Review of methods for data collection experiments with people with dementia and the impact of COVID-19

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Abstract. The development of a wearable-based system for detecting difficulties in the daily lives of people with dementia would be highly useful in the day-to-day management of the disease. To develop such a system, it would be necessary to identify physiological indicators of the difficulties, which can be identified by analyzing physiological datasets from people with dementia. However, there is no such data available to researchers. As such, it is vital that data is collected and made available in future. In this paper we perform a review of past physiological data collection experiments conducted with people with dementia and evaluate the methods used at each stage of the experiment. Consideration is also given to the impacts and limitations imposed by the COVID-19 pandemic and lockdowns both on the people with dementia- such people being one of the most at risk and affected groups- and on the efficacy and safety of each of the methods. It is concluded that the choice of method to be utilized in future data collection experiments is heavily dependent on the type and severity of the dementia the participants are experiencing, and that the choice of remote or COVID-secure methods should be used during the COVID-19 pandemic; many of the methods reviewed could allow for the spread of the virus if utilized during a pandemic.

Keywords: Dementia, wearable, data collection, COVID-19.

1 Introduction

Dementia is a used to describe a range of symptoms which arise from several progressive neurodegenerative disorders which, through causing irreversible damage to neurons of the brain, cause the loss of cognitive functioning [1]. This neuronal damage eventually causes the patient to experience and exhibit symptoms which inhibit their ability to perform tasks in their daily life. In 2018, there were 448,300 people recorded as having dementia in England alone [2] with the global number of cases being estimated at approximately 50 million [3]. As of the writing of this paper, there is no curative treatment for dementia [4]. However, methods for the management of the disease are constantly improving with research and refinements in clinical practice, increasing the Quality of Life (QoL) and independence of people with dementia. However, caregiver burden and patient fears of loss of independence remain high despite progress made [5, 6]. The advent of personalised healthcare and wearable computing to track health could provide hope for overcoming these problems, with a system that could

track and predict the difficulties of people with dementia and automatically intervene being feasible; personalised health systems already exist for other conditions [7-11].

In previous work, we identified that one of the main problems in the development of such a system was there being no publicly available physiological data from people with dementia with which to develop machine learning based systems for identifying dementia-related symptoms and difficulties [12]. As such, it is vital that such data is collected and made available to researchers. However, the conducting of such data experiments has been complicated by the emergence of COVID-19 and resulting lockdowns. Dementia is one of the most common co-morbidities with COVID 19 [13], meaning that it is vital that people with dementia are shielded and prevented from unnecessary contact. Therefore access to participants with dementia for data collection experiments is severely reduced [14]. However, this delay in research could lead to delays in finding better treatments and management techniques which could improve the quality of life for many dementia sufferers. As such, it is important the methods to be employed by future data collection experiments are carefully considered, with special consideration being given to the impact of COVID 19 on those methods.

In this paper, we review the methods used in past data collection experiments which aimed to collect physiological data which could be used to identify dementia related difficulties. We then discuss how the COVID-19 pandemic could potentially impact the tasks required to carry out such methods. This paper is novel as no existing literature could be found which reviewed the impact of COVID-19 on the conductance of physiological data collection experiments with subjects with dementia. The rest of the paper is structured as follows. Section II describes the search methodology used to find papers. Section III elaborates on the various stages or elements of past studies and the methods involved at each, evaluating their efficacy and effectiveness. This section will also describe the difficulties COVID 19 could cause regarding those methods and propose potential solutions to those problems. Finally, section IV provides a conclusion.

2 Methodology

The literature search was performed on the online resources IEEE Xplore, ACM Digital, PubMed, Scopus, Web Of Science and Google Scholar, using pre-specified keywords. Results were filtered to include journal and conference papers from January 2015 to December 2020. A total 1514 results were returned. The title review inclusion criteria were that the title includes: the words “dementia”, “Alzheimer’s”, “cognitive impairment”, or the name of a BPSD or dementia symptom; the words monitoring, smart device, assistive device, system, technology, or the name of a sensors or physiological feature. Excluded were studies whose title mention requirements elicitation, screening, diagnosis, smartphones, mobile applications, or social robots, and review papers. All duplicate results were also removed. For abstract review, the inclusion criteria were to include all studies which: are human studies; discuss the use of wearable devices as part of the system being tested. Excluded were studies which were: Purely smartphone-based; not focused on dementia and related difficulties, or behavioural and

psychological symptoms of dementia (BPSD); not including data collection; using devices to locate missing persons; focusing on caregivers. In full paper screening, the inclusion criteria were to include studies which: include data collection experiments using people with dementia; provide sufficient details of methodology employed. Excluded were papers which: are inaccessible due to paywalls (due to financial constraints); containing data collection but with insufficient detail of methodology for meaningful critique. The methodology is illustrated in Figure 1.

