iSupport-Portugal: Challenges and Insights in Designing a Web Platform for Intervention and Research on Informal Dementia Caregivers

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Abstract: eHealth programmes are increasingly explored to improve access to training and support for informal caregivers of people with dementia (PwD). iSupport-Portugal is an eHealth programme for these caregivers, culturally adapted from the World Health Organization's original iSupport. iSupport-Portugal is the only version being explored internationally as a remote measurement tool (RMT) to collect sociodemographic, health and psychosocial data on care dyads. The aim of this paper is to discuss the challenges and lessons learned in the deployment of iSupport-Portugal. Four studies were conducted, including a mixed-methods cross-sectional study of informal dementia caregivers' attitudes and needs towards eHealth interventions (N=157), a usability study (N=17), a pilot randomised controlled trial (N=42), and an ongoing prospective cohort study (N=173). Insights and recommendations are provided on user uptake of eHealth interventions and user-centred approaches, ethics and data privacy considerations, study design for usability and effectiveness evaluation, and the use of platform data for research. This paper provides insights relevant to researchers, developers, and designers involved in implementing digital solutions for caregivers of PwD and other audiences. To realise the full potential of eHealth interventions and RMTs, it is imperative to establish guidelines that address the ethical, technological, and methodological complexities of the field.

1 INTRODUCTION

Worldwide, 55 million people live with dementia, with 9.9 million new cases reported each year, including 2.5 million in Europe alone (WHO, 2019). Dementia remains a major cause of dependency among older adults (Sousa et al., 2010), with those diagnosed often relying on informal caregivers for daily activities.

Informal caregivers of people with dementia (PwD) are at a heightened risk of experiencing physical and mental health issues compared to both

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the general population and caregivers of people with other chronic diseases (Bertrand et al., 2006; Gilhooly et al., 2016). Psychosocial interventions for informal caregivers have been shown to be effective in improving their well-being, but access to these interventions remains problematic, and they can also be expensive (Cheng et al., 2020). Caregivers may face barriers to participating in these interventions, which are typically delivered in person, such as arranging substitute care, managing work schedules, and dealing with social stigma (WHO, 2015). There is evidence of underutilisation, delayed access, and high dropout rates among dementia caregivers in conventional psychosocial interventions (Stephan et al., 2018).

Recognising this, the World Health Organization (WHO), in its Global Action Plan on the Public Health Response to Dementia (WHO, 2017), aims to strengthen accessible support programmes for informal caregivers and has launched "iSupport for Dementia" to contribute to this goal. iSupport is an eHealth programme tailored to provide support and training to informal caregivers of PwD (Pot et al., 2019). The programme has been culturally adapted for implementation in multiple countries, including Australia (Xiau, 2019), Brazil (Oliveira et al., 2020), India (Baruaha et al., 2021), Switzerland (Fiordelli & Albanese, 2020), Indonesia (Turana et al., 2023), Spain (Molinari-Ulate et al., 2023), Greece (Efthymiou et al., 2022), Japan (Yamashita et al., 2022) and Portugal (Teles, Napolskij, et al., 2020). The European Portuguese version of iSupport was one of the pioneering versions studied for its requirements, usability, acceptability, and feasibility as both an intervention and a data collection tool. It serves the dual purpose of supporting dementia care dyads while facilitating research in the field, distinguishing iSupport-Portugal from other international versions.

Recognised challenges in implementing eHealth interventions such as iSupport include ethical, technological, and research-related barriers. Considerations such as data privacy, security, ethical dilemmas, user trust, sustainability, data preparation and validation, and evaluation of effectiveness are orthogonal to eHealth interventions (Hassan, 2020). It is therefore imperative for the scientific community to collectively address these challenges.

