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Brief Report

Parental home-based pulse oximetry monitoring for adults with intellectual disabilities at risk of serious respiratory problems including COVID-19: a brief report

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Abstract

Background People with intellectual disabilities (ID) are at high risk of developing respiratory health issues. The COVID-19 pandemic has compounded this, with serious consequences, and for some, death. Despite home-based oxygen saturation monitoring being recommended for people with ID, there is a stark lack of evidence in the literature on its feasibility.
Method We conducted 3-day baseline home-based oxygen saturation monitoring, using pulse oximeters, with eight parents of nine adults with ID in Scotland. Two eligible parents also completed a further 2 weeks of monitoring, and returned an evaluation questionnaire on its feasibility.
Results Baseline mean readings for eight adults with ID were within the normal range (%Spo_2 ≥ 95), and for another one 94%. Fluctuations over the 3-day assessment period were experienced by six of these individuals. However, these variations were within limits which are not dangerous (lowest reading 92%), implying that parental home-based pulse oximetry monitoring is likely to be safe for adults with ID. The two parents who completed the evaluation found home-based pulse oximetry monitoring to be easy/very easy to do, and effective/very effective.
Conclusions This is the first research study, albeit with a very small sample, to report on the potential feasibility of parental home-based pulse oximetry monitoring for adults with ID. Home-based pulse oximetry monitoring appears to be safe in adults with ID at risk of developing serious respiratory problems, and not difficult for their parents to do. There is an urgent need to replicate this work, using a larger sample, to promote home-based respiratory health monitoring more widely for people with ID.

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Keywords intellectual disabilities, oxygen saturation, parent-carers, pulse oximetry, respiratory health monitoring

Introduction

People with intellectual disabilities (ID) account for between 1% and 3% of the population globally (Maulik *et al.* 2011), and are defined according to the following set of three ICD-11 criteria: having impairments in adaptive, social and intellectual functioning (IQ < 70); requiring a need for daily support; with the onset in the developmental stage before the age of eighteen (World Health Organization 2022). The number of people on the Learning Disability register of UK General Practitioners (GP) is around 0.5% of the total general practice population (NHS digital 2021). However, this is likely to be an under-estimation of the number of people with ID receiving primary care, as not all these individuals are identified as having ID on GP records (Pouls *et al.* 2022). People with ID are much more likely to experience respiratory system health conditions, compared with the general population, which can lead to serious illness or death. Respiratory disorders are a leading cause of death in people with ID (Truesdale *et al.* 2021). These include asthma, chronic obstructive pulmonary disease (COPD), upper airway obstruction, inability to cough, lung compression from deformities of the spine and thorax, recurring chest infections, and aspiration pneumonia secondary to dysphagia (Emerson *et al.* 2016; Chang *et al.* 2017; Egan & Dalton 2020; Truesdale *et al.* 2021). A recent review of respiratory-associated deaths in people with ID has demonstrated that respiratory mortality is 11 times more common in these individuals compared with the general population. Pneumonia as a cause of death is up to 26 times more likely in people with ID, than their general population counterparts, the largest difference seen in those with severe or profound ID (Truesdale *et al.* 2021). Risk factors identified for this include, low uptake of the influenza vaccine amongst people with ID, aspiration pneumonia secondary to dysphagia, and epilepsy and cerebral palsy in children with ID (Truesdale *et al.* 2021).

During the COVID-19 pandemic, people with ID have been, and still are, particularly at risk, due to their compromised or vulnerable respiratory status. During the spread of COVID-19 in the United Kingdom in 2020, the Care Quality Commission (2020) found that the death rate for adults with ID had doubled over a 5-week period, compared with the same 5-week period in the preceding year (10th April to 15th May 2020). A more recent analysis found that the population of people with ID has been five times more likely to be hospitalised with COVID-19, and eight times more likely to die as a result of COVID-19, compared with the general population (Williamson *et al.* 2021). A more positive picture from Ireland, which reported markedly lower infection and death rates from COVID-19 for people with ID, demonstrated that their recognition there as a vulnerable group during the pandemic, and measures taken to protect them, were key to reducing risk impact (McCarro *et al.* 2021).