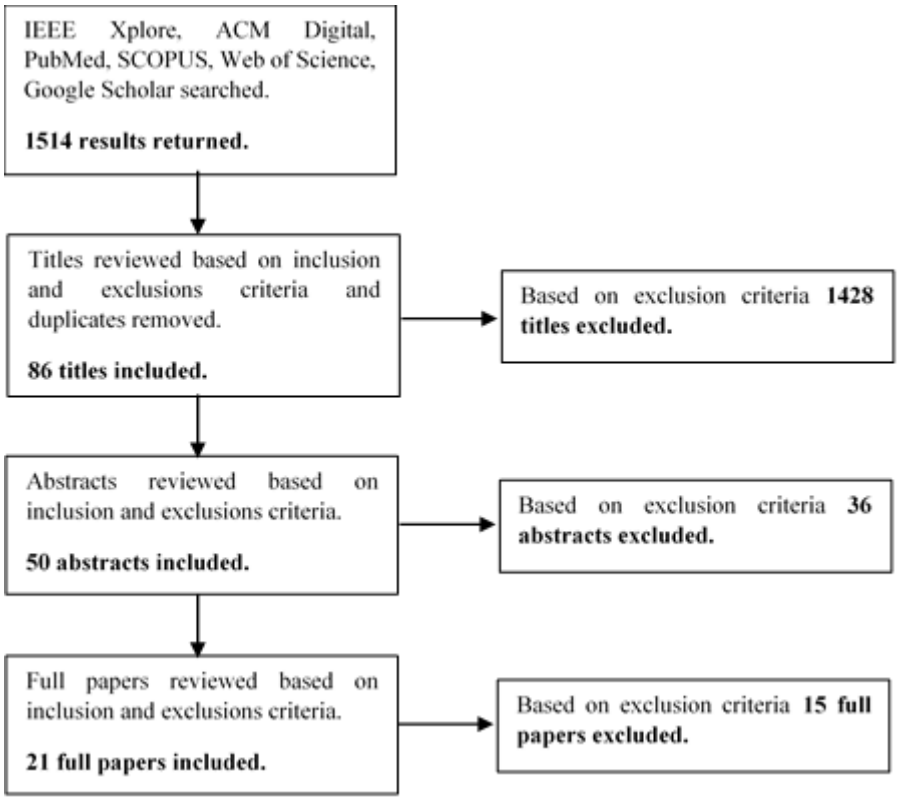

Figure 1. Search and review flow diagram

3 Discussion

3.1 Recruitment

Recruitment is the process by which study participants are identified, approached, informed, and asked to participate [15]. Recruitment was discussed in 14 papers [16-29]. Different recruitment methods are employed depending on the setting of the experiment and stage of dementia studied. In 2 papers, hospitals are used for recruitment [20, 21]. In one, the subjects were recruited as outpatients of the hospital, as the study focused on tracking behaviours in subjects in a residential settings [21]. In another paper, the

subjects were recruited as inpatients of the hospital, expected to remain in the hospital for 10 days [20]. One advantage of recruiting via hospitals is the high volume of patients admitted over any period of time, and thus, as in [20], it is easier to recruit large sample sizes over prolonged periods of time. Furthermore, the presence of trained healthcare professionals means that the patients can be medically and neuropsychological assessed with relative ease. Moreover, hospitals are often where the patient is diagnosed with dementia a, thus hospital recruitment could allow for recruitment of early stage dementia patients [30]. However, COVID 19 is likely to make this channel more difficult to use. During the COVID-19 pandemic, hospitals have been in high demand. Several services have faced delays and cancellations to prevent hospitals becoming overwhelmed [31, 32]. The number of people being diagnosed with dementia experienced a 4% drop in England in 2020 [33]. This reduces the number of potential participants. Furthermore, staff are often busy with increased patients during the pandemic, so it may be difficult to obtain permissions and co-operation from hospitals.