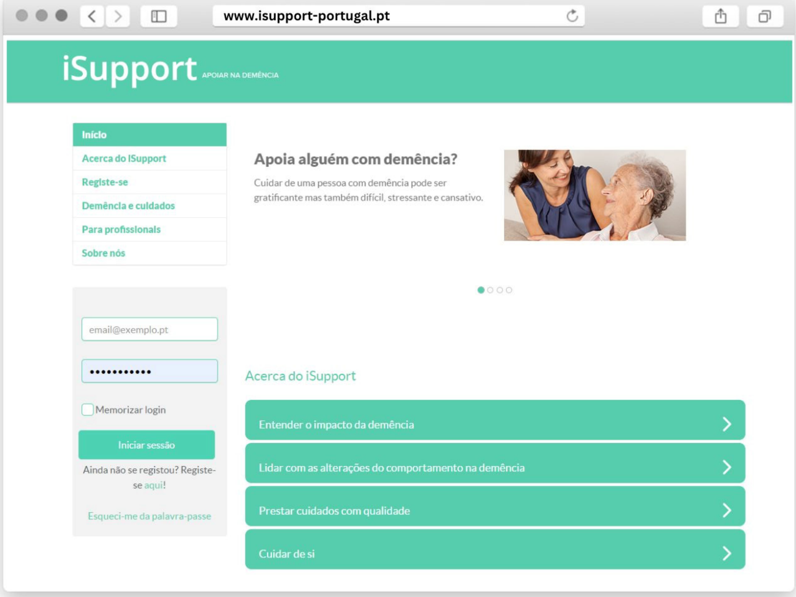
The aim of this paper is to outline and discuss the challenges identified in four comprehensive studies of iSupport-Portugal. These studies examined the eHealth programme both as an intervention tool and as a platform for remote data collection, including i. a cross-sectional study on the attitudes and requirements of informal dementia caregivers towards eHealth interventions; ii. an acceptability and usability study; iii. a pilot randomised controlled trial (RCT) to assess the feasibility of the RCT protocol; and iv. a prospective cohort study to assess the feasibility of iSupport-Portugal for remote data collection of caregiving dyads. By drawing insights from these studies, this paper provides valuable perspectives for researchers, practitioners, developers and designers working on digital solutions for caregivers of people with dementia and similar audiences.

2 iSupport-Portugal

Originally developed by WHO, "iSupport" is a programme that is available 24/7 and free of charge to any registered user via a web interface. The programme consists of five modules and 23 lessons and uses problem-solving and cognitive-behavioural therapy techniques as intervention strategies. These lessons cover topics that are commonly included in psychoeducational interventions for caregivers of PwD, including self-care, managing behavioural and psychological symptoms of dementia, communication and decision making with PwD, and everyday caregiving tasks.

The programme has been designed as a self-directed tool that works without a therapist. It offers complete flexibility in terms of intervention planning, allowing individuals to progress at their own pace and select lesson plans tailored to their needs. To enhance the user experience, the programme incorporates personalisation features (e.g. personal information provided during registration is used to customise in-text references). The programme includes care scenarios that reflect real-life situations, allowing caregivers to practice skills while relating to common experiences. Interactive skill training exercises provide immediate feedback, creating a learning environment. iSupport offers focused lessons that combine textual information with auditory elements, including audio-guided relaxation exercises, but with a primary focus on textual content. Caregivers can assess their mood and track changes over time using a graphical display.

Different versions of iSupport have been developed around the world. The adaptation of iSupport for Portugal (see Figure 1) was prompted by contextual needs, in particular the high prevalence of dementia in the country (21 cases per 1000 inhabitants) compared to other OECD countries (OECD, 2019). In addition, there is a societal expectation in Mediterranean countries for families to



Apoia alguém com demência?

Cuidar de uma pessoa com demência pode ser gratificante mas também difícil, stressante e cansativo.

Ainda não se registou? Registe-se aqui!

Figure 1: iSupport-Portugal landing page.

care for their older relatives, leading to a higher prevalence of informal care, often influenced by social pressure (del-Pino-Casado et al., 2011).