Heslop *et al.* (2021) analysed the deaths of 163 people with ID from COVID-19 in England – 74% of whom had a pre-existing respiratory condition – and found that they were most likely to present with breathing difficulties as their main symptom prior to death (73%). As a result, Heslop *et al.* (2021) highlighted the vital need to be able to detect and act promptly on symptoms of a person's health deteriorating, to avoid death, and strongly recommended that oxygen saturation monitors be made available to carers of people with ID in home-based settings to be able to detect symptoms earlier.

The onset of the COVID-19 pandemic has seen more widespread use of pulse oximeters, which measure oxygen saturation. As people with COVID-19 can experience a potentially dangerous drop in oxygen saturation – known as silent hypoxia – without having clinically obvious breathing problems, a pulse oximeter can be useful for health monitoring in a care setting or remotely at home (NHS England 2020). This is particularly relevant to people with ID, who can experience difficulties communicating discomfort or ill health; and who are already known to be at risk of experiencing respiratory issues across their lifespan. In their recent systematic review of remote pulse oximetry use with COVID-19 patients, Alboksmaty *et al.* (2022) found that Spo_2 monitoring using pulse oximetry did enable identification of an early sign of deterioration.

Paid and unpaid carers of people with ID have a potentially important role in their health monitoring, to promote and maintain health and wellbeing (Hithersay *et al*. 2014). Yet, whilst their role as health care givers (e.g. administering medication) is gaining recognition in the literature (Doyle 2022), little or no attention has been given to their potential roles in health monitoring and promotion. During the COVID-19 pandemic and beyond, it is important to upskill and include carers of people with ID in monitoring their respiratory health, as this may lead to earlier diagnosis, and inform guidance of treatment (NHS England 2020). The vast majority of people with ID in the United Kingdom live in the community, either in residential or supported living settings with paid support, or at home with their families. At least one-third of adults with ID live with their families, mainly their parents (Scottish Commission for Learning Disabilities 2019). Previous research on home-based pulse oximetry monitoring by parent-carers of children with respiratory conditions has demonstrated that, whilst this can increase their confidence/efficacy in the care of their child, they may also worry or become alarmed due to low oxygen level readings (Chi *et al*. 2020). Previous research however, has been limited to parent-carers of children without ID.

The aim of this research was to test the feasibility of home-based pulse oximetry monitoring with parents of adults with ID at risk of developing serious respiratory problems, including COVID-19. In doing so, the intentions were to determine the baseline readings for a sample of adults with ID, for whom respiratory health monitoring was particularly important; and report on the safety and parents' experiences of doing this (e.g. whether they found it easy or difficult).

Method

Participants and procedure

Parents caring for their adult son or daughter with ID at home were invited to take part in this research over a 4-month study period (May to August 2021). The project information was distributed by four third sector organisations in Scotland, who provide advice and support to people with ID and their families. This information was distributed electronically via emails, newsletters, and online carer support groups/forums, as COVID-19 restrictions in Scotland were just beginning to ease over this period. Parents who received the information, and chose to take part, responded by telephone or email. They were included if they cared for an adult son or daughter with ID with a known respiratory condition (e.g. asthma or COPD), or who were at risk of developing a respiratory condition (e.g. people with dysphagia and/or severe or profound ID). Parents caring for an adult son or daughter with ID with an acute respiratory or febrile illness, including COVID-19 diagnosed by a positive swab test, were excluded. All eligible parents who chose to take part were telephoned by the lead researcher (JF), to ensure they understood the project information, and to allow opportunity for them to ask any questions. Their written consent to take part was then obtained by post.

Each parent who returned their written consent was sent a postal questionnaire, to collect demographic and health information about themselves and the person with ID they cared for. They were also sent a pulse oximeter and digital thermometer, with health monitoring instructions and monitoring charts. These instructions and monitoring charts were also talked through, and discussed, with each person via a telephone call from the lead author. Parents were asked to collect the person's oxygen saturation, heart rate and body temperature readings at the same time three times per day (morning, afternoon and evening) – after their relative had rested for at least 5 min – over a 3-day baseline period. They were advised to consult their family GP or NHS 111 if any of these readings were outside the normal range ($\%Spo_2 \geq 95$).

