Original Paper

Blockchain-Based Architecture Design for Personal Health Record: Development and Usability Study

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Abstract

Background: The importance of blockchain-based architectures for personal health record (PHR) lies in the fact that they are thought and developed to allow patients to control and at least partly collect their health data. Ideally, these systems should provide the full control of such data to the respective owner. In spite of this importance, most of the works focus more on describing how blockchain models can be used in a PHR scenario rather than whether these models are in fact feasible and robust enough to support a large number of users.

Objective: To achieve a consistent, reproducible, and comparable PHR system, we build a novel ledger-oriented architecture out of a permissioned distributed network, providing patients with a manner to securely collect, store, share, and manage their health data. We also emphasize the importance of suitable ledgers and smart contracts to operate the blockchain network as well as discuss the necessity of standardizing evaluation metrics to compare related (net)works.

Methods: We adopted the Hyperledger Fabric platform to implement our blockchain-based architecture design and the Hyperledger Caliper framework to provide a detailed assessment of our system: first, under workload, ranging from 100 to 2500 simultaneous record submissions, and second, increasing the network size from 3 to 13 peers. In both experiments, we used throughput and average latency as the primary metrics. We also created a health database, a cryptographic unit, and a server to complement the blockchain network.

Results: With a 3-peer network, smart contracts that write on the ledger have throughputs, measured in transactions per second (tps) in an order of magnitude close to 10^2 tps, while those contracts that only read have rates close to 10^3 tps. Smart contracts that write also have latencies, measured in seconds, in an order of magnitude close to 10^1 seconds, while that only read have delays close to 10^0 seconds. In particular, smart contracts that retrieve, list, and view history have throughputs varying, respectively, from 1100 tps to 1300 tps, 650 tps to 750 tps, and 850 tps to 950 tps, impacting the overall system response if they are equally requested under the same workload. Varying the network size and applying an equal fixed load, in turn, writing throughputs go from 10^2 tps to 10^1 tps and latencies go from 10^1 seconds to 10^2 seconds, while reading ones maintain similar values.

Conclusions: To the best of our knowledge, we are the first to evaluate, using Hyperledger Caliper, the performance of a PHR blockchain architecture and the first to evaluate each smart contract separately. Nevertheless, blockchain systems achieve performances far below what the traditional distributed databases achieve, indicating that the assessment of blockchain solutions for PHR is a major concern to be addressed before putting them into a real production.

(J Med Internet Res 2022;24(4):e35013) doi: 10.2196/35013

KEYWORDS
electronic health record; personal health record; blockchain; smart contract

Introduction

Background

Two closely related concepts have been drawing the attention of the biomedical and health informatics community: electronic health record (EHR) and health information exchange (HIE). The former, broadly speaking, covers all the repositories of digital data concerning retrospective, concurrent, and prospective information for ongoing support for patient health care [1,2]. Some examples of these digital repositories are electronic medical record [3,4], electronic patient record [5,6], and the personal health record (PHR). In particular, PHR systems are thought and developed to allow health data to be controlled and at least partly collected by the patient [7-9]. The latter, in turn, covers all electronic protocols for transferring data among hospitals, clinics, and other health organizations in order to share standard information regarding patient's treatment [10]. The Office of the National Coordinator for Health Information Technology defines 3 strategies for HIE: direct, query-based, and consumer-mediated. In particular, consumer-mediated HIE allows patients to retrieve their health information, share it with health care providers and stakeholders they trust, and then make better decisions in partnership [11]. Even though it is a contentious issue yet, patients should ideally have full control of their own health data—authorizing access, sharing, and use—to reach an actual patient-centered HIE [12,13].

Despite having been separately presented, an EHR repository and an HIE protocol can be incorporated into the same system as a matter of fact. In general, they comprise systems to store, retrieve, and share health data and, invariably, lead to interoperability, scalability, reliability, privacy, and security issues regarding those data. Interoperability can reduce or even eliminate handmade administrative tasks, avoid duplicate clinical services, and facilitate access to relevant information, thereby decreasing cost and waste and improving coordinate and unplanned care [14]. Scalability can impact the scale and the transmission of health data, limiting the overall latency and throughput [15]. Reliability can increase confidence in health organizations and contribute to the total testing process, thereby reducing diagnostic errors and supporting malpractice litigation [15,16].

In particular, privacy and security relating to EHRs have been especially important issues because health data are undoubtedly sensitive. Patients must have their personal information guaranteed by civil rights, that is, only used and disclosed under their consent to indeed have privacy. In this sense, health care providers and regulators should be previously authorized before they are able to examine such information. Furthermore, patients must be protected from unauthorized access, modification, and exclusion of their stored data to really be safe. In general, lack of security can result in data theft and leakage [17]. According to the US Department of Health and Human Services Office for Civil Rights, millions of people have had sensitive information stolen and exposed owing to recurrent database attacks on the health care industry [18]. Although traditional cloud-assisted EHR has been a promising paradigm developed to address these issues, cloud environments rely on trusted and centralized third entities, which do not take full responsibility for privacy and security protection and only ensure it as much as possible [19,20]. However, blockchain-based systems, originally created to replace the trusted third party of the financial transactions [21,22], have been spreading to other fields, arousing the interest of the biomedical and health informatics community because they are tightly related to privacy and security concerns over EHR and HIE [19]. Maintaining a distributed, tamper-resistant, and continuously growing ledger, blockchain networks are systems designed to have decentralized storage and management, avoiding the single point of failure and encouraging health care providers and patients to mutually collaborate without the control of a central intermediary. They are also systems created to have a permanent audit trail and a well-defined and consensual set of transaction rules (smart contracts), supplying and certifying health data provenance and establishing formal criteria to handle sensitive information [23-26].

In view thereof, the aforesaid community has already provided an increasing number of blockchain uses: a decentralized record management to handle electronic medical records [27], a PHR smartphone app to empower patients to take control of their own health data [28], an architecture model to provide a PHR in which patients maintain a unified register of their health history even from different organizations [29], a mobile health system to remotely perform cognitive behavioral therapy for insomnia [30], a teledermatology platform to support diagnosis of skin diseases [31], a privacy-preserving location sharing for telecare medical information systems [32], an authentication service to seal biomedical database requests and the respective responses [33], a pharmaceutical supply chain management to prevent counterfeit medicines [34], a framework to share medical images [35], a platform to remotely watch patient vital signs [36], and an EHR to manage and share data from cancer treatment [37], indicating a wide range of promising applications.

Related Works and Our Contribution

There are several contributions proposing blockchain-based architecture designs to address existing problems with EHR. However, most of them have targeted electronic medical records and electronic patient records, and only few approached PHR [38,39]. Combining traditional database storage, blockchain framework, and smartphone app, Yue et al [28] were among the first to suggest an architecture model to empower the patient's ability to control and share health data. Despite adopting access control policies in different usage scenarios, the authors did not provide a detailed description of the blockchain infrastructure or perform a system assessment.

Roehrs et al [29] presented a distributed and interoperable model, named the OmniPHR, in which patients can gather their health data to optimally manage their health history and in which health care providers, with the patient's consent, can access such data, regardless of the institutional source. Although the work pointed out several relevant concepts about the PHR, it only simulated a peer-to-peer network infrastructure using OverSim [40] and did not, in fact, implement a blockchain routine with the timestamped hashing blocks and the smart contracts. To remotely apply cognitive behavioral therapy for insomnia, Ichikawa et al [30] developed a mobile health system based on a Hyperledger Fabric blockchain infrastructure [41] to store the collected data. With a 4-node network, the authors evaluated the tamper resistance under simulated fault by taking 1 node down and subsequently, uploading new data and verifying the information recovery by lifting that node up and, from this, querying the update of the previous data [30]. Even though the work had proposed a PHR system and tested its failure resilience, it did not provide performance indicators—throughput and latency under workload [42-44]—to assess the distributed network infrastructure.

Liang et al [45] developed a mobile app for users to store their personal health data in a cloud database, from wearable or medical devices and manual inputs as well and to share it with health care providers and health insurance companies they trust. Similar to [30], Hyperledger Fabric was the blockchain framework used to implement a permissioned distributed network. Besides Fabric, to improve scalability and integrity, Merkle tree protocol, via Chainpoint [46], was the tree-based data structure used to aggregate hashed records into leaf nodes until reaching a single root—the final hash to be saved in the blockchain. To evaluate performance, the work measured the average time cost during simultaneous recording. In another work, Liang et al [47] elaborated a web application for PHR. The authors built a patient-centered architecture out of a trusted environment, supplied by Intel Software Guard Extension [48] to maintain health data and control access logs regarding these data, and out of a permanent blockchain network supplied by Tierion [49] to record both hashes of that data, certifying integrity and raw copies of that logs, thereby ensuring traceability. To evaluate performance and estimate overload, the work adopted 2 measures: the average time cost to handle a concurrent number of records and the average time cost to handle a large number of access tokens.

Uddin et al [50] proposed an end-to-end eHealthcare architecture for continuous patient monitoring, including a patient-centered component to oversee access control policies, coordinate sensors and devices, and ultimately, decide which data stream should be stored on a blockchain. Inspired by Bitcoin and Ethereum environments [21,51], the authors designed a customized blockchain infrastructure by using Java programming language, with which they implemented a selection of only trusted mining nodes to perform proof of work as consensus protocol. They compared their customized system with Bitcoin's algorithm performance, analyzing surviving generations value and central processing unit and memory monitoring as metrics [50].

Using an Ethereum-based blockchain network [51], Omar et al [52] developed a privacy-preserving platform in which patients control all health data stored on and retrieved from a blockchain, while having their identity protected by cryptographic functions. Besides that, the authors suggested specific protocols to attain pseudonymity, privacy, integrity, accountability, and security throughout platform transactions. To analyze performance, they evaluated the transaction and execution costs of smart contracts by varying the string length of the data block and employing Ethereum's crypto-fuel as a metric [52].

Roehrs et al [53] extended the OmniPHR model devised in their prior work to a production scenario, considering a private blockchain network in which only verified and authenticated participants can access and manage it. Notwithstanding Ethereum and Hyperledger Fabric had been pondered as suitable blockchain platforms, the authors preferred to develop their own infrastructure by using open application programming interfaces such as Apache Kafka [54], Apache Zookeeper [55], and others. To evaluate performance over many queries, the work observed how throughput and latency varied from 50 to 500, from 1000 to 10,000, and from 13,000 to 40,000 concurrent requests.

Through an Ethereum-based blockchain architecture, Lee et al [56] proposed an international cross-area platform to arrange data from different health care services and manage authorizations for HIE among patients, health care providers, and stakeholders. By considering a test scenario in which a person had traveled from her/his home country to a foreign one and suddenly needed medical attention, the patient, registered on the platform, successfully granted a physician authorization to access her/his PHR. The physician, in turn, also registered on the platform, searched the requested PHR, and according to it and the current patient condition, provided a diagnosis and ordered treatment and medication [56].

Alongside the preceding papers, our work builds a blockchain-based architecture out of a permissioned distributed network in order to supply a PHR system for patients to securely collect, store, share, and manage their health data. Despite the similarities, it brings a novel ledger-oriented architecture model using Hyperledger Fabric, emphasizing the importance of suitable ledgers and smart contracts to operate the overall blockchain. In addition, it provides a detailed assessment of a 3-peer network—applying throughput and latency—under workload, ranging from 100 to 2500 simultaneous record submissions, and analyses, in this case for a fixed load, the impact of increasing the network, ranging from 3 to 13 peers. At the end, our work discusses the necessity of standardizing evaluation metrics to facilitate the comparison between related works.

Methods

Blockchain and Smart Contracts

Blockchain is a distributed, tamper-resistant, and continuously growing ledger for recording desirable assets and transactions in cryptographically chained blocks. It results from a protocol to add data blocks, using public-key cryptography and hash functions, and from a protocol to validate them, using a consensus algorithm on a peer-to-peer network [21]. In this sense, each new block contains the timestamp, the hash of the previous block, and the list of the retrospective and current digitally signed assets and transactions. Each new one is also verified by the majority of the peers in order to provide a reliable full history of the register. Once the assets and transactions are validated by consensus, the new block is recorded in the chain and becomes immutable. Subsequently, the updated ledger is shared by all peers and, thenceforth, can be attested without the need of a central authority [57,58].

Blockchain networks can be arranged either into a permissionless or a permissioned mechanism for selecting participants, to ensure the honest majority assumption, that is, the conjecture that the majority of the peers will be honest and run the consensus protocol correctly [59]. On the one hand, a permissionless blockchain network—a domain of the cryptocurrencies and financial markets [60]—does not have administrators managing membership or banning illegitimate peers; it is literally open to anyone who wants to be part of it [58,61]. In these circumstances, the network maintains incentive alignments as long as participants self-select but must expend computational resources, as in the proof of work, or even money, as in the proof of stake, to run the consensus protocol [59]. On the other hand, a permissioned blockchain network—a domain of the business and institutional practices [60]—has external administrators managing membership and defining which peers have read and write permission on the blockchain [58,61]. Although choosing the participants is outside the scope of the consensus protocol, the network establishes a consortium whereby members obey publicly documented policies to achieve group decision-making [59].

Smart contracts, in turn, are prespecified rules that allow a blockchain to be conducted in a consensual manner by all network participants. In practice, these rules represent transactions, which automatically operate digital assets and can be constructively used to state a bylaw among parties with common goals, attaining a decentralized autonomous organization [51]. Encoding state transition functions, smart contracts are logically and effectively implemented as executable programs in both domain-specific and general-purpose languages and owe their security to the accomplishment of the consensus protocol [41]. Despite opening a way to make digital codes into laws or official statements, blockchain and smart contracts are emerging technologies still. Therefore, they neither are legally binding documents nor have a jurisprudential agreement to be interpreted [61].

As already suggested in the introduction, Ethereum and Hyperledger Fabric have been the main open-source platforms used to develop blockchain frameworks into EHR and HIE [23-26,38,39]. Providing a built-in, Turing-complete, and domain-specific language (Solidity) to write smart contracts and distributed applications, Ethereum is an alternative to the first-generation scripting systems without full programming capabilities [51]. In the beginning, it was launched to create permissionless networks [62], implementing a consensus protocol (Ethash) based on the proof of work, in which a hash puzzle needs to be solved by a prover and validated by a set of verifiers [22]. To mediate this computation and avoid network abuse, Ethereum has an internal cryptocurrency (Ether) to charge transaction fees and reward nodes competing to append new blocks to the chain [63]. By the advent of the permissioned networks, Ethereum was also adapted to support general purpose languages such as Go and C++ [23] and run a consensus protocol based on the proof of authority, in which only a set of known verifiers can be selected to validate a new block [22].

Hosted by the Linux Foundation, Hyperledger Fabric, in turn, is a decentralized operating system to create permissioned networks. It allows smart contracts (chaincodes) and distributed applications to be written in Go, Java, and Node. Using an ordering service implementation based on a crash-tolerance consensus [22], it has an endorsement policy in which the smart contracts themselves, via chaincode lifecycle and private communication mechanisms (channels), specify a set of nodes to endorse transactions. In this sense, the nodes in Hyperledger Fabric have different functions: the client nodes to propose, orchestrate, and broadcast transactions, the peer nodes to execute and validate transactions as well as to maintain the ledger and the smart contracts, and the ordering service nodes to mediate state updates and dependencies during transaction execution. To control the identity of these nodes, Hyperledger Fabric has a membership service provider to handle certificate authorities and public key infrastructure and, from them, issue credentials for authentication and authorization [41,62].

As already mentioned, we opt for the latter platform to implement our permissioned network. Most of the existing platforms, including Ethereum, implement a traditional active replication for the consensus protocol, which first orders and broadcasts transactions to all peers and second waits for each peer to perform such transactions sequentially (order-execute paradigm), limiting performance and requiring an additional mechanism to prevent denial-of-service attacks from untrusted codes [41]. Executing transactions only on a subset of peers, Hyperledger Fabric implements an execute-order-validate paradigm, which first performs and verifies the transactions, then orders through a consensus protocol, and finally validates such transactions by the application-specific trust assumptions [41]. Although there are scalability issues, Hyperledger Fabric has indeed exhibited better throughput and latency values than Ethereum and other blockchain platforms [42,43,62]. In addition to these characteristics, it provides an entire set of privacy-preserving mechanisms to create and submit private transactions [41,62]—a decisive quality that influenced our decision.

Blockchain-Based Architecture Design for PHR

Using Hyperledger Fabric release 2.2, our blockchain network is structured with N peer nodes (P1, P2, …, PN), with N greater than or equal to 3, and an ordering service node. The peer nodes are the basic elements of the network because they store ledgers (L) and smart contracts (S) [64]. Ideally, each peer infrastructure must be under the responsibility of a different corporation. In this sense, they can represent N interested parties—the government, health organizations, civil society institutions, hospitals, among others—acting for the maintenance and evolution of a PHR. Thus, the peer nodes provide network services such as the writing and reading of the ledgers for administrators and users relating to these parties. In theory, there is no upper bound for N other than that imposed by the hardware and software running the consensus protocol. In this sense, we first investigate a 3-peer network because it is the smallest one in which the majority assumption is reasonable and, second, analyze the impact of increasing N.

The peers are associated with their respective client nodes (CL1, CL2, …, CLN)—the elements outside the network that allow an application to be connected to the blockchain, that is, an external application accesses ledgers and smart contracts via client-peer connection. By means of a software development kit [65], Hyperledger Fabric supplies an application programming interface with instructions to perform the aforementioned connection in order to submit transactions as well as to receive responses after these transactions are finished or interrupted earlier due to the lack of consensus. In addition, Hyperledger Fabric conceives of a channel (C) as a primary communication pathway by which peers and clients can establish a consortium with well-defined policies, thus providing a mechanism for isolating assets and transactions from the rest of the network. In this context, each smart contract and the respective ledger can be separately invoked on a specific channel only by users previously registered in the consortium, thereby ensuring interoperability and privacy [64].

The peers get assigned to the consortium—the government, health organizations, civil society institutions, and hospitals in our example—by their respective certificate authorities (CA1, CA2, …, CAN), the elements that generate public and private key infrastructure to issue identities via digital certificates [66]. Hyperledger Fabric has adopted the X.509 standard [67] as its primary certificate system. Whenever one of the consortium members establishes a client-peer connection to access the blockchain resources, these certificate authorities attest to the channel the digital identity of the applicant and her/his rights to use the required smart contract. As already mentioned, the Fabric component mapping identities with their own rights is the membership service provider, which inspects who participates in the network and their channels, identifying roles and limits of all administrators and users [64].

Lastly, the ordering service node mediates the interaction between peers during a transaction submission and ensures a consistent ledger after performing the consensus protocol. In Hyperledger Fabric, the endorsement policy occurs as a result of a 3-phase process: (1) proposal, (2) ordering and packing, and (3) validation and commit. Roughly speaking, in the first phase, a client node submits a transaction proposal, which is distributed to the endorsement peers and is independently executed by them, returning a set of endorsed responses—inconsistent responses can be already detected and discarded, finishing the workflow early. In the second phase, the ordering service node collects these responses and packages them into blocks, preparing for the next step. In the third phase, the ordering service node finally distributes the blocks to the peers, which in turn validate them to verify the endorsement phase and, only after that, commit to the ledger—failed transactions terminate the workflow without writing on the blockchain [64]. Figure 1 summarizes our architecture design, just omitting the ordering service node for a better visualization. The N peers in our network are configured to participate in the endorsement phase.

Turning the analysis to the ledgers and smart contracts, our approach considers 3 classes: (1) for personally identifiable information (PII), (2) for health record information (HRI), and (3) for record sharing information (RSI) (Figure 2). By opting for 2 or more ledgers (3 in our case), blockchains also evolve in an intricate and unpredictable way, which makes any attempt to tamper with health records even more difficult and unlikely as long as the system is in use. Besides the tamper resistance, such configuration permits the blockchain network to be structured in an oriented-ledger architecture design, making data organization aligned with the resource consumption.

PII is designed to store basic form data filled by the user at the moment of registration in the system. There are smart contracts to add, update, retrieve, and view history, respectively, to write a new record, rectify a registration error, perform a system login, and recover an updating log. To add a PII, the user needs to register with a password—converted into a hash value for security—and thus, receive a unique identifier (PII ID). Once registered, the PII ID is only recovered from a login, that is, identity number or email and the correct password hash. All other smart contracts, including those from HRI and RSI, are only able to write and read the ledger by means of a PII ID as the prefix of a composite key. In such a way, each user just accesses her/his data. HRI, in turn, is designed to store metadata from a health document, together with a hash value and a database ID, for reasons to be explained later in the text. Similar to the PII, there are smart contracts to add, update, retrieve—in this case, to recover a single record—and view history, and one further to list all records for a user. Finally, RSI is designed to store HIE logs in order to track every time a copy of a health document leaves the repository, either for downloading or sharing. There are smart contracts to add, retrieve, and list. To keep HIE logs unchanged, we opt for not creating a smart contract to update them; hence, neither one to view history.

Notwithstanding the necessity of smart contracts to list HRI and RSI, for the sake of security, PHR systems do not need one to list PII. One such smart contract would allow an administrator to list users and associate them with their respective HRI and RSI. To prevent such a situation and actually grant to a user the exclusive right of her/his health data ownership, the PII ID is only retrieved with the correct password hash. Because PII ID is a required index prefix to use HRI and RSI smart contracts, the absence of a PII listing function represents an additional security element directly configured in the operation rules of the system. Note that these settings are not just programming practices. Because smart contracts state the logic of the blockchain network, a set of security practices at the present time can evolve to rule status in the near future. Indeed, using smart contracts is a great opportunity to create a bylaw or business logic for PHR, defining which is and is not permitted regarding the access to patient information.

Although there are several smart contracts, they consist of 2 basic network operations: writing and reading. The former is used to invoke either the creation of a new state on the ledger or the modification of an existing one—without deleting past states, evidently. Smart contracts to add and update fall into this type. To perform writing, a client node needs to start an endorsement policy and reach consensus—a process that involves all peers. The latter operation, in turn, is used to query the current state and history of a ledger. Smart contracts to retrieve, list, and view history fall into this another type. To perform reading, a client node just connects to its associated peer and thus queries the stored ledger, independently of the other peers. Similar to the client-peer connection resources, by means of another software development kit [68], Hyperledger Fabric supplies an application programming interface with instructions for the development of smart contracts and business logic. As already mentioned, Fabric provides support for Go, Java, and Node, but we adopt the latter as our primary programming language to build our architecture design.

Figure 1. Design of our blockchain network, considering N endorsement peers and their respective clients and certificate authorities. Each channel is associated with a specific set of ledgers and smart contracts, respectively named as personally identifiable information, health record information, and record sharing information. Ideally, each triple peer-client-certificate authority must be under the responsibility of a different organization or institution. HRI: health record information; PII: personally identifiable information; RSI: record sharing information; P: peer; S: smart contract; L: ledger; CL: client; CA: certificate authority; C: channel.

