1.6)	0 (0)
	Arrhythmogenic right ventricular dysplasia	n/a	n/a	20 (2.2)	0 (0)
	Other cardiomyopathies	207 (21.1)	19 (9.9)	162 (18.2)	0 (0)

Measurements		I-group PM	U-group PM	I-group ICD	U-group ICD
	None	214 (21.9)	23 (12.0)	7 (0.8)	0 (0)
	Data missing	33 (3.4)	2 (1.0)	11 (1.2)	0 (0)

Table 2. Mean direct costs of care per PM patient per year (€, 2011 prices).

Type of cost			Mean direct cost per patient - PM group				Mean difference, €	Confidence interval	*P*
			U-group, €	Confidence interval	I-group, €	Confidence interval			
Investment in the telemedicine application									
	Project start up costs								
		Nurses' training	—	n/a	1.33	1.18-1.46	1.33	n/a	n/a
		Technicians' training	—	n/a	0.12	0.10-0.13	0.12	n/a	n/a
		Specialists' training	—	n/a	4.90	4.60-5.19	4.90	n/a	n/a
		Total start up costs	—		6.35		6.35		
Running costs									
	Travel								
		Cost of transportation of the patient and caregiver to the hospital for outpatient visits and procedures (borne by LHA)	1.41	-2.30 to 6.92	8.47	-0.87 to 4.10	7.06	-5.92 to 4.52	.79
	Staffing								
		Nurses' time used for patient training	—	n/a	4.51	n/a	4.51	n/a	n/a
		Nurses'/technicians' time used for RM	—	n/a	5.51	5.35-5.65	5.51	n/a	n/a
		Specialist's time used for RM	—	n/a	5.21	4.95-5.46	5.21	n/a	n/a
	Changes in the use of health care resources								
		Outpatient visits and procedures	312.80	283.95-351.20	335.09	317.33-352.86	22.29	-20.45 to 55.48	.36
		Emergency room admissions	50.08	36.49-63.66	38.19	32.97-43.39	-11.89	-26.42 to 2.63	.11
		Hospitalizations in acute hospitals	816.47	601.18-1031.75	0	n/a	-816.47	-1031.74 to -601.18	<.001
		Medications (distributed by the hospital)	—	n/a	—	n/a	—	n/a	n/a
		Medications (distributed by pharmacies)	595.07	536.41-653.73	569.09	541.44-596.74	-25.98	-90.75 to 38.78	.43
Total running costs			1775.83		966.07		-809.76		
Total costs			1775.83	1545.41-2007.28	972.42	938.15-1009.12	-803.41	-1036.32 to -569.11	<.001

Table 3. Mean direct costs of care per ICD patient per year (€, 2011 prices).

Type of cost	Mean direct cost per patient - ICD group				Mean difference, €	Confidence interval	*P*
	U-group, €	Confidence interval	I-group, €	Confidence interval			
Investment in the telemedicine application							
Project start up costs							
Nurses' training	—	n/a	1.57	1.51-1.64	1.57	n/a	n/a
Technicians' training	—	n/a	0.16	0.14-0.18	0.16	n/a	n/a
Specialists' training	—	n/a	5.54	5.32-5.75	5.54	n/a	n/a
Total investment costs	—		7.27		7.27		
Running costs							
Travel							
Cost of transportation of the patient and caregiver to the hospital for outpatient visits and procedures (borne by LHA)	0	n/a	3.16	n/a	3.16	n/a	n/a
Staffing							
Nurses' time used for patient training	—	n/a	4.51	n/a	4.51	n/a	n/a
Nurses'/technicians' time used for RM	—	n/a	8.59	8.34-8.84	8.59	n/a	n/a
Specialist's time used for RM	—	n/a	7.94	7.62-8.25	7.94	n/a	n/a
Changes in the use of health care resources							
Outpatient visits and procedures	473.88	391.99-555.76	434.30	411.25-457.33	-39.58	-124.40 to 45.23	.35
ER admissions	20.09	-0.43 to 40.60	46.96	40.14-53.78	26.87	5.35-48.39	.02
Hospitalizations in acute hospitals	866.94	155.15-1578.73	572.13	475.80-668.44	-294.81	-1012.46 to 422.83	.41
Medications (distributed by the hospital)	0.02	0.02-0.073	1.39	0.99-1.79	1.37	0.96-1.77	<.001
Medications (distributed by pharmacies)	758.26	605.01-911.52	726.86	686.50-755.22	-31.40	-194.16 to 119.35	.63
Total running costs	2119.19		1805.84		-313.35		
Total costs	2119.19	1428.01-2812.16	1813.11	1706.12-1908.35	-306.08	-1011.68 to 385.98	.37

Organizational Evaluation

The organizational analysis focused on the workflow and workload. Figures 2 and 3 show the workflow and workload for the RPT and the alert management activities, respectively.

None of the facilities involved in the study had integrated RM data with the cardiology electronic medical record (EMR), nor had they introduced a software capable to generate a single interface allowing the collection and collation of data from all providers. As a result, staff had to use different portals to access data and manually enter them into the cardiology EMR; this process represented a waste of time and contributed to generate data errors. About 48% (7.3/15.2 minutes per patient per year) of time spent by nurses was used to insert data into the health record and to communicate with the patient. An important reason behind why contacts with patients were related to gateway connecting problems (26.0%, 54/207 for PM and 14.3%, 63/439 for ICD of real events). Nurses filtered 80.0% (768/960) of true or false positive alerts. PMs’ false alert totalled 42.2% (151/358), whereas ICDs’ false alert amounted to 27.1% (163/602).

Table 4 shows the mean time (in minutes) spent by a health care professional (nurse or physician) to provide one-year follow-up to a patient in the I-group versus the U-group. The time to deliver the follow-up in the I-group is reported as the time to offer the telemedicine service only, and as the time spent to carry out RM plus in-clinic follow-up.

Table 4. Mean time (minutes) spent by physicians and nurses - usual care versus intervention.