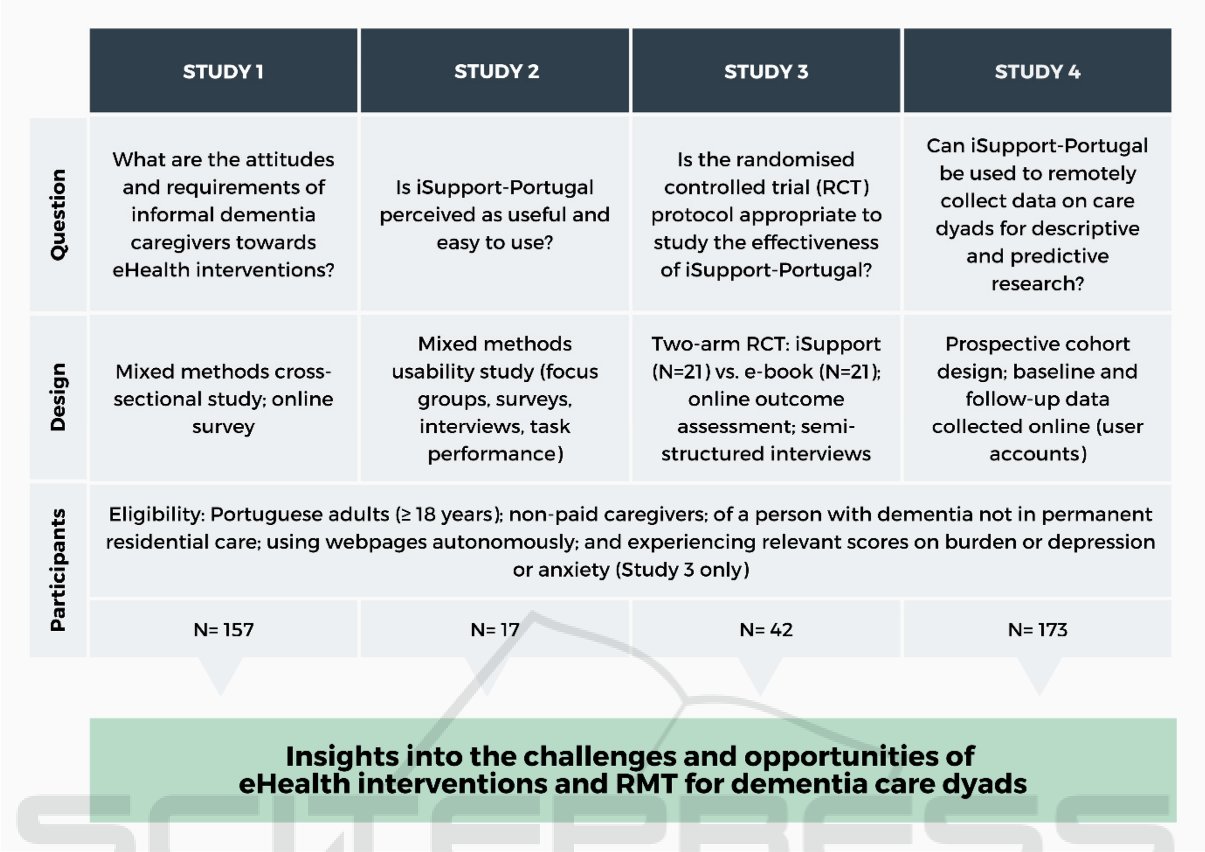
The adaptation of iSupport to Portugal, detailed elsewhere (Teles, Napolskij, et al., 2020), led to several studies, including cross-sectional research on the needs, requirements, and attitudes of dementia caregivers towards online interventions (Teles, Ferreira, et al., 2020; Teles, Paúl, et al., 2020, 2022), as well as research on the acceptability, usability of iSupport-Portugal (Teles, Paúl, et al., 2021) and its feasibility in a mixed-methods pilot RCT (Teles, Ferreira, et al., 2022b).

Current research efforts with iSupport are directed towards extending the platform beyond its original intervention purpose, as a remote measurement tool (RMT) for gathering comprehensive sociodemographic, health and psychosocial data on dementia care dyads. Such data could be invaluable for profiling, understanding needs, and tracing caregiving trajectories. RMTs facilitate the collection of behavioural, health, and well-being data in real time, inexpensively, and unobtrusively through web platforms, mobile apps, sensors, and wearables (Simblett et al., 2018). To use iSupport-Portugal as an RMT, several steps were required to technically and scientifically improve the platform. The following section outlines the approach taken in the iSupport-Portugal studies, which revealed numerous challenges and insights in deploying an intervention-research tool for dementia care dyads.

3 MATERIALS AND METHODS

A set of four studies on iSupport-Portugal aimed to provide a comprehensive understanding of whether and how such an eHealth platform could be usable and useful to support informal dementia caregivers (intervention aim), and to gather information on the profiles, needs and outcomes of dementia care dyads (research aim). Figure 2 summarises the methods used in the iSupport-Portugal studies. First, a mixed-methods cross-sectional study investigated the attitudes and requirements of informal dementia caregivers towards eHealth interventions (Teles, Ferreira, et al., 2020; Teles, Paúl, et al., 2020, 2022). The aim was to provide insights for the implementation of iSupport-Portugal. A non-probability sample of 157 digitally literate informal caregivers of PwD living in the community was recruited nationally through advertising by the national Alzheimer's Association and local dementia-related organisations. Participants completed a web-based survey assessing attitudes and requirements for online interventions using specially designed scales (Teles, Ferreira, et al., 2020).

Secondly, a mixed methods acceptability and usability study of iSupport-Portugal was conducted. Seventeen informal caregivers took part in either focus groups or usability test sessions, during which their task performance on the interface was observed. This evaluation included usability surveys and post-test interviews (Teles, Paúl, et al., 2021).