Another channel for recruitment is dementia-specific care homes or residential institutions, as in 8 papers [22-29].One advantage of this is that the care home will contain many potential participants. However, people in care homes are often in the moderate to severe stage of dementia, so this channel may not be ideal for recruiting people in the early stages. Furthermore, COVID 19 has been prevalent in care homes, with care home residents experiencing one of the highest mortality risks of any group during the pandemic [34, 35]. As such, access to people in care homes may not be granted. Other methods of contacting and communicating with care home residents could be adopted to overcome this, such as video conferencing, however due to the age and impairment of many of the potential participants this solution will rely heavily on the aid of care home staff, who are experiencing increased workloads and stress during the pandemic.

One channel for the recruitment of community-based subjects with dementia is community support and advocacy groups, being used in the Behavioural and Environmental Sensing and Intervention (BESI) study [17-19]. A similar channel is a dementia daycare [16], where community-based dementia patients so that their caregivers can have a break. The support and advocacy groups are likely to be more useful for the recruitment of people in the earlier stages of dementia [16]. Overall, the recruitment channel used in an experiment likely depends heavily on the setting of the experiment and the stage of dementia focused on, with hospital outpatient facilities and community support and advocacy groups being good recruitment channels for community-based experiments and hospital inpatient facilities and nursing homes being good recruitment channels for hospital and care institution-based experiments. However, COVID 19 has caused a number of support groups to cease face-to-face meetings, and that could make it more difficult to contact potential participants and guardians about the study [32]. Therefore, remote communications are likely to provide the best methods for contacting potential participants during the pandemic, but the process may be much slower.

3.2 Consent & assent acquisition

The process for acquiring consent is specifically discussed in 9 papers [16, 20, 22-28]. Due to the subjects in all the studies in the 9 papers having some level of cognitive

decline, the informed written consent is obtained from a proxy who is the subject's legal Power of Attorney (PoA) or guardian, usually a family member. In 8 papers, consent is primarily gained from the PoA, as the subjects are unable to consent [16, 22-28]. This is generally in the moderate to severe stages of dementia [15]. However, it is specified in 2 of those 8 papers that 1 subject is still able to consent, and as such their consent is obtained [25, 26]. In one paper, both the subject and PoA are asked for their consent for participation [20]. In 4 papers, it is specified that assent was gained from the subject, even if they were unable to give informed consent. For example, in [22-24] the participant's consent would be considered withdrawn if they refused to wear the device. In these cases, written consent was also acquired from a proxy, such as a PoA. To ensure that the consent was informed, before each experiment the PoA was given either written, verbal or written and verbal information about the experiment, including the procedures and ways in which they can end the subject's participation in the study should they later change their mind. The combination of written and verbal information is likely the best delivery method, as the written information can be referred back to, but the delivery of information verbally allows for the receiver to ask questions and seek clarification [15, 24]. In [24], written and verbal information was also given to the formal caregivers of the subject's, as they knew the subject well and thus would be able to provide input as to if the subject would be happy and safe to participate. Caregivers may also have to be asked for informed consent for their own participation, especially where the use of video cameras could lead to their own activities being recorded [15, 22, 23, 25, 26]. Overall, it is clearly vital to obtain informed, written consent from the subject's PoA, and assent of the subject to participate in the study should be taken into consideration. All stakeholders who are required to give consent should be given written and verbal information about the experiment. They should also be given the opportunity to withdraw consent at any stage. Moreover, contacting potential participants to inform them of the study and give adequate information to make the informed decision to participate may be difficult due to disruptions during to the pandemic [36].

3.3 Physiological data collection

Collection of physiological data is the central focus of the papers included [16-29, 37-43]. 4 aspects are highlighted: physiological data features monitored; device used; length of experiment; deployment methods and durations.