Type of resource	Mean time U-group (min)	Mean time I-group (only telemedicine) (min)	Mean time I-group (telemedicine + in clinic follow-up performed) (min)	Difference (U-group - I-group) (min)
Physician PM	13.1	4.7	9.0	4.1
Nurse PM	18.1	11.2	18.3	-0.2
Physician ICD	32.8	7.5	19.1	13.7
Nurse ICD	44.2	19.6	36.1	8.1

Figure 2. Workflow and workload diagram for implantable cardiac defibrillator (ICD) and pacemaker (PM) remote programmed transmission (RPT).

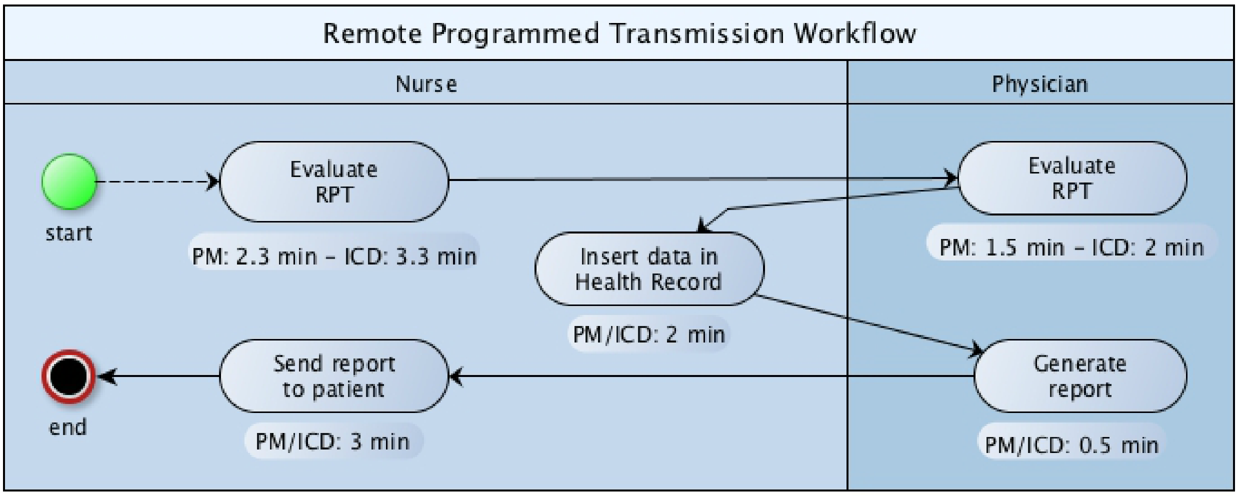
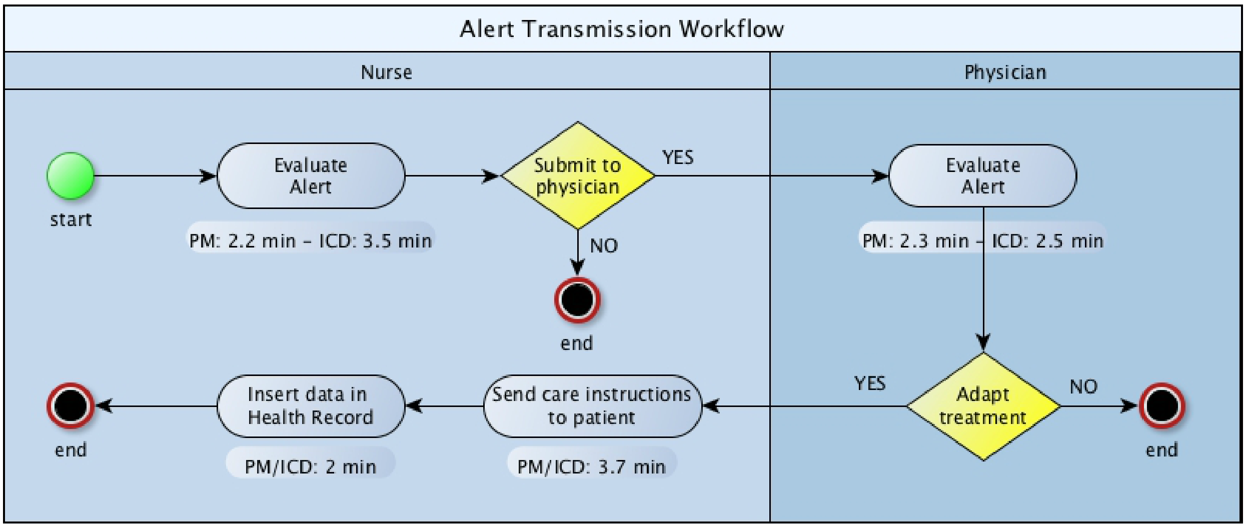


Figure 3. Workflow and workload diagram for implantable cardiac defibrillator (ICD) and pacemaker (PM) alert transmissions.



In-Clinic Follow-Up in U-Group

In the U-group, 74.8% (205/274) of in-clinic follow-ups resulted in no clinical intervention, nor device reprogramming. As expected, reprogramming during routine in-clinic follow-ups occurred less often (14.8%, 31/210) than during the first in-clinic follow-up after the device implantation (30%, 19/64).

Discussion

Principal Findings

Clinical Observations

The study clarifies some key aspects concerning the management of a RM service delivered to a population of PM/ICD patients. The introduction of CIED RM showed to be highly effective in detecting and managing clinical and technical events with remarkably limited manpower and health resource consumption. Alerts generated by devices were reviewed in a median (SD) time of 1.18 (2.08) days in the PM group, and 1.03 (1.68) days in the ICD group. The number of in-clinic CIED follow-ups was significantly lower in the I-group (-60% for PM and -54% for ICD) without compromising the patients' clinical status, with a significant reduction in hospitalizations for the PM-group only, and no significant differences in access to the emergency department for either group (PM, ICD). The significant reduction of cardiologic visits (-56% PM and -7% ICD) in the I-group was probably due to the early detection of clinical events, and the prompt adaptation of treatment by phone.

No other study on PM RM, to our knowledge, has evaluated the reduction of hospitalizations for all causes. The Compas Trial [2] observed a significant reduction in hospitalization for atrial arrhythmia and stroke, confirming the efficacy of early detection of atrial fibrillation events. For the ICD-group, the main studies [1,4] that investigated the number of hospitalizations and the frequency of access to the emergency department, or a composite endpoint including both variables, did not show any significant reduction. It would be useful to design a study with a larger ICD population with the aim to evaluate possible significant effects in hospitalization rates for patients with different heart conditions.