	STUDY 1	STUDY 2	STUDY 3	STUDY 4
Question	What are the attitudes and requirements of informal dementia caregivers towards eHealth interventions?	Is iSupport-Portugal perceived as useful and easy to use?	Is the randomised controlled trial (RCT) protocol appropriate to study the effectiveness of iSupport-Portugal?	Can iSupport-Portugal be used to remotely collect data on care dyads for descriptive and predictive research?
Design	Mixed methods cross-sectional study; online survey	Mixed methods usability study (focus groups, surveys, interviews, task performance)	Two-arm RCT: iSupport (N=21) vs. e-book (N=21); online outcome assessment; semi-structured interviews	Prospective cohort design; baseline and follow-up data collected online (user accounts)
Participants	Eligibility: Portuguese adults (≥ 18 years); non-paid caregivers; of a person with dementia not in permanent residential care; using webpages autonomously; and experiencing relevant scores on burden or depression or anxiety (Study 3 only)			
	N= 157	N= 17	N= 42	N= 173

Insights into the challenges and opportunities of eHealth interventions and RMT for dementia care dyads

Figure 2: Methodological approach of iSupport-Portugal studies. Note: Study 4 mentions 173 caregivers corresponding to those who self-declared as such at registration into the programme.

Thirdly, a mixed-methods pilot RCT was conducted to assess the feasibility of a protocol to determine the effectiveness of iSupport-Portugal (Teles, Ferreira, et al., 2022b). Caregivers with significant scores on burden, depression, or anxiety scales were recruited through referrals from the national Alzheimer's Association and randomised to one of two arms: intervention (iSupport, n= 21) or control (e-book, n= 21). Both groups underwent assessments of burden, anxiety, depression, positive aspects of caregiving, quality of life, and self-efficacy before initiating the programme (baseline) and at 3 and 6 months afterward. Semi-structured interviews were conducted with the intervention group to collect data on their use and perceived outcomes of iSupport.

Fourthly, ongoing research aims to use iSupport-Portugal as an RMT employing a prospective cohort design. Baseline and follow-up data are currently being collected from registered users of iSupport-Portugal who self-identify as informal dementia caregivers, using their personal accounts.

Technical and scientific enhancements were implemented to ensure the integrity, security, and ethical handling of the data collected for this purpose through iSupport-Portugal. Measures to be incorporated into the platform were selected, permission for their use was obtained and they were programmed according to licensing requirements. Complementary data collection forms were created and integrated into the platform, focusing on appropriate form fields and validation processes to increase data accuracy. A unique feature of iSupport-Portugal, compared to other iSupport international versions, is its diagnostic module. This module was custom-built to include assessment scales focusing on sociodemographic, clinical, and psychosocial variables related to caregivers and PwD. Moreover, measures have been taken to ensure proper and secure data storage. In collaboration with the Data Protection Officer and the Digital Services of the University of Porto (platform host), a thorough security audit of the platform was carried out. After the public launch of the platform and the formation of a user group, the collected data underwent extraction, validation, and cleaning processes.

The following section outlines the findings of this comprehensive set of studies.

4 RESULTS AND DISCUSSION: INSIGHTS FOR DEPLOYING AN INTERVENTION-RESEARCH PLATFORM

The studies on iSupport-Portugal revealed challenges and insights for deploying and conducting research on eHealth interventions and RMT, which are detailed next.

4.1 User Uptake of eHealth Interventions and User-Centred Design

i. eHealth interventions don't always address the shortcomings of face-to-face interventions.

While eHealth interventions are often seen as an alternative to mitigate accessibility issues, our research shows that the most important barrier is informational, i.e., caregivers are not aware of the interventions available (Teles, Ferreira, et al., 2021). Simply making an online programme available and searchable (website optimisation) may not be enough, as information overload and concerns about trustworthiness remain significant barriers. Establishing a supportive community around the eHealth platform, disseminated through practitioners, caregiver associations, municipalities, and informal social media groups, is essential to mitigate these information barriers.

Moreover, contrary to previous suggestions that individuals who encounter barriers to accessing face-to-face services are more inclined to turn to internet resources (Bhandari et al., 2014), our research shows that previous access to conventional interventions is linked with the use of eHealth interventions (Teles, Ferreira, et al., 2022a). While it has been suggested that caregivers facing emotional distress may be more likely to turn to internet resources due to factors such as stigma or a reluctance to seek in-person services (Kim, 2015), our observations of iSupport users show lower usage and higher dropout rates among those experiencing greater psychological distress (Teles, Ferreira, et al., 2022b; Teles, Paúl, et al., 2022).

Furthermore, while online interventions were designed to address issues of accessibility and high dropout rates in conventional interventions, they are also susceptible to high dropout rates (Christie et al., 2018). Dropout in online interventions remains a notable challenge, with implications for both intervention effectiveness and research validity (see section 4.3). Consistent with previous research (Christie et al., 2018), we found that design elements such as the ability to customise the intervention schedules and lesson plans, were important in minimising dropout.

ii. Online information and support-seeking behaviours are subdued among informal caregivers, with trustworthiness playing a significant role.