The selection of the device is heavily dependent upon the data features monitored, and the usability of the device for participants. The most used device is a smartwatch or wrist-worn medium, utilised as the lone wearable device in 12 of the included papers [17-24, 29, 40-42]. Accelerometers are the most common sensor deployed on wrists, with all but two of the papers with wrist-worn devices employing accelerometers to track movement and activity [17-20, 22, 23, 29, 40-42]. Wrist worn devices are usable with participant in all stages of dementia. An advantage of these devices is they can allow for the tracking of upper limb movement as well as full body movement, unlike chest or waist-based mediums. Wrist-worn mediums are also used in combination with other wearable devices too, with the most common combination being wrist and ankle

devices, as in 3 papers [25, 26, 44]. Two papers use wrist and ankle accelerometer devices, allowing for the detection of upper body movement and leg movement [25, 26]. In 1 paper, an ankle sensor is the only to employ an accelerometer, as well as a GPS location monitor, while a wrist-worn device tracks EDA [43]. A smartwatch is also utilised in combination with a neck-worn microphone in 1 study to detect agitation [27]. In this study, an Android smartwatch is used to track the subjects' HR and limb movements. The data collected by the smartwatch correlated with the observed instance of agitation, indicating a high degree of accuracy. The combined use of 2 devices can increase the number of data features that can be collected, as in [27] and [43], or increase the number of locations one can acquire that feature from, as in [25] and [26]. A drawback is that the management of 2 devices will be more complicated. Furthermore, the more wearables in a system the more obtrusive and obstructive that system will be.

The placement of sensors on the subject's heel is used in 1 included paper, where the researchers are tracking the walking patterns of the participant to identify disorientation [37]. The participant wears an Inertial Measurement Unit (IMU) and is asked to walk a route in a laboratory setting. The researchers then used the data from the IMU to calculate the acceleration of the subject's foot, their movement duration and speed. Though deployment of a device on the heel is successful in this study, it has a limitation: a device deployed here is very limited as to the physiological data features it can track.

In 1 included paper, a chest-worn device- the Zephyr BioHarness 3.0- is utilised to track HR data in subjects exhibiting PV [28]. The placement of the device on the chest allows for very accurate measurement of ECG, and the device had been verified as useable for elderly people with dementia [28]. However, this deployment medium cannot measure things such as limb movement, and deployment of a device onto a chest is somewhat invasive. Deployment of waist or hip worn devices is less invasive than on the chest and is utilised in 3 of the included papers [16, 38, 39]. In two of the papers, the sensor deployed at the hip is an accelerometer and in 1 paper the device deployed is a Bluetooth sensor, used to track the location of the participant in relation to environmental Bluetooth sensors. In [16], the researchers experimented with placing the sensors on the ankle, wrist or waist, and waist was selected as that was most comfortable. Furthermore, in [38] the device can be attached by a strap, or simply worn in a pocket, the latter presenting the most convenient deployment method in the review. However, the limitation of not being able to track limb movement, EDA or HR from this location, without the addition of obtrusive and invasive wires and electrodes, makes the placement ideal only in situation where one is tracking full body movements and location. COVID 19 may also impact the choice of device for an experiment, as the need to reduce physical or face-to-face contact will mean that investigators may wish to choose a device which the participant or caregiver could simply and easily deploy themselves.

Deployment method and duration are also vital considerations. In the BESI study the Pebble smartwatch is utilised to track movements of the subjects to detect agitated behaviours. The physiological data collection period was 30 days, with subject-carer dyad numbers from 3 to 10 in each study iteration [17-19]. The Pebble is worn continuously, which means that the participant is tracked 24/7 [19]. However, continuous deployment is impractical for other multi-sensor devices. These devices include the Empatica E4 wristband, utilised in [42] to acquire accelerometry, EDA, HR and HR variability data

relating to dementia-related crises, over a prolonged period of time. In this study, the device is deployed only during the day. Therefore, the researchers may miss crises the subjects experience of a night. A similar device deployment pattern is utilised also in the DAAD study, which also uses the Empatica E4 [22, 23]. In [23], the choice of deployment method is likely influenced by the collection experiment duration, with 481 days' of data being collected from 14 patients. Even a device with a low power-consumption is unlikely to last for such periods of time. Thus, for experiments with a long duration, the deployment for specific times is vital. Another deployment method is deploying the device for a short, specific period. This method is used in [28], where the Zephyr BioHarness 3.0 tracked HR in participants exhibiting PV. The belt is deployed for two 2-hour deployments, one being on a day when the participant experienced PVs and another when they did not. A similarly short duration is used in [42], where an android smartwatch and smartphone tracked limb movement, HR, and voice. These short deployment periods and short overall experimental length is thanks to observation of the participants prior to the data collection, allowing researchers to identify the best times to deploy the device. Furthermore, the participants were in the later stages of dementia, so their difficulties occurred more frequently due to their increased cognitive impairment. As such, one could argue that the more advanced participants' stage of dementia the shorter experiment duration required, however this cannot be confirmed as many included papers do not specify participants' stages of dementia. COVID-19 lockdowns may limit the time that data collection can occur, with study visits being lessened to reduce contact [36].