The reaction time was very similar to that found by previous analyses. Studies in the literature show a slightly longer time interval, because they measured time from the alert to the clinician's decision, instead of the time from the alert to the first visualization by clinicians, as in our case. The Home-Guide Registry [7] showed a mean reaction time to alerts of 3 days. The Compas Trial [2] found a substantial improvement in timeliness of response between the I-group and U-group (122 days). For ICD patients, the main results from the literature providing a comparison of reaction time between the I-group and the U-group were, respectively, as follows: 1 versus 35.5 [1]; 4.6 versus 22 [20]; 1.4 versus 24.8 [21]; and 11 versus 183 [22]. Therefore, we conclude that the use of RM of PM/ICD significantly reduces the time from the event to its assessment.

Economic Observations

Economic results also showed substantial savings from RM. The reduction of the average cost of treatment per patient in the PM I-group was € 809.76 ($P<.001$) versus € 313.35 ($P=.55$) in the ICD I-group. The cost saving for the ICD group was not significant and less than for the PM group, probably due to the short duration of the follow-up and the limited number of patients in the U-group. We might also suppose that more frequent detection of clinical and technical events in the ICD group, compared to the PM group, have contributed to the above mentioned difference in cost saving. Unfortunately, wide discrepancies between populations' health and health care systems' organization, costs, and reimbursements mean that any generalization may result as inaccurate.

Organizational Observations

This is the first study, to our knowledge, that has evaluated the overall time spent by health care providers to manage CIED patients (data reviews, patient calls, medical report generations, data entries in health record). Further, this analysis has distinguished between the workload assigned to nurses and physicians. The reduction in time spent by physicians delivering care to PM and ICD patients in the I-group compared with the U-group was apparent. The time required to review a single RPT or alert was similar [23-25], or lower [26,27] to that published by different authors. Nurses, who filtered 80.0% (768/960) of generated alerts, allowed physicians to focus on serious clinical or technical events and other relevant tasks. Confirming other studies [1,2,20,28-30], our analysis showed that the RM service could reduce in-clinic follow-ups that do not require specific interventions by clinicians.

Although all LHAs had been using RM systems for more than 3 years, RM implementation was rather haphazard and fragmented. Recently, this problem was also pointed out by two studies of the European Heart Rhythm Association [12,31] and an Italian nationwide survey [32]. Moreover, cardiology units had not designed a strategy to involve other physicians, especially general practitioners, referring cardiologists, and other specialists. In other words, there was no integrated health care delivery.

Streamlining the process of RM delivery and adjusting the technology would contribute to reduce the waste of time due to manual data entry, false alerts, and gateway connection problems. A centralized eHealth center, that manages RM of patients belonging to different LHAs, could contribute toward the improvement of follow-up, the standardization of patient care, and the optimization of health care resources' use. This eHealth center could also simplify the division of labor between clinical and administrative/technical staff. A recent study [33] testing a centralized RM model in which one monitoring center screened and filtered daily RM data in PM /ICD patients from nine satellite clinics, concluded that this model is feasible, reliable, safe, and clinically useful.

Limitations

This is an observational study that did not assign patients to the I-group and the U-group randomly. Furthermore, the U-group was rather small. We used hospitalization rates for all causes instead of atrial fibrillation, stroke, and congestive heart failure. The use of five different vendors devices might have introduced a systematic bias in the assessment of RM performance.

Conclusions

This study contributes to strengthen current evidence regarding the effectiveness and efficiency of PM and ICD RM in detecting and managing clinical and technical events through limited use of manpower and other health care resources. It also shows that RM is implemented inconsistently, because it is not supported by a solid strategy. This problem is common across national health care systems in Europe. To fully exploit the potential of RM technology, it will be necessary to formulate, implement, and monitor an overall strategy that standardizes the whole process, connects different clinicians, integrates data from different sources into an EMR, and adopts a single platform capable to manage patients monitored by different devices.

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Conflicts of Interest

None declared.

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Abbreviations

AF: atrial fibrillation
CIED: cardiac implantable cardiac electronic device
CRF: case report form
DRG: diagnosis related group
EMR: electronic medical record
ICD: implantable cardiac defibrillator
IQR: interquartile range
LHA: local health authority
MAST: model for assessment of telemedicine
PM: pacemaker
RM: remote monitoring
RPT: remote programmed transmission
WRM: wireless remote monitoring

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Original Paper

Elderly Learners and Massive Open Online Courses: A Review

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Abstract

Background: Massive open online courses (MOOCs) have become commonplace in the e-learning landscape. Thousands of elderly learners are participating in courses offered by various institutions on a multitude of platforms in many different languages. However, there is very little research into understanding elderly learners in MOOCs.

Objective: We aim to show that a considerable proportion of elderly learners are participating in MOOCs and that there is a lack of research in this area. We hope this assertion of the wide gap in research on elderly learners in MOOCs will pave the way for more research in this area.

Methods: Pre-course survey data for 10 University of Reading courses on the FutureLearn platform were analyzed to show the level of participation of elderly learners in MOOCs. Two MOOC aggregator sites (Class Central and MOOC List) were consulted to gather data on MOOC offerings that include topics relating to aging. In parallel, a selected set of MOOC platform catalogues, along with a recently published review on health and medicine-related MOOCs, were searched to find courses relating to aging. A systematic literature search was then employed to identify research articles on elderly learners in MOOCs.

Results: The 10 courses reviewed had a considerable proportion of elderly learners participating in them. For the over-66 age group, this varied from 0.5% (on the course “Managing people”) to 16.3% (on the course “Our changing climate”), while for the over-56 age group it ranged from 3.0% (on “A beginners guide to writing in English”) to 39.5% (on “Heart health”). Only six MOOCs were found to include topics related to aging: three were on the Coursera platform, two on the FutureLearn platform, and one on the Open2Study platform. Just three scholarly articles relating to MOOCs and elderly learners were retrieved from the literature search.