The perception of online information as overwhelming and the inability to differentiate between trustworthy and untrustworthy websites have been identified in our research as barriers to caregiver adoption of online interventions (Teles, Paúl, et al., 2021, 2022). Trust in online platforms depends on various factors including user characteristics and design/technology-related features. In the case of iSupport-Portugal, the authority of the owner emerged as the most significant element of trust, underscored by the clear endorsement of reputable organisations involved in the programme through logos, written statements, and contact information (Teles, Paúl, et al., 2021). Illustrations also influenced preconceptions about the content of the programme; if perceived as juvenile or outdated, they could lead to expectations of basic programme content (Teles, Paúl, et al., 2021).

iii. Online resources are primarily used for "altruistic" purposes and can be perceived as a caregiving task, with design playing a key role. In a sample of Portuguese dementia caregivers, a moderate frequency of online help-seeking was observed. We found that caregivers were less likely to seek information and support for their own benefit than for the benefit of the care recipient (Teles, Paúl, et al., 2022). Caregivers seem to perceive the use of internet resources as a caregiving task. We've learned that the design of most online resources for caregivers, which are often text-based and resemble formal training or scholarly programmes, may reinforce such perceptions (Teles, Paúl, et al., 2021). Insights from iSupport users suggest that programmes that incorporate gaming elements, social networking, and multimedia components can help to make interventions into enjoyable activities rather than adding to caregiver' responsibilities (Teles, Paúl, et al., 2021).

iv. Even within digitally literate groups, attitudes towards eHealth interventions warrant consideration.

In a sample of Portuguese dementia caregivers, attitudes towards online interventions were moderately positive, with more participants expressing a preference for face-to-face interventions, which were perceived as more trustworthy and effective (Teles, Ferreira, et al., 2022a). These findings are particularly relevant as they stem from a group of digitally literate caregivers who do not require new skills to use an eHealth programme. Most caregivers expressed greater trust in online interventions for training purposes rather than for emotional support, suggesting a need to raise awareness about the therapeutic aspects of this intervention modality, possibly through the establishment of a network of advocates (professionals and caregivers). It is also crucial to involve the target groups throughout the entire development process, with an up-front assessment of their tendencies to seek health and care-related information online.

v. eHealth interventions must not be seen as substitutes for conventional interventions or divert investment from the latter.

Findings from the iSupport-Portugal studies suggest that there are multiple caregiver profiles that may prefer and benefit more from face-to-face interventions, online interventions, or a combination of both (Teles, Ferreira, et al., 2022a). Most caregivers did not favour online interventions as a stand-alone support but rather as an adjunct care. Caregivers who valued self-personalisation, self-monitoring, shorter sessions, and exhibit reluctance in sharing their feelings with others had more positive attitudes towards online interventions, suggesting a profile of users who may benefit the most from them (Teles, Ferreira, et al., 2022a). Caregivers have also expressed that online interventions can serve as a gateway to conventional ones, particularly for caregivers who have recently become aware of the dementia diagnosis (Teles, Paúl, et al., 2021).

vi. Online interventions cannot simply replicate face-to-face formats.

With the proliferation of online interventions, especially during the COVID-19 pandemic, there has been a tendency to emulate face-to-face schemes both in intervention delivery and research methodology (see section 4.3). However, findings from iSupport studies suggest that transferring face-to-face intervention models to online formats can result in long sessions with limited interactivity, which may be an unfitting format for online interventions. Online resources are typically consumed quickly and dynamically, with users spending minimal time on web pages (Liu et al., 2010). Designing online interventions requires a more nuanced approach than simply mirroring in-person programmes. It necessitates a user-centred and interdisciplinary approach that integrates clinical expertise with interaction design knowledge.

vii. Trade-offs in the design of eHealth programmes are often challenging.

Insights from iSupport studies highlight the consistent value caregivers place on easy-to-navigate interfaces, plain language, personalisation, interactivity, feedback, and self-monitoring features of eHealth interventions (Teles, Ferreira, et al., 2022a; Teles, Paúl, et al., 2021). For example, customisable content on iSupport, tailored to include in-text references to the name, gender, and kinship of the PwD, enhanced the sense of engagement. Additionally, interactive and immediate feedback on caregiving scenarios was praised for promoting insights (Teles, Paúl, et al., 2021). Theoretical discussions on feedback (immediate vs. delayed) have persisted across learning theories, demonstrating the complexity of the issue. iSupport aligns with extensive research on learning (Metcalfe, 2017), utilizing immediate corrective feedback for skills training.