Table 1 Summary of physiological data collection methods and impact of COVID-19

Consideration	Methods/options	Impacts of COVID-19
Device type & placement	Wrist-worn devices have good usability, sensing modalities can be less accurate. Chest and waist devices less convenient but highly accurate sensors.	Easy to deploy devices preferable as can be deployed by the participant or caregiver, reducing human contact.
Features monitored	Limb-worn devices track limb movement and whole-body, chest and waist worn devices track whole-body. HR & EDA reliably tracked from wrist, could be more accurate from chest/palm.	The choice of features monitored not directly affected by pandemic, however features should be monitored using a pandemic-appropriate device.
Experiment duration	Shorter durations required for severe dementia as difficulties more frequent. Longer data collection periods used for people in community settings and with milder dementia.	Study visits reduced due to need for less interaction or unwillingness of participants or researchers to travel and risk disease.

3.4 Observational data collection

Observational data is a record of difficulties observed during experiments. Observational data collection methods are discussed in 16 papers. 4 different methods were

identified: self-reporting; caregiver observation; cameras; and combined caregiver and camera observation.

Self-reporting is utilised in 2 studies [21, 43]. One of the studies focused on tracking and supporting situation awareness of dementia patients outdoors [43]. Each participant completed a mobility diary, in which they recorded details on journeys outside. The paper states that the information from the mobility diary had a low accuracy when comparing it to the activities demonstrated by the physiological data. This could suggest inaccuracy in self-reporting methods. Self-reporting of observations was also utilised in [21], with the subject similarly being asked to record on a printed weekly program notes about their activities, wake up times and more. No judgement is made on the accuracy of the self-reporting. One advantage of the use of self-reporting is that it is low cost [15]. Another advantage is that this method has the fewest ethical concerns of the 4 methods as the subject is not having their privacy compromised by other people [15, 45]. Moreover, this is the most COVID-secure of the methods as it requires no contact with the participant. However, one problem with self-reporting is that a disorientated or agitated participant may be incapable or unwilling to record the experienced difficulty [46]. Furthermore, people with mild dementia are often reluctant to admit that they have experienced problems beyond what is normal for an adult [47, 48], meaning self-reporting could be skewed to only include the most undeniable difficulties. The subject may also misplace the medium for self-reporting [49, 50].

Caregiver observation is utilised alone in 8 included papers [16-19, 24, 27, 41, 42]. There are two main categories: paper-based and app-based. Paper based observations are when the caregiver records observations on paper, in a journal [41, 42] or observation chart [24]. In [42], the caregiver recorded observed difficulties primarily with an event marker button on the wearable device, but were also given a journal in which to also record the difficulties. One reason for the journals use was that while the subject was experiencing difficulties, the button may be inaccessible. Also, the button could be accidently pressed, and the journal allowed distinction of accidental presses from genuine difficulties. Finally, the journal allowed the observer to give extra context about difficulties, which could be invaluable to properly understand the collected data. Paper-based recording is also used in [41], with a caregiver recording in a sleep diary the participant's sleep patterns. The diary was accurate as a strong correlation was found between the information in the diary and the physiological data. However, the information recorded in the diary is simple and easy to quantify and the accuracy could be reduced if the information recorded was more complicated. A printed observation chart is utilised for observation recording in [24], and this overcomes the difficulty of quantifying behaviours inherent in the use of free-form mediums. This is achieved by the observer, in a 24-hour observation chart, marking specific colours for different difficulties. This means that the observations for all subjects are standardised, making it easy to compare one with another. However, a drawback of this method is that the observer may be able to record less context than if a journal or diary were used. This could make it more difficult to make full sense of the physiological data collected.