With the parent's consent, the family GP was notified by the research team that they were taking part in the research.

Parents who reported one or more $\%Spo_2$ baseline readings less than 95 over the 3-day assessment period, were not asked to continue with the evaluation component of this research. They were advised to contact their family GP if they did not know why their relative with ID's $\%Spo_2$ reading was lower than 95. Similar advice was applicable to heart rate or body temperature readings outside the normal range. Parents who did not report a $\%Spo_2$ reading less than 95 over the baseline assessment period for their relative with ID, were then asked to take part in the

evaluation. This involved taking and recording their relative's oxygen saturation, heart rate and body temperature readings at the same time three times per day for a further 2 weeks, and completing an evaluation questionnaire. Any %Spo_2 reading below 95 reported during the evaluation period was followed up by the lead researcher (J. F.), who telephoned the parent to learn what advice they sought and who from, and what action they took, if any.

Materials

Two postal questionnaires were developed by the research team, with assistance from an advisory team of three parents of adults with ID, and one respiratory nurse consultant. These were piloted with two other parents of people with ID. Health monitoring recording sheets, and an accessible guide on how to use the pulse oximeter and thermometer, were also developed by the research and advisory teams.

A *Kinetik Wellbeing* finger pulse oximeter, and a *Reliance Medical* oral digital thermometer, were posted to each parent. Both models were the same ones being issued by the NHS at the time, and were available to buy cheaply on the high street. Most pulse oximeters do not require calibration, as this is done during the development phase. According to the manufacturer, the pulse oximeter reads %Spo_2 with an accuracy of +/− 2% between 70–100%, and measures pulse with an accuracy of +/− 2 beats per minute.

Analysis

IBM SPSS version 26 was used to compute frequency and descriptive statistics. Baseline and 2-week oxygen saturation, heart rate, and body temperature readings were calculated as means of all readings taken over the assessment period. Qualitative data collected via open-ended questions in the evaluation questionnaire were reported verbatim.

Results

Baseline readings for adults with ID

Eight parents of nine adults with ID took part in this research (one mother cared for a son and daughter), and returned baseline oxygen saturation, heart rate and body temperature readings for their relative (Table 1). None of the parents reported any difficulties collecting this data, or found it burdensome, during a follow-up telephone call with the lead author. Six of these nine adults with ID experienced at least one Spo_2 reading below 95% over the 3-day assessment period, and therefore were not included in further assessment or evaluation as per our research protocol.

About the parents and their relatives with ID

Six of the eight parents also returned a demographic and health questionnaire about seven relatives with ID. Four of the six parents were mothers, and their mean age was 68 years (ranging from 59 to 80 years).

Table 1 Baseline pulse oximeter and temperature readings of adults with ID ($N = 9$)

Adult with LD	Pulse oximeter: Oxygen level (%$Sp0_2$)			Pulse oximeter: Heart rate (bpm)			Thermometer: Body temperature (°C)		
	Mean	Range	SD	Mean	Range	SD	Mean	Range	SD
1	94	93–97*	1.25	75	74–78	1.13	36.5	35.9–37.0	0.32
2	96	96–97	0.49	66	62–78	4.69	35.7	35.1–35.9	0.38
3	95	93–96*	0.94	67	60–72	3.89	35.1	33.9–36.1	0.69
4	95	92–98*	1.88	80	63–99	12.97	36.9	36.4–37.7	0.43
5	98	96–99	0.82	84	80–94	4.14	36.7	36.2–36.9	0.19
6	96	92–99*	1.99	51	42–58	4.76	35.9	35.5–36.7	0.49
7	96	93–98*	1.66	78	67–88	6.96	35.9	34.9–36.8	0.65
8	96	94–98*	1.37	57	48–66	5.12	35.8	34.8–36.7	0.64
9	96	95–96	0.47	91	85–106	5.98	36.7	36.3–37.2	0.39

At least one %Sp02 reading less than 95 over the 3-day assessment period.

All six parents had used a thermometer with their relative with ID at home before, but four had never used a pulse oximeter with their relative before, or any other type of health monitoring device (e.g. blood pressure monitor).

