

NARRATIVE/SYSTEMATIC REVIEWS/META-ANALYSIS

The Use of Telehealth Technology in the Medical Management of Adults With Intellectual Disability: A Scoping Review

Chuka Bonaventure Ohazurike, MBBS, MS Public Health¹, Sarah Abere, MBBCH, FMCP, AGAF, MSc Gastroenterology & Hepatology (USW), Cert Digital Health (QMUL)², and Boma Oyan, MBBS, FMCP²

School of Medicine, University of Limerick, Limerick, Ireland; ²Department of Internal Medicine, Rivers State University Teaching Hospital, Port Harcourt, Nigeria

Corresponding Author: Sarah Abere, sarah.abere@ust.edu.ng

DOI: https://doi.org/10.30953/thmt.v9.524

Keywords: adults, applications, intellectual disability, management, technologies, telehealth

Abstract

Background: Individuals with intellectual disability (ID) experience substantial inequalities and barriers to accessing healthcare despite requiring ongoing access to their healthcare providers, as they are more likely to die from avoidable causes of death than those without ID. Telehealth technologies have the capacity to improve access to healthcare providers and information and could reduce morbidity and mortality rates in this population. This review explores the application of mobile health technology in the medical management of adults with ID.

Methodology: PubMed, Institute of Electrical and Electronic Engineers Xplore (IEEE Xplore), Association of Computing Machinery, and Scopus databases were examined to extract peer-reviewed articles published between January 2000 and January 2022. Original research published in English on the use of telehealth technologies in the medical management of ID was deemed eligible. A narrative synthesis of study results structured around telehealth technologies used and outcomes was completed.

Results: Thirteen of 1,008 reviewed articles—mostly small-scale cross-sectional studies—were eligible for inclusion. Most of the studies (n = 8) used videoconferencing platforms for real-time telehealth, while three focused on symptom or medication monitoring applications. The evidence supports the feasibility and potential effectiveness of telehealth to manage ID among adults. Users were generally satisfied with the telehealth technologies. Accessibility issues, including poor internet connectivity and poor knowledge of technology, might limit the use of telehealth in the management of ID.

Conclusion: The use of telehealth was feasible, acceptable, and potentially effective for the management of ID among adults, although the varied methodology of included studies may be inadequate. A more structured methodology will be useful in future studies.

Plain Language Summary

People with intellectual disability (ID) have challenges accessing healthcare and are likely to die from avoidable causes of death. Telehealth technologies can help improve access to healthcare in these individuals. In this review, databases on the use of telehealth technologies in the medical management of ID published between January 2000 and January 2022 were examined, and 13 studies were extracted. Telehealth platforms such as videoconferencing were found to be feasible, acceptable, effective, and satisfying for the management of adults with ID, although poor technological knowledge and internet access could limit their use.

Received: September 2, 2024; Accepted: October 9, 2024; Published: October 31, 2024

(page number not for citation purpose)

ccording to the World Health Organization, intellectual disability (ID) connotes a reduction in the ability to understand new or complex information and learn and apply new skills, which often leads to a reduced ability for independent living, causing impaired social functioning. It begins during childhood and has a continuous effect on development. In addition, the American Association on Intellectual and Developmental Disabilities defines ID as "a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 22."2 Hence, ID affects two general areas: intellectual functioning (such as learning ability, problemsolving, and judgment) and adaptive functioning (e.g., independent living and communication).3

The prevalence of ID varies across countries and continents, although most of the studies about its burden are conducted in high-income countries. A meta-analysis of 52 studies from 27 countries found a prevalence of 1% for ID, with the highest rates seen in low- and middle-income countries.⁴ A more recent systematic review reported a prevalence range of 0.05% to 1.55%.⁵ In the United States, 1.2% of the population is intellectually disabled,⁶ which is similar to 1.4% of the population in Ireland.⁷

In addition to the general burden of ID, its effects on the families of those who are intellectually disabled are enormous. Caregivers of persons with ID experience numerous disruptions in their daily routines and are often burdened with frequent hospital visits for follow-up of the patients, even up to adulthood. These caregivers experience significant emotional, physical, and financial challenges as a result of caring for an individual with ID.8

Technological advancements in the health sector have brought substantial improvement in ensuring access to and smooth delivery of quality health care. 9,10 These technological advancements are particularly useful in the management of chronic diseases—improving health management and health promotion. 10–12 Management of ID places significant pressure on patients, communities, and healthcare systems worldwide. 8 Most chronic conditions, such as ID, are managed with the inclusion of home-management programs in routine management. 10

It has also been shown that people with ID can be trained to varying extents of self-management.¹³ Hence, the use of mobile applications in the medical management of ID is innovative and feasible, especially with the surge in the usage of smartphones and personal computers.

Individuals with ID experience substantial health inequalities and barriers to accessing health care. 14,15 They require constant accessibility to their healthcare providers as they are more likely to die from avoidable

causes of death than those without ID.^{14,15} Mobile technologies can be utilized to improve access to health providers, and to health information when needed. This has the potential to reduce the morbidity and mortality rate among people with ID. Several studies have been conducted on the use of such health technologies in the management of ID.^{16,17}

This scoping review sets out to identify and synthesize the available evidence on the usefulness, advantages and/ or limitations of telehealth technologies, especially mobile health technologies for all forms of adult ID. This review also assessed the impact and the user acceptability/satisfaction of telehealth technology for the medical management of adults with ID.

Methodology

Rationale for Carrying Out a Scoping Review

Scoping reviews are a "preliminary assessment of the potential size and scope of available research literature." The aim is to identify the nature and extent of available research evidence. The use of technology in the management of ID is relatively new, which necessitates the use of a scoping review. Healthcare practitioners are typically expected to incorporate the best available current information in their clinical practice. Hence, evidence-based practice requires a systematic approach to acquire and use the available medical knowledge. The results reported here assess the current usage of mobile technologies in the management of ID among adults.

Information Sources

It is recommended that multiple databases be used along with additional methods in order to identify all relevant studies related to the subject of interest. ^{20,21} The following databases were searched to identify relevant articles for this study: PubMed, Institute of Electrical and Electronic Engineers Xplore, Association of Computing Machinery (ACM), and Scopus. They were searched for articles published from January 2000 to January 2022. This time frame was set in order to identify only contemporary mobile health applications that are likely to be still relevant today. Furthermore, the bibliographies of included articles were hand-searched to identify relevant studies. Google Scholar was searched as well.