App-based recording of caregiver observations is utilised in 4 papers [17-19, 27]. In the BESI study, the caregiver is asked to record temporal, spatial and characteristic

observations about agitation episodes that they observe, using a daily survey in an Android app. No information is given on the exact nature of the survey which makes evaluating it difficult [17-19]. An Android app is also used in [27], with the observer recording difficulties by selecting from a predetermined list. This is quick and easy for the observer, allowing them to record observations in a timely manner. Furthermore, predetermined options make the observations standardised and understandable.

Another consideration for use of caregivers is if the caregiver is informal or formal. Informal caregivers (ICs) are family or friends of the participant, who care for them in a non-professional role. Formal caregivers (FCs) care for the participant professionally. FCs, as utilised in [24, 27, 42], are trained professionals and so are more likely to understand and communicate their observations using accepted medical terms, meaning their observations have a higher likelihood of being standardised and understood [51]. Furthermore, FCs will likely better understand the difficulties and when they are occurring than an IC, as FCs tend to care for multiple patients over their professional life. Moreover, FCs are likely to be available for long periods in institutional settings, where subjects are more likely to have moderate to severe dementia [52, 53]. Alternatively, ICs –used in [17-19, 41]- are more likely to be caring for the participant dementia in a home setting, as in [41] where the caregiver is the subject's sister. This means ICs are likely available to observe participants for extended periods. However, ICs are highly susceptible to stress and burden resulting from caregiving responsibilities [54, 55]. Moreover, COVID-19 may restrict time ICs can spend with the participant. In institutional settings, PCs may be in contact with participants for long periods, but likely care for multiple residents [36]. ICs who reside with participants may be able to spend more time with them, and where they cohabitate, the method is relatively COVID-secure.

Cameras are utilised alone in 2 included papers [28, 39]. In [39], cameras are set up in a mock waiting room where participants complete tasks, with the recording being later analysed to identify the types and durations of behaviours exhibited by participants. The preliminary results of the study suggest a correlation between the observation and physiological data, supporting the use of cameras in such settings. Their use is further supported in [28], where the cameras were used to record subjects on a day when they experienced PVs and a day they did not. The video was then put into analysis software and matched with the physiological data, with great accuracy. One major advantage of cameras is that the videos can be re-watched and the observations refined, increasing accuracy [22]. Furthermore, as recording of video is passive this method does not increase burden on participants or caregivers. Moreover, cameras require no interaction with participants, thus are COVID-secure. However, cameras have privacy concerns. As such, the use of cameras should be limited to shared spaces and avoided in private areas [23]. Another disadvantage of cameras is the cost [15].

A combination of caregivers and cameras is utilised in 4 of the papers included in the review [22, 23, 25, 26]. Two of those papers are from the DAAD study [22, 23]. In these studies, the caregivers recorded the agitation episodes in observational charts, highlighting when agitation occurred and recording the location and context. Simultaneously, cameras recorded the behaviours of the person with dementia in shared spaces in the care facility, and the recorded clips were later used to check and refine the initial observations. A similar combination was utilised in [25], with the researchers videoing

the subjects behaviours in the care facilities' shared spaces as a FC also recorded their observations on an observation chart. As the cameras were to be used in a shared space in the institution it was necessary for all who use that space to consent. One staff member in one home did not consent due to privacy concerns and thus cameras were not used there [25]. Similar privacy concerns are discussed in [26], in which the same combination is used. However, the authors mitigate the privacy concerns by limiting access to the recordings to 2 qualified, necessary individuals. This protects the privacy of the participant and informing them of it could allay concerns and increase the likelihood of them agreeing to participate. However, if consent is not given for the use of cameras despite this, caregivers can still gather valuable observational data.

Table 2 Summary of observational data collection methods and impacts of COVID-19.

Consideration	Methods/options	Impacts of COVID-19
Observer	Self-reporting cheap and COVID-secure but can lack accuracy. FCs accurate but lower availability while ICs less accurate but more availability. Cameras are accurate however have expense and privacy concerns.	FCs may not be able to attend or be with the participant due to increased risk of virus. Cameras and self-reporting are COVID-secure. methods as they require no human interaction.
Recording medium	Paper-based methods allow context, have low cost and are easy to use. App-based methods can be more convenient for the observer.	FCs likely to have less time with patient so app-based methods with predefined answers preferrable.