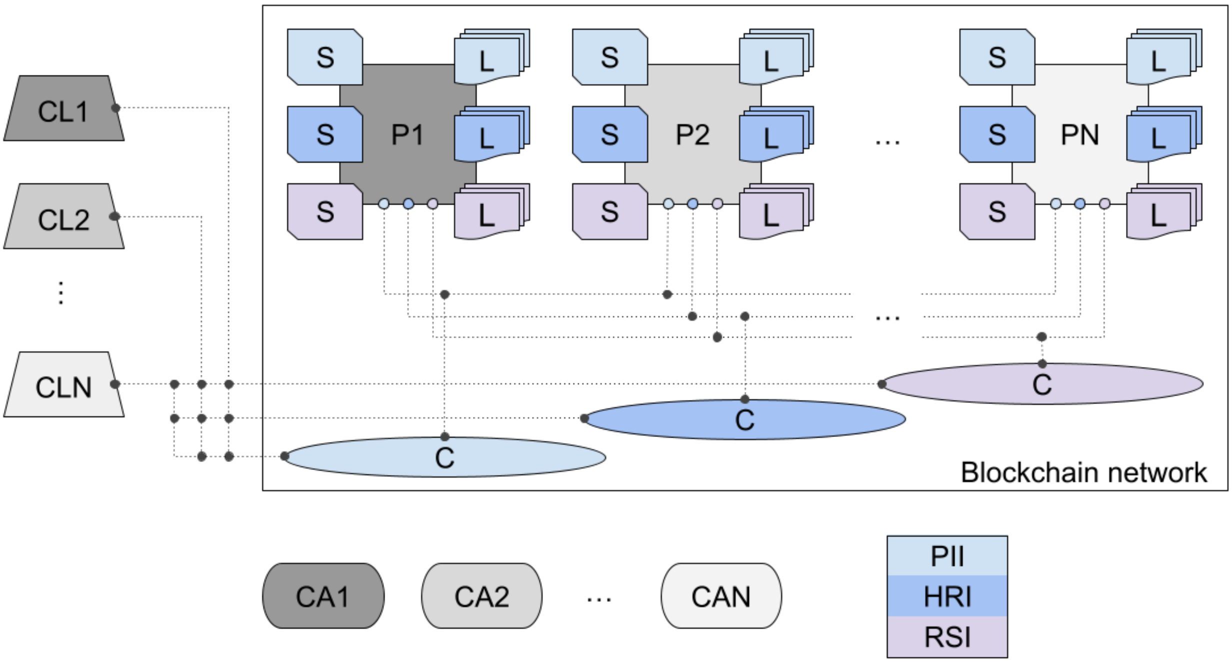
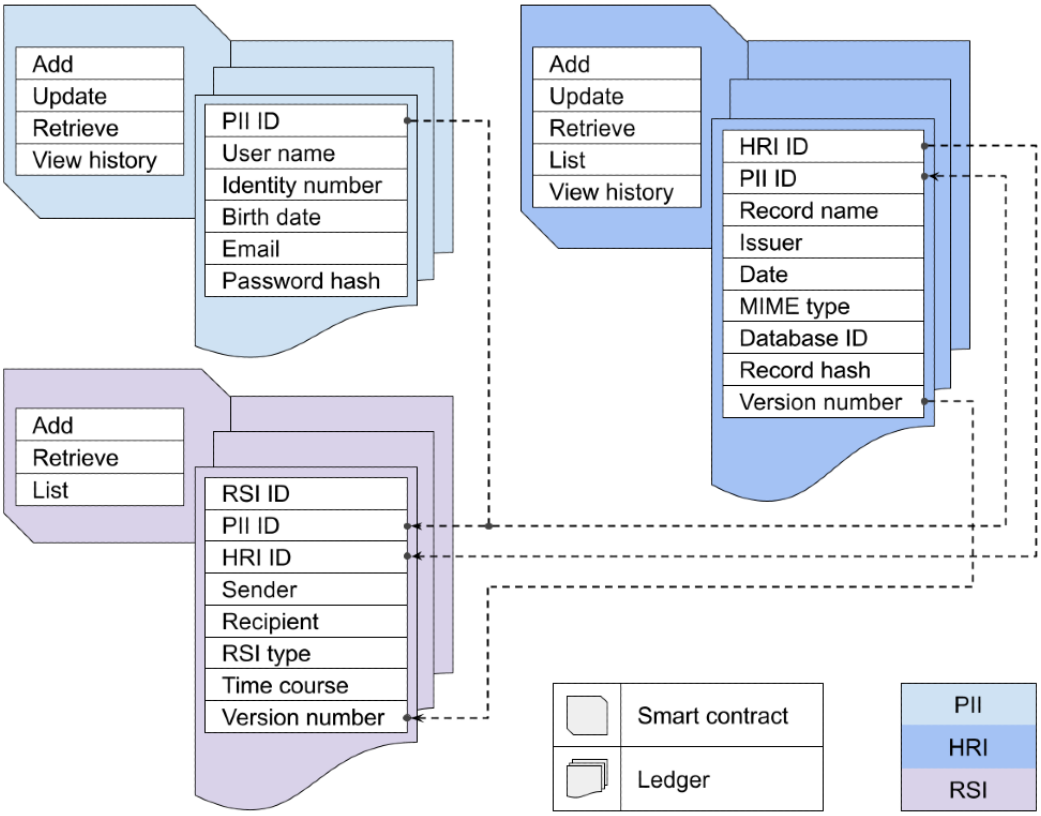


Figure 2. Design of the ledgers and their respective smart contracts. They fall into 3 classes: personally identifiable information, health record information, and record sharing information. HRI: health record information; MIME: Multipurpose Internet Mail Extensions; PII: personally identifiable information; RSI: record sharing information.



Health Database, Cryptographic Unit, and Server

Although blockchain technology provides security tools against record tampering, it is still not suitable for storing a large volume of data, despite the efforts made to meet this requirement [69]. Nowadays, only metadata such as PII, HRI, and RSI can be recorded and maintained in a blockchain network. Therefore, our system also includes a NoSQL database to permit the scaling of all sorts of health data (text, signals, and images) in clusters of machines. To implement our NoSQL health database, we adopted MongoDB, a document-oriented database, which indeed supports methods to distribute and replicate data across multiple machines and provides lower execution times than a relational one, making the scaling out easier for applications demanding both a large volume of data and a large number of queries [70]. In summary, while metadata (PII, HRI, and RSI) are stored on the blockchain network, data, that is, digital health documents, are stored on a distributed health database as soon as the network achieves consensus. In these circumstances, the health documents are hashed and their hash values are included as metadata in HRI to shield them from breaches. Note that the blockchain network represents an audit system [71] and the health documents can be anonymized in the health database, apart from a database ID in the sole possession of the user.

As a further safeguard, the data and metadata are encrypted. When a user registers in our system, she/he automatically receives a key to encrypt information entering the system as well as to decrypt that leaving out by means of a cryptographic unit. Each user obtains her/his own key and is only capable of decrypting her/his own data evidently. Because our health database is configured to store documents smaller than or equal to 100 MB, we opt for using the advanced encryption standard (AES), a symmetric key block encryption algorithm recommended by the National Institute of Standards and Technology. The AES handles block sizes of at least 128 bits and key sizes of 128, 192, and 256 bits. The AES also accepts 5 modes of operation, that is, electronic codebook, cipher block chaining (CBC), cipher feedback, output feedback, and counter, for preventing identical ciphertexts to be generated from blocks containing the same data, a breach that facilitates a malicious opponent to accumulate enough plaintext-ciphertext pairs and thus find the key by exhaustion in a feasible time. In particular, CBC requires an initialization vector, which takes an exclusive-OR operation with the first plaintext block and, if randomly generated, provides different ciphertexts from the same data [72,73]. We adopt CBC as our mode of operation and 256 bits as our key and initialization vector sizes, resulting in the AES-256-CBC algorithm. The key and initialization vector of each user are allocated in a private wallet/folder, alongside her/his digital certificate.

As a final module, we build a server infrastructure out of a Node framework to host the blockchain clients and, thereby, provide blockchain resources for external applications. Through a control unit, and performing specific calls for each smart contract as well as for each database operation, this server supports the registration and access of users, the inclusion, updating and retrieval of health documents, and the creation of links to download and share these documents—only with the consent and supervision of the respective user, evidently. Roughly speaking, this server executes 3 basic steps: (1) it receives requests from external applications, (2) according to each request, it accesses the corresponding network and database resources, and (3) it returns consistent responses to those applications. Because the server works as an intermediate system between blockchain network, health database, and external applications, it conveniently accommodates the cryptographic unit. In this way, sensitive information is encrypted as soon as it enters the system and only decrypted when leaving out. Figure 3 highlights all these interconnected modules and Figure 4 exemplifies the flow of information during the query or record request of a health document.

Figure 3. Sketch of the overall system, exhibiting the interconnections between server, health database, and blockchain network, in order to provide personal health record resources for external applications. HRI: health record information; PII: personally identifiable information; RSI: record sharing information.

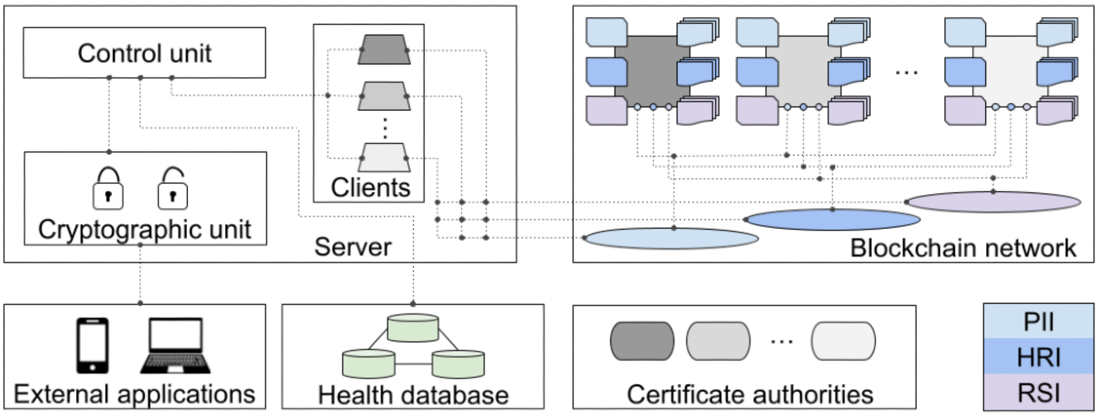
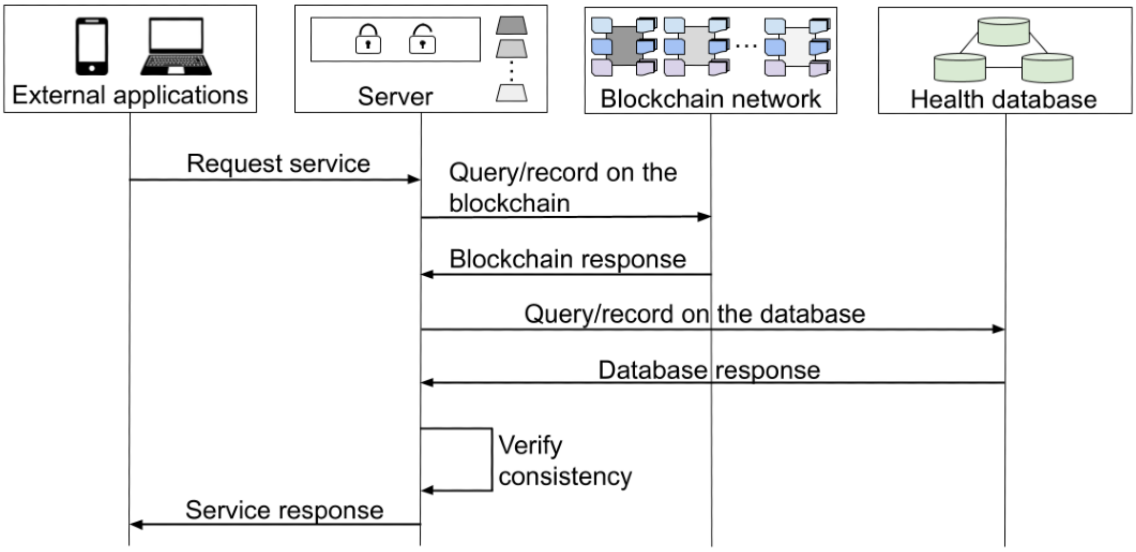


Figure 4. Flow of information during the query or record request of a health document. The server only returns a successful response if data and metadata are consistent. The flow can be interrupted earlier owing to lack of consensus.



Evaluation Benchmark

To evaluate our blockchain-based architecture design, we use Hyperledger Caliper—a benchmark tool released by the Hyperledger community for measuring the performance of blockchain systems and producing reports containing metrics commonly accepted, such as throughput and latency. Caliper supports Ethereum and Hyperledger Fabric, allowing computer scientists and engineers to compare EHR proposals developed from the 2 main platforms at present. It is capable of generating a workload for a system under test (SUT) and continuously monitoring responses from this SUT [44,74].

To run an experiment, Caliper requires a benchmark file, a network file, and workload modules. The first one presents custom configurations to run the benchmark, such as the number of workers to perform a workload, the round settings, the number of submissions, the round length in seconds, the rate at which transactions are sent to the blockchain, among others. The second one presents the layout of the SUT—basically, the addresses and identities of the nodes and the channels and smart contracts to be used during the test. Lastly, workload modules are Node functions exported to simulate client nodes sending requests to the SUT, that is, in each round, a different workload module can be used to generate and submit transactions to the SUT, according to the configurations in the benchmark and network files. Therefore, Caliper can emulate many clients injecting workloads in a blockchain network [44,74].

As already mentioned, 2 basic metrics to assess blockchain performance are throughput and latency. The former, usually given in transactions per second (tps), represents the total number of valid transactions reached in a period of time [42]. In this sense, invalid transactions are subtracted from the total to yield the valid ones. Because transactions fall into reading and writing operations, throughput also falls into these types. On the one hand, reading throughput may be informative, but it only measures operations taken on a single client-peer connection, independently of the other peers, and therefore, is not a primary measure. On the other hand, writing throughput considers operations invoking the consensus protocol and thus committing transactions at all endorsement peers, making it much more informative than the preceding rate [75].

The latter, in turn, usually given in seconds, represents the time taken for a transaction to conclude and return a response [42]. Similar to the throughput, latency also falls into reading and writing types: the first one measures delays from a single client-peer connection, while the second one from all endorsement peers. In particular, writing latency includes the propagation and settling times due to the consensus protocol, considering delays measured over the entire network. Although this metric is generally calculated per transaction, the average latency is more suitable to assess blockchain performance [75].

Results

With a 3-peer network, our first benchmark is set to run a workload, from 100 to 2500 simultaneous submissions of health metadata, with steps of 100, on each smart contract of the PII, HRI, and RSI templates. We limit our test to 2500 loads because Hyperledger Fabric is standardly configured to perform a maximum of 2500 concurrent requests. Writing scenarios are configured to use 5 workers submitting at the same time 10,000 transactions, each one totalizing 50,000. Reading scenarios are configured to use the same 5 workers in parallel but to randomly request records during 600 seconds of continuous operation. The rate controller is kept in a fixed-load mode, starting at 50 tps and 500 tps, for writing and reading transactions, respectively, and growing to reach maximum rates. Because PII, HRI, and RSI are designed to store ciphertexts only, in our test, all simulated submissions of health metadata are randomly generated as strings of fixed length for each smart contract field. An empty blockchain network is raised in each load test to guarantee an equal condition. Our test environment consists of a machine having an Intel Xeon E-2246G processor (12 MB cache, 3.60 GHz, 6 cores, 12 threads), an NVIDIA Quadro P1000 graphic adapter, and a random access memory of 16 GB, running Ubuntu 18.04.5 LTS 64 bits operating system.

Figure 5 exhibits the throughputs and average latencies in relation to PII, HRI, and RSI smart contracts under workload. We do not report transaction errors because not one occurred. Disregarding the small variations inherent in each workload trial, and albeit with different baselines, the throughputs of all smart contracts remain fairly constant over the interval, a consistent behavior given that the system responses appear to be invariant to load. Smart contracts to add and update a record have rates with an order of magnitude close to 10^2 tps, while those to retrieve, list, and view history have rates close to 10^3 tps. As already suggested, this difference arises mainly because writing transactions trigger the consensus protocol, mobilize the network as a whole, and then need more time to process all submissions, whereas reading ones only involve a single client-peer connection. Although with different upward slopes, the average latencies of all smart contracts present a linear growth as workload range varies, a reasonable behavior inasmuch as an increase in submissions demands a proportional increase in processing. In this case, smart contracts to add and update a record have delays with an order of magnitude close to 10^1 seconds, while those to retrieve, list, and view history have delays close to 10^0 seconds. In analogy with the throughput, there is an obvious difference between writing and reading transactions, for the same reason as before.

Even though throughputs of reading transactions present a similar order of magnitude, they have significant differences between them. Smart contracts to retrieve, list, and view history have throughputs varying, respectively, from 1100 tps to 1300 tps, from 650 tps to 750 tps, and from 850 tps to 950 tps. Their latencies, in turn, grow at slightly different linear rates, albeit alike. These 2 pieces of evidence suggest that reading transactions can impact the overall system response if they are equally requested. An external application under a real situation has to consider the smallest of these values as the upper limit to avoid overload. With a fixed load at 2000 submissions, our second benchmark is set to increase the network size from 3 to 13 peers, with steps of 2, and perform, for each case, the writing and reading scenarios of the previous experimental protocol. We limit the largest network to 13 peers because by considering our test environment, Hyperledger Fabric has a very poor performance beyond this value, resulting in many transaction failures. Figure 6 displays the throughputs and average latencies when the size of the network increases. For reading smart contracts, they remain fairly constant over the interval, sustaining orders of magnitude close to 10^3 tps and 10^0 seconds, respectively, a consistent behavior given that such operations rely on a single client-peer connection. Writing smart contracts, in turn, start with throughputs close to 10^2 tps but end with rates close to 10^1 tps, exhibiting an exponential decay. They also start with latencies of 10^1 seconds but end with delays of 10^2 seconds, presenting a linear growth. Both pieces of evidence corroborate the well-known scalability issue of Hyperledger Fabric when the number of endorsement peers increases.

As a final comment when observing throughputs and average latencies in Figures 5 and 6, despite the obvious differences regarding each smart contract operation (to add, update, retrieve, list, and view history), the ongoing metrics of the 3 proposed templates (PII, HRI, RSI) do not reveal large deviations within a single operation, indicating a similar performance even with slightly different sizes of health metadata.

Figure 5. Throughput (measured in transactions per second) and average latency (measured in seconds) of all smart contracts under workload, ranging from 100 to 2500 concurrent submissions of health metadata, with steps of 100. HRI: health record information; PII: personally identifiable information; RSI: record sharing information; tps: transactions per second.

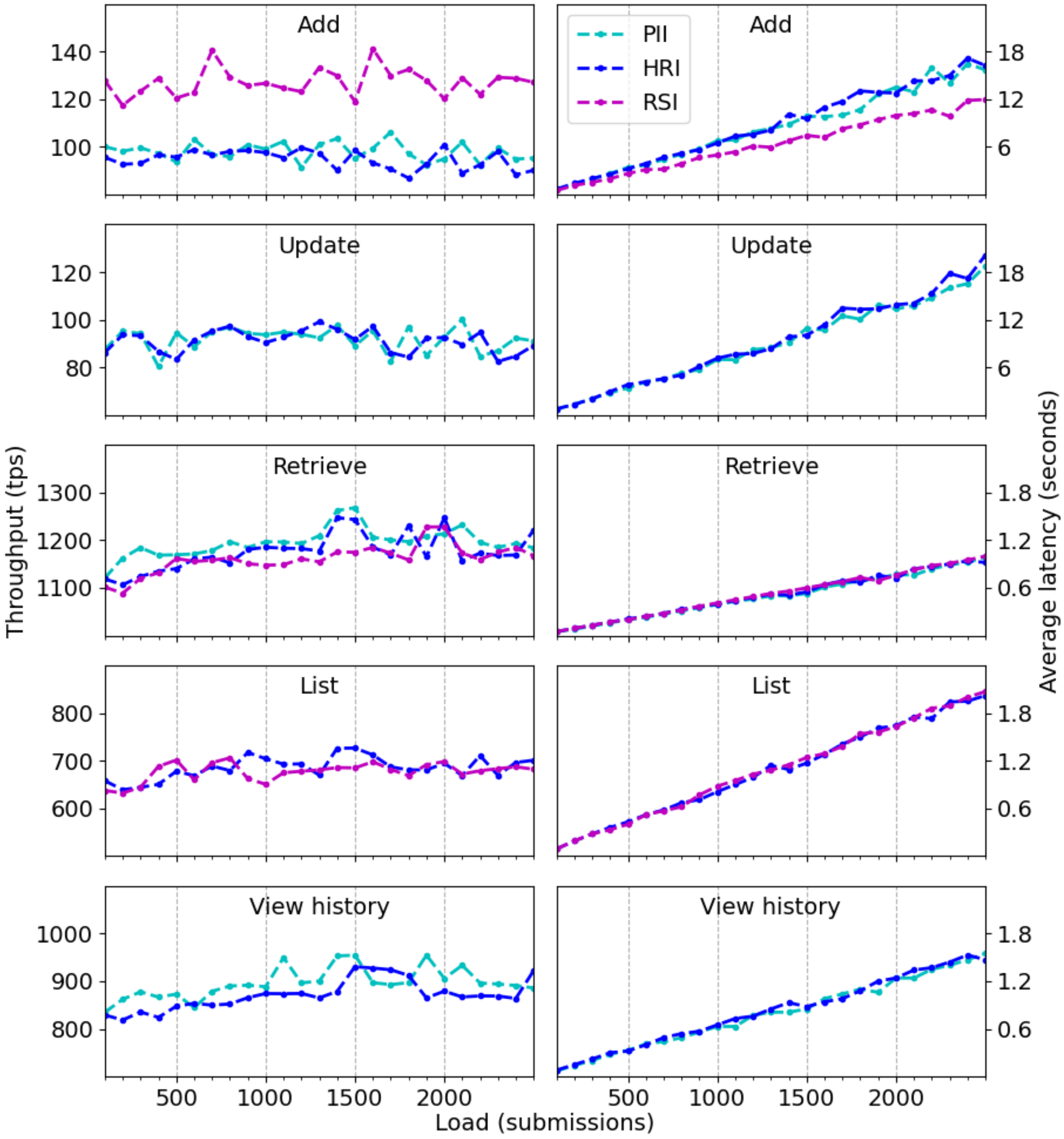
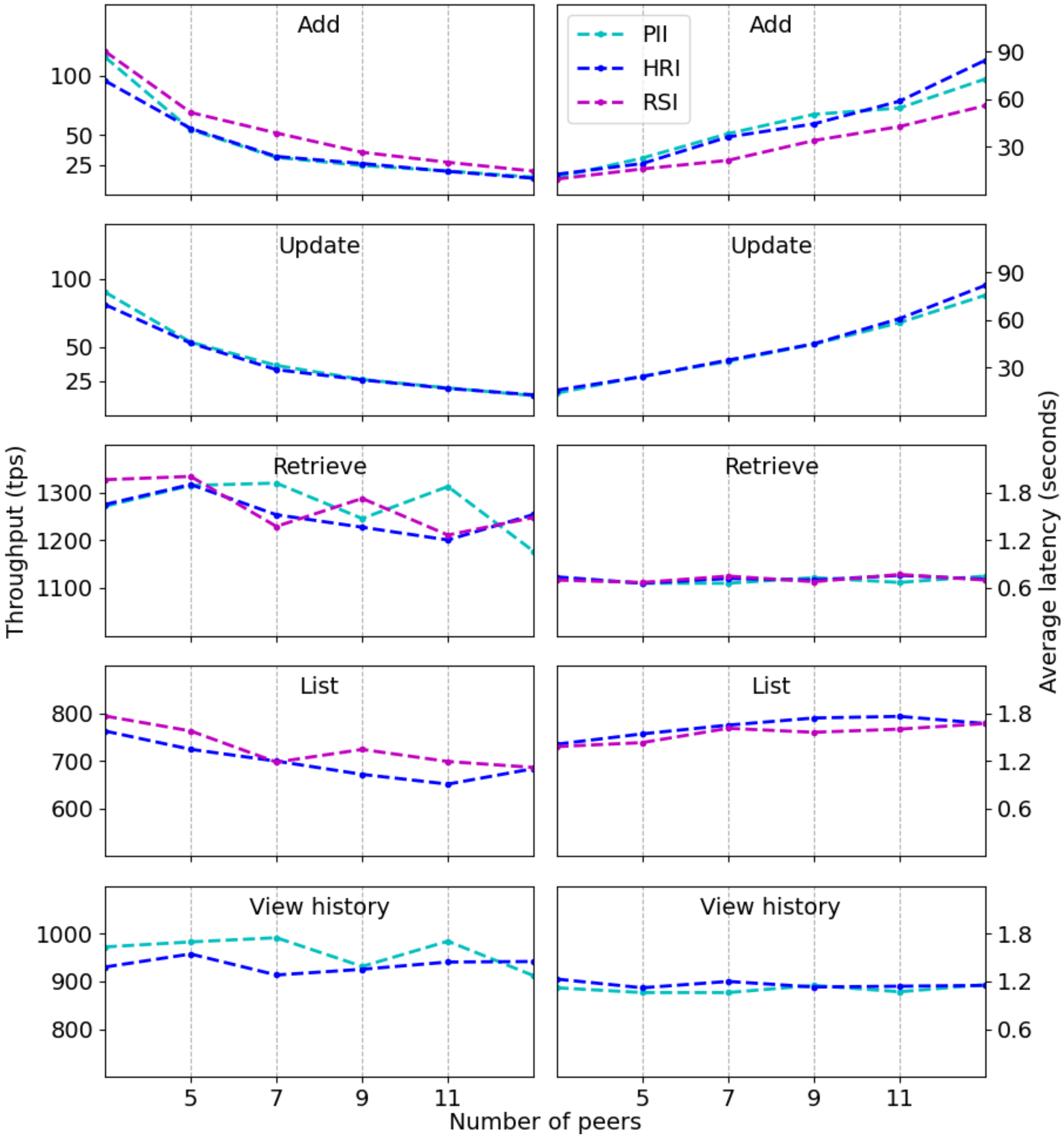


Figure 6. Throughput (measured in transactions per second) and average latency (measured in seconds) of all smart contracts, by considering a network increase from 3 to 13 endorsement peers, with steps of 2. HRI: health record information; PII: personally identifiable information; RSI: record sharing information; tps: transactions per second.