Search Strategy

The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines for reporting scoping reviews were followed.²² The Population, Intervention, Comparison, and Outcome (PICO) format was used to arrive at the search terms for this review. Free text and Medical Subject Headings (MeSH) terms were combined in order to arrive at a comprehensive search strategy. The

common types of ID were specified in the search term to allow for retrieval of as many relevant articles as possible. The keywords were combined with Boolean search connectors to streamline the search.²³ The Boolean connector "OR" was used between similar words to expand the search, while "AND" was used to join the key terms with the aim of narrowing the search. It was optimized and translated for use in each database.²⁴

Eligibility Criteria

Table 1 lists inclusion criteria using the PICO framework. Exclusion criteria included studies focused only on other cognitive impairments, such as dementia and traumatic brain injury, as well as studies using health technologies limited to inpatient management of people with ID. Additionally, studies using other forms of mobile technologies besides health-related ones (e.g., gaming applications) were not included in this review. Studies on applications and telehealth services that were not focused on the health aspect of ID were excluded, including mobile health for improving social interactions, diet only, or exercise only. All articles published in a language other than English, secondary papers (e.g., literature reviews), editorials, as well as opinion papers were excluded from this review.

Selection Process

All studies identified in each database were imported into Rayyan software for screening using their title and abstract. Three reviewers were involved in the title and abstract screening. Firstly, the first 100 publications were screened, and the screening criteria were amended based on the results. Afterward, two reviewers carried out full-text screening, and disagreements were resolved

by consensus and by a discussion with the third reviewer. Subsequently, all relevant studies were exported to the EndNote reference manager.

Data Extraction and Synthesis

Data extraction was carried out by a single reviewer and verified by another reviewer (supervisor). Errors were limited by the use of a pre-structured data extraction sheet, which two reviewers carefully designed. This was initially pre-tested using three studies to ensure all the required information was extracted. The data extracted from the included studies are listed in Table 2.

Data synthesis was conducted using a narrative synthesis approach to collate and summarize the literature.

Table 2. Data extracted from the included studies.

Parameter	Inclusion criteria	
Study characteristics	Authors	
	• Country	
	Population	
	Sample size	
	Study design	
	Year of data collection	
	Year of publication	
Intervention	Device used	
	• End users	
	• Name	
Outcome	 Findings 	
	Framework	
	Outcome scale	
Limitations	 Study/technology 	

Table 1. Inclusion criteria using the PICO framework.

Parameter	Inclusion criteria		
Participants	Individuals over 18 years of age		
	Both genders		
	Any form of intellectual disability		
Intervention:	Various telehealth technologies for the medical management of ID at home.		
	• Studies on consulting applications, telehealth websites, prescription applications etc., used by the patient/caregiver to assess healthcare for the management of ID.		
Comparison studies	Use of these technologies for regular face-to-face healthcare provision.		
Outcome measures	• Effectiveness, utility, advantages, disadvantages, or patient satisfaction rate when using mobile health technologies to manage ID.		
Study design	Randomized control trials		
	Non-randomized control trials		
	Observational studies of primary research articles		
Regions, languages and	No limitation on the region or countries of publication		
publication date:	 *English language studies between January 2000 and January 2022 		

^{*}In order to focus on the review of recent technologies developed in the last 22 years, which are likely still in use. ID: intellectual disability.

Similar technologies were grouped into descriptive categories and generated narrative summaries of the information per topic. The narrative synthesis was conducted using these categories to allow for the transparent synthesis of the results.²⁵ The studies were grouped based on their function and the study outcomes.

Results

Study Selection Process

A detailed search of the four databases selected for the study retrieved 1,008 articles, which were reduced to 785 after de-duplication. Furthermore, searches of other sources, including Google Scholar and a manual reference search, retrieved 17 articles. A total of 806 articles underwent title/abstract screening, after which 96 were considered eligible for full-text screening. After full-text screening, 13 articles were eligible to be included in this review. A PRISMA flow diagram illustrating the study selection process is shown in Figure 1.

Characteristics of Included Studies

The included studies were conducted between 2016 and 2021, most of which were quantitative studies and observational studies with sample sizes ranging from 1 in a single-case experimental study, to 947 participants (Table 3).

Intervention Platforms, Design, Outcomes and Key Findings The interventions in this review ranged from web-based applications to mobile applications and videoconferencing

applications (Table 4). Most studies used videoconferencing platforms.8 For instance, Hepburn et al.38 used a videoconferencing program known as OoVoo because it allowed for up to six simultaneous users, and the screen configuration included a window for each of the participating families and therapists. Two studies focused on tracking applications for symptoms, 28,36 and one on medications.³⁷ One study used a web-based application²⁸ developed to support in-person treatment sessions. Hence, it reminded clients of weekly goals and exercises, and it contained a "help" button, among other features, with which clients could reach the providers.³² Conversely, Gibson and Dunlop²⁷ designed an application that helped patients communicate their symptoms using imagery. The majority of the interventions were designed for patients, caregivers and their service providers. These included a symptom-tracking, and monitoring application³⁶ and a medication management application.³⁷ All but three of the intervention designs involved only the researchers and service providers, excluding the end users (patients and/or caregivers). 27,28,32

Many of the interventions in this study^{26,29–31,33–35} involved teletherapy to provide general health services to the patients. However, one study specifically addressed substance use disorders in those with mild ID,³² and another specifically addressed anxiety in those with autism spectrum disorder (ASD).³⁸

Different types of teletherapy were studied (Figure 2). For instance, Høye et al.³⁵ studied a mindfulness groupbased intervention, while Hepburn et al.³⁸ focused on a

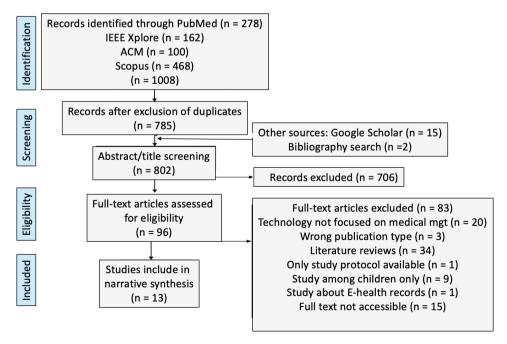


Fig. 1. PRISMA chart of study selection. ACM: Association of Computing Machinery; IEEE: Institute of Electrical and Electronic Engineers Xplore; PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

Table 3. Characteristics of included studies.