Of the seven adults with ID, five were male, and their mean age was 34 (ranging from 19 to 53 years). Their health information is provided in Table 2.

By the time of conducting this research, all six parents and their seven relatives with ID had received two doses of a COVID-19 vaccine. Only one parent, and one adult with ID, had tested positive for COVID-19 prior to their vaccination.

Home-based pulse oximetry evaluation

Three of the initial eight parents were eligible to take part in the evaluation, which included a further 2-week assessment period following the 3-day baseline assessment. However, as one withdrew for personal reasons, only two parents took part in the evaluation. A summary of the oxygen saturation, heart rate and thermometer readings for their relatives with ID over this 2-week period are presented in Table 3.

One of the adults with ID experienced a low $\%Spo_2$ reading of 66 once during this period. His parent did not seek advice, or take action for this, as she believed the low reading was due to his hands being cold after being outside.

Evaluation of home-based pulse oximetry monitoring completed by two parents is reported in Table 4.

Discussion

Summary

Baseline assessment of nine adults with ID at risk of serious respiratory problems showed that in eight cases mean oxygen saturation was within the normal range ($\%Spo_2 \geq 95$), and in one case it was 94% over a 3-day period with three measurement/s per day. However, fluctuations over this period were experienced by six of the nine adults, the lowest reading being 92%. Adults with ID at risk of developing serious respiratory problems can experience fluctuations in their oxygen levels; and as such, input from their GP or health care professional who knows them well is recommended, to tailor home-based respiratory health monitoring to the individual with ID, and offer support and guidance to their carer/s. However, as the fluctuations demonstrated in this study are within limits which are not dangerous, this implies that home-based oxygen levels monitoring by carers of adults with ID are probably safe once the correct measuring technique has been mastered. Following their systematic review of the literature on remote pulse oximetry monitoring, which was published after our study was completed, Alboksmaty *et al.* (2022) have made the following best practice recommendations: both at-rest (after 5–10 minutes of rest) and post-exertional (e.g. after conducting the one-minute sit-to-stand test) Spo_2 readings should be taken for each person; and that Spo_2 of 92% should be considered as the minimum threshold to indicate care escalation, or a decrease of Spo_2 by 3% for more vulnerable people with multiple comorbidities.

In terms of the feasibility of parental home-based pulse oximetry monitoring, all of the initial eight parents complied with monitoring during the 3-day baseline assessment. None of these parents found it difficult to do, or burdensome. Of the two eligible parents who completed a further 2 weeks of monitoring and its evaluation, both parents found the pulse oximeter easy or very easy to use, and effective or very effective in monitoring their relative's respiratory health. Both parents highlighted potential issues around taking inaccurate readings One parent related this to a previous experience with his son with ID, who previously had been admitted to hospital unnecessarily, due to a health professional not realising that his low blood pressure reading was actually normal for him. This accentuates our earlier point about the importance of health professionals who know the person with ID and their medical history well, to optimise their health monitoring, to promote and maintain wellbeing.

Five of seven adults with ID in this research had severe or profound ID (six being reported by their parents as having complex needs), with four having multiple co-morbidities (three or more health conditions). Despite this, four of six parents had never used a health monitoring device, other than a thermometer, at home with their relative before. This may indicate a wider need to include and support parents of ID in monitoring their relatives' health.