Conclusions: This review presents evidence to suggest that elderly learners are already participating in MOOCs. Despite this, there has been very little research into their engagement with MOOCs. Similarly, there has been little research into exploiting the scope of MOOCs for delivering topics that would be of interest to elderly learners. We believe there is potential to use MOOCs as a way of tackling the issue of loneliness among older adults by engaging them as either resource personnel or learners.

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KEYWORDS

massive open online courses; loneliness; older adults; elderly; eLearning; education; continuing education; computer-assisted instruction

Introduction

According to a United Nations Report [1], over the last 50 years the number of older people in the world has tripled, and this number will increase exponentially in the next 50 years. In 1950, the number of people aged 60 or over in the world was estimated to be 205 million, with only three countries (China, India, and the United States) having more than 10 million older people.

In 2000, the number was 606 million and 12 countries had more than 10 million people aged 60 or over. What is striking is that the rate of increase in the number of people aged 60 or over (1.9%) is significantly higher than that of the total population growth (1.2%). According to the projections, the difference between the two rates is expected to increase, and from 2025-2030 the over-60 age group will be growing 3.5 times faster than the total population.

Population Aging

Every country is encountering population aging, but each country is at a different stage of transition [2]. Developed countries in general have encountered population aging earlier than other parts of the world and currently almost 20% of the population in developed countries are 60 years old or above, as opposed to developing regions where just 8% of the population is aged 60 or above. In particular, the population aged 60 or over in Europe is projected to be around 37% by 2050, up from 20% in 2000 [1]. However, by 2050, 80% of the world’s older people are likely to be living in low- and middle-income countries [2].

Population aging presents various challenges to society such as an increasing demand for health services, an increasing need for long-term care and social services, and increasing strain on pension and social security systems. Conversely, an aging population will also make important contributions to society as family members, caregivers, volunteers, and being part of the workforce. Fostering good health in older age is a primary factor in preventing isolation and maintaining the independence and productivity of older people [2].

The decline of both mental and physical capacities is a feature of aging, often coupled with the loss of friends and family. For many people, this results in loneliness [3]. Loneliness is a concept that has been defined in a multitude of ways. Cambridge Dictionaries Online [4] interprets it as the “state of being lonely” and further describes “lonely” as being “unhappy because you are not with other people,” while Oxford Online dictionary [5] defines loneliness as “sadness because one has no friends or company.” Victor et al [6] showed that in various studies loneliness has been defined as “perceived deprivation of social contact, the lack of people available or willing to share social and emotional experiences, a state where an individual has the potential to interact with others but is not doing so and a discrepancy between the actual and desired interaction with others” (p. 408).

Aging and Isolation

In general, older people are at risk of social isolation because of diminished contact with colleagues (possibly due to retirement) and with family and relatives, especially if they are in poor health, disabled or bereaved, or because of their geographic location. According to the charity Age UK [7], there are over 1 million older people in the United Kingdom who feel lonely [8]. The increasingly complicated and busy lifestyles that characterize the contemporary world mean that finding time to visit or spend time with an elderly relative or friend may get deferred unintentionally, leaving elderly people feeling lonely and isolated. Maintaining ties with others is an important aspect of successful aging, which encompasses “the avoidance of disease and disability, the maintenance of high physical and cognitive function, and sustained engagement in social and productive activities,” p. 433 [9].

Research into Internet use and loneliness in older adults has shown promise for the use of online communication to tackle loneliness. For example, a study of 222 Australians who were over 55 years of age showed that the use of the Internet as a communication tool was associated with lower levels of social loneliness [10]. Similar findings are reported by other studies looking at computer and Internet use by older adults [11-13]. Another review [14] found that computers were most commonly used by older adults for the purposes of communication and social support, increased contact with family and friends, especially grandchildren, and dealing with geographic barriers or limited mobility, all of which help tackle loneliness. The same review also reported an increase in attention by researchers to examine the computer use by older adults.

Notess and Lorenzen-Huber [15] discuss the opportunities that e-learning offers to older adults. They identify the added benefits of online learning for older adults who are either geographically isolated or have mobility issues. They acknowledge that the potential of online learning for older adults “is far from realized.” Online communities such as the thirdAGE [16] and SeniorNet [17] are some of the sites that have been offering learning opportunities for older adults; for example, SeniorNet offers courses on literature and poetry [15]. Githens [18] categorizes e-learning programs for older adults as programs for personal growth and social change, workforce development, and workplace learning. The new wave of Massive Open Online Courses (MOOCs) offers courses that address all three of these areas.

Massive Open Online Courses

Massive open online courses or MOOCs are a recent, but immensely popular addition to the online learning landscape. They offer lectures, forums, quizzes, assignments, and various other learning materials that in general can all be accessed online. Since their emergence in 2008, there have been many commercial and non-commercial platforms dedicated to offering MOOCs, and hundreds of universities have partnered with these platforms to offer courses. The courses are free to register and participate in, thus attracting thousands of participants. The recent offering from the British Council, “Understanding IELTS: Techniques for English language test,” had over 380,000 learners registered on it [19]. With such massive numbers registering on courses, MOOCs present a plethora of challenges and opportunities that are discussed elsewhere in the literature [20,21].

Elderly Learners in Massive Open Online Courses

According to the latest edX [22] report, 10% of participants (ie, people who register for a course and have actually accessed the course material) on the edX platform are over 50 years old while 4% are over 60 years old [23]. Given that edX has over 1.03 million unique participants, the figure for participants aged over 50 is about 130,000, which is a considerable number. A total of 17% of the participants in the first 21 courses of the

FutureLearn platform [24] were 56-65 years old and another 9% were over 66 years old. Thus, the percentage of over-56 age group on the FutureLearn platform is 26% [25]. Given that FutureLearn has over 1.2 million learners (as of March 2015), the number of students over 56 years is likely to be considerable. Looking at the profile of actively engaged MOOC participants in the University of Reading's course "Begin programming: Build your first mobile game," where authors are among the educator team, and which has completed five iterations since October 2013, older adult participants reported that they were spending many hours a week on the course.