Study	Country	Study design	Study population	Sample size (N)
Adamou et al. ²⁶	United Kingdom	Quantitative/Cross Sectional	Patients with autism	117
Gibson and Dunlop ²⁷	United Kingdom	Qualitative/Longitudinal	Caregivers	14
			Experts in ID	
Ferrucci et al. ²⁸	Italy	Quantitative/Longitudinal	 Patients with complex health needs, including autism 	51
Harris et al. ²⁹	USA	Qualitative/Cross Sectional	Autistic adults	19 (7 autistic adults;12 caregivers)
Shawler et al.30	USA	Quantitative/Single Case Experimental Study	Autistic adults	1
Thang et al.31	USA	Qualitative/Cross-Sectional	Autistic adultsEssential service providers	14 (10 providers and 4 adults with IDD)
Gosens et al.32	Netherlands	Intervention Mapping	• N/A	N/A
Johnsson and Bulkeley ³³	Australia	Mixed/Cross-Sectional	• AHP	N = 947 (141 AHP,
			 Service users 	806 service users)
Nohelty et al.34	USA	Quantitative/Longitudinal	 Patients with autism 	7
Høye et al.35	Norway	Mixed/Longitudinal	 Adults with cerebral palsy 	6
Bangerter et al.36	USA	Quantitative/Nonintervention Clinical Trial	ASD caregivers	144
Salgado et al. ³⁷	USA	Quantitative/Cross-Sectional	 Experts in IDD, persons with developmental disabilities, caregivers 	52
Hepburn et al. ³⁸	USA	Quantitative/Randomized Control Trial	Youths with ASD and anxiety	N = 33 families: Intervention ($n = 17$), waitlist ($n = 16$)

AHP: allied health practitioners; ASD: autism spectrum disorder; ID: intellectual development.

family-focused cognitive behavioral intervention (CBI) for anxiety in patients with ASD.38 They also reported making use of the "face your fears" technique, a manualized CBI technique with slight modifications for videoconferencing.38 In another study, a user-centered design approach was utilized in designing the graphic user interfaces (GUIs), which considered users' points of view and needs as central while designing the intervention.28 Whereas in Gosens et al.32 an intervention mapping approach was used. One application tracked and monitored the symptoms of the patients,36 while another application was developed for medication management for patients with ID.37 The included studies assessed the efficacy and usability plus end users' satisfaction with the studied technology.

Efficacy and Usability

Seven studies assessed the usability/feasibility of the technology studied. However, four of these were explicitly designed as pilot studies. 26,28,36,38 The conclusion reached in all seven studies was that the technologies tested were usable for individuals with ID, 26-28,32,36-38 with some shortcomings.

One of the studies that assessed the usability of a tracking application, "My JAKE" app, found that caregivers were able to use the app successfully to report mood, overall type of day and sleep patterns. However, there was a decline in weekly reporting as the study progressed.36 Similar to the "My JAKE" app, Gibson and Dunlop²⁷ reported that despite the good reviews, their participants identified some accessibility barriers with their application relating to medical imagery, the abstract nature of certain conditions, and the overloading of information. Another study reported that the usability of the technology was a problem for some families during videoconferencing sessions and impeded some sessions significantly.38

The efficacy of technologies in the management of ID was assessed by some studies both quantitatively 30,34,35,38 and qualitatively.27 Two studies used provider observation, 30,34 while another two made use of patient reported outcome (PRO) scales to assess the efficacy of their intervention.35,38 In addition to a PRO scale, Hepburn et al.38 also used a treatment fidelity checklist to assess the efficacy of their CBI.38 A qualitative study by Gibson and Dunlop²⁷ used narration to obtain information on the performance of their application. The studies mostly reported that the applications were efficacious in the management of ID.

End-User Satisfaction and Experience

Five studies assessed the user experience and satisfaction of the participants with their technology (Figure 3). 28,31,33,35,38 These included the use of qualitative method to obtain

Table 4. Study interventions, outcomes, and key findings.

Study	Intervention	Outcome/Outcome scale	Key findings
Telephone and video	conferencing		
•	Telephone and video conferencing for patient-clinician	• Usability	• Service users reported that remote telecommunication was useful, effective, reliable, and satisfactory.
	consultations.	Telehealth useability questionnaire	• However, nearly half of service users stated a general preference for face-to-face consultations.
Harris et al.29	Real-time telehealth consulta-	Advantages and disadvantages	Advantages of virtual visits over in-person visits.
[N = 19]	tions via videoconferencing and	• Narration	Increased patient comfort
	text messaging (patient-physician consultations).		2. Increased safety
			3. Similar or improved patient–provider communication
			Disadvantages of virtual visits over in-person visits.
			1. Internet instability and other technological issues
			2. Inability to receive hands-on care
			Reduced patient engagement due to environmental distractions
[N = I] ment	Function-based ABA treatment via telehealth on Zoom (patient-clinician consultation).	• Efficacy	 Functional analysis procedures led to the devel- opment of a function-based treatment to reduce challenging behavior and increase functional communication.
		Provider observation	 Caregivers demonstrated high procedural integrity across all phases of the study and found the interven- tion highly acceptable and effective.
Thang et al.31	Videoconferencing via zoom	Experience report	Providers
1, 1, 1, 1	and phone calls (patients-clini- cians/job coaches).	• Narration	 The number of weekly sessions had to be increased with shorter duration of each session due to internet connection and comfort with telehealth.
			 Phone sessions were challenging as it brought informality and boundary crossing.
			Clients
			• Felt supported by the providers they worked with.
			 However, clients described the transition to telehealth as difficult due to a lack of technical resources.
			 Although they appreciated the opportunity to con- tinue consultations, clients expressed desire to return to in-person interactions.
Johnsson and Bulkeley ³³	Teletherapy (patient-speech therapist, occupational therapist, psychologist and social worker).	Satisfaction with technical quality	The average rating on satisfaction by service users was 4.5/5 and technical quality was 4.0/5.
[N = 141 AID, 806 service users]		Service user rating scale	Teletherapy was more engaging and just as effective as in-person services.
,	Direct telehealth ABA therapy (patient-behavioral analyst).	• Efficacy	 All seven participants demonstrated mastery and maintenance for all targets.
		Provider observation	 The study showed that telehealth is effective and can be considered for all patients when assessing the appropriate location of treatment.
[N = 6]	An 8-week mindfulness group- based program via videocon- ferencing (patient-physician/ psychologist).	• Feasibility: self-reported experience of pain and quality of life; user satisfaction.	 All but one participant (N = ?) observed a decrease in pain as a result of the program and would recommend it to others with cerebral palsy.
		Questionnaire and narration.	All were satisfied with the form and content of the intervention as well as access via videoconferencing.
			 Intervention and delivery were feasible with no major adverse effects.