3.5 Data transfer & storage

There are 2 methods identified for inclusion for the storage of physiological data. In 7 of the papers included in the review, the data is stored locally on the wearable's internal memory as it is collected and then transfer later. In 3 of these papers, the data is transferred from the device on to a computer. In 4 of the papers, the data is transferred on from the computer onto an online or cloud service. Both methods are potentially limited by COVID 19, as the devices would need to have a wired connection established to a computer. The investigators physically removing the smartwatch would require strict COVID-secure measures such as mask wearing and hand washing before and after handling the devices [56, 57]. Alternatively, participant or caregiver could upload the data, however this may require them to have certain computer competencies and be hampered by some devices requiring licenced software do so [58].

Another method for storing the data is to have it transfer automatically, via wireless connectivity, to an edge device or a computer or server. In the BESI study, the data is transferred via Bluetooth to room level nodes set up in the experimental environment, and these edge computing devices send the data on to a server where it is stored [17-19]. In [38], the data is temporarily stored on the Bluetooth anchors and then sent to a server via Wi-Fi, while in [40], the data is transferred to a base station which then sends the data onwards to cloud-based storage. The storage of the data locally on the device

for later transfer to a computer needs little environmental infrastructure and can lead to extended battery life. However, it also means an increased workload for the researcher or caregiver who downloads the data. Wireless transfer of the data to edge computing devices or servers means reduced workloads for researchers and is useful where the data collection is to be continuous for prolonged periods. It is also the most COVID-secure method of data transfer, requiring little contact with the participants. However, this method requires the implementation of more infrastructure, which can increase the complexity and cost of the experiment [17-19]. Transfer of data to cloud-based services can allow for storage of large amounts of data [26]. However, online and cloud resources must be secured with access limited to authorised personnel.

Table 3 Summary of methods and COVID-19 considerations.

Experimental stage	Methods	COVID-19 Considerations
Recruitment	Hospitals and support groups best channels for people with mild to moderate dementia. Care homes best recruitment channel for moderate to severe dementia.	Reduced hospital services and fewer diagnoses of dementia. Care homes and hospitals are busy and less likely to cooperate.
Consent & assent acquisition	If participant has the capacity, the participant should give written informed consent. If participant does not have capacity, assent should still be obtained but written, informed consent gained from legal guardian.	Difficult to reach the participants and get consent. May be more difficult for guardians or next of kin to discuss study with the participant.
Physiological data collection	Position of one or multiple wearables can be on various body parts and depends heavily on the difficulty being tracked. Longer duration of data collection required for participants in earlier stages; they may exhibit difficulties less frequently.	Set-up or deployment of devices is more difficult to do in COVID-secure manner. Participants may be less willing or unable to travel to study locations.
Observation data collection	Self-reporting best for early stages of the disease. Can be unreliable. Caregiver observation is more reliable than self-reporting but is impractical in data collection experiments of longer duration. Cameras reliable but privacy concerns.	Self-reporting and cameras COVID-secure as no increased contact required. Formal caregivers may have less time to observe due to increased safety and hygiene requirements.
Data transfer & storage	Storing data locally on device has less infrastructure. Best for short experiments. Data streaming has increased set-up. Best for use in long experiments.	COVID-secure upload of data stored locally more difficult. Data streaming most COVID-secure as least interaction

4 Conclusion

In conclusion, there are many considerations at each stage of the experimental process, with each being given extra weight and limitations thanks to the COVID-19 epidemic. It is important that accurate and reliable physiological and observational data are collected, however participant confidentiality and dignity must be always retained, especially where the participant is vulnerable. Furthermore, dementia sufferers are a group highly impacted by COVID-19, being some one of the most likely to contract the virus, be isolated from support, and have increased risk of mortality. All of this should mean any experiments during the pandemic have minimal contact and risk of transmission. Overall, though a data collection experiment is possible during the pandemic, there are extra considerations which may make it impractical for many researchers.

Future work could aim to understand the impact of COVID-19 on data collection experiments in other domains, especially domains in which the participants have heighten risk of mortality COVID-19. Work could also focus on the collection of a physiological dataset from people with dementia, which can be used to identify the occurrences of difficulties. Such a dataset could then be used to develop a system that could detect and predict the difficulties and automatically provide a digital intervention, reducing caregiver burden and increasing patient independence and QoL.

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