Table 2 Demographic and health information questionnaire

	Adults with LD
Sex	Male 5
	Female 2
Median (range) age in years	38 (19–53)
Ethnicity	White 7
Have they been tested for COVID-19?	Yes, positive result 1
	Yes, negative result 4
	No 2
Have they had a COVID-19 vaccine?	Yes, two doses 7
Cause of LD	Down syndrome 4
	Unknown 2
	Birth trauma 1
Level of LD	Moderate 2
	Severe 3
	Profound 2
Do they have complex needs?	Yes 6
	No 1
Number of known health conditions	1-2 health conditions 3
	3–4 health conditions 3
	5–6 health conditions 1
Known health conditions	Cerebral palsy 3
	Hypothyroidism 3
	Epilepsy 2
	Asthma 2
	Autism 2
	Unspecified heart condition 1
	Aortic stenosis 1
	Heart murmur 1
	Dysphagia 1
	Scoliosis 1
	Sleep apnoea 1
	Anxiety 1
	Depression 1
	Bowel problems 1
	Obesity 1
Number of prescribed medications	No prescribed medications 2
	1–2 prescribed medications 3
	3–4 prescribed medications 0
	5–6 prescribed medications 0
	More than 6 prescribed medications 2
Did the parent anticipate their relative with LD would have at least one %Sp02 reading less than 95 during baseline assessment?	Yes, because of having Down syndrome 2
	Yes, because of their dysphagia 1
	Yes, because of their asthma 1
	No 3
Has the person with LD ever been admitted to hospital with respiratory problems, or developed respiratory problems whilst in hospital?	Yes, chest infections 1
	Yes, %Sp02 reading less than 90 1
	No 5

Strengths and limitations

This is the first study to evaluate the feasibility of parental home-based pulse oximetry monitoring for adults with ID at risk of developing serious respiratory problems. The main limitation is the extremely small sample size, preventing conclusions. However, no concerns arise as a result of this study in relation to

Table 3 Summary of pulse oximeter and thermometer readings collected over the 2-week evaluation period for two adults with LDs

Adult with LDs	Pulse oximeter: Oxygen level (%Sp02)			Pulse oximeter: Heart rate (PR bpm)			Thermometer: Body temperature (°C)		
	Mean	Range	SD	Mean	Range	SD	Mean	Range	SD
1	96	95–99	1.03	67	57–80	5.52	35.6	34.4–36.8	0.52
2	96	66–99	5.44	82	60–88	4.66	36.3	34.6–36.8	0.36

the safety of vital signs measurement in the home by parents of people with ID. Indeed, our very limited evidence only shows potential benefits, which implies that further studies should be pursued.

Our recruitment strategy was only able to recruit eight (27%) of our target sample of 30 parents of adults with ID, and was therefore ineffective. However, this may at least partly be due to the inability of meeting potential study participants in person within a research study, which was caused by COVID-19 restrictions. The lack of an in-person demonstration of a technique for measurement of vital signs might have been a key reason for potential participants not to join the study. An alternative recruitment strategy, to recruit participants via general practices or community ID health care teams, would not have been feasible during the pandemic either, as health care services were under extreme strain during this time. The study period was also once both parents and their relatives with ID had received a double COVID-19 vaccine, and COVID-19 restrictions were being eased, so self-selecting parents may not have felt respiratory health monitoring was as important by this time. We do not know how many parents were able to access information about our research during participant recruitment, and as such, strongly recommend that future studies do not attempt to recruit parent-carers of adults with ID via electronic means only.

We did find that eight parents found pulse oximetry monitoring easy to do, in terms of, for example, following instructions, and was not burdensome. However, any potential issues were only considered over a 3-day assessment period for six of the eight parents, and monitoring over a longer period should be conducted to check for and identify any challenges, and how they may be overcome. In terms of long-term or continual pulse oximetry monitoring, for example, the use of smart technology (e.g. smart watches) or wearable pulse oximeters (Buekers *et al.* 2019) may have more utility for this (Alboksmaty *et al.* 2022).

Comparison with existing literature

The lack of comparable literature is stark, given that people with ID are at much higher risk of developing serious respiratory conditions, compared with the general population (Truesdale *et al.* 2021), and have been particularly vulnerable during the COVID-19 pandemic (Williamson *et al.* 2021). Evaluation of home-based pulse oximetry monitoring by two parents of adults with ID in this study did report the same confidence in monitoring their health and respiratory health as other parents, but not the same worry or alarm about low readings (Chi *et al.* 2020); although they did voice concerns about taking inaccurate readings. Indeed, one parent who reported one Spo_2 of 66% for her son with ID, did not panic and realised the reading was inaccurate due to her son having cold hands after being outside. However, our strict study protocol excluded those adults with ID who did experience at least one Spo_2 reading below 95% during baseline assessment. Hence, the views and experiences of parents who were more likely to record lower, thus worrying readings, were not sought. There is an urgent need to refine and replicate this study in a larger sample of parents, to determine the views and experiences of parents of people with ID in respiratory health monitoring, and its feasibility. Further research on paid carers of adults with ID is also warranted.