Discussion

The results of this study are comparable to those reported previously in the literature [42-44], indicating that blockchain systems achieve performances far below what the traditional distributed databases achieve [76,77]. Traditional databases make use of concurrency control, for example, 2-phase locking to ensure atomicity, consistency, isolation, and durability. By and large, they exhibit better performance because they consider simple failure models such as crash failure. Oppositely, blockchain systems consider Byzantine failure and, in the worst scenario, a hostile environment in which nodes can join and leave the network, which undeniably makes the overhead of concurrency control much more difficult to handle [42]. However, despite being widely recommended by the blockchain community [42-44], throughput and latency have not been commonly adopted metrics for evaluating PHR. Yue et al [28] did not even perform a system assessment; Roehrs et al [29] only simulated a peer-to-peer network and then, provided an inferred latency; Ichikawa et al [30] assessed the tamper resistance in a fault simulation context; Liang et al [45] and Liang et al [47] measured an average time cost to handle simultaneous records; Uddin et al [50] employed surviving generations value as well as central processing unit and memory monitoring; Omar et al [52] opted for Ethereum's crypto-fuel; and Lee et al [56] proposed a test scenario in which a person and a doctor actually used the system [56]. Only Roehrs et al [53] observed how throughput and latency varied, under workload, from 50 to 500, from 1000 to 10,000, and from 13,000 to 40,000 concurrent requests as light, medium, and heavy scenarios, respectively. The authors achieved, in the heavy one, impressive values: 2298 tps and 0.404 seconds on average [53]. However, the authors arranged health data on single data blocks with writing and reading capabilities as a unified view of patients, thus not performing a bylaw or business logic for PHR and only assessed reading transactions considering these blocks. Furthermore, they did not develop their network from an open-source platform, hindering system reproducibility.

In practice, most of the works focus more on describing how blockchain models can be used in a PHR scenario than whether these models are in fact feasible to support a large number of users. Because the health industry can easily cover tens or even hundreds of millions of patients in a single country, we think the assessment of blockchain solutions for PHR is a major concern to be addressed before putting them into a real production. In view thereof, there is a latent necessity of standardizing evaluation metrics to facilitate the comparison between related works. We think that throughput and average latency are suitable metrics for this purpose as well as Hyperledger Caliper and BLOCKBENCH [42] adequate frameworks to perform this evaluation.

Toward a consistent, reproducible, and comparable PHR evaluation, and by regarding throughput and latency, we are the first to evaluate with Hyperledger Caliper the performance of a PHR blockchain architecture. Because Caliper is the official benchmark to access blockchain networks built out of Fabric, we believe that our results bring important insights to the limits and advantages of using Fabric to design PHR repositories. Moreover, Caliper can be adapted to access Ethereum-based systems, facilitating the comparison between architectures created with the 2 main open-source platforms at the present time. To the best of our knowledge, we are also the first to evaluate each smart contract separately. Previous works considered smart contracts as falling only into writing and reading transactions and have just identified dissimilarities between these 2 types. However, we reveal that, especially in relation to reading ones, throughput and latency can have significant differences, impacting the overall system response if these transactions are equally requested under the same workload.

Specifically in relation to our proposal, as a first implementation, the blockchain network, the health database, and the server are allocated through virtual machines on a single physical device, only simulating a decentralized system, which represents a limitation of our work. Furthermore, because we are primarily interested in the blockchain architecture, the health database and the server are incorporated in the model but they are not actually tested considering an external application under a real situation, which represents an additional limitation. We leave these improvements for future work because we believe that our current results already provide important advice to the biomedical and health informatics community.

In conclusion, the importance of blockchain-based architectures for PHR lies in the fact that they are thought and developed to allow a patient to control and at least partly collect health data, as well as to share health information on her/his own. Ideally, these systems should provide the full control of such data for the respective owner [78]; that is, each patient must authorize health care providers and stakeholders (s)he trusts before they can access her/his personal health data. Exactly because blockchain systems are tightly related to privacy and security concerns, several works are proposing blockchain-based solutions to the health care industry. In line with these efforts, we build a novel ledger-oriented architecture out of a permissioned distributed network in order to support a PHR system for patients to securely collect, store, share, and manage their health data. We emphasize the importance of suitable ledgers and smart contracts to operate the overall blockchain network and provide a detailed assessment of this network under workload, ranging from 100 to 2500 concurrent submissions, and increasing the network size from 3 to 13 peers. To the best of our knowledge, we are the first to evaluate with Hyperledger Caliper the performance of a PHR blockchain architecture and the first to evaluate each smart contract separately. However, our system elements are allocated through virtual machines on a single physical device, only simulating a decentralized system. Besides this limitation, our health database and server are incorporated in the model but they are not actually tested considering an external application under a real situation. We intend to perform these enhancements in future works.

Acknowledgments

We thank Foxconn for the financial support and Instituto do Coração, Hospital das Clínicas, Faculdade de Medicina, Universidade de São Paulo for the research infrastructure.

Conflicts of Interest

None declared.

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Abbreviations

AES: advanced encryption standard
CBC: cipher block chaining
EHR: electronic health record
HIE: health information exchange
HRI: health record information
PHR: personal health record
PII: personally identifiable information
RSI: record sharing information
SUT: system under test
tps: transactions per second

Edited by G Eysenbach; submitted 16.11.21; peer-reviewed by A Uddin, TT Kuo; comments to author 22.12.21; revised version received 14.02.22; accepted 07.03.22; published 13.04.22

Please cite as:
Costa TBDS, Shinoda L, Moreno RA, Krieger JE, Gutierrez M
Blockchain-Based Architecture Design for Personal Health Record: Development and Usability Study
J Med Internet Res 2022;24(4):e35013
URL: https://www.jmir.org/2022/4/e35013
doi: 10.2196/35013
PMID:

Review

Consumers' Evaluation of Web-Based Health Information Quality: Meta-analysis

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Abstract

Background: The internet has become a major source of health information for general consumers. Web-based health information quality varies widely across websites and applications. It is critical to understand the factors that shape consumers' evaluation of web-based health information quality and the role that it plays in their appraisal and use of health information and information systems.

Objective: This paper aimed to identify the antecedents and consequences of consumers' evaluation of web-based health information quality as a means to consolidate the related research stream and to inform future studies on web-based health information quality.

Methods: We systematically searched 10 databases, examined reference lists, and conducted manual searches. Empirical studies that investigated consumers' evaluation of web-based health information quality, credibility, or trust and their respective relationships with antecedents or consequences were included.

Results: We included 147 studies reported in 136 papers in the analysis. Among the antecedents of web-based health information quality, system navigability (ρ=0.56), aesthetics (ρ=0.49), and ease of understanding (ρ=0.49) had the strongest relationships with web-based health information quality. The strongest consequences of web-based health information quality were consumers' intentions to use health information systems (ρ=0.58) and satisfaction with health information (ρ=0.46). Web-based health information quality relationships were moderated by numerous cultural dimensions, research designs, and publication moderators.

Conclusions: Consumers largely rely on peripheral cues and less on cues that require more information processing (eg, content comprehensiveness) to determine web-based health information quality. Surprisingly, the relationships between individual differences and web-based health information quality are trivial. Web-based health information quality has stronger effects on cognitive appraisals and behavioral intentions than on behavior. Despite efforts to include various moderators, a substantial amount of variance is still unexplained, indicating a need to study additional moderators. This meta-analysis provides broad and consistent evidence for web-based health information quality relationships that have been fractured and incongruent in empirical studies.

(J Med Internet Res 2022;24(4):e36463) doi: 10.2196/36463

KEYWORDS

online health information; information quality; credibility; trust; consumer health information behavior; meta-analysis

Introduction

The internet has become a major source of health information for general consumers. However, health information quality (IQ) varies widely across websites and web applications, and the overall quality is concerning [1,2]. Low-quality information conveys incomplete, inaccurate, or outdated knowledge, which may lead users to form erroneous health beliefs and cause negative, or even detrimental, health outcomes. Owing to the immense ramifications, web-based health IQ has attracted continued attention from researchers, health care professionals, and consumers alike.

The IQ construct has been defined in a disparate fashion. Some researchers have taken an objective view, defining IQ in relation to currently accepted medical guidelines [3]. Others recognized that the evaluation of IQ is contingent on users' tasks, goals, and value judgments [4-6] and defined IQ, from a subjective view, as users' perceptions of IQ [7] or "fitness for use" [8]. For the purpose of this review, we adopted the view of IQ in the study by McKinney et al [7] and defined web-based health IQ as users' perceptions of the quality of health information on the internet. In the internet context, two other concepts share this notion: credibility and trust. Credibility is often defined as perceived IQ, whereas trust denotes users' willingness to trust web-based information [9].

Some researchers have differentiated these 3 concepts. For instance, some view IQ as a dimension of credibility or a factor that influences credibility judgment [10], whereas others view credibility as a major dimension of IQ [11]. Some view IQ [12-14] or credibility [15] as antecedents of trust, whereas others view trustworthiness as a major dimension of credibility [16]. Despite these differences, the 3 concepts are intertwined. In the literature on consumers' web-based health information seeking, they all, to some degree, refer to consumers' perceived quality of web-based health information [17,18]. To achieve comprehensive coverage of the literature, we included studies that used any of the 3 terms to refer to health consumers' perceptions of web-based health IQ.

Systematic reviews concerning IQ, trust, and credibility of web-based health information have recently been published. Sun et al [19] identified the criteria and indicators that consumers use to evaluate web-based health IQ. Sbaffi and Rowley [18] identified factors that affect consumers' trust in and the perceived credibility of web-based health information. Kim [20] identified antecedents of trust in web-based health information. On a related note, Diviani et al [17] examined the relationship between health literacy and consumer evaluation of web-based health information. These reviews provide a comprehensive view of how consumers evaluate web-based health IQ and outline categories of antecedents of web-based health IQ, such as individual factors (eg, sociodemographic and health status), source factors (eg, reputation), content factors (eg, relevance and usefulness), and design factors (eg, layout and ease of use).

However, these reviews have several limitations. First, a plethora of antecedents of web-based health IQ was identified; however, few syntheses and comparisons were performed, resulting in a rather murky view of the most influential antecedents and how they affect web-based health IQ evaluation. Second, little effort was made to amalgamate the consequences of web-based health IQ. Third, little effort was made to explain inconsistent results across studies. For example, health literacy (and education levels and other skill-based proxies for health literacy) had a significant positive effect on perceived web-based health IQ and trust in some studies [21-24] but a negative [25-27] or insignificant [28-30] effect in others. These inconsistent results indicate that web-based health IQ relationships may be moderated by contextual factors [31].

To further enhance our knowledge of the existence, nature, and magnitude of web-based health IQ relationships and elucidate the conceptual and practical significance of the concept [32], we performed a meta-analysis to address the following research questions: (1) what antecedents and consequences are relevant to consumers' evaluations of web-based health IQ, and (2) what moderators intervene in web-based health IQ relationships?

Methods

Search Strategy

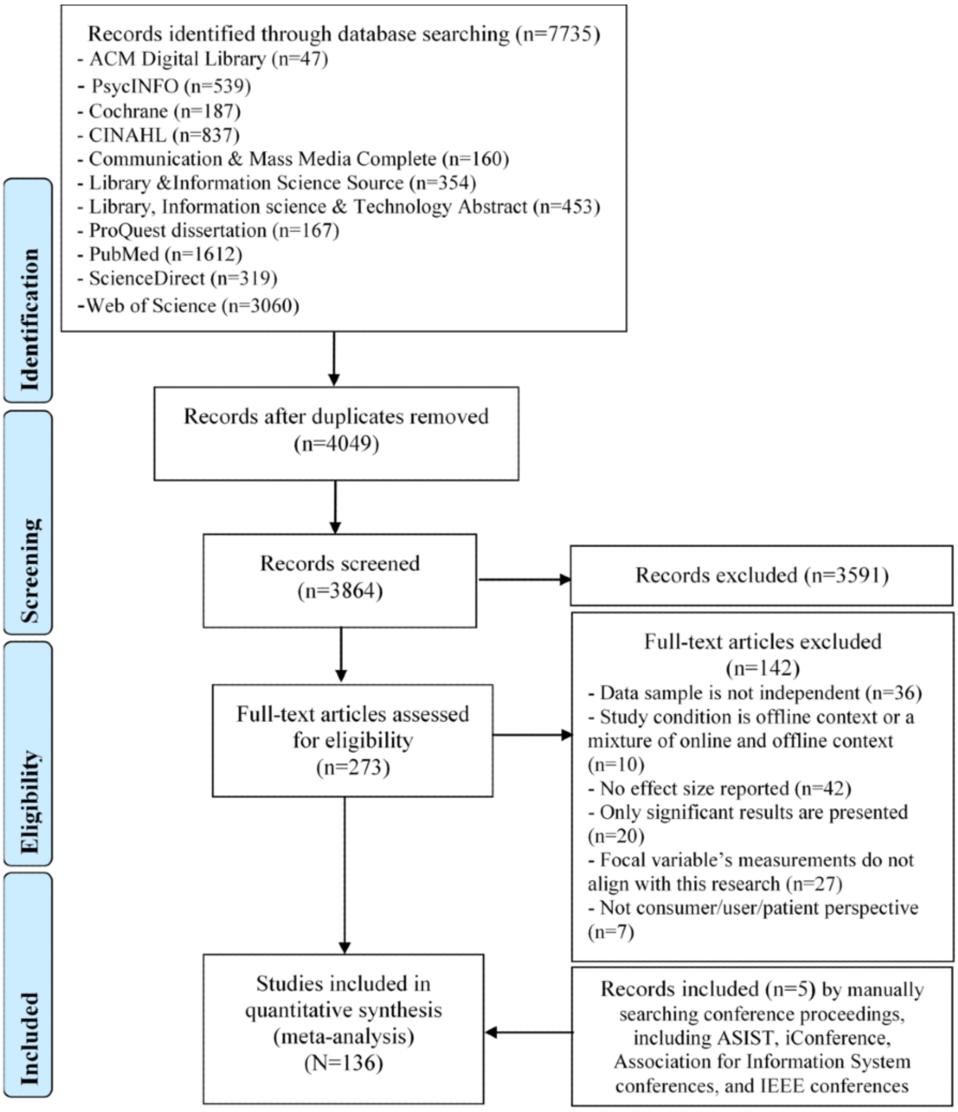
A systematic search of the literature published since 2000 was performed in July 2020 on 10 databases (eg, PubMed, CINAHL, and PsycINFO), using the search query *health information* AND (*credibility* OR *quality* OR *reliability* OR *trust*) AND (*online* OR *Internet* OR *web*) within the title, abstract, and keyword fields of these databases. In addition, we tracked the references of the included papers using Google Scholar. To reduce publication bias, we also searched the ProQuest dissertation and thesis database and reviewed the proceedings of several related conferences.

Inclusion Criteria, Exclusion Criteria, and Screening

The studies included in this review were empirical studies that reported effect sizes for web-based health IQ relationships. Studies were excluded if they met the following criteria: (1) focused on health care providers, (2) used qualitative research methods, (3) studied patients' or consumers' perceptions of the quality of information from noninternet sources (eg, health care providers and newspapers), (4) were not independent samples, (5) did not report effect sizes, (6) only reported significant results, and (7) were not in English.

Unique records resulting from the search were screened against the inclusion and exclusion criteria. First, two reviewers (YZ and SS) independently reviewed the titles and abstracts of the 100 randomly selected records. The full text was retrieved and perused when a decision could not be reached based on the title and abstract. The intercoder agreement was moderate (Cohen κ=0.51). Discrepancies were discussed, and we clarified the inclusion and exclusion criteria. Then, the 2 coders independently coded another 50 randomly selected records. The intercoder agreement reached 0.71. Discrepancies were discussed and resolved again. SS then screened the rest of the records. The screening was purposely kept broad to avoid missing relevant studies. The overall process resulted in 273 papers. YK reviewed the full text of these papers and further excluded 142. Relevant papers from related conference proceedings were added, resulting in a final sample of 136 papers, which reported 147 studies. The paper screening and identification procedures are illustrated in Figure 1. The list of studies is reported in Multimedia Appendix 1.

Figure 1. Paper screening and identification procedure.



Data Extraction and Meta-analytic Approach

One of the reviewers (YK) extracted and coded the following data from the included studies using Microsoft Excel:

1. Basic paper features: title, publication outlet, author, publication year, and publication type (journal and nonjournal)
2. Research design: stimulus type (specific vs general), technology context (social media vs nonsocial media), sample size, sample clinical status (patient vs nonpatient), sample type (student vs nonstudent), operationalization (quality vs credibility vs trust), sample year, number of instrument items, measurement reliability, sample country, sample culture dimensions, and study methods (survey vs experiment); the values for cultural dimensions were obtained by inputting the sample country into the website of Hofstede [33]
3. Antecedents and consequences: antecedent and consequence variables (when authors of the included papers used different terms to describe the same or similar concept, the terms were grouped under a preferred name; eg, the construct of direct experience with cancer in the study by Feng and Yang [34] and the construct of perceived severity of mental health in the study by McKinley and Ruppel [35] were coded as health experience and beliefs; constructs were categorized as antecedents or consequences as in the original studies), reliability scores when available, and effect sizes for specific antecedents and consequences (ie, correlations, odds ratio, β, chi-square, *F* statistic, and *t* statistic; the latter 4 were subsequently converted into correlations using formulas [36-38]).

YZ reviewed the coded data against the original full-text papers to ensure accuracy and consistency. The interrater agreement (Cohen κ) reached 0.93 for basic paper features and research design, 0.87 for grouping concepts, and 0.91 for effect sizes. Disagreements were discussed and resolved. Interested readers can contact the authors to obtain the meta-analysis database.

Following the methods by Hunter and Schmidt [36], this meta-analysis used a random-effects model to analyze correlations (*r*s). Weighted mean correlations (ρ or main effects) were computed by correcting for measurement and sampling errors. Reliabilities from each study were used to correct measurement errors. In studies that did not report a reliability value, the mean reliability (Multimedia Appendix 2) was used as the substitute. Reliability was set at 1.00 for variables assumed to have no measurement error (eg, gender, age, education, income, and race). Sample sizes were used to correct for sampling errors. Various supporting statistics such as the 95% CI, 90% credibility interval, *Q* statistic, I^2 statistic, and Begg test were computed in addition to ρs. Heterogeneity was detected if the *Q* statistic was significant ($P<.05$), the I^2 was >75%, or the 90% credibility interval was *wide*. The Begg test [39] exposes where publication bias exists in the meta-analysis via funnel plot asymmetry, whereby $P<.05$ implicates publication bias.

Informed by prior meta-analyses on relevant topics [40-42] and the characteristics of the included studies, we examined three categories of moderators—cultural, research design, and publication—and the operationalization of web-based health IQ (quality, credibility, and trust), resulting in a total of 13 factors (Table 1).

All moderators were categorical; thus, subgroup analyses using a random-effects model [43] were conducted to calculate the mean ρs. Q_M, an omnibus test, was calculated to statistically compare subgroup means. Antecedents and consequences with a sufficient number of observations (≥20) were analyzed against moderators. Those without sufficient observations were combined into composite variables for the analysis based on conceptual similarities. The metafor package [44] in R was used to analyze the main and moderating effects.

Table 1. Moderators for web-based health information quality relationships.

Moderator	Definition and operationalization
Sample culture	This refers to the culture that sample participants belong to. It is operationalized by 5 cultural dimensions outlined in the cultural dimension theory by Hofstede [45].
Individualism versus collectivism	Individualism is “a preference for a loosely-knit social framework” where people are supposed to take care of only themselves or their close family members [46]. Collectivism represents a preference for in-group loyalties. People in a collectivistic society must unconditionally be in service to other in-group members to show their loyalty [47].
Power distance	This refers to the degree to which “the less powerful members of a society accept and expect that power is distributed unequally” [46]. In a society with high power distance, people “accept a hierarchical order in which everybody has a place and which needs no further justification.” In a society with low power distance, people strive to “equalize the distribution of power and demand justification for inequalities of power” [46].
Uncertainty avoidance	This expresses “the degree to which members of a society feel uncomfortable with uncertainty and ambiguity.” Societies with strong uncertainty avoidance are “intolerant of unorthodox behavior and ideas” [46], whereas societies with weak uncertainty avoidance exhibit a more relaxed attitude [48].
Long-term versus short-term orientation	A society with a long-term orientation fosters virtues oriented toward future rewards, in particular, perseverance and thrift [48]. A society with a short-term orientation “prefers to maintain time-honored traditions and norms while viewing societal change with suspicion” [46].
Indulgence versus restraint	Indulgence stands for a society’s tendency to allow “relatively free gratification of basic and natural human desires related to enjoying life and having fun.” Restraint stands for “a society that suppresses gratification of needs and reregulate it by strict social norms.” [46,48].
Research design	This refers to the study’s research methods to address research problems, including research settings, data collection, measurement, and the analysis of data.
Technology context	This refers to the internet technology platforms where a study situates their examination of web-based health information quality. The technology context was categorized into social media (eg, web-based health communities, Twitter, and Facebook) and non–social media (ie, general health websites).
Sample type	This refers to whether a sample comprises students or nonstudents.
Sample clinical status	This refers to people who assume to have no specific conditions or patients who have been diagnosed with particular conditions.
Study methods	This refers to the research methods that a study used to collect data. Two specific research methods were frequently used and thus coded for this meta-analysis: survey and experiment.
Stimulus type	This refers to the stimuli used in the included studies. Two types of stimuli were identified: general and specific. General stimuli are web-based health information in general (without specifications of information source and content). Specific stimuli are specific health information or health information systems (eg, a specific health website or a specific health message).
Publication	
Publication outlet	This refers to the venue where a study was published. Two types of publication outlets were defined: journal and nonjournal (including conference proceedings and theses and dissertations).
Time	This refers to when a study was published. Two periods were defined—before 2014 and in or after 2014—by applying the median split on the publication year.
Operationalization of web-based health information quality	This refers to the three focal concepts included in the analysis: web-based health information quality, credibility, and trust in web-based health information.

Results

Basic Characteristics of the Included Papers

The 136 papers included 109 (80.1%) journal articles, 20 (14.7%) conference papers, and 7 (5.2%) theses and dissertations. The publication years ranged from 2000 to 2020, with 75% (102/136) of the papers published after 2010. The health domains covered included both general and specific health topics (eg, schizophrenia, cancer, HIV, and prescription medications).

The included papers reported 147 independent studies. Sample sizes ranged from 34 to 8586 (median 252); 67.3% (99/147) of samples involved nonstudents, 32.7% (48/147) involved students, 8.8% (13/147) of samples were patients, and 91.2% (134/147) were nonpatients. Among the 133 samples that reported countries (15 countries), 76 (57.1%) were from the United States, followed by 16 (12%) from China, 10 (7.5%) from Korea, 8 (6%) from Germany, and 5 (3.8%) from Australia.