On the other hand, participants in the iSupport-Portugal studies showed inconsistencies regarding features such as remote advice from health or social support professionals (Teles, Ferreira, et al., 2022a; Teles, Paúl, et al., 2021). While many caregivers endorsed online communication with professionals, others expressed concerns about receiving generic advice that may not adequately address the complexities of their individual cases. Our research suggests that individuals with longer caregiving experience tend to prefer self-guided interventions over professional mediation (Teles, Paúl, et al., 2020). Among caregivers valuing professional guidance, the convenience of eHealth interventions is also highly regarded. However, these preferences may conflict, as professional guidance often requires coordination of schedules and plans between caregivers and professionals. From a pragmatic standpoint, self-guided interventions allow for rapid expansion of support at a lower cost compared to interventions that rely on professional or volunteer guidance (Blom et al., 2015).

Also from a cost perspective, iSupport was intentionally designed to rely primarily on text-based content, necessitating less investment in country-specific adaptation than multimedia resources.

However, we concluded that incorporating visual, auditory, and interactive elements into eHealth programmes not only caters to users' abilities, preferences, and learning styles but also enhances the overall experience, making it more enjoyable, engaging, and accessible (Teles, Paúl, et al., 2021).

Another trade-off is the flexibility of the intervention: while fully customisable schedules that allow users to define their lesson plans have been seen as a means of minimising attrition (Teles, Ferreira, et al., 2022b), questions remain about the minimum intervention delivery required to observe clinical effectiveness (Teles, Ferreira, et al., 2022b).

It was also to minimize dropouts that reminders were implemented for iSupport-Portugal. However, we have learned that for some users, reminders were perceived as anxiety triggering (Teles, Ferreira, et al., 2022b), suggesting the need to consider the mental costs of notifications and the imperative to redesign digital environments with well-being in mind.

User-centred design is crucial for making decisions about these trade-offs, and users should be involved from the beginning of technological development to avoid the costs of corrective measures at later stages.

4.2 Ethics and Data Privacy

In our efforts to ensure ethical and secure data collection for iSupport-Portugal, we have encountered several challenges.

i. Academic institutions need to improve their capacity to address privacy issues in a timely and effective manner.

While institutions are increasingly attentive to data privacy regulations, they may lack the resources to handle the diverse requests and categories of personal data involved in projects. This can lead to project deviations that need to be justified to funding bodies. Ethics committees often rely on the opinions of data protection officers (DPOs), which makes the overall process cumbersome. Additionally, researchers may lack knowledge of data protection procedures and terminology, making it difficult to communicate with DPO personnel. Institutions should prioritise the establishment of clear data protection procedures and guidelines, and the training of researchers to navigate those procedures. In parallel, they need to reinforce DPO teams and their capacity to engage effectively with projects.

These challenges were encountered during the development of iSupport-Portugal and led to delays in its public launch, which were only mitigated by the early initiation of processes and strategic partnerships.

ii. Guidance on collecting e-consent is necessary.

iSupport-Portugal studies relied on data collected entirely online, like other international iSupport research (Mehta et al., 2018). While this approach enables large-scale and geographically diverse data collection with minimal resources, it also presents challenges, particularly regarding online consent procedures. Without direct contact with participants, confirming identity, ensuring comprehension of study information, and ability to give consent becomes difficult. In iSupport-Portugal studies, a comprehension test was implemented to ensure understanding of the study information. However, the lack of guidance on e-consent is evident, highlighting the need for further discussion on this issue. Additionally, the user-friendliness and accessibility of information provided to participants on eHealth platforms regarding their personal data is crucial, as concerns about data misuse or security threats may deter users from engaging with such platforms.

iii. The awareness of navigation tracking can influence self-determination.

In iSupport-Portugal studies, some caregivers reported that their awareness of being monitored, such as through user logs tracking their programme usage, could influence their decisions on how to engage with the programme, i.e., pressure to increase programme usage (Teles, Ferreira, et al., 2022b; Teles, Paúl, et al., 2021). In traditional face-to-face interventions, social desirability towards the facilitating professional is commonly observed unlike in online non-mediated interventions. However, among some iSupport-Portugal users, there was a perception of being observed, a phenomenon increasingly scrutinised in digital technology usage. This perception can trigger affective responses, either positive or negative, potentially influencing users' tendency to conform and limit their autonomy (Lefkeli et al., 2022). Assessing this perception could yield valuable insights into its effects, whether positive (e.g., feeling secure) or negative (e.g., feeling anxious), among users of iSupport-Portugal and other eHealth interventions.