Implications for research and practice

New research (Heslop *et al.* 2021) has highlighted that the COVID-19 pandemic has compounded the

Table 4 Parents' evaluation of home-based pulse oximeter and thermometer monitoring for their relatives with LD ($N = 2$)

1	**How easy was it for you (or another member of your household/care team) to use the pulse oximeter with your relative?**	**Very easy 1** **Easy 1**
2	How useful did you (or another member of your household/care team) find it using the pulse oximeter to monitor your relative's respiratory health?	Very useful 2
3	How effective do you (or another member of your household/care team) think the pulse oximeter is for monitoring your relative's respiratory health?	Very effective 1 Effective 1
4	How easy was it for you (or another member of your household/care team) to use the thermometer to monitor your relative's body temperature?	Very easy 1 Easy 1
5	How useful did you (or another member of your household/care team) find it using the thermometer to monitor your relative's body temperature?	Very useful 2
6	How effective do you (or another member of your household/care team) think the thermometer is for monitoring your relative's body temperature?	Very effective 2
7	How confident do you (or another member of your household/care team) feel now about being able to monitor your relative's general health at home?	Very confident 1 Confident 1
8	How confident do you (or another member of your household/care team) feel now about being able to monitor your relative's respiratory health at home?	Very confident 1 *Missing data 1*
9	Please tell us about any positive aspects or benefits you (or another member of your household/care team) found, to using the pulse oximeter and thermometer with your relative.	Parent 1: *My son has congenital hard disease, and at times he can experience cold hands and/or pins and needles. I thought this may be due to poor circulation and oxygen not getting through due to his condition. This study has shown me that his oxygen levels are good.* Parent 2: *Useful skill to learn due to the COVID-19 pandemic. Very handy to have at home for my son and the family. Very simple to use.*
10	Please tell us about any negative aspects or benefits you (or another member of your household/care team) found, to using the pulse oximeter and thermometer with your relative.	Parent 1: *It was difficult to follow the instructions for using the pulse oximeter at first. Not being able to follow advice/instructions can result in taking wrong readings.* Parent 2: *Potential risk of the pulse oximeter failing/being inaccurate and an illness, particularly a heart problem, not being detected.*
11	Did you (or another member of your household/care team) use the pulse oximeter to monitor your own health at any time during the two-week period?	No 1 Yes 1
12	Is there anything else you would like to tell us?	Parent 1: *Studies need to 'look at the individual and not the manual'. My son previously took part in a research project about health. He was identified as having low bloods pressure (which is normal for him) and sent to hospital unnecessarily. The cardiologist at the hospital gave him the all clear, but he missed an important social event because he had to go to hospital.* Parent 2: *Definitely a valuable addition to any family home with medical needs or not. It takes away the element of many worries instantaneously.*

Responses to 1–8 are based on 5-point Likert scales. Responses to 9, 10 & 12 are based on open-ended questions. Responses to 11 are based on a closed question.

respiratory health concerns of people with ID, with serious and for some, fatal consequences. It has also shown the vital need to upskill carers on oxygen saturation monitoring for the people with ID they care for or support. Our study is a first step in this direction, as it demonstrates that parental home-based pulse oximetry monitoring is likely to be safe for adults with ID who live at home with their families. However, there is need for support and guidance from a family GP or health professional who knows the person with ID, and their medical history, well. It will also be important to instil best practice recommendations on home-based pulse oximetry use when promoting respiratory health monitoring for people with ID community-wide (Alboksmaty *et al*. 2022). People with ID experience a number of health issues more commonly, compared with the wider population. Our study also indicates that parent-carers of adults with ID, and perhaps carers of adults with ID more widely, could benefit from further support and guidance with overall health monitoring at home.

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Conflict of interest

The authors have no conflicts of interests to declare.

Ethical approval

This research was ethically approved by the School of Health and Life Sciences Research Ethics Committee, Glasgow Caledonian University, Scotland, UK.

Data availability statement

The data is available on request from the authors.

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