In this paper, we present demographic data from 10 courses offered by the University of Reading in various disciplines from programming to heart health on the FutureLearn platform, to show that a considerable proportion of elderly learners are participating in these free online courses. We also show that there is currently a lack of scholarly literature investigating this group of learners and their engagement with MOOCs, despite the existence of a few MOOCs that explore aging and related issues. We then argue that the engagement of elderly learners in MOOCs could be used as a way to tackle the social isolation felt by the elderly and that more research in this area should be commissioned to explore whether MOOCs could be used more widely for this purpose.

Methods

Data for this study were collected using three independent data sources: pre-course survey data for MOOCs, course details that offered subject matter relating to aging, and literature on MOOCs and elderly learners. Next we describe how the data were collected from these sources.

Pre-Course Survey

We analyzed pre-course survey data for 10 University of Reading courses offered on the FutureLearn platform to identify the proportion of elderly learners engaging in MOOCs in various disciplines. There is no easy way of identifying learners' demographic data for FutureLearn courses, despite knowing the number of learners registered in a given course. In the pre-course survey sent to all learners at the start of a FutureLearn course, there is a question that captures their age. The question "What is your age group?" is presented as a multiple choice question with the responses: 18 years old or under, 18-25 years old, 26-35 years old, 36-45 years old, 46-55 years old, 56-65 years old, and 66 years old or over. As a FutureLearn partner, the University of Reading receives anonymized data for pre-course surveys, and we have gathered these pre-course survey data for 10 course runs (some courses have more than one iteration considered) for analysis.

We analyzed pre-course survey data for the following courses:

- Obesity: Causes and consequences (Obesity) – two iterations
- Our changing climate: Past, present and future (Climate)
- Our hungry planet: Agriculture, people and food security (Hungry Planet)
- Managing people: Engaging your workforce (Managing People)
- Heart health: A beginner's guide to cardiovascular diseases (Heart)
- A beginner's guide to writing in English for university study (English) – two iterations
- Begin programming: Build your first mobile game (Programming) – two iterations

Courses on Aging

In identifying relevant MOOCs that included topics related to aging, a range of methods was used to obtain related information that would form a more complete dataset for the analysis similar to the method used by Liyanagunawardena and Williams [26].

- The two popular MOOC aggregator sites Class-Central [27] and MOOC-List [28] were searched on March 24, 2015, to identify courses that explored aging and related issues. The search terms "age," "old," and "elderly" were used.
- Course catalogues from the MOOC platforms FutureLearn [24], Coursera [29], edX [22], and Canvas [30] were checked to identify MOOCs on aging or related areas (March 24, 2015).
- The list of health-related and medicine-related MOOCs published in Liyanagunawardena and Williams [26] was also consulted to identify relevant courses.

The Literature

When conducting literature searches, researchers typically use different methods to identify papers to be considered [31,32]. In this study, a literature search was performed using the search term (MOOC* AND ((age* OR elderly) OR old*)) on two large bibliographic databases: Scopus and the Web of Science. We also searched Google Scholar using the same search terms to identify articles that may not be present in the databases. In our searches, the search period was limited to the period from the year in which the first MOOC was run (2008) to the present (2015).These searches were carried out on March 15, 2015.

Analysis

Pre-Course Survey

The response rate and the number of responses received for each course in the pre-course survey are shown in Table 1. As can be seen, there is very good response rate when taken as a percentage of the actual number of "learners" in the course.

Table 1. Pre-course survey response numbers.

Course name	Course start date	Pre-course survey responses (N)	N as a percentage of learners[a]
Obesity: Causes and consequences – Obesity 1	June 9, 2014	1073	24.1
Obesity: Causes and consequences – Obesity 2	Feb. 16, 2015	1590	47.0
Our Changing Climate: Past, present and future – Climate	Nov. 10, 2014	1544	33.9
Our Hungry Planet: Agriculture, people and food security – Hungry Planet	Feb. 9, 2015	1931	59.5
Managing People: Engaging your workforce – Managing People	Jan. 12, 2015	3143	26.7
Heart Health: A beginner's guide to cardiovascular diseases – Heart	Sept. 8, 2014	904	19.3
A Beginner's Guide to Writing in English for University Study – English 1	Jan. 19, 2015	4973	28.3
A Beginner's Guide to Writing in English for University Study – English 2	Feb. 17, 2014	1356	10.2
Begin Programming: Build your first mobile game – Programming 1	Oct. 28, 2013	3607	79.8
Begin Programming: Build your first mobile game – Programming 2	Feb. 24, 2014	2657	13.6

[a] In the FutureLearn statistics, "learners are joiners who viewed at least one step in the course" [25].

Courses on Aging

Searching Class-Central and MOOC-List aggregator sites with the words "age," "old," and "elderly" resulted in a large number of entries. For example, searching with "age" as a keyword resulted in the return of 98 entries in Class-Central and 638 entries in MOOC-List. However, the actual relevant numbers shown in the Results section were very few. Many search results related to course topics such as "age of globalization" or "the age of sustainable development." The first author analyzed the list of search results manually to identify relevant courses. Only three related courses were found using Class-Central and MOOC-List searches. These were offered on Coursera (two) and FutureLearn (one) platforms.

By browsing course catalogues on selected platforms, another course on the FutureLearn platform was identified. Consulting the recent publication by Liyanagunawardena and Williams [26], two more courses were identified: one on the Open2Study [33] platform and the other on the Coursera platform.