Table 4. (Continued)

Study	Intervention	Outcome/Outcome scale	Key findings
Hepburn et al. ³⁸ [<i>N</i> = 33]	Manualized, family-focused,	Usability	Acceptability was strong
	cognitive-behavioral group intervention for anxiety among youth with ASD.	Potential efficacy and user satisfac- tion/participant monitoring form	• Use of the technology was difficult for some families, thus significantly limiting some sessions.
		 Parent and youth satisfaction ratings based on treatment fidelity checklist. 	 Preliminary efficacy analyses showed improvements in youth anxiety over time (relative to a comparison group waiting for live intervention) and parent sense of competence (within group).
Tracking application	os .		
Ferrucci et al. ²⁸ [N = 116]		Usability and user satisfaction	 42 of 51 (82%) patients were satisfied or very satisfied.
sorting of with ID.	sorting of clinical data for those with ID.	Questionnaire	 The user interface's disease specificity crucially improved app usability and patient engagement.
	My JAKE for ASD symptom tracking and monitoring	• Usability	 Caregivers using the app reporting 4–5 days weekly were able to use "my JAKE" app successfully to report mood, overall type of day and sleep patterns.
		Ease of use questionnaire	 There was some decline in the weekly reporting as the study progressed.
•	Medication management app for those with ID	 Features of medication manage- ment app that would promote independence in those with ID 	In addition to the medication list, medication reminder, and medication administration record features, experts selected the following top three most important additional features.
		Questionnaire	Automatic refills through pharmacies
			• Ability to share medication information from the app with providers
			• Ability to share medication information from the app with family, friends, and caregivers.
Others			
Gibson and Dunlop ²⁷ [N = 14]	Tablet application to aid those with mild ID during GP consultations using medical imaging and audio playbacks.	• Usability	 The application has the potential to increase com- munication, reduce time constraints, and overcome diagnostic overshadowing.
		Efficacy narration	 Nevertheless, the participants also reported some accessibility barriers.
Gosens et al. ³² $[N = N/A]$	Take it Personal! A personalized substance use disorder treatment for people with mild ID.	model and an mHealth application that supports the sessions	 The application supported the treatment sessions and promoted transfer-of-training to daily life.
		Not applicable	

ABA: applied behavior analysis; ASD: autism spectrum disorder; ID: intellectual disability; GP: general practitioner; My JAKE: Janssen Autism Knowledge Engine; N/A: not available; AID: adult intellectual disability.

information on user satisfaction, use of structured questionnaire, and previously validated user satisfaction scales such as Parent and Youth Satisfaction rating scale and Service User rating scale. The majority (82%) of the users in Ferrucci et al. Rescribed themselves as satisfied or very satisfied with the wed-based application, while in Johnsson and Bulkeley, the average rating on satisfaction by service users was 4.5/5 and technical quality was 4.0/5 showing good user experience and satisfaction. Similarly, one study reported that all participants were satisfied with the mindfulness-based program for cerebral palsy, and the video conferencing technology. In a single study, however, providers experienced informality and boundary crossing with the use of telehealth, while the

clients experienced difficulties due to a lack of technical resources.³¹

Advantages and Disadvantages of the Technology

The advantages and disadvantages of a real-time telehealth consultation were only captured by Harris et al.²⁹ and their reported advantages include increased patient comfort from avoidance of commute to the clinic, aversion of packed waiting rooms, and other sensory stressors; reduction in contact with other sick people; and equally better patient—provider communication than in-person visits. The disadvantages enumerated include challenges with technology such as internet instability; a lack of hands-on care from the

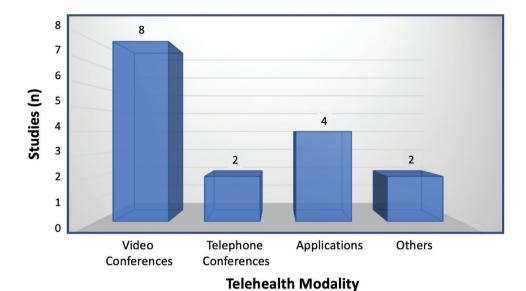


Fig. 2. Classification of telehealth modalities used in the included studies.

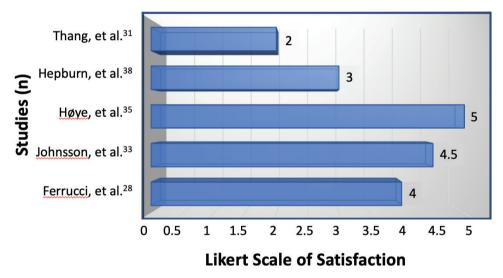


Fig. 3. End-user satisfaction rating of the technology used.

provider; and reduced patient engagement due to environmental distractions.²⁹

Limitations of the Included Studies

Limitations of the included studies consist of the methodology (e.g., sample size, study design, and outcome measures). Number of participants per study was also a limitation as this varies from a single person as observed in Shawler et al to seven.^{30,34} This limits the generalization of the outcomes.