Antecedents and Consequences of Web-Based Health IQ

Table 2 presents 18 antecedents and 8 consequences of web-based health IQ with at least 6 observations. Those with the number of samples <6 were not included in the analysis as the results tend to be less generalizable [41]. The antecedents fell into four categories: individual difference, source, content, and design. The consequences fell into three categories: cognitive appraisals, behavioral intentions, and behaviors.

Table 3 presents the main effects of the antecedents and consequences. Using the Cohen criteria [49] for judging the magnitude of correlation effect sizes, the design factor—navigability—was most strongly related to web-based health IQ (ρ=0.56), followed by the other design factor—aesthetics (ρ=0.49)—and a content factor—ease of understanding (ρ=0.49). Four other factors—source trustworthiness (ρ=0.28), health knowledge (ρ=0.15), internet experience (ρ=0.13), and social endorsement (ρ=0.10)—showed significant but weak relationships with web-based health IQ.

On the basis of the Begg test, which takes into account publication bias (Begg *P*=.02), and using the trim-and-fill method [50] with 10 imputed studies on the right side of the funnel plot, age had a significant association with web-based health IQ (ρ=0.27; 95% CI 0.06-0.48; Q=3753.86). Thus, the age and web-based health IQ relationship changed from nonsignificant to significant, with individuals who were older rating the web-based health IQ higher than those who were younger. The remaining factors were not significantly related to web-based health IQ.

Regarding consequences, the web-based health IQ exerted the strongest effect on intentions to use health information systems (ρ=0.58). Its relationship with intentions to use health information was also significant but not as strong (ρ=0.37). Web-based health IQ's relationships with cognitive appraisal factors were mostly moderate, with the effect size for satisfaction being the largest (ρ=0.46). Web-based health IQ was moderately related to health information seeking (ρ=0.30) and did not have a significant relationship with health information use.

Across the results of the main effects, Q statistics were *substantial*, indicating that the effect size distribution was heterogeneous and that some variables other than subject-level sampling and measurement errors contributed to the effect size variances [51]. Confirming the Q statistics, the I^2 statistics indicated wide dispersion. The credibility interval for all relationships was wide, further implying that the effect size distribution was heterogeneous.

Table 2. Antecedents and consequences of web-based health information quality with at least 6 observations.

Variable	Definition
Antecedents	
Individual differences	
Gender	The gender of the participants included in study samples (female=1 and male=0)
Age	The age of the participants included in study samples
Education	The education levels of the participants included in study samples
Income	The income of the participants included in study samples
Race	The race of the participants included in study samples (White=1 and non-White=0)
Internet experience	An individual's experience with using the internet, as manifested in aspects such as the length or frequency of use and the use of the range of web-based services [52]
Personal involvement	An individual's perceived personal relevance of the web-based health information [53]
Perceived health status	Individuals' self-assessment of the status of their overall personal physical and mental health [54,55]
Condition experience and beliefs	An individual's experience with a health condition, perceived risk for developing the condition, and perceived severity of the condition
Health literacy	Individuals' ability to obtain health information from both electronic and nonelectronic sources and their ability to process, understand, and apply the obtained health information to solve health problems and make appropriate health decisions [56,57]
Health knowledge	Individuals' knowledge about their health problems and the care for the problems [58]
Source-related factors	
Source trustworthiness	The extent to which an individual believes that a specific web-based health information provider has attributes (eg, reputation) that are beneficial to the consumer [14]
Source expertise	The extent to which the source or the author of a message, webpage, or website is perceived to be capable of making correct assertions [59]
Content factors	
Ease of understanding	Whether the provided information is easy to understand (eg, in everyday language) and informative to users [60,61]
Social endorsement	Endorsements from other users of a website and could be manifested in forms ranging from sharing, commenting, and rating to liking [62]
Content comprehensiveness	Whether information provided is comprehensive, providing users with comparatively complete information (eg, necessary information to establish a medical claim, statistics, references, testimonials, source and author information, and user support information) [63,64]
Design factors	
Navigability	Whether a website has clear navigation menus and effective hyperlinks and whether the information is easy to access by searching or browsing [65,66]
Aesthetics	The visual design of a website, including the structural features such as typography, images, color, and aesthetics (eg, whether the website is professional and appealing) [67]
Consequences	
Cognitive appraisals	
Attitudes	Individuals' evaluations of and feelings about health websites or web-based health information [64,68]
Perceived usefulness	The degree to which consumers believe that using health information on the internet would enhance their health-related activities [47]
Perceived health benefits	The perceived level of rewards or risks that people have about the consequences of using or acting on web-based health information [14,65]
Satisfaction with health information	Individuals' satisfaction with health websites or web-based health information
Behavioral intentions	
Intentions to use health information	Individuals' intentions or willingness to use web-based health information to make health decisions, manage health problems, or inform health behaviors

Variable	Definition
Intentions to use health information systems	Individuals' intentions or willingness to use web-based health information systems to seek health information
Behavior	
Health information seeking	Individuals' use of web-based or offline sources to find health-related information, which is manifested in aspects such as the types of information sought and the frequency and intensity of health information seeking
Use health information	Individuals' use or application of health information (from web-based or offline sources) to make health decisions, manage health problems, or inform health behaviors

Table 3. Antecedents and consequences of quality of web-based health information.

Factors	Samples, n	Sample size, N	r[a]	ρ[b], mean (SD)	95% CI	90% CV[c]	Q[d]	I^2 (%)[e]	Begg *P* value[f]
Antecedents									
Individual differences									
Gender (female)	25	20,101	0.04	0.04 (0.13)	–0.04 to 0.13	–0.17 to 0.25	216.29[g]	86.45	.22
Age	20	23,463	0.04	0.04 (0.13)	–0.11 to 0.20	–0.18 to 0.26	834.84[g]	97.15	.02
Education	15	16,874	0.05	0.05 (0.17)	–0.09 to 0.20	–0.23 to 0.33	332.32[g]	94.29	.70
Internet experience	14	6235	0.12	0.13 (0.15)	0.01 to 0.24	–0.11 to 0.37	186.18[g]	91.99	.75
Personal involvement	13	4171	0.11	0.13 (0.22)	–0.05 to 0.31	–0.23 to 0.49	465.37[g]	97.08	.31
Perceived health status	9	26,207	0.04	0.04 (0.21)	–0.12 to 0.19	–0.31 to 0.39	715.44[g]	98.55	.92
Income	9	18,177	0.05	0.05 (0.10)	–0.08 to 0.19	–0.11 to 0.21	270.04[g]	95.65	.61
Race (White)	9	14,162	–0.07	–0.08 (0.26)	–0.52 to 0.37	–0.51 to 0.35	2609.14[g]	99.56	.08
Condition experience and beliefs	7	7772	0.05	0.05 (0.10)	–0.01 to 0.11	–0.12 to 0.22	18.74[g]	48.88	.99
Health literacy	6	3661	0.18	0.22 (0.28)	–0.01 to 0.45	–0.25 to 0.69	298.22[g]	97.83	.27
Health knowledge	6	2797	0.13	0.15 (0.11)	0.07 to 0.22	–0.03 to 0.33	18.26[g]	63.64	.72
Source-related factors									
Source trustworthiness	17	4154	0.25	0.28 (0.25)	0.10 to 0.45	–0.14 to 0.70	950.38[g]	97.78	.66
Source expertise	13	5988	0.17	0.20 (0.27)	–0.08 to 0.49	–0.25 to 0.65	649.35[g]	97.66	.44
Content-related factors									
Ease of understanding	14	3981	0.41	0.49 (0.28)	0.35 to 0.63	0.03 to 0.95	698.28[g]	97.90	.47
Social endorsement	7	2267	0.09	0.10 (0.17)	0.00 to 0.19	–0.18 to 0.38	32.03[g]	77.57	.14
Content comprehensiveness	7	1373	0.18	0.21 (0.30)	–0.11 to 0.54	–0.29 to 0.71	549.04[g]	97.57	.56
Design-related factors									
Navigability	12	3099	0.47	0.56 (0.33)	0.44 to 0.67	0.02 to 1.00	436.08[g]	96.85	.21
Aesthetics	11	4307	0.40	0.49 (0.26)	0.30 to 0.68	0.06 to 0.92	434.41[g]	95.99	.06
Consequences									
Cognitive appraisals									
Attitudes	14	3934	0.38	0.43 (0.24)	0.36 to 0.50	0.04 to 0.82	1871.08[g]	88.04	.75
Perceived usefulness	10	11,110	0.25	0.29 (0.23)	0.08 to 0.50	–0.09 to 0.67	557.55[g]	97.78	.60
Perceived health benefits	9	6292	0.32	0.37 (0.16)	0.26 to 0.49	0.10 to 0.64	189.17[g]	94.86	.61

Factors	Samples, n	Sample size, N	r[a]	ρ[b], mean (SD)	95% CI	90% CV[c]	Q[d]	I^2 (%)[e]	Begg *P* value[f]
Satisfaction with health information	9	3334	0.41	0.46 (0.29)	0.41 to 0.51	–0.01 to 0.93	1699.85[g]	84.31	.36
Behavioral intentions									
Intentions to use health information	17	7663	0.32	0.37 (0.33)	0.32 to 0.43	–0.18 to 0.92	4162.85[g]	99.23	.66
Intentions to use health information systems	8	1614	0.49	0.58 (0.24)	0.43 to 0.72	0.19 to 0.97	290.34[g]	95.73	.55
Behavior									
Health information seeking	18	26,259	0.25	0.30 (0.28)	0.15 to 0.46	–0.16 to 0.76	12,308.96[g]	99.59	.08
Health information use	15	15,021	0.21	0.25 (0.28)	–0.00 to 0.50	–0.21 to 0.71	1083.33[g]	98.36	.77

[a] Weighted mean correlation.

[b] Corrected weighted mean correlation and SD of ρ.

[c] 90% credibility interval.

[d] Heterogeneity statistic.

[e] Percentage of variation across studies that is because of heterogeneity.

[f] The Begg test for funnel plot asymmetry.

[g] *P*<.01.

Moderators of Web-Based Health IQ Relationships

Substantial heterogeneity calls for moderator analyses to explain the variance. The examined moderators included culture, research design, publication factors, and one operationalization-related moderator—the focal variable. The analysis was performed on web-based health IQ's relationships with eight factors: two individual factors—gender and age—enabled by adequate sample numbers and six composite factors—source, content, design, cognitive appraisals, behavioral intentions, and behavior—formed by combining lower-level antecedents and consequences to offer adequate observations for the analysis. For the moderator analysis involving age and web-based health IQ, we did not include the 10 imputed studies, given that incorporating simulated data can distort the subgroup comparison. Table 4 presents the subgroup mean values and Q_M statistics. Other relevant statistics (95% CI, 90% credibility interval, Q_E, and R^2) can be found in Multimedia Appendices 3-10. All moderators were significantly related to the effect size of at least one web-based health IQ relationship examined; 6 moderators significantly affected ≥3 relationships. The following interpretations focused on subgroups with significant differences.

Culture moderated the three antecedents of web-based health IQ: gender, age, and source. Females in individualistic (ρ=0.06 vs ρ=–0.11), low power distance (ρ=0.06 vs ρ=–0.02), and high uncertainty avoidance (ρ=0.08 vs ρ=–0.03) cultures rated web-based health IQ higher than males. Older individuals in low uncertainty avoidance (ρ=0.21 vs ρ=–0.07) and indulgence cultures (ρ=0.19 vs ρ=–0.05) rated web-based health IQ higher. Individuals with high uncertainty avoidance (ρ=0.37 vs ρ=0.20), long-term orientation (ρ=0.32 vs ρ=0.19), and restraint (ρ=0.37 vs ρ=0.17) cultures exhibited a stronger source and web-based health IQ relationship.

Culture moderated two consequences of web-based health IQ: cognitive appraisals and behavioral intentions. Individuals in long-term cultures had higher cognitive appraisals of web-based health IQ (ρ=0.40 vs ρ=0.27). Individuals with low uncertainty avoidance (ρ=0.59 vs ρ=0.41), short-term orientation (ρ=0.80 vs ρ=0.43), and indulgence cultures (ρ=0.60 vs ρ=0.43) had higher behavioral intentions as a result of the web-based health IQ than individuals in their respective counterpart cultures.

Research design moderated two antecedents of web-based health IQ: gender and content. Women rated the web-based health IQ higher in studies using the survey method (ρ=0.06 vs ρ=–0.06), non–social media technology context (ρ=0.06 vs ρ=–0.10), and nonpatient samples (ρ=0.09 vs 0.00). The content and web-based health IQ relationships were stronger in studies using the survey method (ρ=0.51 vs ρ=0.21), general stimuli (ρ=0.73 vs ρ=0.30), and nonstudent samples (ρ=0.43 vs ρ=0.24).

Research design moderated three consequences of web-based health IQ: cognitive appraisals, behavioral intentions, and behavior. Studies using specific stimuli (ρ=0.48 vs ρ=0.27) and nonstudent samples (ρ=0.35 vs ρ=0.26) produced larger effect sizes for the web-based health IQ and cognitive appraisals relationship. Studies using specific stimuli (ρ=0.54 vs ρ=0.32), social media context (ρ=0.45 vs ρ=0.39), and student samples (ρ=0.53 vs ρ=0.39) reported higher behavioral intentions. Student samples also produced a larger effect size for the web-based health IQ and behavior relationship (ρ=0.66 vs ρ=0.20).

Publication factors moderated the gender and web-based health IQ relationship. Journal articles (ρ=0.06 vs ρ=–0.08) and papers published before 2014 (ρ=0.08 vs ρ=–0.01) reported larger effect sizes than their respective counterparts. Publication year moderated web-based health IQ and cognitive appraisals and web-based health IQ and behavioral intentions, with recent publications (2014 and after) reporting lower cognitive appraisals (ρ=0.32 vs ρ=0.37) but higher behavioral intentions (ρ=0.55 vs ρ=0.25).

The three focal variables—quality, credibility, and trust—produced significant differences in 2 web-based health IQ relationships. The quality subgroup reported a stronger design and web-based health IQ relationship than the credibility subgroup (ρ=0.58 vs ρ=0.33). The omnibus test for comparing the focal variables in the web-based health IQ and behavioral intentions was significant (Q_M=30.50; *P*<.01). Post hoc tests revealed that the significant difference was because of the trust group being higher than the quality group (Q_M=13.63; *P*<.01) and the trust group being higher than the credibility group (Q_M=26.85; *P*<.01).

Table 4. Influence of moderators on quality of web-based health information relationships.

Moderators	Gender (female=1)	Age	Source-related factors	Content-related factors	Design-related factors	Cognitive appraisals	Behavioral intentions	Behavior
Culture								
Individualism versus collectivism, Q_M[a]	10.50[b]	0.32	3.20	0.03	0.24	1.88	2.71	1.67
Individualism, mean (k; N)[c]	0.06 (18; 17,745)	0.05 (12; 19,834)	0.22 (21; 7645)	0.37 (20; 5491)	0.39 (9; 2127)	0.31 (23; 15,533)	0.43 (13; 4684)	0.27 (20; 33,688)
Collectivism, mean (k; N)	–0.11 (4; 1242)	0.03 (5; 2542)	0.44 (6; 1460)	0.46 (4; 468)	0.57 (6; 1917)	0.39 (11; 4008)	0.58 (7; 1977)	0.37 (9; 5515)
Power distance, Q_M	3.85[d]	0.07	3.20	0.03	0.24	1.88	2.71	1.67
High, mean (k; N)	–0.02 (5; 1901)	0.01 (6; 3201)	0.44 (6; 1460)	0.46 (4; 468)	0.57 (6; 1917)	0.39 (11; 4008)	0.58 (7; 1977)	0.37 (9; 5515)
Low, mean (k; N)	0.06 (17; 17,086)	0.05 (11; 19,175)	0.22 (21; 7645)	0.37 (20; 5491)	0.39 (9; 2127)	0.31 (23; 15,533)	0.43 (13; 4684)	0.27 (20; 33,688)
Uncertainty avoidance, Q_M	6.78[b]	7.37[b]	6.25[d]	0.13	0.25	1.23	109.01[b]	2.02
High, mean (k; N)	0.08 (10; 13,180)	–0.07 (8; 12,795)	0.37 (14; 3022)	0.45 (11; 2177)	0.61 (4; 969)	0.31 (17; 7284)	0.41 (9; 4344)	0.42 (12; 14,139)
Low, mean (k; N)	–0.03 (12; 5807)	0.21 (9; 9581)	0.20 (13; 6083)	0.33 (13; 3782)	0.43 (11; 3075)	0.33 (17; 12,257)	0.59 (11; 2317)	0.21 (17; 25,064)
Orientation, Q_M	0.57	2.93	7.21[b]	0.52	0.02	3.88[d]	457.96[b]	.08
Long-term, mean (k; N)	0.07 (15; 14,013)	–0.05 (13; 14,411)	0.32 (19; 4457)	0.48 (15; 3551)	0.52 (9; 2556)	0.40 (23; 7935)	0.43 (15; 5761)	0.29 (17; 13,738)
Short-term, mean (k; N)	–0.01 (7; 4974)	0.22 (4; 7965)	0.19 (8; 4648)	0.22 (9; 2408)	0.39 (6; 1488)	0.27 (11; 11,606)	0.80 (5; 900)	0.28 (12; 25,465)
Indulgence versus restraint, Q_M	0.00	3.86[d]	11.47[b]	0.13	0.04	0.37	165.28[b]	0.92
Indulgence, mean (k; N)	0.00 (10; 6213)	0.19 (6; 8974)	0.17 (9; 5223)	0.34 (11; 3582)	0.41 (7; 1862)	0.31 (13; 11,190)	0.60 (8; 1704)	0.20 (14; 22,776)
Restraint, mean (k; N)	0.07 (12; 12,774)	–0.05 (11; 13,402)	0.37 (18; 3882)	0.43 (12; 2307)	0.53 (8; 2182)	0.38 (20; 6945)	0.43 (12; 4957)	0.29 (12; 11,502)
Methods								
Study method, Q_M	5.39[d]	0.01	0.57	9.55[b]	2.46	0.49	3.39	N/A[e]
Survey, mean (k; N)	0.06 (17; 17,929)	0.04 (13; 21,681)	0.25 (7; 4884)	0.51 (10; 3271)	0.56 (14; 5795)	0.34 (27; 21,314)	0.40 (22; 8870)	—[f]
Experiment, mean (k; N)	–0.06 (8; 2172)	–0.01 (7; 1782)	0.22 (23; 5258)	0.21 (17; 3772)	0.26 (6; 897)	0.41 (10; 1702)	0.46 (3; 407)	N/A
Stimulus type, Q_M	2.13	0.05	1.31	9.53[b]	0.49	4.74[a]	100.36[b]	1.04
General, mean (k; N)	0.06 (13; 16,088)	0.05 (11; 20,648)	0.35 (4; 1321)	0.73 (5; 822)	0.60 (9; 3963)	0.27 (18; 15,477)	0.32 (11; 5688)	0.29 (25; 35,528)
Specific, mean (k; N)	–0.01 (12; 4013)	–0.02 (9; 2815)	0.22 (26; 8821)	0.30 (22; 6221)	0.39 (11; 2729)	0.48 (19; 7539)	0.54 (14; 3589)	0.27 (6; 3983)
Technology context, Q_M	4.55[d]	0.06	3.33	0.72	N/A	N/A	5.18[d]	N/A
Social media, mean (k; N)	–0.10 (4; 2092)	0.02 (3; 1397)	0.32 (10; 2011)	0.24 (10; 2493)	—	—	0.45 (6; 1107)	—
Non–social media, mean (k; N)	0.06 (21; 18,009)	0.04 (17; 22,066)	0.21 (20; 8131)	0.41 (17; 4550)	N/A	N/A	0.39 (19; 8170)	N/A

Moderators	Gender (female=1)	Age	Source-related factors	Content-related factors	Design-related factors	Cognitive appraisals	Behavioral intentions	Behavior
Sample clinical status, Q_M	7.18[b]	N/A	N/A	N/A	N/A	N/A	0.57	0.04
Nonpatients, mean (k; N)	0.09 (4; 9478)	—	—	—	—	—	0.24 (3; 1646)	0.11 (6; 4192)
Patients, mean (k; N)	0.00 (21; 10,623)	N/A	N/A	N/A	N/A	N/A	0.44 (22; 7631)	0.31 (25; 35,319)
Sample type, Q_M	0.00	0.03	0.00	5.63[d]	.04	9.20[b]	4.69[d]	3.71[d]
Students, mean (k; N)	0.01 (7; 1978)	–0.03 (3; 594)	0.22 (13; 2959)	0.24 (13; 2947)	0.50 (4; 841)	0.26 (8; 1693)	0.53 (6; 1133)	0.66 (9; 7008)
Nonstudents, mean (k; N)	0.05 (18; 18,123)	0.04 (17; 22,869)	0.24 (17; 7183)	0.43 (14; 4096)	0.52 (16; 5851)	0.35 (29; 21,323)	0.39 (19; 8144)	0.20 (22; 32,503)
Publication								
Outlet, Q_M	6.41[d]	0.02	0.18	0.73	2.85	0.41	N/A	0.01
Journal, mean (k; N)	0.06 (17; 18,204)	0.05 (12; 21,288)	0.24 (20; 7528)	0.38 (19; 5426)	0.50 (13; 4751)	0.33 (30; 21,454)	—	0.29 (26; 38,726)
Nonjournal, mean (k; N)	–0.08 (8; 1897)	–0.01 (8; 2175)	0.21 (10; 2614)	0.26 (8; 1617)	0.54 (7; 1941)	0.45 (7; 1562)	N/A	0.22 (5; 785)
Year, Q_M	5.26[d]	0.15	0.00	0.01	0.21	6.42[d]	146.34[b]	0.00
Before 2014, mean (k; N)	0.08 (9; 12,145)	0.07 (7; 16,892)	0.26 (13; 5463)	0.33 (8; 1684)	0.52 (12; 4380)	0.37 (21; 14,357)	0.25 (10; 4430)	0.27 (15; 24,416)
2014 and after, mean (k; N)	–0.01 (16; 7956)	–0.02 (13; 6571)	0.20 (17; 4679)	0.36 (19; 5359)	0.52 (8; 2312)	0.32 (16; 8659)	0.55 (15; 4847)	0.31 (16; 15,095)
Focal variable, Q_M	0.07	0.94	0.09	2.19	9.34[b]	3.59	30.50[b]	4.12
Quality, mean (k; N)	—	0.04 (3; 737)	0.30 (8; 1899)	0.31 (6; 1632)	0.58 (10; 4815)	0.45 (11; 4510)	0.40 (7; 3355)	0.40 (6; 4095)
Credibility, mean (k; N)	0.02 (9; 2867)	0.22 (8; 7801)	0.20 (18; 4859)	0.29 (16; 3943)	0.33 (9; 1704)	0.26 (17; 9301)	0.31 (8; 1577)	0.19 (7; 7341)
Trust, mean (k; N)	0.06 (9; 14,572)	–0.05 (8; 14,290)	0.25 (4; 3384)	0.57 (5; 1468)	—	0.36 (9; 9205)	0.45 (10; 4345)	0.30 (17; 27,889)

[a] Omnibus test comparing group means.

[b] *P*<.01.

[c] Cell entries show subgroup means (weighted mean correlation corrected for measurement unreliability); each parenthesis contains *k* (number of samples) and N (total sample size).

[d] *P*<.05.

[e] N/A: not applicable; insufficient effect sizes for subgroup comparison.

[f] Not available.

Discussion

Using a comprehensive meta-analytic approach, this study analyzed antecedents and consequences of consumer web-based health IQ evaluations and contextual factors that moderate the relationships based on 147 independent studies. The major findings are discussed in the following sections.