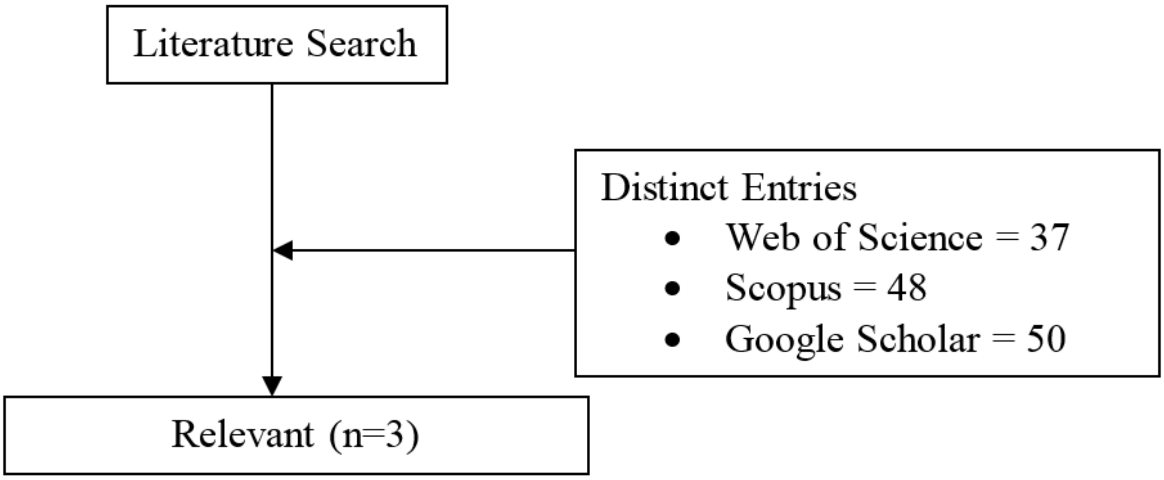
The Literature

The database Web of Science returned 38 entries (37 distinct entries) while Scopus returned 49 entries (48 distinct) (March 15, 2015). Reading through the abstracts, only two relevant papers were extracted from the Web of Science entries, and the Scopus entries returned the same two. One additional entry was added to the list by analyzing Google Scholar search results. Many of the returned entries included words such as "information age," "digital age," "Internet age," "computer age," "age of MOOCs," "moocher," "old debates," "… year old," "old news," "external agents," "intelligent agents," and "software agents," while a few included chemical compounds such as MoOC14, MoOC15, and mooceroftii that satisfied the search terms. One paper referred to Mooca (a district in Sao Paulo), while another was about a classical scholar named Moocheomdang Lee Euiyoon. A summary of the literature search is presented in Table 2 and Figure 1.

Table 2. The literature search summary.

Source	Entries returned	Distinct entries	Relevant	Non-relevant
Web of Science	38	37	2	36
Scopus	49	48	2	47
Google Scholar	Over 5000	First 50 distinct entries analyzed	1	49

Figure 1. Summary of the literature search.



Results

Pre-Course Survey

Using the pre-course survey data for the FutureLearn courses offered by the University of Reading described above, we identified learner demographics. The results are presented in Figure 2.

As Figure 2 shows, a large percentage of elderly learners were observed to have responded to the pre-course surveys in the “Heart health” course and the “Our changing climate” course.

Further analysis showed that the “Our changing climate” course had 16.3% (251) learners over the age of 66, while in the “Heart health” course the over-66 age group represented 15.3% (138) of the cohort. In both these courses, the over-66 age group represented the third largest age group in the course (Figure 3).

Observing the over-56 age group in these courses, it can be seen that in the “Heart Health” course nearly 40% of the participants were in this age category (Table 3). It can also be seen that “A beginner’s guide to writing in English for university study” was the least popular course among this age group, followed by the “Managing people” course.

Table 3. Percentage of students over 66 and over 56 years old in courses.

Course name	Over-66, % replies	Over-56, % replies
Obesity: Causes and consequences – Obesity 1	4.9	24.9
Obesity: Causes and consequences – Obesity 2	5.7	21.1
Our changing climate: Past, present and future – Climate	16.3	36.7
Our hungry planet: Agriculture, people and food security – Hungry Planet	6.5	18.2
Managing people: Engaging your workforce – Managing People	0.5	6.7
Heart health: A beginner’s guide to cardiovascular diseases – Heart	15.3	39.5
A beginner’s guide to writing in English for university study – English 1	0.6	3.0
A beginner’s guide to writing in English for university study – English 2	1.5	6.7
Begin programming: Build your first mobile game – Programming 1	5.0	17.7
Begin programming: Build your first mobile game – Programming 2	3.8	12.6

Figure 2. Learner age distribution in University of Reading offerings on FutureLearn.