Most of the studies were observational, which could have been subject to confounding variables (e.g., level of ID and bias). Furthermore, some studies used only subjective outcome measures^{27,29,31,36} while one study³⁶ reported increase in caregiver burden. In addition, most of the studies focused on a narrow range of outcomes,

overlooking other important aspects of telehealth's effectiveness and impairing comprehensive understanding on the intervention's impacts on this population; however, this might be due to limited resources or scope.

Additionally, in some of the studies, participants had difficulty understanding and using the technology due to the complexity of the system and user interface, which impeded some sessions significantly.^{27,36} In addition, inaccessibility to high quality internet connectivity impeded study interventions especially those with real time technologies, generally affecting the studies' results.

Discussion

This review set out to explore the use of telehealth technologies in the medical management of adults with ID.

Thirteen papers were identified and synthesized. It was found that while there are publications regarding the use of e-health technologies in the day-to-day life of adults with ID, there is a scarcity of studies on the use of these technologies in the medical management of adults with ID. The evidence generated showed a range of services provided via telehealth modalities for treatment (behavior management, anxiety intervention, and medication management) and monitoring of ID (symptom tracking, transfer of training to daily life). Most of the technologies were designed to be used by the patient or caregiver on one end and the service provider on the other end. The outcomes from the majority of the studies suggested that the use of telehealth services for the management of ID was feasible, effective and had good user satisfaction. This is congruent with similar reviews among children with ID.39,40

Videoconferencing was the most popular means of remote health service delivery. 26,29-31,33-35,38 This form of real-time telehealth service not only reduces transportation time and stress for the patient and provider, but also helps bring healthcare to localities with less healthcare options.⁴¹ Hence, patients with ID located in remote areas can have timely access to their health providers.⁴² Other interventions used store-and-forward telehealth services, where the patient's health history was documented outside of real-time and then forwarded to their healthcare provider. Hence, these patients can go for longer periods without the added complexity of hospital visits, while ensuring early detection of any complications or escalation of the illness that may arise. 42,43 These two types of telehealth technologies have been successfully used for patient care in a myriad of health conditions. 44,45 One study designed an application that reminded patients of their weekly exercises and goals. This innovative application not only works as an automated reminder to ensure compliance to the treatment regimen, but also gave the patients access to the health providers by including a "help" button.46

A major contentious finding was that most of the studies did not include the patients and caregivers in the design of the intervention or technology, thus limiting their preferential input. Remarkably, evidence reveals that involvement of patients and the public in intervention research improves the quality of the outcomes. 47,48 Hence, future projects should incorporate patients and caregivers in the design phase.

Teletherapy was the intervention of concern in the majority of the studies, ranging from group-based interventions to family-based and individual interventions. This is similar to findings by Ellison et al. These evidence-based psychological therapies are the current in-person interventions for people with ID. Hence, delivering these via telehealth improves access,

particularly those in remote areas and in low- and middle-income countries where access to these therapies is limited. 42,49,50

It is essential to assess the technological accessibility of telehealth in terms of internet connectivity and equipment. Although all the studies that assessed usability of the technologies reported that the technologies were usable, this was not without some technological difficulties. This is comparable to the findings in previous reviews^{39,51} where poor internet connectivity was highlighted in some of the studies^{29,31,38} as a barrier to the interventions and particularly problematic for interventions that use real-time technologies. It therefore highlights the importance of store-and-forward technologies/remote patient monitoring, whereby the patient's information is documented and sent to the health providers when there is sufficient internet connectivity.

For some patients, the technology itself was problematic, which impeded some treatment sessions. 38,52 This is another point in favor of including the patients and caregivers in the intervention design in order to identify and develop features to improve the efficiency of the technology, such as not to increase the burden of the patients and their caregivers.

In addition, the evidence presented in this review suggests that the use of telehealth in the medical management of ID is efficacious as reported in other studies. 40,53 However, none of the studies used an experimental design. Hence, to accurately ascertain the efficacy of these technologies, experimental studies such as randomized controlled trials should be done.

Patient satisfaction is an important variable in the uptake of new interventions,54 and the evidence in this review showed high satisfaction with telehealth among users (patients, caregivers, and health providers). However, Thang et al.³¹ pointed out the boundary crossing and informality that could arise from continuous access to health providers. Boundaries are highly important in the treatment relationship; hence, efforts must be made to ensure that boundaries are not sacrificed while improving accessibility to care. 55 However, the one-off method of measuring satisfaction used in the studies could be biased and isolated⁵⁶ as patients can benefit from a telemedicine consultation in the first follow-ups and be harmed later by the lack of screening options and non-pharmacological treatments. Satisfaction should therefore be measured continuously to ensure optimal standard of care.

Limitations

This review was conducted on studies published in English, hence relevant papers written in other languages may have been overlooked. Secondly, only a small number of studies were included due to the paucity of research on telehealth technologies among adults with ID; and of these, only one study used an experimental study design. Furthermore, most of the included studies had small sample sizes, although this may be anticipated as the population of interest is a small proportion of the population. However, designing and testing technologies require a sufficient number of people to arrive at accurate results.

Another key limitation was that the included studies all originated from developed countries, leaving a pertinent knowledge gap to be filled in developing countries. Despite these limitations, this review highlights the current research carried out on telehealth technologies for the medical management of ID among adults and could serve to inform future researchers and health providers.

Conclusions

The findings from this scoping review emphasize the significant potential of telehealth technologies to enhance the medical management of adults with ID. These technologies—ranging from videoconferencing to symptom tracking and medication management applications demonstrate feasibility, user satisfaction, and the potential efficacy in supporting healthcare access and delivery.

However, the review also highlights several limitations, including small sample sizes, non-rigorous study designs, and technological challenges such as internet instability. Most studies point to telehealth's advantages, such as reduced travel time, improved patient-provider communication, and increased convenience for both caregivers and patients. Yet, the lack of hands-on care and patient engagement issues are notable drawbacks. Importantly, the exclusion of patients and caregivers in the design of these technologies is a significant concern, as their involvement might address usability barriers and improve adoption.

In conclusion, while telehealth technologies present a promising solution for addressing healthcare access challenges among adults with ID, the current body of research is insufficient to draw robust conclusions about their overall impact. Future research should focus on rigorous, well-structured methodologies to ensure comprehensive evaluations of telehealth's effectiveness in managing intellectual disabilities.