Web-Based Health IQ Antecedents

Consistent with systematic reviews of consumer web-based health information evaluation behavior [18,19], we identified four major categories of antecedents of web-based health IQ: individual, source, content, and design factors. Furthermore, we revealed the magnitude of the antecedents' effect. We found that among the 18 antecedents examined, navigability (design) was the strongest predictor of web-based health IQ, followed by ease of understanding (content) and aesthetics (design). Four factors had significant but weak relationships with web-based health IQ: source trustworthiness (source), health knowledge (individual), internet experience (individual), and social endorsement (content). Age (individual) was significantly related to web-based health IQ after correcting for publication bias. However, this result needs to be viewed with caution as imputed data were generated to obtain this result. The remaining 10 antecedents were not substantially related to web-based health IQ evaluation.

These results suggest that consumers rely prominently on peripheral cues (eg, navigability, aesthetics, and ease of understanding) and less on systematic cues (eg, content comprehensiveness) to evaluate web-based health IQ. This is consistent with the Fogg et al [69,70] findings from large-scale surveys that website design look and ease of use (including navigability) were the most prominent influencers of website credibility, exerting stronger impacts than source expertise and trustworthiness. According to dual processing models of information processing and assessment, such as the Elaboration Likelihood Model and Heuristic-Systematic Model [71,72], these results can be attributed to consumers' lack of motivation and/or ability to evaluate web-based health IQ [73,74]. However, the results were not conclusive. First, it is possible that theoretically significant motivational and ability factors, such as personal involvement and source expertise [71,72], did not show a significant direct impact on web-based health IQ in this research because their relationships were moderated by contextual factors, which were not analyzed because of insufficient observations. Second, other theoretically and/or empirically significant influencers of web-based health IQ that are closely related to systematic information processing, such as augment strength [14] and content consistency [75,76], were not analyzed because of insufficient observations; thus, their effects were not accounted for in this research. More research is needed to elucidate the antecedent and web-based health IQ relationships.

Consequences

Web-based health IQ was significantly related to all the consequences identified in the research, except for health information use. The effect of web-based health IQ on behavioral intentions (particularly intentions to use health information systems) was the strongest, followed by cognitive appraisal factors (particularly satisfaction with health information). The relationship of web-based health IQ with health information–seeking behaviors was moderate, consistent with the findings of another meta-analysis of credibility and health information seeking [77].

The information system success model posits that IQ predicts users' intention to use or use of and satisfaction with an information system [78,79]. The model of information adoption posits that IQ determines users' attitudes toward information (ie, usefulness) [80,81]. Empirical research in information systems has provided strong support for the IQ-satisfaction relationship [40], whereas support for the IQ-use relationship has been mixed [79]. Our meta-analyses of web-based health IQ consequences are largely consistent with these findings, suggesting that web-based health IQ is important for consumers' intentions to use and satisfaction with web-based health information systems and information and information-seeking behavior. The 2 aforementioned models, although primarily developed and tested in organizational or individual work settings, are applicable in the context of consumers' web-based health information seeking.

Moderators

Culture moderated three antecedent and web-based health IQ relationships (ie, age, gender, and source) and two web-based health IQ and consequence relationships (ie, cognitive appraisals and behavioral intentions), demonstrating itself as an important factor shaping both web-based health IQ evaluation and its consequences. However, few empirical studies have directly examined the culture and web-based health IQ relationships. Future studies should fill this gap, which is critical for informing the design of health information systems and policies that serve different cultural groups in and across nations.

Research design factors moderated two antecedent and web-based health IQ (ie, gender and content) and all 3 consequence and web-based health IQ relationships, reinforcing the importance of careful research design in studying web-based health IQ. It is worth noting that sample type and stimulus type affected the greatest number of relationships, with student samples and studies using general stimuli reporting stronger content and web-based health IQ relationships and having lower cognitive appraisals but stronger behavioral intentions (and stronger behavior for the student samples). The results caution the use of student samples and general stimuli when studying web-based health IQ relationships. The clinical status of the sample moderated the gender and web-based health IQ relationship. It may moderate more relationships for patients' personal involvement [72]; however, it remains inconclusive because of insufficient observations.

Limited publication venue bias was observed as the publication outlet moderated only the gender and web-based health IQ relationship. As a proxy to detect how web-based health IQ relationships have fluctuated over time, the publication year moderated three relationships—gender and web-based health IQ, web-based health IQ and cognitive appraisals, and web-based health IQ and behavioral intentions—revealing that individuals' cognitive appraisals of web-based health IQ lessened; however, intentions to act on the information increased over time. It is plausible that consumers are becoming more critical as arbiters of web-based health information; however, they are also becoming more receptive to web-based health information and information systems.

The focal variables (credibility, trust, and quality) moderated two relationships—design and web-based health IQ and web-based health IQ and behavioral intentions—out of the 8 relationships examined, indicating that some theoretical and/or methodological issues exist that promulgate this effect size disparity. Studies using quality identified a larger effect size than studies that used credibility in the design and web-based health IQ relationship. This can be attributed to the fact that studies that examined the relationship viewed quality as intrinsic merit of information (eg, accuracy, argument strength, consistency, and comprehensiveness) [14,82] and credibility as perceived reliability or trustworthiness of information [64]. In such a case, we speculate that consumers had more difficulty determining IQ than credibility [83]; thus, they need to rely more on design factors to form IQ perceptions. For the web-based health IQ and behavioral intentions relationship, studies using trust produced the largest effect size, followed by studies using quality and credibility, indicating that trust most strongly predicts behavioral intentions, followed by quality and credibility. This may be because studies on web-based health IQ and behavioral intentions were more likely to consider risk and gain assessment as part of the trust formation process [84-86], such that trust showed a higher predictive power for behavioral intentions [12,14].

Limitations

As with all meta-analysis studies, the main effects of a small number of observations or small sample size (eg, race or health knowledge with web-based health IQ relationships) should be interpreted with caution. Insufficient observations also limit moderator analyses, whereby moderator analyses of some theoretically or practically important relationships (eg, race, personal involvement, and health literacy with web-based health IQ relationships) were not performed. Relatedly, some antecedents and consequences were combined to form high-level categories to enable moderator analyses, which inevitably masks how some important specific relationships (eg, web-based health IQ and use of health information) might be affected by moderators.

In terms of moderator analysis, consistent with prior meta-analysis findings, student-based results were biased [79], and survey-based results produced larger effect sizes than experience-based results [41]. The most noteworthy finding concerning moderator analyses was that the three conceptualizations of web-based health IQ (ie, quality, credibility, and trust) moderated two out of the eight relationships examined (ie, design and web-based health IQ and web-based health IQ and behavior intentions), suggesting that despite a significant conceptual overlap, theoretical and/or operationalization differences exist among the 3 constructs. This result should be interpreted in light of the fact that we took a phenomenological approach, adopting the authors' conceptualizations of web-based health IQ (quality, credibility, and trust). A detailed examination of the definitions and measures of these constructs is warranted to elucidate the differences among the concepts. A preliminary examination of the included papers revealed that not many studies provided explicit definitions of the constructs and that measures of the same construct varied, with many articles not including specific and complete measures. These observations call for future empirical studies to offer clearer definitions of the constructs and complete measures to enable a fair assessment of these concepts for future literature synthesis.

Despite attempts to apply various moderators to explain the variance across web-based health IQ relationships, substantial variance remained. Future research should prudently select additional moderators to explain this variance. For example, health topics merit investigation as an important contextual factor with theoretical significance for studying information-seeking behavior [87,88]. Website type also merits investigation in light of recent findings that it influences how consumers apply content, design, and source factors to evaluate web-based health IQ [89,90].

Conclusions

On the basis of a meta-analysis of 147 empirical studies, our study confirmed that consumers' evaluation of web-based health IQ significantly affects their cognitive appraisals of web-based health information, intentions to use web-based information systems and information, and information-seeking behavior, suggesting the important role that web-based health IQ plays in promoting health information seeking. The study also confirmed that consumers' evaluation of web-based health IQ is shaped by source, content, design, and individual factors, with the most influential factors being design, particularly navigability and aesthetics, and ease of understanding of content. Many individual factors, such as gender, race, education, personal involvement, and health literacy, did not show significant relationships with web-based health IQ. However, moderator analyses and the residual variance after the analyses suggest that these relationships may be moderated by numerous methodological and nonmethodological moderators. Patient empowerment and active participation in health care require individuals to have equal access to high-quality health information. More studies are needed to elucidate individual factors and web-based health IQ relationships to address potential information access disparities among different user groups.

Acknowledgments

The authors would like to thank Stephanie Tomasky and Shijie Song for their assistance in the article search and screening processes.

Conflicts of Interest

None declared.

Multimedia Appendix 1

List of studies included in sample.
[DOCX File , 59 KB-Multimedia Appendix 1]

Multimedia Appendix 2

Mean reliabilities.
[DOCX File , 13 KB-Multimedia Appendix 2]

Multimedia Appendix 3

Influence of moderators on the relationship between gender and web-based health information quality.
[DOCX File , 18 KB-Multimedia Appendix 3]

Multimedia Appendix 4

Influence of moderators on the relationship between age and web-based health information quality.
[DOCX File , 18 KB-Multimedia Appendix 4]

Multimedia Appendix 5

Influence of moderators on the relationship between source-related factors and web-based health information quality.
[DOCX File , 18 KB-Multimedia Appendix 5]

Multimedia Appendix 6

Influence of moderators on the relationship between content-related factors and web-based health information quality.
[DOCX File , 18 KB-Multimedia Appendix 6]

Multimedia Appendix 7

Influence of moderators on the relationship between design-related factors and web-based health information quality.
[DOCX File , 17 KB-Multimedia Appendix 7]

Multimedia Appendix 8

Influence of moderators on the relationship between web-based health information quality and cognitive appraisals.
[DOCX File , 18 KB-Multimedia Appendix 8]

Multimedia Appendix 9

Influence of moderators on the relationship between web-based health information quality and behavioral intentions.
[DOCX File , 18 KB-Multimedia Appendix 9]

Multimedia Appendix 10

Influence of moderators on the relationship between web-based health information quality and behavior.
[DOCX File , 18 KB-Multimedia Appendix 10]

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Abbreviations

IQ: information quality

Edited by A Mavragani; submitted 15.01.22; peer-reviewed by DJ Lim, E Sillence, S Song; comments to author 05.02.22; accepted 15.03.22; published 28.04.22

Please cite as:
Zhang Y, Kim Y
Consumers' Evaluation of Web-Based Health Information Quality: Meta-analysis
J Med Internet Res 2022;24(4):e36463
URL: https://www.jmir.org/2022/4/e36463
doi: [10.2196/36463](https://doi.org/10.2196/36463)
PMID:

Original Paper

Mechanism of Impact of Big Data Resources on Medical Collaborative Networks From the Perspective of Transaction Efficiency of Medical Services: Survey Study

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Abstract

Background: The application of big data resources and the development of medical collaborative networks (MCNs) boost each other. However, MCNs are often assumed to be exogenous. How big data resources affect the emergence, development, and evolution of endogenous MCNs has not been well explained.

Objective: This study aimed to explore and understand the influence of the mechanism of a wide range of shared and private big data resources on the transaction efficiency of medical services to reveal the impact of big data resources on the emergence and development of endogenous MCNs.

Methods: This study was conducted by administering a survey questionnaire to information technology staff and medical staff from 132 medical institutions in China. Data from information technology staff and medical staff were integrated. Structural equation modeling was used to test the direct impact of big data resources on transaction efficiency of medical services. For those big data resources that had no direct impact, we analyzed their indirect impact.

Results: Sharing of diagnosis and treatment data (β=.222; *P*=.03) and sharing of medical research data (β=.289; *P*=.04) at the network level (as big data itself) positively directly affected the transaction efficiency of medical services. Network protection of the external link systems (β=.271; *P*=.008) at the level of medical institutions (as big data technology) positively directly affected the transaction efficiency of medical services. Encryption security of web-based data (as big data technology) at the level of medical institutions, medical service capacity available for external use, real-time data of diagnosis and treatment services (as big data itself) at the level of medical institutions, and policies and regulations at the network level indirectly affected the transaction efficiency through network protection of the external link systems at the level of medical institutions.

Conclusions: This study found that big data technology, big data itself, and policy at the network and organizational levels interact with, and influence, each other to form the transaction efficiency of medical services. On the basis of the theory of neoclassical economics, the study highlighted the implications of big data resources for the emergence and development of endogenous MCNs.

(J Med Internet Res 2022;24(4):e32776) doi: 10.2196/32776

KEYWORDS

medical collaborative networks; big data resources; transaction efficiency

Introduction

Background

There has been a long-term coexistence of imbalanced allocation and low use efficiency of medical resources in China. Most health care reforms have tried to encourage a variety of medical collaborative practices as a means to improve the quality and efficiency of health care delivery. For example, the New Rural Cooperative Medical Scheme was launched to protect rural households from catastrophic medical expenditure [1] and various medical consortia were mainly used to improve the system of tiered medical services to balance inadequate medical resources [2]. These studies often assumed that medical collaborative networks (MCNs) are exogenous and had already been formed. However, many medical collaborative practices have not achieved the desired results. Su et al [3] showed that there was no statistically significant difference between the distribution of inpatients in county and township hospitals before and after the implementation of the New Rural Cooperative Medical Scheme in China. The practice of collaborative health care will produce various forms of MCNs. The MCNs' structures are always complex [4]. It was corroborated that the MCNs' structures and collaborative practices influence each other [5], the mutual recursive influence becoming meaningful through a complex net of organizational and institutional features, as well as patients' nosological profiles [6]. MCNs are often assumed to be exogenous; however, they are endogenous. It is very important to pay attention to how endogenous MCNs emerge and develop.

At the same time, the development of the internet and big data technology has promoted the transformation of medical service patterns and management modes [7,8], leading to the emergence of various MCNs, such as collaboration between hospitals of different levels [2,9]. Furthermore, many internet companies (such as Hao Daifu, Chunyu Doctor, and Weiyi) have been pouring into the medical service industry to lead more diverse forms of medical collaborative practices [10]. Big data resources in health care have advanced the development of MCNs, which in turn further promotes the application of big data in the health care field [11]. It is generally believed that big data resources affect the emergence and development of MCNs; yet, there is a lack of understanding of the mechanism of the impact of big data resources on the emergence and development of MCNs.

As the organizational network has increasingly become an important form of business operation, the commercial value of information technology (IT) to the organizational network has gradually become an issue of concern. Han et al [12] analyzed the value of the relationship, based on the enterprise resource planning system, between suppliers of the enterprise resource planning system and their partners through case studies. Ceccagnoli et al [13] explored the cocreation of value in a platform ecosystem based on the resource-based view of the firm. These studies have emphasized the organizational privatization of traditional IT resources [14,15] without considering the particularity of big data resources or the coexistence of shared and private resources in the organizational network [16]. The value realization of big data should be analyzed from the work practice, organizational, and supraorganizational levels [17] and be integrated information, technology, policy, and so on [18,19].

This study aims to explore and understand the influence of the mechanism of shared and private big data resources on the emergence and development of MCNs. The coexistence of labor division and cooperation is not only the most basic phenomenon of MCNs, but also the most basic driving force of survival and development. On the basis of neoclassical economics, this paper took the transaction efficiency of medical services as a key variable to represent the emergence and development of endogenous MCNs. Next, we classified big data resources related to value cocreation of MCNs according to two dimensions: (1) public big data resources at the network level versus private big data resources at the medical institution level and (2) the three elements of big data value (data itself, technology, and various organizational elements). At the level of medical institutions in the MCN, there are external web-based big data (health care big data itself) and outward interaction security (big data technology); at the public level of the MCN, there are sharing of big data (health care big data itself) and policies and regulations related to big data (data policy). Finally, we empirically analyzed the direct and intermediary effects of all kinds of big data resources on the transaction efficiency of medical services.

Hypotheses and Modeling

Transaction Efficiency of Medical Services

Medical collaboration refers to a process that occurs when a group of autonomous stakeholders with various medical resources communicate and coordinate with each other to share decision-making, goal setting, and implementation of a plan of care [2,5,6,20].

Extant empirical studies often assumed that MCNs are exogenous and found that medical collaborative practices may be affected by factors at individual, organizational, and system levels, such as mutual trust [20,21], IT infrastructure [22-24], medical policies, investment of public funds [9], and remuneration methods [4]. However, the conclusions drawn regarding the influence of these factors are inconsistent and contradictory [5]. Because of the interaction of many factors, it is necessary to analyze the nature of the impact of these factors on medical collaborative practices from the perspective of system and process [5,6].

From the perspective of system and process, various forms of medical collaborative practices have been explored. Touati et al [6] elicited three specific modalities of collaboration: quasi-inexistent, restrained, and extended. Braun and Cusick [25] explored four innovative care models that aimed to expand access to dental care: expanded coordinated care, colocated care, integrated care, and virtual dental home. Huang and Li [26] divided the medical alliance into three types (compact, semicompact, and loose) according to the closeness of the contact. The recursive interaction between structures and collaborative practices has been corroborated [5] and becomes meaningful through a complex network of organizational and institutional characteristics and the nosological profiles of patients [6]. However, to explore the influence of the mechanism of big data resources on the emergence and development of MCNs, we need to integrate factor research and structure research to determine a theoretical construct that can reflect the changes in network structure and embody various factors influencing collaborative practices.

The neoclassical economics framework proposed by Yang and Ng [27] studied organizational topological properties by introducing transaction costs. The increase in division of labor will increase the number of transactions, and each transaction will produce transaction costs. If the transaction efficiency is low, the transaction cost is greater than the specialized economy generated by the division of labor and individuals will choose to be self-sufficient. If the transaction efficiency is fully improved, the transaction cost is offset by the specialized economy and individuals will choose division of labor. Therefore, organizational topological properties are closely related to transaction efficiency: the smaller the size of the organization, the more the cooperation with the outside world [28].

MCN members are afforded both cooperation and division of labor. Touati et al [6] emphasized that transaction cost cannot be ignored in all kinds of collaboration involving various factors at individual, organizational, and clinical levels. Collaborative practice requires collaborators to share rules, beliefs, and codes of conduct [5], regarding which there are often differences in the collaborators’ cognitions. These differences will incur transaction costs, affecting the results of collaborative practice. McComb et al [20] showed that physicians and nurses in general medical units have different perceptions of role, responsibility, and mutual trust, which act as obstacles to cooperation in these units. Communication problems among collaborators often persist and seriously affect the implementation of collaborative practices. Without videoconferencing, some diagnostic pathways (visual and clinical examination) would be lost in the interaction between cardiologists and family physicians [23]. The traditional written referral usually led to incomplete information, thus affecting the quality and comprehensiveness of communication [24]. There are also some factors at the system level, such as poor public infrastructure [9], that lead to low transaction efficiency and high transaction cost.

Because of the characteristics of autonomy and limited resources, there is division of labor everywhere in MCNs. At the same time, the collaborative community is different from the simple addition of the original individuals and relies on value rationality among members to create a unique social structure oriented to the ultimate goal of common commitment, which can support members to work collaboratively [29]. The decision of whether to choose medical collaborative practice is based on the trade-off between the health care specialized economy and transaction cost. Collaborators make decisions in their own self-interest under a specific MCN, but their decisions are affected by other decision-makers in the MCN. Finally, through the interaction of all parties and the balance of interests, a specific structure will emerge. The MCN’s structure and individual decision-making are entangled to produce and reproduce. To sum up, MCNs are endogenous and the transaction efficiency of health care is the key variable for the emergence and development of MCNs.

In this paper, the transaction efficiency of medical services refers to the quality of the medical transaction service. The higher the quality of the transaction service, the smaller the transaction cost and the higher the transaction efficiency. At this time, it is more likely that MCNs will be chosen to provide medical services in a cooperative way.

Big Data Resources

There were 2 main concepts of big data. The first is based on the characteristics of the generated data, such as the 3V model [30], 4V model [31], and 5V model [32]. The second is focused on various technologies and methods such as big data storage and management [33], cloud computing and cloud service [34], big data security and privacy [31], real-time data-processing technology [7], and various big data analysis technologies [35]. De Mauro et al [18] proposed that the four elements (technology, method, information, and impact) that affect the value of big data should be integrated. Wamba et al [19] believed that the business value of big data is enabled through data policy, technology, organizational change, data access, industry structure, and so on. However, the classification of these value factors lack a theoretical basis.

The IT resources of a single organization were often conceptualized and classified based on the resource-based view of the firm [14,15], which emphasized the organizational privatization of resources with a clear definition of property rights. Dover [16] studied the business value of IT based on the relationship theory, expanded the limitations of the resource-based view of the firm on the assumption of ownership and control of resources, and distinguished shared resources from nonshared resources. In network organizations, IT resources (especially big data resources) are both publicly owned by the network and privately owned by a specific organization.

We applied and further extended the classification of IT resources for a single organization [14,15] to that of big data for MCNs and extended the process of realizing IT business value to the process of realizing big data business value. Big data resources for MCNs involve health care big data itself, big data technology, and data policy at both the public level of MCNs and the institution level in MCNs. At the level of medical institutions in the MCN, external web-based big data (health care big data itself) and outward interaction security (big data technology) form the conditions and basis for medical institutions to export or import medical services as decision-makers. At the public level of MCNs, the sharing of big data (health care big data itself) and policies and regulations related to big data (data policy) affect all kinds of support conditions and constraints for the operation of medical institutions in MCNs by forming or changing the public environment at the network level.

At the level of medical institutions in the MCN, external web-based big data resources (big data itself) play a balancing and optimizing role in ensuring the supply of medical service resources to other hospitals or institutions and include real-time data of diagnosis and treatment services and medical service capacity available for external use. Real-time data of diagnosis and treatment services refers to the degree to which a medical institution provides information on physician suspending the diagnosis and treatment and opening consultations for external systems (such as remote consultation platforms, government public platforms, and medical networking). Real-time data of diagnosis and treatment services are the data source of the catalog of external services provided by medical institutions [36,37]. Medical service capacity available for external use is a medical institution's ability to determine medical service resources such as consultation services and appointment services that can be provided to other hospitals or institutions and can be obtained by comparing the real-time use status of the medical service resources with the ideal status [38,39]. Medical service capacity available for external use is a relevance index of health care big data that reflects the connectivity of health care data [40,41].

As big data technology, outward interaction security at the level of medical institutions provides security for stable and continuous connection of data distributed at different medical institutions. It includes encryption security of web-based data and network protection of external link systems. Encryption security of web-based data is the perceived ability of a medical institution to ensure data security during interaction with other hospitals or institutions [42,43]. Network protection of the external link systems is the perceived ability of a medical institution to deploy the physical security foundation for the connection between medical institutions and the outside world [24,44].

At the public level of MCNs, sharing of big data may improve medical service and research capabilities by sharing health care big data with each other [45]. This includes the sharing of diagnosis and treatment data as well as medical research data. Sharing of diagnosis and treatment data refers to the degree to which a medical institution within MCNs can obtain diagnosis and treatment data from other medical institutions through government public platforms or third-party platforms [41,46]. Sharing of research data refers to the degree to which a medical institution within MCNs can obtain research data from other medical institutions through Chinese National Knowledge Infrastructure, PubMed, and so on. Policies and regulations related to big data at the public level of MCNs refers to the degree to which policies, laws, and regulations (such as 3-level referral from the Health and Family Planning Commission, medical consortium, and regional medical treatment center) can support the construction of the regional medical service platform [19].