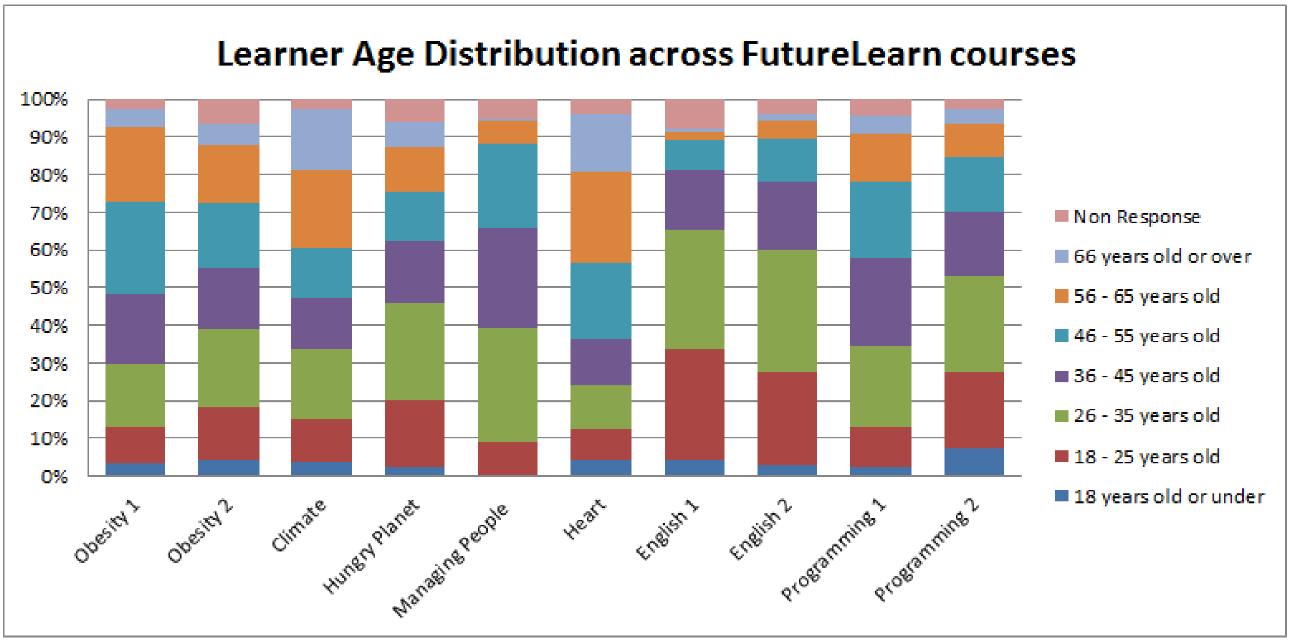
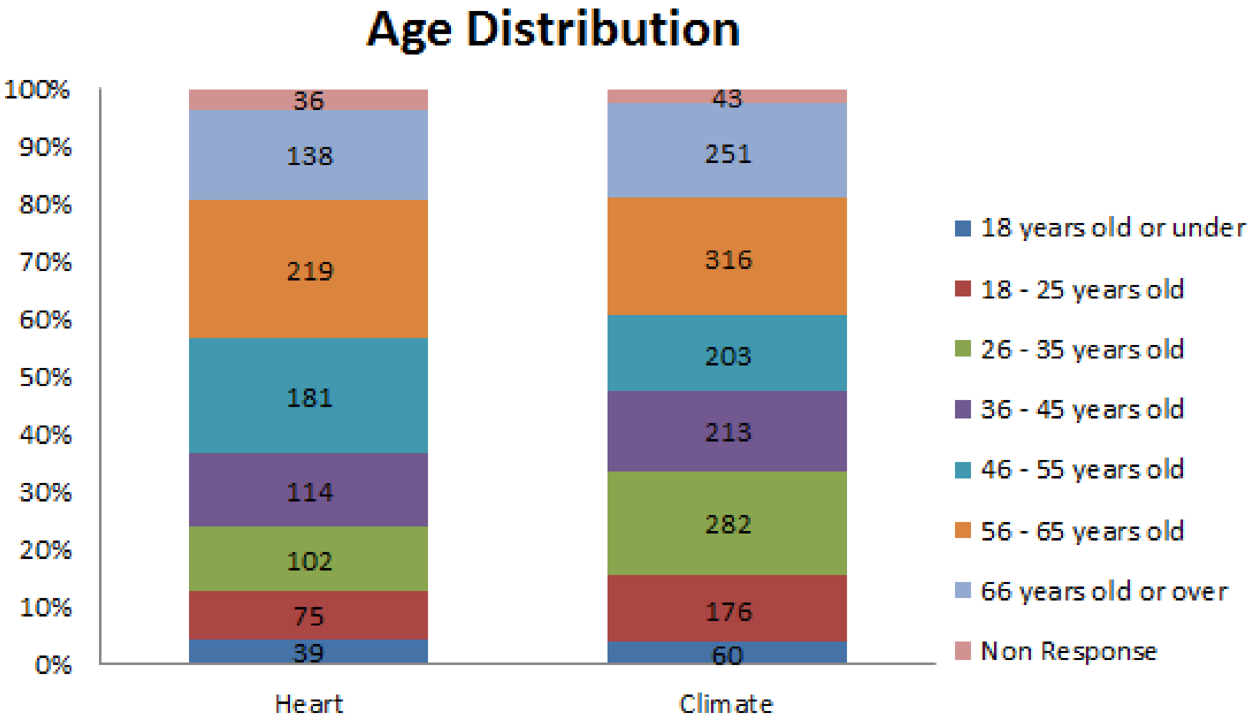


Figure 3. Age distribution of learners.



Courses on Aging

Six MOOCs related to aging were found from the searches and are shown in Table 4. Coursera offered three courses, FutureLearn offered two, and Open2Study offered one course. The details of these courses are presented in Table 5.

Table 4. Courses relating to aging.

Course name	Class-Central	MOOC-List	Authors' previous work	Platform course catalogue
Growing old around the globe	Yes	Yes		Yes
Rethinking aging: Are we prepared to live longer?	Yes	Yes		Yes
Aging well: Falls		Yes		Yes
Why do we age? The molecular mechanisms of aging				Yes
Understanding dementia			Yes	
Care of elders with Alzheimer's disease and other major neurocognitive disorders			Yes	

Table 5. MOOCs related to aging.

Course name	Platform	Offered by
Growing old around the globe	Coursera	University of Pennsylvania
Rethinking aging: Are we prepared to live longer?	Coursera	University of Melbourne
Aging well: Falls	FutureLearn	Newcastle University
Why do we age? The molecular mechanisms of aging	FutureLearn	University of Groningen
Understanding dementia	Open2Study	University of Tasmania
Care of elders with Alzheimer's disease and other major neurocognitive disorders	Coursera	Johns Hopkins University

The Johns Hopkins University now offers "Living with dementia: Impact on individuals, caregivers, communities and societies" course and this too is a 5-week course similar to "Care of elders with Alzheimer's disease and other major neurocognitive disorders." Both courses were offered by the University's School of Nursing and because of this we believe these two to be the same course with an updated course title.

The Literature

The three articles found to be relevant from the literature search are King et al [34], Sanchez-Gordon et al [35], and King et al [36].

Discussion

Elderly Online Learners

From the above analysis, we have shown that a considerable proportion of elderly learners are already engaging in MOOCs. For example, in the "Heart health: A beginner's guide to cardiovascular diseases" course, 15.3% of the learners were over 66 years old while another 24.2% were in the 56-65 age group. That is, in this course, 39.5% of the learners were over 56 years old. Observing the spread of elderly learners in the courses offered by the University of Reading, it can be seen that some types of courses are more popular with this age group. Nevertheless, elderly learners do engage in courses in a multitude of disciplines.

However, the available information is insufficient to gauge the geographical spread of these elderly learners. Thus, it is possible that most of these learners are from developed countries with high levels of education, similar to the general MOOC learner demographics shown by other studies. For example, four out of five participants in University of Pennsylvania courses on Coursera platform had a Bachelor's degree or higher [37], while the data obtained from the first 21 courses of the FutureLearn platform showed that 78% of its participants had a university degree or higher [25].