Recommendations

Foremost among areas for future research include the need to evaluate the use of telehealth in adults with ID using more rigorous experimental methods that will strengthen the evidence on the efficacy of telehealth in managing ID. This will provide more definite conclusions on the benefits and limitations of this technology.

Future studies should include larger sample size and control groups to increase generalizability and compare outcomes and determine effectiveness of telehealth interventions. Secondly, development of comprehensive

outcome measures including the use of objective outcomes (clinical tests) is recommended to capture a wider range of effects.

Additionally, to improve the usability and effectiveness of telehealth interventions, patients and caregivers should be involved in the design and development process. Incorporating their feedback can help address specific needs and preferences, ensuring that the telehealth tools evolve in response to their changing needs. In addition, patient and caregiver satisfaction should be continuously monitored over time rather than relying on one-off assessments. This will ensure that any emerging issues with telehealth services are addressed promptly, maintaining high-quality standards of care.

Third, future researchers should develop user-friendly telehealth platforms with simple navigation, clear language and minimal cognitive load. Persons with ID may face unique difficulties in line with their disabilities; therefore, researchers should collaborate with specialists in ID and human-computer interaction to ensure that platforms meet the unique needs of this population Also, healthcare providers, patients, and caregivers should receive adequate training on telehealth platforms to maximize their use. Ensuring that all stakeholders are comfortable and competent with these technologies will facilitate their wider adoption and effective use.

Telehealth effectiveness hinges on stable internet connectivity, particularly for real-time applications like videoconferencing. Governments and healthcare providers should invest in improving broadband infrastructure, especially in rural and underserved areas where internet access is often unreliable. Technology support can be provided by ensuring that telehealth platforms are designed to function smoothly even in low-bandwidth environments, possibly by adopting more store-and-forward technologies, which allow information to be transmitted during periods of stable internet connectivity.

Furthermore, with the growing use of telehealth technologies, privacy and data security must be ensured. Policymakers and healthcare providers should develop clear guidelines on patient data protection, liability, and confidentiality in the telehealth ecosystem.

Strong encryption protocols can be implemented across all telehealth platforms to safeguard patient data during transmission and storage. In addition, comprehensive consent protocols can be established where patients and caregivers are fully informed about how their data are collected, stored, and used. This transparency will reduce concerns over potential privacy breaches.

Finally, the legal responsibilities of healthcare providers in the telehealth environment should be clearly defined, including malpractice concerns and cross-jurisdictional licensing for telehealth services that cross state or national boundaries. Clear guidelines regarding data ownership should be established, making it transparent who controls, accesses, and uses the data generated by telehealth technologies.

By addressing these areas, telehealth technologies can become more robust, accessible, and effective, contributing to the improved medical management of adults with intellectual disabilities.

Funding

This study was not supported by any sponsor or funder.

Conflicts of Interest

The authors declare that no competing interests exist.

Contributors

Dr. Ohazurike contributed to conceptualization, data collection & analysis, basic template. Dr. Abere contributed to study design, review, and editing. Dr. Oyan performed data analysis and review.

Data Availability Statement (DAS), Data Sharing, Reproducibility, and Data Repositories

Data or references and links to secondary data-sets are contained within the published work itself.

Application of Al-Generated Text or Related Technology

No generative AI technologies such as Large Language Models (ChatGPT, COPILOT, etc.) and text-to-image generators have been used during writing or editing of the manuscript.

Acknowledgments

This work would have been incomplete without the support of Prof. (Mrs.) NC Ohazurike and Pharm. Dervla Kelly.

References

- WHO. Definition: intellectual disability [Internet]. World Health Organization Regional Office for Europe; 2010 [cited 2022 Jan 22]. Available from: https://www.euro.who.int/en/health-topics/ noncommunicable-diseases/mental-health/news/news/2010/15/ childrens-right-to-family-life/definition-intellectual-disability
- Schalock RL, Luckasson R, Tassé MJ. Intellectual disability: definition, diagnosis, classification, and systems of supports [Internet]. 12th ed. AAIDD; 2021 [cited 2022 Jan 22]. Available from: https://www.aaidd.org/publications/bookstore-home/ product-listing/intellectual-disability-definition-diagnosis-classification-and-systems-of-supports-12th-edition
- Schaepper MA, Hauser M, Kragadkar F. What is intellectual disability? [Internet]. American Psychological Association; 2021 [cited 2022 Jan 22]. Available from: https://www.psychiatry.org/patients-families/intellectual-disability/what-is-intellectual-disability
- Maulik PK, Mascarenhas MN, Mathers CD, Dua T, Saxena
 Prevalence of intellectual disability: a meta-analysis of