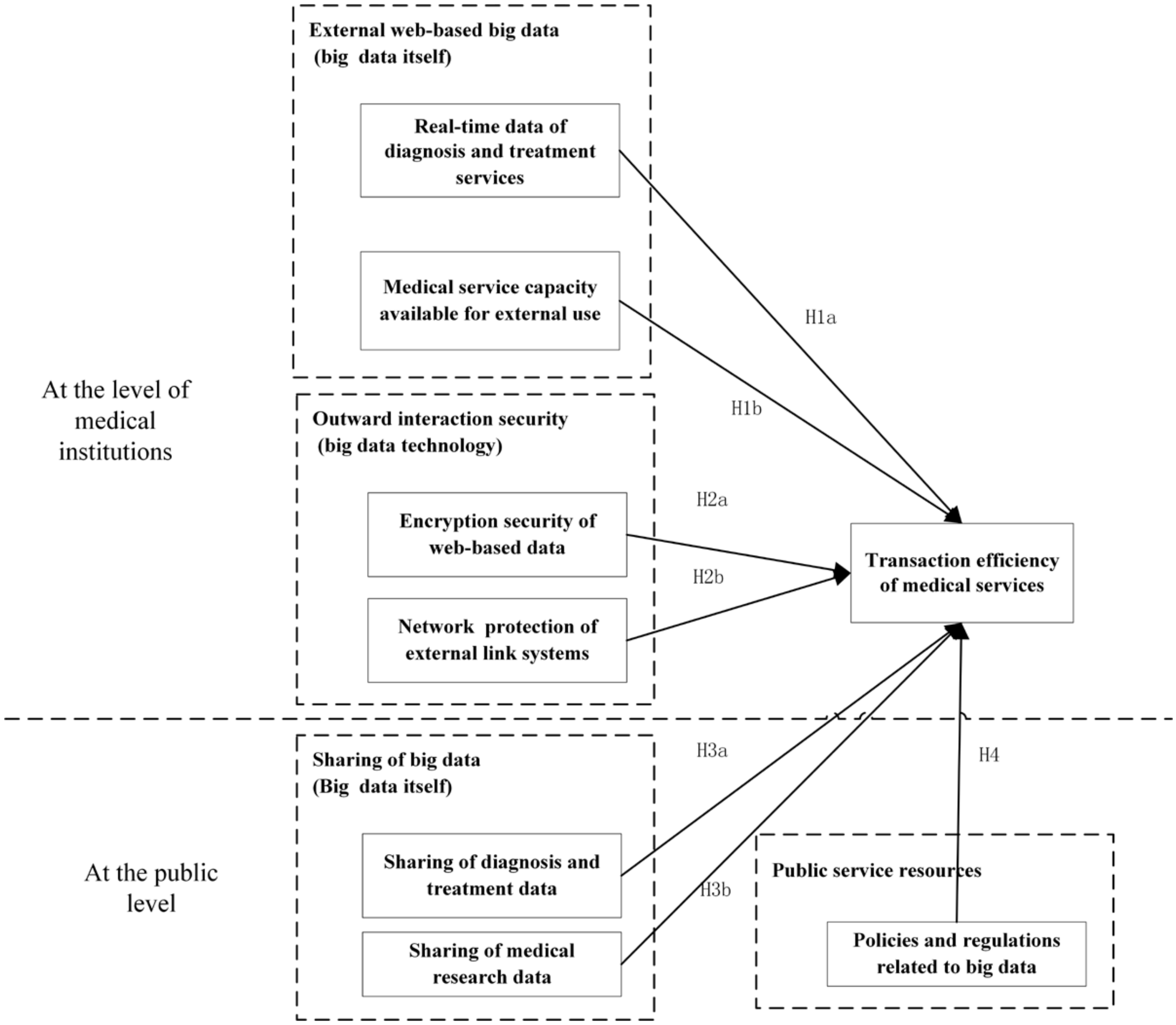
Model

On the basis of the assumption that MCNs are endogenous and that the transaction efficiency of health care is the key variable for the emergence and development of MCNs, this study aims to explore and understand the mechanism of the influence of shared and private big data resources in MCNs on transaction efficiency to reveal the impact of big data resources on the emergence and development of MCNs. The research questions are as follows:

1. What big data resources at the two levels (shared and private) directly affect transaction efficiency?
2. When there is no direct impact, what are the paths of indirect influence of these big data resources on transaction efficiency?

Figure 1 presents the model examined in this research. It shows relationships that are hypothesized to exist among big data resources at the level of medical institutions in the MCN, big data resources at the public level of the MCN, and the transaction efficiency of medical services.

Figure 1. Conceptual model: the impact of big data resources of medical collaborative networks on transaction efficiency of medical services. H: hypothesis.



Methods

Measurement Instruments and Questionnaire Development

Overview

For most constructs, measures validated in previous studies were adapted. For constructs unique to the model, multiple operational measures based on field interviews were developed. All constructs were measured using a 7-point Likert-scale ranging from 1=*strongly disagree* to 7=*strongly agree*. Details of the measures are presented in Multimedia Appendix 1.

Transaction Efficiency of Medical Services

In this study, collaborative medical care was mainly carried out through third-party platforms such as Baiyulan and cloud hospitals. The transaction efficiency of medical services depends on the quantity and quality of medical service resources provided by the platform. The first concerns the scope and level of experts available on the platform. The accuracy, real-time nature, and comprehensiveness of information on the experts enable the requester to know the experts in time, make correct judgments, and reduce unnecessary transaction costs caused by the provision of asymmetric information. The second concerns the performance of the communication mechanism provided by the platform for all partners. To better cooperate with collaborative diagnosis and treatment, the platform needs to support multiple medical institutions to read medical records and images on the web and in real time at the same time to ensure that the image data can be transmitted to the consultation experts without distortion. Inefficient web-based reading will lead to long waiting periods, resulting in uncontrollable average visit time. The smooth reading of required data is not only a powerful guarantee for the rapid completion of services, but also the basis for the continuous demand for collaborative medical services.

On the basis of the studies by DeLone and McLean [47] and Taylor and Todd [48], the transaction efficiency of medical services was measured with 6 items that reflect the extent to which the platform provides reliability, timeliness, and comprehensiveness of expert information, as well as timeliness and stability of communication.

Big Data Resources

To ensure content validity, the measures for most constructs were used, expanded, and modified from the studies by DeLone and McLean [47], Taylor and Todd [48], Bailey and Pearson [49], and Goodhue [50]. For constructs unique to the big data resources for MCNs, items were self-developed.

The real-time data of diagnosis and treatment services were measured by 3 items that reflect the extent of timeliness, accuracy, and accessibility of physician suspending the diagnosis and treatment as well as the opening information provided by medical institutions to the external systems. The medical service capacity available for external use was measured with 4 items that reflect the extent of the ability and accuracy of external consultation and appointment services provided by medical institutions according to the physician's workload. The encryption security of web-based data was measured by 4 items that reflect the extent of effect, convenience, transmission efficiency, and coverage of the encryption and decryption technology used by medical institutions when interacting with external systems. The network protection of external link systems was measured with 4 items that reflect the extent of effect, convenience, satisfaction, and coverage of network protection and application protection deployed by medical institutions.

The sharing of diagnosis and treatment data with other medical institutions was measured by 7 items that reflect the extent of accessibility, accuracy, and integrity of diagnosis and treatment data of other medical institutions, as well as the effect of the data sharing on effectively shortening diagnosis time, avoiding repeated examination, avoiding repeated medication, and avoiding adverse drug-drug reactions. Sharing of medical research data with other medical institutions was measured by 3 items that reflect the extent of convenience, functional completeness, and accuracy of research data provided by other medical institutions. The policies and regulations were measured by 3 items that reflect the extent of rationality, existence, and functional completeness of relevant policies, laws, and regulations supporting the construction of a regional medical service platform.

Data Collection and Demographic Profiles

Data were collected using a survey questionnaire. In China, public hospitals are the main institutions providing health care services. Accordingly, we mainly chose public hospitals, along with some private hospitals. It is very important for medical staff to cooperate closely with IT staff to ensure the implementation of collaborative medical services. Accordingly, each medical institution selected 1 medical staff member and 1 IT staff member as respondents.

The specific data collection plan was designed as follows:

1. Contact the relevant personnel at the target medical institution through WeChat and ask whether they were willing to participate in the survey.
2. Through the relevant personnel, ask the medical institution to determine the respondents, administer the questionnaire on-site, and collect it after completion.
3. If the medical institution is located far away and if the relevant person agrees, provide the questionnaire through WeChat to the person responsible for administering it.

The survey packages were mailed to the appropriate IT executive at each target hospital, with a request that the recipient complete the survey.

The survey packages were also mailed to the appropriate business executive at each target hospital. Part A of the questionnaire was distributed among the appropriate medical staff to complete the measurement items regarding sharing of diagnosis and treatment data, sharing of research data, and transaction efficiency of medical services. Part B was distributed among the appropriate IT executive staff to complete the items related to real-time data of diagnosis and treatment services, medical service capacity available for external use, network protection of external link systems, encryption security of web-based data, and policies and regulations. The questionnaire was administered between August 1, 2017, and October 31, 2017.

Of the 150 medical institutions (involving 18 provinces, autonomous regions, and municipalities) that participated in the survey, 132 (88%) provided valid questionnaires. A total of 264 respondents took part: 132 (50%) IT staff and 132 (50%) medical staff. The sample profile is shown in Table 1.

Table 1. Statistical description of the sample (N=132).

Variables and categories	Values, n (%)
Hospitals	
Hospital level	
Tertiary general hospitals	39 (29.5)
Tertiary specialty hospitals	15 (11.4)
Second-class general hospitals	75 (56.8)
Second-class specialty hospitals	4 (3)
Community hospitals	1 (0.8)
Type of hospital	
Public hospitals	126 (95.5)
General practice	6 (4.5)
IT[a] staff	
Sex	
Male	83 (62.9)
Female	49 (37.1)
Age (years)	
20-30	35 (26.5)
31-40	79 (59.8)
41-50	18 (13.6)
Education	
High school graduate	8 (6.1)
Bachelor’s degree	114 (86.4)
Master’s degree	10 (7.6)
Medical staff	
Sex	
Male	74 (56.1)
Female	58 (43.9)
Age (years)	
20-30	23 (17.4)
31-40	72 (54.5)
41-50	30 (22.7)
51-60	7 (5.3)
Education	
High school graduate	5 (3.8)
Bachelor’s degree	75 (56.8)
Master’s degree	50 (37.9)
Doctorate	2 (1.5)

[a] IT: information technology.

Ethics Approval

The study protocol was reviewed and approved by the ethics review committee at the Shanghai Chest Hospital (IS[P]22003). Before the research was conducted, all participants gave their consent in writing after being informed of the purpose and procedure of the study. We ensured the confidentiality and anonymity of the information collected from the participants.

Data Analysis Process

SmartPLS is a component-based path-modeling software tool based on the partial least squares regression method. We used

SmartPLS (version 2.0) to evaluate the measurement properties and test our hypotheses. Our strategy for data analysis was as follows. First, we evaluated the measurement model by analyzing reliability and validity (including convergent and discriminant validity). Next, applying SmartPLS by using the standard bootstrap resampling procedure (5000 samples) to estimate the significance of the paths, the direct impact of big data resources on transaction efficiency of medical services was examined. For those big data resources that had no direct impact on transaction efficiency, we analyzed their indirect impact.

Results

Reliability and Validity

The measurement model was evaluated using the following criteria:

1. Reliability: The outer loading for the indicator should be ≥0.70 (indicator reliability). The cutoff value for Cronbach α was .70 and that for composite reliability was 0.70 (internal consistency reliability) [51].
2. Validity: The average variance extracted (AVE) should be ≥0.50 (convergent validity), based on the Fornell-Larcker criterion [52] (discriminant validity).

As shown in Table 2, the factor loading values of all items were higher than 0.89 and significant at *P*=.001, with composite reliability value=0.9, above the normal value of 0.7. All values met the minimum requirement for indicator reliability and internal consistency reliability. In addition, the AVE used to assess the convergent validity was >0.70 for all constructs, proving that the model had good convergence validity.

Table 2. Reliability and convergence validity test results.

Constructs and items	Values, mean (SD)	Load value	Composite reliability	Average variance extracted
Encryption security of web-based data			0.970	0.891
ES[a]_1	4.99 (1.532)	0.959		
ES_2	4.95 (1.536)	0.928		
ES_3	5.09 (1.395)	0.951		
ES_4	4.85 (1.515)	0.937		
Network protection of external link systems			0.961	0.862
NP[b]_1	5.72 (1.236)	0.912		
NP_2	5.69 (1.253)	0.941		
NP_3	5.51 (1.224)	0.944		
NP_4	5.47 (1.383)	0.916		
Real-time data of diagnosis and treatment services			0.995	0.983
RT[c]_1	5.15 (1.619)	0.990		
RT_2	5.11 (1.644)	0.995		
RT_3	5.11 (1.611)	0.991		
Medical service capacity available for external use			0.995	0.982
SC[d]_1	4.33 (1.812)	0.991		
SC_2	4.30 (1.788)	0.992		
SC_3	4.44 (1.798)	0.988		
SC_4	4.31 (1.781)	0.993		
Policies and regulations related to big data			0.956	0.879
PR[e]_1	5.5 (1.297)	0.968		
PR_2	5.64 (1.151)	0.919		
PR_3	5.33 (1.292)	0.925		
Sharing of diagnosis and treatment data			0.990	0.931
TS[f]_1	4.4 (1.654)	0.964		
TS_2	4.57 (1.687)	0.950		
TS_3	4.39 (1.681)	0.973		
TS_4	4.54 (1.656)	0.958		
TS_5	4.47 (1.820)	0.972		
TS_6	4.56 (1.715)	0.968		
TS_7	4.45 (1.836)	0.970		
Sharing of medical research data			0.984	0.952
RS[g]_1	4.66 (1.690)	0.966		
RS_2	4.82 (1.587)	0.978		
RS_3	4.79 (1.717)	0.984		
Transaction efficiency of medical services			0.973	0.859
TE[h]_1	4.84 (1.621)	0.937		
TE_2	4.92 (1.574)	0.947		
TE_3	4.89 (1.580)	0.953		
TE_4	4.91 (1.551)	0.925		

Constructs and items	Values, mean (SD)	Load value	Composite reliability	Average variance extracted
TE_5	4.86 (1.528)	0.906		
TE_6	4.95 (1.541)	0.890		

[a] ES: encryption security of web-based data.

[b] NP: network protection of external link systems.

[c] RT: real-time data of diagnosis and treatment services.

[d] SC: medical service capacity available for external use.

[e] PR: policies and regulations.

[f] TS: sharing of diagnosis and treatment data.

[g] RS: sharing of medical research data.

[h] TE: transaction efficiency of medical services.

Table 3 presents the test results of discriminant validity. The square root of the AVE values of each construct were greater than the correlation coefficient between the constructs, which conforms to the Fornell-Larcker criterion [52], proving that the measurement model had good discriminant validity.

Table 3. Discriminant validity test results.

	ES[a]	NP[b]	RT[c]	SC[d]	PR[e]	TS[f]	RS[g]	TE[h]
ES	0.944	—[i]	—	—	—	—	—	—
NP	0.540	0.928	—	—	—	—	—	—
RT	0.475	0.613	0.992	—	—	—	—	—
SC	0.690	0.432	0.615	0.991	—	—	—	—
PR	0.637	0.601	0.527	0.658	0.938	—	—	—
TS	0.359	0.286	0.423	0.417	0.346	0.965	—	—
RS	0.430	0.318	0.508	0.433	0.521	0.698	0.976	—
TE	0.466	0.527	0.554	0.500	0.519	0.581	0.621	0.927

[a] ES: encryption security of web-based data.

[b] NP: network protection of external link systems.

[c] RT: real-time data of diagnosis and treatment services.

[d] SC: medical service capacity available for external use.

[e] PR: policies and regulations.

[f] TS: sharing of diagnosis and treatment data.

[g] RS: sharing of medical research data.

[h] TE: transaction efficiency of medical services.

[i] Not applicable.

Influence Path

Overview

The results of the influence path analysis, including the standardized regression weights and levels of significance, are presented in Table 4 and Figure 2. The coefficient of determination R^2 was used to measure the explained variance of the latent dependent variables compared with the total variance. The cutoff levels were as follows: 0.190, weak; 0.333, moderate; and 0.670, substantial; 55.3% of the variance in transaction efficiency of medical services, 53.3% of the variance in the network protection of external link systems, and 48.7% of the variance in sharing of diagnosis and treatment data were moderately explained, whereas 27.2% of the variance in sharing of medical research data was weakly explained, but met the cutoff level.

Table 4. Direct effect test results.

Hypothesis	Direct path	β coefficient (SE)	*P* value	Support
H1a	RT[a] to TE[b]	.070 (0.121)	.56	Not supported
H1b	SC[c] to TE	.116 (0.123)	.35	Not supported
H2a	ES[d] to TE	−.011 (0.115)	.93	Not supported
H2b	NP[e] to TE	.271 (0.101)	.008	Supported
H3a	TS[f] to TE	.220 (0.105)	.03	Supported
H3b	RS[g] to TE	.289 (0.135)	.04	Supported
H4	PR[h] to TE	.023 (0.118)	.85	Not supported

[a] RT: real-time data of diagnosis and treatment services.

[b] TE: transaction efficiency of medical services.

[c] SC: medical service capacity available for external use.

[d] ES: encryption security of web-based data.

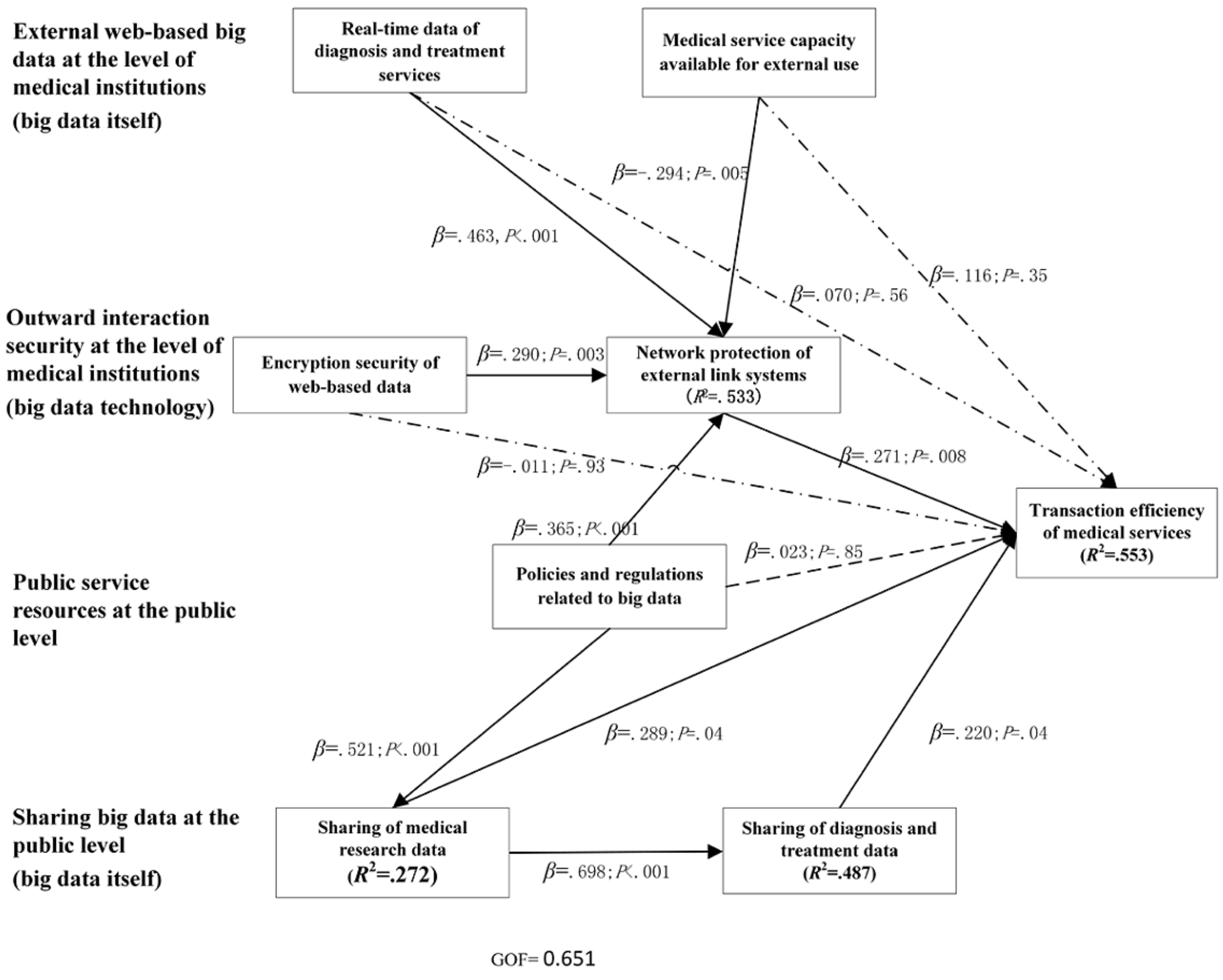
[e] NP: network protection of external link systems.

[f] TS: sharing of diagnosis and treatment data.

[g] RS: sharing of medical research data.

[h] PR: policies and regulations.

Figure 2. Model results, including direct and indirect effects. GOF: goodness of fit.



The model's goodness of fit was our last criterion to assess the overall fit of the model. The model's goodness of fit for this study as calculated was 0.651, which was deemed large [53].

Direct Influence Path

From Figure 2, it can be observed that the direct effects of the network protection of external link systems (β=.271; *P*=.008), sharing of diagnosis and treatment data (β=.220; *P*=.04), and sharing of medical research data (β=.289; *P*=.04) on transaction efficiency of medical services were significant. Hypotheses H2b, H3a, and H3b gained empirical support.

The direct effects of real-time data of diagnosis and treatment services, medical service capacity available for external use, encryption security of web-based data, and policies and regulations on transaction efficiency of medical services were not significant. Hypotheses H1a, H1b, H2a, and H4 did not gain empirical support.

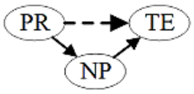
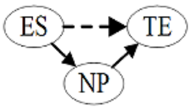
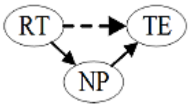
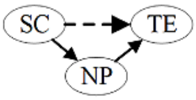
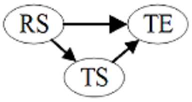
Indirect Influence Analysis

As the encryption security of web-based data, real-time data of diagnosis and treatment services, medical service capacity available for external use, and policies and regulations had no direct impact on transaction efficiency of medical services, the indirect effects of these 4 variables on transaction efficiency of medical services were further analyzed. The results of the mediation test are presented in Table 5 and Figure 2. To assess the magnitude of the indirect effect [54], the variance accounted for (VAF) value was calculated, which represents the relationship between the indirect effect and the total effect.

From Table 5, we can observe the following:

1. The indirect impact of policies and regulations. Although the policies and regulations had no direct impact on transaction efficiency of medical services, there was a completely mediated path (policies and regulations → network protection of external link systems → transaction efficiency of medical services) in which the network protection of external link systems played a mediating role in the effect of policies and regulations on transaction efficiency of medical services (VAF=0.945; *P*=.03). It indicated that the government's establishment of regulations in network security should be conducive to ensuring transaction efficiency and data security.
2. The indirect impact of the encryption security of web-based data. Although the encryption security of web-based data in the external web-based security environment had no direct impact on the transaction efficiency of medical services, there was a completely mediated path (encryption security of web-based data → network protection of external link systems → transaction efficiency of medical services) in which the network protection of external lnk systems played a mediating role in the effect of encryption security of web-based data on transaction efficiency of medical services (VAF=0.879; *P*=.03). It indicated that the encryption security of web-based data improved people's perception of the degree of network protection of external systems and indirectly affected the transaction efficiency of medical services.
3. The indirect impact of real-time data of diagnosis and treatment services. Although the real-time data of diagnosis and treatment services in the external big data analysis environment had no direct impact on the transaction efficiency of medical services, there was a completely mediated path (real-time data of diagnosis and treatment services → network protection of external link systems → transaction efficiency of medical services) in which the network protection of external link systems played a mediating role in the effect of real-time data of diagnosis and treatment services on transaction efficiency of medical services (VAF=0.678; *P*=.02). It indicated that the stronger the ability of internal data extraction, the safer the external data pipeline and the higher the transaction efficiency.
4. The indirect impact of medical service capacity available for external use. Although the medical service capacity available for external use in the external big data analysis environment had no direct impact on the transaction efficiency of medical services, there was a completely mediated path (medical service capacity available for external use → network protection of external link systems → transaction efficiency of medical services) in which there was the indirect effect of medical service capacity available for external use through the network protection of external link systems on transaction efficiency of medical services (VAF=0.391; *P*=.05). From Figure 2, it can be observed that medical service capacity available for external use has a significant direct negative effect on the network protection of external link systems (β=−0.294; *P*=.005), which indicated that frequent service adjustment will increase the complexity of security control and indirectly reduce the transaction efficiency of medical services.
5. The indirect impact of sharing of medical research data. In addition to the direct and significant impact of medical services on the transaction efficiency, there was a partial mediated path (sharing of medical research data → sharing of diagnosis and treatment data → transaction efficiency of medical services) in which sharing of diagnosis and treatment data played a mediating role in the effect of sharing of medical research data on transaction efficiency of medical services (VAF=0.345; *P*=.04). The sharing of research data was conducive to the ability of physicians to interpret the patient's past medical history to issue an accurate diagnosis faster, promote the sharing of diagnosis and treatment data, and indirectly promote transaction efficiency of medical services.