Promoting Courses

Elderly learners are likely to have more time to devote to learning. While there are elderly learners who do take part in these free courses, it is possible that there are many others who are not aware that such courses exist. Thus, promoting free online courses to this age group would allow elderly people to become leisure learners. Courses could be promoted at local events (eg, coffee mornings), through charities working with elderly (such as AgeUK), hospitals, libraries, in residential or retirement homes, higher and further education collages, and religious places (such as churches or temples). Providing this information will allow these time-rich elderly learners the opportunity to explore a wide variety of topics of interest via free online courses. Engaging in MOOCs can provide a virtual support group as the learning community helps individuals in their learning and could be a way of instilling a sense of "belonging" to a community and combating isolation. However, as we have shown above there is a lack of research about elderly learners in MOOCs. Research into elderly learners' engagement in MOOCs and the effects on their well-being would be a worthwhile avenue to explore.

Creating Courses for Elderly Learners

Elderly learners may have complex accessibility needs. For example, background music in a lecture may work as a stimulus for younger learners but for older people who are more prone to be hard of hearing, it may become an additional barrier to accessing content. Sanchez-Gordon and Luján-Mora [38] show the need to address the Web accessibility needs of elderly learners in MOOCs. They analyze a sample of five Coursera courses for Web accessibility and in two of the three test cases they used, all courses failed to comply with Web accessibility guidelines. Even though these results are based on a small sample, they highlight the need to adhere to Web accessibility guidelines when designing and presenting MOOCs.

It is likely that certain topics will be of special interest to elderly learners. For example, in our data analysis we have shown that the courses “Our changing climate” and “Heart health” had a large proportion of elderly learners in them. Similarly, it is plausible to expect that topics exploring issues such as health problems that are more common in later life, specific interests (eg, travel, history, nature, poetry, baking, or gardening), or historical events of interest to elderly learners will have higher numbers of leisure learners registering on them. On the other hand, courses relating to management of workforce (“Managing people”) and learning English for academic writing (“A beginner’s guide to writing in English for university study”) were less popular among this age group.

Thus, an opportunity exists to engage elderly learners by offering courses with topics that are closer to their interests. Organizations such as AgeUK or the University of the Third Age [39], a movement that provides learning opportunities for retired and semi-retired people and that is run by community members who are typically older adults, could offer or could partner with other institutions interested in offering MOOCs in topics that elderly learners have a special interest in. Courses especially targeted at elderly learners will allow them to study with other people with similar interests, providing a virtual network of connections and friendships.

Elderly as Resource Personnel

Course providers could use the expertise/experience of elderly learners in other ways; for example, giving elderly learners the opportunity to co-create community courses by providing an open space for discussions and collaborations (eg, see [40]). For example, elderly learners who lived through World War II, the apartheid period in South Africa, or the Spanish Civil War will have their own personal experiences of these events that may differ from “accepted” documentation. Courses exploring these topics and social histories (eg, changes in the kitchen) could be created by building on learners’ personal stories and could become valuable resources for researchers and future generations.

Additionally, highly educated and retired personnel (eg, professors) who are authorities of their field of knowledge, may have spare time and be prepared to share their knowledge for the “greater good.” Therefore, there is an opportunity to utilize this expertise in MOOCs either as content creators, educators, or mentors.

When elderly learners engage with MOOCs, they may be able to spend many hours exploring course materials and related readings. This may be because they are time-rich compared to other learners who may have to continue their studies alongside employment and caring duties. This has certainly been our experience as educators in the “Begin programming” course. Once a course finishes, if the elderly learners have been engaged and successfully completed the course, they may be willing to join subsequent sessions of the same course as mentors. As MOOCs are free courses, the support for participants mainly comes from within the course community. Time-rich elderly participants with life experience are likely to be resourceful mentors. Being able to support others in their learning provides self-satisfaction, and this could be mapped to higher levels of needs (esteem and self-actualization needs) in accordance with Maslow’s hierarchy of needs [41].

Elderly Learners as Consumers

Organizations wishing to offer MOOCs especially for the elderly participants could seek sponsorship from organizations providing services that are mostly required by older adults: for example, suppliers of stair lifts, mobility scooters, or cruise holidays. This would provide the necessary funding for courses to be created for older adults while the sponsoring organizations would benefit from promotion of their services or products.

Limitations

In this review, we collected data using various sources. However, due to resource limitations the authors had to limit the search scope. Collecting course details through aggregator sites could have the disadvantage of not including all MOOCs that are on offer as Liyanagunawardena and Williams [26] have shown; however, the authors have consulted other sources to minimize the possibility of such occurrence. Liyanagunawardena et al [21] discuss the limitations of literature searches and the difficulty of including blogs in such analysis. In this study, similar to the study by Liyanagunawardena et al [21], we have discounted blog posts, which could mean that some articles may have been missed.

Not all learners respond to pre-course surveys, and some of those who do take part in the surveys do not want to reveal their age. It could also be argued that time-rich elderly learners are more likely to answer pre-course surveys, thus further skewing results. As the pre-course survey is a self-administered questionnaire, it is not possible to validate the answers provided by respondents. These limitations should be considered when interpreting the results of pre-course survey data.

Another consideration is that the authors looked only at publications and courses presented in English and again because of resource limitations. If there were articles or courses in languages other than English, it would not have been possible to consider them here.

Conclusions

All over the world, countries are encountering population aging as a result of both increased life expectancy and declining birth rates. Population aging presents both various challenges and opportunities to society. Challenges include increasing demand for health services, long-term care and social services, and increasing strain on pension and social security systems; conversely, older adults can make significant contributions as family members, caregivers, volunteers, and members of workforces. Older people are at risk of social isolation due to a variety of reasons: diminished contacts with colleagues, bereavement, mobility issues, and ill health. The use of the

Internet has shown promising prospects for solutions to tackle loneliness in older adults.

In this paper, we have shown the lack of research into the use of Massive Open Online Courses (MOOCs) by elderly learners while at the same time establishing their presence in MOOCs by analyzing MOOC demographic data from 10 courses offered by the University of Reading.

Despite the considerable number of elderly learners participating in these courses, there is lack of data to identify more precisely what other characteristics are shared by these learners. We show that promoting courses to the elderly and creating courses specifically targeting this age group could be another way of tackling loneliness felt by a growing number of older people. We further show that engaging elderly learners as resource personnel in creating and offering MOOCs would help them keep engaged while bringing greater good to society by using the vast knowledge and experience accumulated by older adults.

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Conflicts of Interest

None declared.

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Abbreviations

MOOCS: massive open online courses

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