- population-based studies. Res Dev Disabil. 2011;32(2):419–36. doi: 10.1016/j.ridd.2010.12.018
- McKenzie K, Milton M, Smith G, Ouellette-Kuntz H. Systematic review of the prevalence and incidence of intellectual disabilities: current trends and issues. Curr Dev Disord Rep. 2016;3(2):104–15. doi: 10.1007/s40474-016-0085-7
- Eilfen J. Developmental disability prevalence in U.S. children by condition 2015–2018. Statista; 2020 [cited 2022 Jan 22]. Available from: https://www.statista.com/statistics/1101297/ prevalence-us-children-diagnosed-with-developmental-disability-by-condition/
- Central Statistics Office. Types of disability. Census of population 2016—profile 9 health, disability and carers [Internet].
 2016 [cited 2022 Jan 22]. Available from: https://www.cso.ie/en/releasesandpublications/ep/p-cp9hdc/p8hdc/p9tod/
- Singh U, Sweta, Singh B. Effect of opioid-free anaesthesia on perioperative period: a review. Int J Cogn Behav. 2020;3(1):005. doi: 10.23937/2690-3172/1710005
- Alotaibi YK, Federico F. The impact of health information technology on patient safety. Saudi Med J. 2017;38(12):1173. doi: 10.15537/smj.2017.12.20631
- Kao CW, Chuang HW, Chen TY. [The utilization of health-related applications in chronic disease self-management]. Hu li za zhi. J Nurs. 2017;64(4):19–25. doi: 10.6224/JN.000050
- 11. Debon R, Coleone JD, Bellei EA, De Marchi ACB. Mobile health applications for chronic diseases: a systematic review of features for lifestyle improvement. Diabetes Metab Syndr. 2019;13(4):2507–12. doi: 10.1016/j.dsx.2019.07.016
- Whitehead L, Seaton P. The effectiveness of self-management mobile phone and tablet apps in long-term condition management: a systematic review. J Med Internet Res. 2016;18(5):e97. doi: 10.2196/jmir.4883
- Sandjojo J, Eltringham EG, Gebhardt WA, Zedlitz AMEE, Embregts PJCM, Evers AWM. Self-management interventions for people with intellectual disabilities: a systematic review. Patient Educ Couns. 2020;103(10):1983–96. doi: 10.1016/j. pec.2020.06.009
- O'Leary L, Cooper SA, Hughes-McCormack L. Early death and causes of death of people with intellectual disabilities: a systematic review. J Appl Res Intellect Disabil. 2018;31(3):325–42. doi: 10.1111/jar.12417
- Trollor J, Srasuebkul P, Xu H, Howlett S. Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data. BMJ Open. 2017;7(2):e013489. doi: 10.1136/bmjopen-2016-013489
- 16. Haque MM, Rabbani M, Dipal DD, Zarif MII, Iqbal A, Akhter S, et al. Grant report on mCARE: mobile-based care for children with autism spectrum disorder (ASD) for low- and middle-income countries (LMICs). J Psychiatr Brain Sci. 2021;6:e210004. doi: 10.20900/jpbs.20210004
- Rehman IU, Sobnath D, Nasralla MM, et al. Features of mobile apps for people with autism in a post COVID-19 scenario: current status and recommendations for apps using AI. Diagnostics (Basel). 2021;11(10):1923. doi: 10.3390/diagnostics11101923
- 18. Grant MJ, Booth A. A typology of reviews: an analysis of 14 review types and associated methodologies. Health Info Libr J. 2009;26(2):91–108. doi: 10.1111/j.1471-1842.2009.00848.x
- 19. Haidich AB. Meta-analysis in medical research. Hippokratia. 2010;14(Suppl 1):29–37.
- Levay P, Raynor M, Tuvey D. The contributions of MEDLINE, other bibliographic databases and various search techniques to NICE public health guidance. Evid Based Libr Info Pract. 2015;10(1):50–68. doi: 10.18438/B82P55

- 21. Zheng MH, Zhang X, Ye Q, Chen YP. Searching additional databases except PubMed are necessary for a systematic review. Stroke. 2008;39(8):e139-40. doi: 10.1161/STROKEAHA.107.
- 22. Tricco AC, Lillie E, Zarin W, et al. PRISMA extension for scoping reviews (PRISMA-ScR): checklist and explanation. Ann Intern Med. 2018;169(7):467–73. doi: 10.7326/M18-0850
- 23. Gusenbauer M, Haddaway NR. Which academic search systems are suitable for systematic reviews or meta-analyses? Evaluating retrieval qualities of Google Scholar, PubMed, and 26 other resources. Res Syn Meth. 2020;11(2):181-217. doi: 10.1002/ jrsm.1378
- 24. Bramer WM, De Jonge GB, Rethlefsen ML, Mast F, Kleijnen J. A systematic approach to searching: an efficient and complete method to develop literature searches. J Med Libr Assoc. 2018;106(4):531. doi: 10.5195/jmla.2018.283
- 25. Campbell M, McKenzie JE, Sowden A, Katikireddi SV, Brennan SE, Ellis S, et al. Synthesis without meta-analysis (SWiM) in systematic reviews: reporting guideline. BMJ. 2020;368:16890. doi: 10.1136/bmj.16890
- 26. Adamou M, Jones SL, Fullen T, Galab N, Abbott K, Yasmeen S. Remote assessment in adults with autism or ADHD: a service user satisfaction survey. PLoS One. 2021;16(3):e0249237. doi: 10.1371/journal.pone.0249237
- 27. Gibson CR, Dunlop M. Evaluating the usability of a tablet application to support adults with mild intellectual disabilities during primary care consultations. In: Extended Abstracts of the 2021 CHI Conference on Human Factors in Computing Systems. New York, NY: Association for Computing Machinery; 2021. doi: 10.1145/3411763.3451718
- 28. Ferrucci F, Jorio M, Marci S, Bezenchek A, Diella G, Nulli C, et al. A web-based application for complex health care populations: user-centered design approach. JMIR Hum Factors. 2021;8(1):e18587. doi: 10.2196/18587
- 29. Harris L, Gilmore D, Hanks C, Coury D, Moffatt-Bruce S, Garvin JH, et al. "It was surprisingly equivalent to the appointment I had in person": advantages and disadvantages of synchronous telehealth for delivering primary care for autistic adults. Autism. 2022;26(6):1573-1580. doi: 10.1177/13623613211060589
- 30. Shawler LA, Clayborne JC, Nasca B, O'Connor JT. An intensive telehealth assessment and treatment model for an adult with developmental disabilities. Res Dev Disabil. 2021;111:103876. doi: 10.1016/j.ridd.2021.103876
- 31. Thang T, Liang A, Choi Y, Parrales A, Kuang SH, Kurniawa S, et al. Providing and accessing support during the COVID-19 pandemic: experiences of mental health professionals, community and vocational support providers, and adults with ASD. In: The 23rd International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS'21). Association for Computing Machinery; 2021;38:1-6. doi: 10.1145/3441852.3476470
- 32. Gosens LCF, Otten R, de Jonge JM, Schellekens AFA, VanDerNagel JEL, Didden R, et al. Development of a personalised substance use disorder treatment for people with mild intellectual disabilities or borderline intellectual functioning: an intervention mapping approach. J Intellect Dev Disabil. 2022;47(2):131-40. doi: 10.3109/13668250.2021.1925529
- 33. Johnsson G, Bulkeley K. Practitioner and service user perspectives on the rapid shift to teletherapy for individuals on the autism spectrum as a result of COVID-19. Int J Environ Res Public Health. 2021;18(22):11812. doi: 10.3390/ ijerph182211812
- 34. Nohelty K, Bradford CB, Hirschfeld L, Miyake CJ, Novack MN. Effectiveness of telehealth direct therapy for individuals with