Table 5. Mediation test results.

Indirect effect/direct path	*P* value	Mediated paths	Sobel test		VAF[a]	Type of relationship
			Sobel statistic (SE)	*P* value		
PR[b] to TE[c]			2.170 (0.046)	.03	0.945	Full mediation
PR to TE	.85					
PR to NP[d]	<.001					
NP to TE	.008					
ES[e] to TE			2.122 (0.042)	.03	0.879	Full mediation
ES to TE	.93					
ES to NP	.003					
NP to TE	.008					
RT[f] to TE			2.313 (0.054)	.02	0.678	Full mediation
RT to TE	.56					
RT to NP	<.001					
NP to TE	.008					
SC[g] to TE			−1.958 (0.041)	.05	0.391	Full mediation
SC to TE	.35					
SC to NP	.005					
NP to TE	.008					
RS[h] to TE			2.086 (0.075)	.04	0.345	Partial mediation
RS to TE	.04					
RS to TS[i]	<.001					
TS to TE	.04					

[a] VAF: variance accounted for.

[b] PR: policies and regulations.

[c] TE: transaction efficiency of medical services.

[d] NP: network protection of external link systems.

[e] ES: encryption security of web-based data.

[f] RT: real-time data of diagnosis and treatment services.

[g] SC: medical service capacity available for external use.

[h] RS: sharing of medical research data.

[i] TS: sharing of diagnosis and treatment data.

Discussion

Principal Findings

On the basis of the assumption that MCNs are endogenous and that service transaction efficiency is the key variable for the emergence and development of MCNs, this study empirically analyzed the impact of big data resources of MCNs on the transaction efficiency of health care and provided evidence regarding the following:

1. Sharing of diagnosis and treatment data (big data itself) at the network level directly affected the transaction efficiency of medical services.

   An important challenge of implementing precision medicine based on big data is to share data in MCNs [45]. Sharing diagnosis and treatment data with other hospitals or institutions is an important part of the big data–sharing environment [41]. Only by formulating the classification, grading, and domain-sharing system of medical big data can we steadily promote the opening of medical big data. The sharing of diagnosis and treatment data can result in many obvious benefits, including timely and effective improvement in diagnosis accuracy, strengthening of physician-patient communication and coordination, reduction in repeated treatments, and decrease in the risk of medical errors. By accessing the entire treatment record of the patient through government or third-party platforms, physicians can quickly review the patient's condition, reduce medical expenses, and avoid adverse medical events such as drug-drug interactions and drug contraindications, thus improving the overall transaction efficiency of medical services.

2. Sharing of research data (big data itself) at the network level directly affected the transaction efficiency of medical services.
   The sharing of research data is another important factor in the overall improvement of medical service quality. Be it clinical effectiveness research, new drug development, or basic medical research, each is often based on the research results of others [40,55]. There are already many shared and free medical research databases such as the electrocardiogram database of the National Institutes of Health, Brain-CODE [43], and Alzheimer disease big data [56] that have advanced related medical research. Integrating the research data of multiple medical institutions is conducive to overcoming the limitations of scientific research and improving the scientific research ability of physicians. With the advent of the era of precision medicine, more and more knowledge-sharing methods have come into being, which has promoted the improvement of multidisciplinary diagnosis and treatment ability and improved the transaction efficiency of medical services.
3. Network protection of external link systems (big data technologies) at the level of medical institutions directly affected the transaction efficiency of medical services.
   Outward interaction security (big data technologies) at the level of medical institutions provides a safe and efficient web-based environment in which a medical institution can be connected with other hospitals or institutions and exchange data. To connect data distributed in different medical institutions steadily and continuously, the first thing to address is the security problem [7,31,57].
   In the past, medical institutions only needed to pay attention to the security of the internal network, which was basically isolated from the outside world. The local area network had high security but poor interoperability. With the development of the internet and big data, the applications of telemedicine are changing rapidly [23,24] and medical institutions are facing increasing need for connections to other hospitals or institutions. The network protection of an outreach system is an important security guarantee for contact between medical institutions and the outside world. Network protection must take into account both security and efficiency, and it should not reduce the efficiency and availability of facilities while ensuring the security of data exchanged by external systems. Abbasi et al [58] point out that through a secure and stable link, the activities of the cooperating parties in the network can be more closely linked and the transaction is more efficient.
4. Real-time data of diagnosis and treatment services (big data itself), medical service capacity available for external use (big data itself), encryption security of web-based data (big data technologies) at the level of medical institutions, and policies and regulations at the network level indirectly affected the transaction efficiency of medical services through network protection of the outreach system (big data technology) at the level of medical institutions. These 4 big data resources will affect the perception of physicians regarding the deployment of a physical security foundation for the connection between medical institutions and the outside world [24,44]. These results highlight that big data technology, big data, and policy at the network and organizational levels interact with, and influence, each other to form the service transaction efficiency of various MCNs.

Theoretical Implications

This study contributes to research in 3 ways. First, we highlighted the important role of service transaction efficiency in MCN research. Prior research has largely emphasized that service transaction efficiency is one of the factors that affect the operation effect of specific MCNs [6]. In these studies, it was often assumed that MCNs are exogenous and that there is an absolute standard for the quality of MCNs. But this paper emphasized that an MCN is not exogenous; rather, many factors are responsible for its emergence and development. On the basis of the theory of neoclassical economics [27], this study took service transaction efficiency as the key variable for the emergence and development of MCNs and connected the 2 perspectives of factor-oriented research and process-oriented research in current collaborative medical research. From the perspective of MCN being endogenous, the foothold of the study was not the absolute quality of the MCN but the fitness of the MCN to the specific environment. On the basis of transaction efficiency, the study provided the basis for future research on the emergence and development of MCNs. This logic may help explain why there are various contradictions in prior studies on the factors responsible.

Second, we conceptualized big data resources oriented to MCNs from the network and medical institution levels, including big data itself, big data technology, and policy. The combination of big data resources at the level of medical institutions in the MCN and the network public level of the MCN thus affected the transaction efficiency of medical services as a key variable for the emergence and development of MCNs. It emphasized the coexistence and intertwined influence of public big data resources of MCNs and private big data resources in MCNs. This study expanded the limitation of the existing IT-enabling value based on the resource-based view of the firm, which emphasized the private and exclusive nature of IT resources. It also corresponded to the call for research on analyzing the value realization of big data from the work practice, organizational, and supraorganizational levels [17].

Third, this study provided empirical support for De Mauro et al [18] and Wamba et al [19], who proposed integrating big data technology, big data itself, and policy to realize the value of big data. The results further refined and enriched this insight to reveal the detailed impact path of big data technologies, big data itself, and policies on transaction efficiency of medical services. Big data itself was divided into the network level and the organizational level. Big data assets at the network level have a direct impact on transaction efficiency of medical services. However, big data assets at the organizational level affected the transaction efficiency by affecting people's perception of outward interaction security technology at the organizational level. The negative impact of medical service capacity available for external use on network protection of external link systems indicated that an increase in external services would make people develop a great sense of insecurity. Policies and regulations related to big data at the public level cannot directly affect the services' transaction efficiency, but they affected the overall formation and operation of MCNs by affecting the public big data resources and the perception of outward interaction security technology at the organizational level.

Practical Implications

The results have several implications for practice. This study provided the corresponding theoretical guidance for the government to formulate policies. The government should specify corresponding strategies to develop policies regarding sharing of big data resources at the public level and promote various institutions to strengthen the security of external collaborative networks. These policies will affect the ecological service environment of an MCN's operation to improve transaction efficiency and ultimately enhance the development of MCNs. In addition, all kinds of medical institutions that are willing to interact with the outside world to form an MCN must first strengthen network security, which can especially balance the negative effects caused by the increase in external collaborative services.

Study Limitations

This study includes several limitations. The data collection was based on the convenient sampling method. Although the medical institutions covered were basically in line with the relative proportion of public and private hospitals in China's medical institutions, the selection of regions was based on the principle of convenient sampling. Furthermore, this study only considered the transaction efficiency of medical services to reveal the impact of big data resources on the emergence and development of MCNs. In fact, other variables, such as the learning cost of medical services, can affect the emergence and development of MCNs. Future research can analyze the impact of big data resources on the emergence and development of MCNs from the perspective of the learning cost of medical services.

Conclusions

Our study contributes to both theory and practice. First, it focused on the effects of big data resources on the transaction efficiency of medical services and highlighted how MCNs emerge and develop. Second, it theorized that there are two levels of big data resources—network level and medical institution level—and highlighted the intertwined effect of public and private big data resources on transaction efficiency (including direct impact and intermediary impact). Third, it focused on the effects of health care big data itself, big data technology, and policy on transaction efficiency and revealed the interaction and influence mechanism of these 3 elements of big data value as well as their impact on the formation and development of MCNs.

Acknowledgments

This work was funded by the Information Development Project of the Shanghai Economic and Information Commission (202002009).

Authors' Contributions

JY and SW were responsible for the study conception and design. JY was responsible for the acquisition of data. SW analyzed and interpreted the data. SW and JY drafted the manuscript, and CP was responsible for its critical revision.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Questionnaire items.
[DOCX File , 16 KB-Multimedia Appendix 1]

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Abbreviations

AVE: average variance extracted
IT: information technology
MCN: medical collaborative network
VAF: variance accounted for

Edited by R Kukafka; submitted 10.08.21; peer-reviewed by H Shi, P Seth; comments to author 23.10.21; revised version received 16.03.22; accepted 21.03.22; published 21.04.22

Please cite as:
Yuan J, Wang S, Pan C
Mechanism of Impact of Big Data Resources on Medical Collaborative Networks From the Perspective of Transaction Efficiency of Medical Services: Survey Study
J Med Internet Res 2022;24(4):e32776
URL: https://www.jmir.org/2022/4/e32776
doi: 10.2196/32776
PMID: 35318187

Original Paper

Gap in Willingness and Access to Video Visit Use Among Older High-risk Veterans: Cross-sectional Study

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Abstract

Background: The recent shift to video care has exacerbated disparities in health care access, especially among *high-need, high-risk (HNHR)* adults. Developing data-driven approaches to improve access to care necessitates a deeper understanding of HNHR adults’ attitudes toward telemedicine and technology access.

Objective: This study aims to identify the willingness, access, and ability of HNHR veterans to use telemedicine for health care.

Methods: WWe designed a questionnaire conducted via mail or telephone or in person. Among HNHR veterans who were identified using predictive modeling with national Veterans Affairs data, we assessed willingness to use video visits for health care, access to necessary equipment, and comfort with using technology. We evaluated physical health, including frailty, physical function, performance of activities of daily living (ADL) and instrumental ADL (IADL); mental health; and social needs, including Area Deprivation Index, transportation, social support, and social isolation.

Results: The average age of the 602 HNHR veteran respondents was 70.6 (SD 9.2; range 39-100) years; 99.7% (600/602) of the respondents were male, 61% (367/602) were White, 36% (217/602) were African American, 17.3% (104/602) were Hispanic, 31.2% (188/602) held at least an associate degree, and 48.2% (290/602) were confident filling medical forms. Of the 602 respondents, 327 (54.3%) reported willingness for video visits, whereas 275 (45.7%) were unwilling. Willing veterans were younger (*P*<.001) and more likely to have an associate degree (*P*=.002), be health literate (*P*<.001), live in socioeconomically advantaged neighborhoods (*P*=.048), be independent in IADLs (*P*=.02), and be in better physical health (*P*=.04). A higher number of those willing were able to use the internet and email (*P*<.001). Of the willing veterans, 75.8% (248/327) had a video-capable device. Those with video-capable technology were younger (*P*=.004), had higher health literacy (*P*=.01), were less likely to be African American (*P*=.007), were more independent in ADLs (*P*=.005) and IADLs (*P*=.04), and were more adept at using the internet and email than those without the needed technology (*P*<.001). Age, confidence in filling forms, general health, and internet use were significantly associated with willingness to use video visits.

Conclusions: Approximately half of the HNHR respondents were unwilling for video visits and a quarter of those willing lacked requisite technology. The gap between those willing and without requisite technology is greater among older, less health literate, African American veterans; those with worse physical health; and those living in more socioeconomically disadvantaged neighborhoods. Our study highlights that HNHR veterans have complex needs, which risk being exacerbated by the video care shift. Although technology holds vast potential to improve health care access, certain vulnerable populations are less likely to engage, or have access to, technology. Therefore, targeted interventions are needed to address this inequity, especially among HNHR older adults.

(J Med Internet Res 2022;24(4):e32570) doi: 10.2196/32570

KEYWORDS

high-risk veterans; older adults; telemedicine; video visits; health disparities; Area Deprivation Index; mobile phone

Introduction

Background

The onset of the COVID-19 pandemic led to sudden and dramatic changes in the delivery of health care in the context of social distancing and lockdown decisions. Telemedicine has emerged as a solution to caring for patients who are medically complex during the pandemic [1]. Institutions have diverted resources toward purchasing necessary telemedicine equipment and expansion of technological infrastructure and hastily implemented telemedicine training sessions for providers [2,3]. Telemedicine reimbursement models also saw formula adjustments. For example, the Centers for Medicare and Medicaid Services (CMS) insurance models changed in March 2020 to reduce the costs of telemedicine [4], and the CMS issued waivers that allowed providers to care for patients remotely without financial penalties [5]. These factors have contributed to the accelerated implementation of telemedicine across health care systems [2,3].

The Veterans Affairs (VA) has been a leader in integrating the use of technology into health care. The implementation of telemedicine technologies and new programs at the VA has accelerated in recent years to expand access to more veterans. Since 2018, the VA's *Anywhere to Anywhere* initiative expanded the scope of telehealth so that care can be delivered via telehealth across state borders and even in the veterans' homes [6]. During the COVID-19 pandemic, similar to other health care systems, the VA moved rapidly to leverage its telemedicine capabilities to provide needed care to veterans at home [2,7]. A major pivot by the VA during the COVID-19 pandemic was the rapid adoption and use of the VA's telemedicine platform, Veteran Video Connect (VVC), which allowed most visits to be done via telemedicine at home. VVC is a videoconferencing application for veterans and their providers. It securely connects veterans to their health care team from any internet-enabled computer, tablet, or mobile device. In the face of this public health emergency, the VA also suspended previous Health Insurance Portability and Accountability Act compliance requirements to allow providers to connect with patients on non–public-facing technology if VVC was not working or at overcapacity [8].

Nevertheless, despite the rapid pivot to telemedicine, there have been valid concerns regarding patient-level challenges to wider implementation and integration of technology into health care. Using 2018 data from the National Health and Aging Trends Study of community-dwelling adults, Lam et al [9] estimated that approximately one-third of the older adults in the United States were not ready for video visits, which is largely attributed to inexperience with technology. Individuals who face barriers to accessing care in person are also likely the same individuals who face challenges accessing telemedicine and include those who are older and minority; have lower educational attainment, lower income, and self-reported poor health status [9-11]; and live in rural areas [9,12-14]. Therefore, disparities in health care access risk exacerbation by the ongoing shift to adopt telemedicine [9,11], especially among the highest risk patients with the most complex clinical scenarios [9,12].

Objective

To develop data-driven approaches and understand how best to deploy telemedicine to increase access to care for older adults who are complex and frail, it would be beneficial to form a deeper understanding of their attitude toward using video visits for receiving health care. Using a population health approach, the VA identifies a subgroup of veterans called *high-need, high-risk (HNHR)* veterans, who represent the VA population that would qualify for Medicare's demonstration of home-based primary care (HBPC; ie, independence at home) [15]. The primary aim of this study is to evaluate HNHR older veterans' willingness, access, and ability to use video visits for health care purposes. Our secondary aim is to characterize the willingness for telemedicine in the context of their physical, emotional, and social determinants. Our hypothesis is that among HNHR older adults, the access and ability to use video visits would be lower than that shown previously among community-dwelling adults [9].

Ultimately, this paper seeks to add to the ongoing efforts to provide actionable data that may help health care systems leverage telemedicine as a means of increasing access to health care. We can expect the increased reliance on telemedicine to be sustained, and increasing our understanding of the factors contributing to digital disparities will help identify targeted interventions to address the identified challenges to telemedicine for HNHR patients, who are also the patients most likely in need of support.

Methods

Overview

This cross-sectional observational study was part of a larger quality improvement study to better define the needs of HNHR veterans in the Miami VA Healthcare System. Here, we analyzed the willingness, technology access, and ability to use video visits in the HNHR veteran group.

Study Population

The VA Geriatrics and Extended Care Data Analysis Center uses population health VA data to identify HNHR veterans who are medically complex and functionally impaired and at the highest risk for hospitalization and long-term institutionalization and, therefore, eligible for HBPC. The criteria for the Geriatrics and Extended Care Data Analysis Center HNHR designation include hospitalization in the prior 12 months and medical complexity measures that include the 13-condition JEN Frailty Index (JFI) [16] score ≥6, suggesting dependency in ≥2 activities of daily living (ADL), and NOSOS (VA version of the CMS measure to project cost). Patients were excluded if they had end-stage renal disease; were enrolled in HBPC or medical foster home; had received hospice, palliative care, or nursing home care in the past 12 months; or lived >60 minutes away from the closest VA primary care site as VA HBPC programs were less likely to be available at this distance [15].

Over a 1-year period that extended from October 2017 to September 2018, 2543 Miami VA Healthcare System veterans were listed as HNHR. Of those 2543 veterans, 1300 (51.12%) were randomly selected and sent a questionnaire via the US Postal Service. The mailings were sent in two waves: May 2018 and November 2018. The questionnaires were conducted by mail only once, with no reminders to improve the response rate. An additional group of 173 HNHR veterans scheduled for a geriatric frailty clinic appointment completed the questionnaire.

Questionnaire Design and Variables

We designed a questionnaire to assess physical health, including frailty—with the Fatigue, Resistance, Ambulation, Illnesses, and Loss of Weight scale [17]—physical function, mobility, ADL [18], instrumental ADL (IADL) [19], and homebound status [20]; assess mental health using the Patient Health Questionnaire [21] for depression screening and perception of aging [22]; and assess social support, social isolation [23], and transportation. We assessed for willingness to use video visits for VA health care; among those willing to use video visits, we asked about access to the video-capable technology. Furthermore, we assessed the ability to use technology by asking about comfort in performing an internet search and using email. We also asked about My Healthe*e*Vet use and access and the desired mode of communication with VA. The used questions were either study specific, validated, or modified from validated questions. The details of the questionnaire are presented in Table 1. We have tried to segment and label our variables into those that relate to the level of the patient's need for telehealth versus barriers and facilitators that we can do something about, although this distinction is somewhat arbitrary and case dependent, as only some of the factors are addressable some of the time. Physical and mental health characteristics may often relate to the level of patient need for telehealth but may also present a barrier, whereas the social and technology characteristics are the surrounding factors that act as facilitators or barriers, depending on the situation.

Table 1. Survey components.

Indicator	Source	Details
Demographics		
Education	Study specific	Highest level of education completed
Health literacy [24]	Question to identify patients with inadequate health literacy	Confidence filling medical forms; score ranged from 1 to 5, with a higher score indicating more confidence; a score of 5 was considered health literate
Physical health (need or barrier)		
Frailty [17]	5-item FRAIL[a] scale	The 5-item FRAIL scale includes fatigue, resistance, ambulation, illness, and weight loss. The final score ranges from 0 to 5 and represents frail (score 3-5), prefrail (score 1-2), and robust (score 0) health status. A score of 3 to 5 was considered a positive screen.
General health [25]	Modified from the Stanford Chronic Disease Self-Management Program Questionnaire	Self-rated general health; scores ranged from 1 to 5, with a higher score indicating better self-rated general health
Self-rated physical status	Self-rated physical status	Scores for self-rated physical status ranged from 1 to 10, with a higher score indicating better physical status
Walking, falls, and exercise	Study specific	Issues with walking, stepping, and balance; assistive devices used; number of falls in the past year; barriers to exercise; pedometer use
ADL[b] [18]	Barthel index for ADL	Barthel ADL score (range 0-100), with a higher score indicating greater independence
IADL[c] [19]	Lawton score for IADL	Lawton IADL score (range 0-8), with a higher score indicating greater independence
Homebound status [20]	Determining homebound status as part of a mobility questionnaire using validated questions from the National Health and Aging Trends Study	Individuals were categorized as homebound, semihomebound, and not homebound based on their responses to how often they left their home, how much help they had in leaving their home, and how much difficulty they had in leaving their home in the previous month, similar to the reference study.
Mental health (need or barrier)		
Depression screen [21]	PHQ-2[d]	PHQ-2 scores ranged from 0 to 6; a score ≥3 is considered positive for the likelihood of depression
Self-perception of aging [22]	Attitude Toward Own Aging subscale of the Philadelphia Geriatric Center Morale Scale	The 5-question scale (range 0-5) was treated as a binary variable. For the first (*feeling worse as I get older*) and third (*feeling useless as I get older*) questions on the scale, the responses *strongly disagree, disagree, somewhat disagree* were scored as 0, whereas the responses *somewhat agree, agree, strongly agree* were scored as 1. The responses to the second (*as much pep as last year*), fourth (*as happy as when I was younger*), and fifth (*things are better than I thought it would be*) questions were scored in a reverse manner. A higher score indicated a negative perception of aging.
Social characteristics (facilitator or barrier)		
Social support	Study specific	Having a formal or informal caregiver; caregiver's distance from home
Social isolation [23]	Berkman–Syme Social Network Index	Scoring was performed as the following: married (no=0; yes=1), meeting and talking to close friends and relatives (<3 times a week=0; ≥3 times a week=1), participation in religious meetings or services (<4 times a year=0; ≥4 times a year=1), and attend meetings of the clubs or organizations (never or does not belong=0, all the responses=1). Scores were summed: 0 or 1 being the most isolated category, and 2, 3, or 4 formed the other 3 categories of increasing social integration.
Transportation [26]	Questions assessing transportation barriers	Trouble with transportation, delayed physicians' appointments because of transportation troubles, and travel time from home to their physician
Technology (facilitator or barrier)		
Technology willingness, access, and ability	Study specific	Willingness to use video visits with VA[e] providers; access to video-capable equipment among those willing to use video visits; ability to do an internet search and use email; My Health*e*Vet enrollment and use; preferred mode of contact

[a] FRAIL: Fatigue, Resistance, Ambulation, Illnesses, and Loss of Weight.

[b] ADL: activities of daily living.

[c] IADL: instrumental activities of daily living.

[d] PHQ-2: Patient Health Questionnaire-2.

[e] VA: Veterans Affairs.

Additional measures obtained from VA records included the Care Assessment Needs score (VA measure for hospitalization and mortality risk) [27] and the Hierarchical Condition Categories score [28]. We also obtained the Area Deprivation Index (ADI), an established measure of socioeconomic disadvantage at the census tract level, from the Neighborhood Atlas [29].

Statistical Analysis

Descriptive characteristics were presented as frequency (percentage) for categorical variables and as mean (SD) for continuous variables. We compared the characteristics of respondents who were willing to use video visits with those who were not; among those willing to use video visits, we further compared those with and without self-reported access to video-capable technology. The chi-square test was used for comparing categorical variables, and the 2-tailed *t* test was used for comparing continuous variables. We reported all *P* values and considered them to be significant when <.05. Multivariable logistic regression was conducted to identify predictors for willingness to use video visits. All statistical analyses were performed using SAS (version 9.4; SAS Institute, Inc).