iv. eHealth interventions may still be targeting a niche of users.

eHealth interventions may have a dual impact on health inequalities. While they can enhance access to services and information, thereby reducing information asymmetries (e.g., information held exclusively by professionals), they may also exacerbate disparities between digitally literate and non-literate individuals. Benefiting from these interventions requires not only digital skills but also eHealth literacy, i.e., the ability to understand, and use online health information. Lack of digital literacy and eHealth literacy disproportionately affects older, less educated, and economically disadvantaged populations (OCDE, 2011). iSupport-Portugal studies indicate that the programme has primarily reached a niche of highly educated and professionally active caregivers (Teles, Ferreira, et al., 2022b). However, as internet usage trends evolve and the digital divide narrows, eHealth programmes like iSupport may reach a broader spectrum of caregivers. Ultimately, both face-to-face and online interventions exclude certain caregiver segments, such as employed individuals in the former case and the digitally illiterate in the latter. Therefore, it is crucial to offer diverse intervention options.

Additionally, the significant registration of professionals on iSupport-Portugal (47.7%), indicates their interest in using it as a tool for intervention with digitally illiterate caregivers. This use of the programme with professional mediation warrants further research, as iSupport-Portugal has thus far been studied only in its self-managed mode.

4.3 Research Design

In studying the feasibility of iSupport-Portugal, several challenges were identified.

i. The timing of follow-ups in eHealth interventions should be informed by a thorough analysis of usage patterns.

Follow-ups in RCTs of eHealth interventions often mirror the timing of face-to-face interventions. International studies of iSupport have typically scheduled follow-up assessments at 3 and 6 months after baseline, in line with the usual duration of face-to-face psychosocial interventions of around 12 weeks (Mehta et al., 2018; Yamashita et al., 2022). However, in the iSupport-Portugal feasibility study, we observed an intensive pattern of use, with a median of 13 lessons completed in just two weeks, after which the usage curve begins to decline (Teles, Ferreira, et al., 2022b). This finding indicates that a 3-month post-test evaluation may be too late. Therefore, patterns of use need to be analysed before defining follow-up schedules for RCTs.

In addition, conventional follow-up may be impractical unless access to the e-programme is revoked, as users may continue to engage with the intervention.

ii. Personalised intervention plans are desirable but challenging for research.

Self-directed e-interventions such as iSupport-Portugal allow for personalised training, a desired feature in eHealth interventions (see section 4.1). However, this introduces variability into the intervention pathway, making it difficult to replicate and determine effectiveness. Implementing a per-protocol analysis to counterbalance an intention-to-treat protocol is challenging due to the variable number and combination of lessons resulting from personalised plans. The number of hours required to meet the needs of a caregiver varies, making the application of standard rules to the intervention pathway arbitrary. Emphasizing adherence to best practices in RCTs, an intention-to-treat approach emerges as the most practical or perhaps the sole viable solution to address this issue.

iii. Defining a comparator to measure the effectiveness of eHealth interventions is not straightforward.

While a classic research question is whether online interventions are as effective or more effective than traditional face-to-face interventions, iSupport studies have shown that individuals with different profiles or at different caregiving stages may prefer different intervention modalities (Teles, Ferreira, et al., 2022a). Comparing both intervention modalities requires enrolling only digitally literate caregivers to ensure that they can use the intervention regardless of which group they are randomised to. This limitation may affect the external validity of such studies and poses challenges when comparing eHealth with face-to-face interventions. Studies comparing these types of intervention need to consider their implications and discuss their limitations, to ensure that resources are not inappropriately diverted from non-digital approaches. For iSupport-Portugal, as there is no standard of care for psychosocial support for caregivers in the country, a minimal education-only e-book was chosen as the comparator (Teles, Ferreira, et al., 2022b). Compared with a passive/waiting list control group, this allowed weekly reminders to be maintained in both conditions (iSupport and e-book) without introducing a follow-up bias, where effects can result at least partially from different interactions with both groups besides the intervention itself. To avoid follow-up bias, similar prompts, whether reminders to improve retention or other forms of contact, need to be extended to the control group.

iv. The generalisability of conclusions drawn from eHealth interventions is often challenging.

eHealth interventions often attract a niche group of participants, making it difficult to generalise results. In the iSupport studies, there is an over-representation of highly educated and employed caregivers (Teles, Ferreira, et al., 2022b). In addition, recruitment for usability studies often succeeds in attracting early adopters of digital innovations, which may lead to overly optimistic conclusions. While we were able to recruit a diverse profile of testers for the iSupport-Portugal usability studies, capturing such diversity was time-consuming (Teles, Paúl, et al., 2021). Strategies such as working with user associations to build a pool of potential testers are useful to minimise these issues.