- autism spectrum disorder. Behav Anal Pract. 2021;15(3):643-58. doi: 10.1007/s40617-021-00603-6
- 35. Høye H, Jahnsen RB, Løvstad M, Hartveit JF, Sørli H, Tornås S, et al. A mindfulness-based stress reduction program via group video conferencing for adults with cerebral palsy—a pilot study. Front Neurol. 2020;11:195. doi: 10.3389/fneur.2020.00195
- 36. Bangerter A, Manyakov NV, Lewin D, Boice M, Skalkin A, Jagannatha S, et al. Caregiver daily reporting of symptoms in autism spectrum disorder: observational study using web and mobile apps. JMIR Ment Health. 2019;6(3):e11365. doi: 10.2196/11365
- 37. Salgado TM, Fedrigon A, Riccio Omichinski D, Meade MA, Farris KB. Identifying medication management smartphone app features suitable for young adults with developmental disabilities: Delphi consensus study. JMIR Mhealth Uhealth. 2018;6(5):e129. doi: 10.2196/mhealth.9527
- 38. Hepburn SL, Blakeley-Smith A, Wolff B, Reaven JA. Telehealth delivery of cognitive-behavioral intervention to youth with autism spectrum disorder and anxiety: a pilot study. Autism. 2016;20(2):207-18. doi: 10.1177/1362361315575164
- 39. Sutherland R, Trembath D, Roberts J. Telehealth and autism: a systematic search and review of the literature. Int J Speech Lang Pathol. 2018;20(3):324-36. doi: 10.1080/17549507.2018.1465123
- 40. Ellison KS, Guidry J, Picou P, Adenuga P, Davis TE, 3rd. Telehealth and autism prior to and in the age of COVID-19: a systematic and critical review of the last decade. Clin Child Fam Psychol Rev. 2021;24(3):599-630. doi: 10.1007/s10567-021-00358-0
- 41. Johnsson G, Kerslake R, Crook S, Cribb C. Investigation of training and support needs in rural and remote disability and mainstream service providers: implications for an online training model. Aust Health Rev. 2017;41(6):693-7. doi: 10.1071/AH16132
- 42. Mechanic OJ, Persaud Y, Kimball AB. Telehealth systems [Internet]. StatPearls Publishing; 2021 [cited 2022 Jun 22]. Available from: http://www.ncbi.nlm.nih.gov/books/NBK459384/
- 43. NEJM Catalyst. What is telehealth? [Internet]. NEJM Catalyst; 2018 [cited 2022 Jun 22]. Available from: https://catalyst.nejm. org/doi/full/10.1056/CAT.18.0268
- 44. Neville CW. Telehealth: a balanced look at incorporating this technology into practice. SAGE Open Nurs. 2018;4: 2377960818786504. doi: 10.1177/2377960818786504
- 45. Hollander JE, Carr BG. Virtually perfect? Telemedicine for covid-19. N Engl J Med. 2020;382(18):1679-81. doi: 10.1056/ NEJMp2003539
- 46. Gosens LCF, Otten R, Didden R, Poelen EAP. Evaluating a personalized treatment for substance use disorder in people with mild intellectual disability or borderline intellectual functioning: a study protocol of a multiple baseline across individuals' design. Contemp Clin Trials Commun. 2020;19:100616. doi: 10.1016/j.conctc.2020.100616
- 47. Hoddinott P, Pollock A, O'Cathain A, Boyer I, Taylor J, MacDonald C, et al. How to incorporate patient and public perspectives into the design and conduct of research. F1000Res. 2018;7:752. doi: 10.12688/f1000research.15162.1
- 48. Modigh A, Sampaio F, Moberg L, Fredriksson M. The impact of patient and public involvement in health research versus healthcare: a scoping review of reviews. Health Policy. 2021;125(9):1208-21. doi: 10.1016/j.healthpol.2021.07.008
- 49. Williams V. Evidence-based practice and intellectual disabilities and psychological therapies for adults with intellectual disabilities. Disabil Soc. 2015;30(4):662-7. doi: 10.1080/ 09687599.2015.1014670
- 50. Krysta K, Romańczyk M, Diefenbacher A, Krzystanek M. Telemedicine treatment and care for patients with intellectual

- disability. Int J Environ Res Public Health. 2021;18(4):1–12. doi: 10.3390/ijerph18041746
- Boisvert M, Lang R, Andrianopoulos M, Boscardin ML. Tele practice in the assessment and treatment of individuals with autism spectrum disorders: a systematic review. Dev Neurorehabil. 2010;13(6):423–32. doi: 10.3109/17518423.2010.499889
- 52. Gibson AN, Bowen K. Developmental personal health libraries: supporting independence through design. In: The 21st International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS'19). Association for Computing Machinery; 2019, pp. 627–9. doi: 10.1145/3308561.3354635
- Oudshoorn CEM, Frielink N, Nijs SLP, Embregts PJCM. Psychological eHealth interventions for people with intellectual disabilities: a scoping review. J Appl Res Intellect Disabil. 2021;34(4):950–72. doi: 10.1111/jar.12877
- 54. Becevic M, Boren S, Mutrux R, Shah Z, Banerjee S. User satisfaction with telehealth: study of patients, providers,

- and coordinators. Health Care Manag. 2015;34:337–49. doi: 10.1097/HCM.0000000000000081
- Drum KB, Littleton HL. Therapeutic boundaries in telepsychology: unique issues and best practice recommendations. Prof Psychol Res Pr. 2014;45(5):309–15. doi: 10.1037/a0036127
- Almeida R, Bourliataux-Lajoinie S, Martins M. Satisfaction measurement instruments for healthcare service users: a systematic review. Cad Saúde Pública. 2015;31:11–25. doi: 10.1590/0102-311X00027014

Copyright Ownership: This is an open-access article distributed in accordance with the Creative Commons Attribution Non-Commercial (CC BY-NC 4.0) license, which permits others to distribute, adapt, enhance this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, and the use is non-commercial. See http://creative-commons.org/licenses/by-nc/4.0.