v. Components of eHealth interventions evaluated in RCTs often lack continuity.

iSupport was originally designed as a self-managed programme and was evaluated as such in the iSupport-Portugal feasibility study (Teles, Ferreira, et al., 2022b). However, in many cases, RCTs of eHealth interventions include mechanisms to reduce attrition, such as reminders or professional chats, which are often discontinued after the trial is completed. This may lead to overly optimistic conclusions about programme effects if these effects are at least partly due to such components. Finally, technological advances and iterative changes commonly implemented in eHealth interventions can challenge the long-term relevance of RCTs. Study updates may be required more often than in other fields.

4.4 Exploitation of Platform Data for Research Purposes

In exploring the feasibility of using iSupport-Portugal as an RMT to collect data for dementia care dyad research, several insights were gained.

i. Ensuring the quality and integrity of platform data is challenging and overlaps with design features.

iSupport-Portugal required significant effort from a multidisciplinary team to improve the technical capabilities of the platform for efficient data collection, storage, export and visualisation. Design decisions such as form field options (e.g. calendar or numeric entry for a date) can affect data accuracy but are not always obvious to designers, developers or researchers, often leading to multiple iterations and potentially invalid or wasted data. There is a growing need for researchers and developers working with eHealth interventions to develop skills in online psychometrics.

ii. The psychometric properties of measures administered online are often not well described.

iSupport-Portugal has been designed to collect data remotely from caregiver-PwD dyads over time, using a combination of validated and newly developed self-report instruments. This approach facilitates nationwide assessments of caregivers with minimal resources. However, challenges arise from factors such as lack of control over the assessment environment, surrogates completing measures, and participant understanding of questions. In addition, managing multiple activity logs (e.g. considering the first spontaneous response or the final response in multiple clicks) and addressing potential variations in the psychometric properties of scales used in an online format are issues to be considered. While there have been discussions about the psychometric properties of scales administered online versus on paper (APS Tests and Testing Expert Group, 2018), here is a general lack of guidance on the implementation of scales online or the psychometric implications of doing so. Given the increasing prevalence of online research, addressing these issues is more important than ever.

iii. Remote data collection requires additional efforts to identify unwanted profiles.

Although iSupport-Portugal is intended for informal caregivers, initial testing revealed that health and social care professionals were creating dummy profiles to use the programme as an intervention tool. While this reflects professional interest, these dummy profiles affect the quality of the research data. To address this, registration steps and filtering questions were introduced into iSupport-Portugal to better identify different user profiles, albeit at the cost of increased response burden.

iv. Using an eHealth platform for predictive research requires mechanisms to maintain user engagement.

iSupport-Portugal's potential to monitor caregivers over time depends on maintaining user engagement with the platform. To prevent it from becoming a one-time visit site, investment in user retention is needed, including the addition of features such as social networking or gamification.

v. Creating an automated workflow for data extraction, preparation and data quality checks is time consuming.

It is vital to have a curated and updated dataset that not only enables research, but also adds functionality to the platform, e.g., profiling caregivers to provide user-centred interventions and increase user retention; outcome prediction for targeted interventions; and provide feedback for the improvement of the platform's design and data collection. While there are inherent challenges in the process of building and maintaining a curated dataset, the benefits go beyond the research effort to influence the usability and effectiveness of iSupport-Portugal and similar platforms.

5 CONCLUSIONS

eHealth interventions have gained popularity in healthcare delivery, offering benefits such as improved accessibility and scalability. Similarly, RMTs offer an affordable and non-intrusive way to collect data remotely through web platforms, mobile apps, sensors and wearables. They enable large-scale and geographically unrestricted studies to be conducted cost-effectively, eliminating the costs associated with face-to-face data collection. RMTs can be particularly useful for research aimed at designing timely interventions, such as those aimed at supporting caregivers of people with dementia.

However, these advances also present ethical, technological and research hurdles. Several challenges and lessons have emerged from numerous studies on iSupport-Portugal, a platform used to support informal dementia caregivers and collect data on dementia care dyads. In a nutshell, these findings highlight the need for innovation in the design, implementation and research (especially on effectiveness) of eHealth interventions and RMTs. Simply replicating traditional procedures and methods may prove insufficient.

The lessons learned from the deployment of iSupport-Portugal are relevant for international researchers, practitioners, developers and designers involved in the implementation of digital solutions for caregivers of PwD and other target groups. There is an urgent need to develop guidelines that address the ethical, technological and methodological complexities of the field to fully realise the potential of eHealth interventions and RMTs.

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