Ethical Considerations

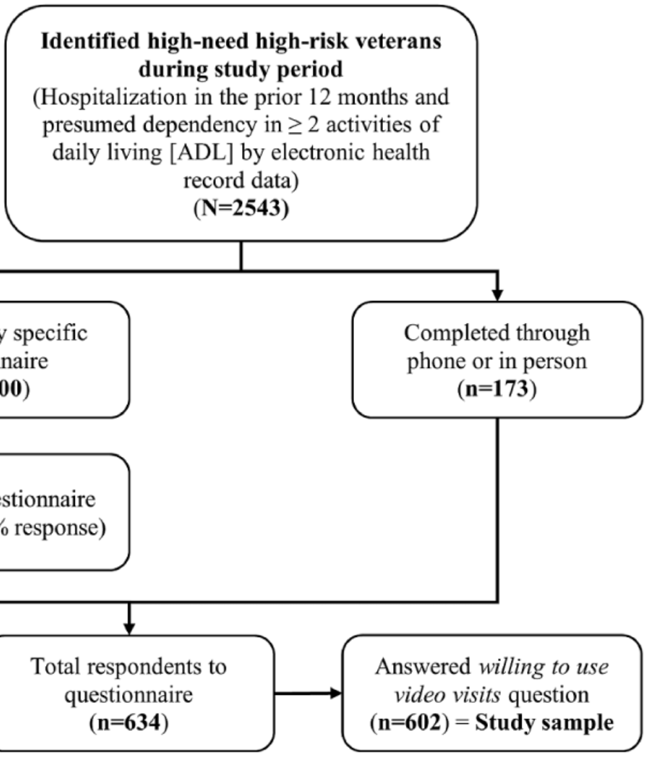
The Miami VA institutional review board granted this study a waiver and deemed it as a quality improvement study (reference number 1360043-3).

Results

Survey Respondents

A total of 1300 HNHR veterans were mailed the questionnaire, of which 461 (35.46%) were returned. In addition, 102 veterans filled the questionnaire over the phone and 71 in person in the frailty clinic, for a total of 634 respondents. Of the 634 individuals returning the survey, 602 (94.9%) respondents answered the *willing to use video visits* question. These 602 respondents represent the main focus of our study (Figure 1). When asked about their willingness to use video visits with their VA care team, 54.3% (327/602) reported their willingness, henceforth labeled as *willing*, whereas 45.7% (275/602) were not willing to use video visits, henceforth labeled as *unwilling*.

Figure 1. Flowchart showing completed questionnaires.



The average age of our 602 respondents was 70.6 (SD 9.2; range 39-100) years. Among them, 20.3% (122/602) were aged <65 years, 25.4% (153/602) were aged 65 to 69 years, 25.7% (155/602) were aged 70 to 75 years, 13.8% (83/602) were aged 75 to 79 years, and 14.8% (89/602) were aged >80 years. Only 0.3% (2/602) of the respondents were female. Approximately 61% (367/602) of the respondents were White, 36% (217/602) respondents were African American, and 17.3% (104/602) were Hispanic. Among the 602 responders, 290 (48.2%) were confident filling medical forms by themselves, and 188 (31.2%) had at least an associate degree.

Difference Between Respondents by Mail versus In Person and Telephone

Individuals completing the survey via mail were significantly more confident filling out medical forms (224/440, 50.9% vs 66/162, 40.7%; *P*=.03); in significantly worse physical health, as measured by their JFI (mean 7.2, SD 1.2 vs mean 6.8, SD 1.2; *P*<.001), Care Assessment Needs scores (mean 94.2, SD 6.8 vs mean 91.6, SD 8.1; *P*<.001), and the total number of Hierarchal Condition Categories conditions (mean 5.7, SD 2.4 vs mean 4.9, SD 1.9; *P*<.001); and significantly more socially isolated (Social Networking Index of 1.5, SD 1.1 vs 1.7, SD 1.1; *P*=.049). There were no other differences between those veterans who completed the mailed survey versus those completing the survey by phone or in person.

Furthermore, we compared the willingness to use video visits between veterans who finished the survey in person and those who did not, and the difference was not significant (*P*=.13). Although more veterans reported no trouble for transportation in those who filled out the survey in person (52/80, 65%) than those who did not (321/531, 60.5%), the difference was not statistically significant (*P*=.05). Similarly, the difference in the percentage of veterans who missed an appointment owing to transportation between those who filled out the survey in person and not in person was not significant (*P*=.28).

Difference Between Respondents Who Were Willing Versus Unwilling to Use Video Visits

We characterized the differences between 54.3% (327/602) patients *willing* (to use video visits) versus 45.7% (275/602) patients *unwilling* (to use video visits), as shown in Table 2. Those who were willing were significantly younger (average age 68.9, SD 8.8 years) than those unwilling (average age 72.5, SD 9.1 years; *P*<.001). There appears to be a sharp drop in willingness after the age of 75 years. They were also more likely to have at least an associate educational degree (120/327, 36.7% vs 68/275, 24.7%; *P*=.002) and be more health literate (180/327, 55% vs 110/275, 40%; *P*<.001). Those who were willing were more likely to not use assistive devices for walking (137/327, 41.9% vs 80/275, 29.1%; *P*=.002) and less dependent in their IADL (mean 1.8, SD 2.0 vs mean 2.2, SD 2.2; *P*=.02). Willing veterans reported worse self-rated general health compared with those of unwilling veterans (mean 2.8, SD 0.9 vs mean 3.0, SD 1.0; *P*=.01) and worse physical status (mean 5.2, SD 2.0 vs mean 5.7, SD 2.2; *P*=.004). Willing veterans were also less likely to live in disadvantaged areas (*P*=.048).

When asked about their ability to use technology, a significantly higher number of those willing were able to perform an internet search if given access to a computer (242/327, 74% vs 109/275, 39.6%; *P*<.001); were using email (226/327, 69.1% vs 88/275, 32%; *P*<.001); and were enrolled in the VA's patient portal, My Healthe*V*et (199/327, 60.9% vs 76/275, 27.6%; *P*<.001). The willing and the unwilling to use video visits groups differed regarding the preferred modes of contact (*P*=.003). Compared with those unwilling to use video visits, willing veterans were more likely to prefer contact by the VA via cell phone (189/327, 57.8% vs 129/275, 46.9%) or via My Healthe*V*et secure message (24/327, 7.3% vs 10/275, 3.6%) and less likely to prefer contact by *landline home phone* (67/327, 20.5% vs 73/275, 26.5%) or mail (44/327, 13.5% vs 57/275, 20.7%).

Table 2. Patient characteristics of those willing to use video visits versus not willing to use video visits with their Veterans Affairs care team (N=602).

Characteristics	All completed surveys for study	Willing to use video visits (n=327)	Not willing to use video visits (n=275)	*P* value
Demographics				
Age (years)[a]				
Values, mean (SD; range)	70.6 (9.2; 39-100)	68.9 (8.8; 39-95)	72.5 (9.1; 42-100)	<.001
Age group, n (%)[a]				<.001
<65	122 (20.3)	83 (25.4)	39 (14.2)	
65-69	153 (25.4)	83 (25.4)	70 (25.5)	
70-75	155 (25.7)	88 (26.9)	67 (24.4)	
75-79	83 (13.8)	44 (13.5)	39 (14.2)	
≥80	89 (14.8)	29 (8.9)	60 (21.8)	
White, n (%)	367 (61)	207 (63.3)	160 (58.2)	.23
African American, n (%)	217 (36)	110 (33.6)	107 (38.9)	.21
Hispanic, n (%)	104 (17.3)	56 (17.1)	48 (17.5)	.99
Education (at least associate degree)[a], n (%)	188 (31.2)	120 (36.7)	68 (24.7)	.002
Confident filling out medical forms[a], n (%)	290 (48.2)	180 (55)	110 (40)	<.001
Physical health				
JEN Frailty Index[a,b], mean (SD)	7.1 (1.2)	7.0 (1.2)	7.2 (1.2)	.04
Care Assessment Needs score[b], mean (SD)	93.5 (7.3)	93.1 (7.5)	93.9 (7.7)	.20
Total number of Hierarchical Condition Categories[b], mean (SD)	5.5 (2.3)	5.4 (2.3)	5.6 (2.3)	.29
FRAIL[b,c] scale screen positive (score ≥3), n (%)	253 (42)	132 (40.4)	121 (44)	.41
Self-rated physical status score[a,d], mean (SD)	5.4 (2.1)	5.2 (2.0)	5.7 (2.2)	.004
Issue with walking, stepping, and balance, n (%)	444 (73.8)	237 (72.5)	207 (75.3)	.49
No prosthetic use[a], n (%)	217 (36)	137 (41.9)	80 (29.1)	.002
General health score[a,d], mean (SD)	2.9 (0.9)	2.8 (0.9)	3.0 (1.0)	.01
ADL[e] score[d], mean (SD)	84.3 (20.1)	84.9 (19.4)	83.1 (21.0)	.28
ADL deficits[b], mean (SD)	2.3 (2.8)	2.2 (2.6)	2.4 (2.9)	.38
IADL[f] score[a,d], mean (SD)	6.0 (2.1)	6.2 (2.0)	5.8 (2.2)	.02
IADL deficits[a,b], mean (SD)	2.0 (2.1)	1.8 (2.0)	2.2 (2.2)	.02
Homebound or semihomebound, n (%)	169 (28.1)	91 (27.8)	78 (28.4)	.96
Mental health				
PHQ-2[g] depression screen positive (score ≥3), n (%)	196 (32.6)	117 (35.8)	79 (28.77)	.08
Self-perception of aging score [b], mean (SD)	3.2 (1.5)	3.3 (1.5)	3.1 (1.5)	.10
Social characteristics				

Characteristics	All completed surveys for study	Willing to use video visits (n=327)	Not willing to use video visits (n=275)	*P* value
Area Deprivation Index Score[a,b], n (%)				.048
1-25	113 (18.8)	66 (20.2)	47 (17.1)	
26-50	155 (25.7)	95 (29.1)	60 (21.8)	
51-75	192 (31.9)	99 (30.3)	93 (33.8)	
76-100	138 (22.9)	64 (19.6)	74 (26.9)	
Have a caregiver, n (%)	204 (33.9)	106 (31)	98 (35.6)	.46
Social Networking Index[d], mean (SD)	1.5 (1.1)	1.6 (1.1)	1.5 (1.1)	.27
Having no trouble in transportation, n (%)	373 (62)	198(60.6)	175(63.3)	.49
Travel time to physician >60 minutes, n (%)	177 (29.4)	107 (32.7)	70 (25.5)	.06
Have delayed physicians' appointments owing to transportation troubles, n (%)[a]	136 (22.6)	82 (25.1)	54 (19.6)	.14
Technology ability[a]—facilitator, n (%)				
Use email[a]	314 (52.2)	226 (69.1)	88 (32)	<.001
Able to do an internet search[a]	351 (58.3)	242 (74)	109 (39.6)	<.001
Use email and internet search	296 (49.2)	214 (65.4)	82 (29.8)	<.001
Enrolled in My Health*e*Vet (MHV)[a]	275 (45.7)	199 (60.9)	76 (27.6)	<.001
Preferred mode of contact[a]				.003
By home phone	140 (23.3)	67 (20.5)	73 (26.5)	
By cell phone	318 (52.8)	189 (57.8)	129 (46.3)	
By MHV secure message	34 (5.6)	24 (7.3)	10 (3.6)	
By email	101 (16.8)	44 (13.5)	57 (20.7)	

[a] *P*<.05 defined statistical significance.

[b] Lower score is better.

[c] FRAIL: Fatigue, Resistance, Ambulation, Illnesses, and Loss of Weight.

[d] Higher score is better.

[e] ADL: activities of daily living.

[f] IADL: instrumental activities of daily living.

[g] PHQ-2: Patient Health Questionnaire-2.

Differences Between Willing Respondents With and Those Without Access to Video-Capable Technology

Upon being asked about their access to technology, of the 327 veterans who were willing to use video visits, 248 (75.8%) had a smartphone or computer with a camera, whereas 69 (21.1%) did not. The characteristics of these subgroups are presented in Table 3. Patients with access to the necessary devices were younger (mean 68.3, SD 8.9 vs mean 71.8, SD 8.6; *P*=.004), more health literate (144/248, 58.1% vs 28/69, 41%; *P*=.01), and less likely to be African American (73/248, 29.4% vs 33/69, 48%; *P*=.007) than those without technology access. Veterans with video-capable technology were more functionally independent in their ADL (Barthel ADL score: mean 86.4, SD 17.8 vs mean 77.3, SD 24.3, *P*=.005; number of ADL deficits: mean 2.0, SD 2.5 vs mean 3.2, SD 3.2, *P*=.005) and IADL (Lawton IADL score 6.3, SD 1.9 vs 5.7, SD 2.2, *P*=.04; and number of IADL deficits 1.7, SD 1.9 vs 2.3, SD 2.2 and *P*=.04). They were less likely to report issues with walking, stepping, or balance (173/248, 69.8% vs 58/69, 84%; *P*=.03) and more likely to not use assistive devices for walking (115/248, 46.4% vs 18/69, 26%; *P*=.004). They were less likely to live in disadvantaged areas (*P*=.049). They were also less likely to have trouble with transportation (167/248, 67.3% vs 25/69, 36%; *P*<.001) and less likely to have delayed their physicians' appointments because of transportation troubles (54/248, 21.8% vs 26/69, 38%; *P*=.01). Veterans with access to a video-capable device were more likely to be able to use the internet (204/248, 82.3% vs 28/69, 41%; *P*<.001), use email (196/248, 79% vs 20/69, 29%; *P*<.001), and be enrolled in My Health*e*Vet (173/248, 69.8% vs 17/69, 25%; *P*<.001).

Table 3. Patient characteristics by access to a video-capable technology of those willing to use video visits who answered both questions (N=317).

Characteristics	Access to a video-capable device (n=248)	No access to a video-capable device (n=69)	*P* value
Demographics			
Age (years)			
Values, mean (SD; range)	68.3 (8.9; 39-95)	71.8 (8.6; 55-94)	.004
Age group, n (%)[a]			.02
≤64	68 (27.4)	12 (17.4)	
65-69	64 (25.8)	14 (20)	
70-74	66 (26.6)	21 (30)	
75-79	31 (12.5)	12 (17)	
≥80	19 (7.7)	10 (14)	
White, n (%)[a]	168 (68)	34 (49)	.007
African American, n (%)[a]	73 (29.4)	33 (48)	.007
Hispanic, n (%)	46 (18.5)	9 (13)	.37
Education (at least associate degree), n (%)	91 (36.7)	22 (32)	.55
Confident filling out medical forms, n (%)[a]	144 (58.1)	28 (41)	.01
Physical health			
JEN Frailty Index[b], mean (SD)	7.0 (1.1)	7.1 (1.2)	.53
Care Assessment Needs score[b], mean (SD)	92.9 (7.0)	93.4 (6.7)	.59
Total number of Hierarchical Condition Categories[b], mean (SD)	5.4 (2.5)	5.5 (1.9)	.72
FRAIL[c] scale screen positive (score ≥3), n (%)	100 (40.3)	28 (41)	.99
Physical status score[d], mean (SD)	5.3 (2.0)	5.0 (1.8)	.23
Issue with walking, stepping, balance, n (%)[a]	173 (69.8)	58 (84)	.03
No prosthetic use, n (%)[a]	115 (46.4)	18 (26)	.004
General health score[a,d], mean (SD)	2.8 (0.9)	2.6 (0.8)	.08
ADL[e] score[a,d], mean (SD)	86.4 (17.8)	77.3 (24.3)	.005
ADL deficits[a,b], mean (SD)	2.0 (2.5)	3.2 (3.2)	.005
IADL[f] score[a,d], mean (SD)	6.3 (1.9)	5.7 (2.2)	.04
IADL deficits[a,b], mean (SD)	1.7 (1.9)	2.3 (2.2)	.04
Homebound or semihomebound, n (%)	70 (28.2)	17 (25)	.66
Mental health			
PHQ-2[g] screen positive (score ≥3), n (%)	86 (34.7)	26 (38)	.75
Self-perception of aging score[b], mean (SD)	3.2 (1.6)	3.5 (1.3)	.11
Social characteristics			
Area Deprivation Index Score[a,b], n (%)			.49
1-25	54 (21.8)	11 (15.9)	
26-50	76 (30.6)	19 (28)	
51-75	69 (27.8)	25 (36)	
76-100	46 (18.5)	14 (20)	

Characteristics	Access to a video-capable device (n=248)	No access to a video-capable device (n=69)	*P* value
Have a caregiver, n (%)	81 (32.7)	25 (36)	.68
Social Networking Index[d], mean (SD)	1.6 (1.1)	1.5 (1.1)	.51
Have no trouble with transportation, n (%)[a]	167 (67.3)	25 (36)	<.001
Travel time to physician >60 minutes, n (%)	83 (33.5)	23 (33)	.99
Have delayed physicians' appointments owing to transportation troubles, n (%)[a]	54 (21.8)	26 (38)	.01
Technology ability, n (%)[a]			
Use of email[a]	196 (79.0)	20 (29)	<.001
Able to do an internet search[a]	204 (82.3)	28 (41)	<.001
Use email and internet search	187 (75.4)	17 (25)	<.001
Enrolled in My Health*e*Vet (MHV)[a]	173 (69.8)	17 (25)	<.001
Preferred mode of contact[a]			.03
By home phone	46 (18.6)	20 (29)	
By cell phone	144 (58.1)	39 (57)	
By MHV secure message	22 (8.9)	0 (0)	
By email	34 (13.7)	9 (13)	

[a] *P*<.05 defined statistical significance.

[b] Lower score is better.

[c] FRAIL: Fatigue, Resistance, Ambulation, Illnesses, and Loss of Weight.

[d] Higher score is better.

[e] ADL: activities of daily living.

[f] IADL: instrumental activities of daily living.

[g] PHQ-2: Patient Health Questionnaire-2.

Number of Willing Respondents With Access and Ability to Use Video Visits

In our HNHR group, 54.3% (327/602) were willing to receive care from their VA health care team via video visits (Table 2), and of those, 78.2% (248/317) had access to video-capable technology (Table 3). Therefore, 41.2% (248/602) participants were willing and had the technology for a video visit. Among the willing 248 patients with access to a video-capable device, only 204 (82.3%) were likely to be comfortable using technology when factoring in previous use of the internet or email (Table 3). Therefore, the percentage of HNHR veterans with access and ability likely decreases to approximately 33.9% (204/602).

Multivariable Logistic Regression

Multivariable logistic regression was conducted to give a sense of the relative importance of different predictors of willingness. The odds ratios for willingness estimated for age, degree, confidence in filling out forms, JFI score, self-perception of health, prosthetics use, general health, IADL score, ADI, use of email, use of the internet, and My Health*e*Vet use are presented in Table 4. As shown in Table 4, age, confidence in filling out forms, prosthetics use, general health, and use of the internet were significantly associated with willingness of video visit use in the multivariable analysis, indicating that they are the strongest predictors compared with others that were only significant in the univariate analysis.

Table 4. Odds ratio for predictors of willingness to use video visits in multivariable logistic regression.

Characteristics	Odds ratio (95% CI)	*P* value
Age	0.97 (0.95-0.995)	.02
Education (at least associate degree)	1.39 (0.94-2.07)	.10
Confidence in filling medical forms	1.47 (1.01-2.14)	.046
JEN Frailty Index score	1.03 (0.89-1.20)	.70
Self-perception of aging	0.92 (0.82-1.03)	.15
Prosthetics use	1.85 (1.23-2.80)	.003
General health	0.72 (0.56-0.92)	.01
Instrumental activities of daily living score	1.03 (0.93-1.14)	.60
Area Deprivation Index score	0.99 (0.99-1.00)	.06
Use of email	0.98 (0.67-1.43)	.91
Use of the internet	2.34 (1.65-3.34)	<.001
My Health*e*Vet use	1.29 (0.90-1.85)	.17

Discussion

Principal Findings

Our study aimed to identify the readiness of using video visits for health care by assessing willingness, access, and ability in older HNHR patients with complex needs, functional limitations, and a variety of chronic conditions [30]. A little over half were willing to use video visits, three quarters of those had access, and only 80% of them were comfortable with technology. Overall, we believe that only one-third of the HNHR veterans had the willingness, access, and ability to use video visits for health care. Therefore, data from our project suggest that among vulnerable HNHR older adults, the proportion not ready for video visits may be much higher than the one-third previously reported for a cross-section of community-dwelling older adults [9] and likely is approximately two-thirds of the HNHR veterans.

The access gap between those willing yet without technology was larger among those who were older, less health literate, or African American or lived in disadvantaged areas. Veterans who did not have a device were less healthy, more likely to be dependent and have transportation challenges, and less well-versed with using the internet and email. In contrast, veterans who were willing to use video visits were younger, more literate, more adept at using technology, more functionally independent in their IADL, and less likely to live in disadvantaged areas but had worse self-rated health. Age, confidence in filling out forms, prosthetic use, general health, and internet use were significantly associated with willingness to use video visits in the multivariable analysis. Age is a strong predictor, and there appears to be a sharp drop in willingness after the age of 75 years. Moreover, there was a very strong correlation of both technology access and digital skills on willingness.

In addition, willingness was correlated with a previous history of having missed their in person physicians' appointments because of issues involving transportation. Although the HNHR population's willingness to use video visits represents an opportunity to address critical access barriers often seen in this population, these inequities in access to video visits and their lack of prior technology use warrant further attention, as reliance on telemedicine visits could exacerbate the gap in access to care for vulnerable populations. Although there were no differences in the willingness to use video visits and insignificant differences in transportation barriers between veterans who finished the survey in person and those who did not, individuals completing the survey via mail were more confident filling out medical forms but in worse physical health and more socially isolated than those who completed by phone or in person. Although not significant, these results may be an indirect reflection regarding the availability of resources for attending in person appointments and need further inspection.

Owing to the unprecedented challenges to health care during the COVID-19 pandemic, there has been a substantial increase in patients' willingness to use technology to reduce in person appointments to safeguard against COVID-19 [2]. However, even as telemedicine willingness increases, not only is it necessary to address the lack of access to technology in and of itself but also other strategies to address telemedicine unreadiness are needed. Some ways of addressing technology access challenges may be providing necessary equipment and bandwidth via the health care system [31] or helping patients acquire affordable devices and broadband internet [11]. In August 2020, the Assistant Under Secretary for Health for Clinical Services submitted a memorandum for expanding access to telehealth for veterans through a digital divide consult. This consult is available to veterans who do not have a video-capable device or connectivity for eligibility in participating in the Lifeline program to receive a loaned device (eg, iPads or iPhones) for accessing telemedicine in their home or location of choice. The VA offers tablets and data plans to veterans who qualify using a digital divide consult and has simplified the use of technology for video visits by configuring VA-loaned tablets to allow for a single-use mode [31]. The single-use mode replaces the complexity of multiple VA functions, features, and apps on the device with a VVC icon that readily connects the veteran to a telemedicine medical room [31].

Strategies are needed to address technology literacy and offer necessary education and support so that patients may engage successfully in video visits. Specific outreach efforts need to target communities that have been found to be less ready for video visits, including African Americans and those with high area deprivation scores. More systems need to implement initiatives that enable trained staff or even volunteers to help patients navigate the complexities of devices and applications [4] and programs that enhance self-efficacy, which have proven successful in the adoption of technology [32]. Other potential approaches include offering technology education and support, using nonmedical staff to conduct a mock visit before the actual visit to train older adults in navigating the technology, using trained peers or community health workers to provide in-home training or act as telepresenters for in-home video visits with high-risk older adults, and encouraging family caregivers and friends to participate during telemedicine encounters.

Moreover, the presentation of video versus in person visits is somewhat of a false dichotomy. Video visits may have more capacity to address multi-morbid diseases, as indicated by longer visit durations and a larger number of visit diagnoses than those of telephone visits [33]. However, there is a population that has significant barriers to both physical (transportation) and video (digital literacy) interactions. For this group, telephone visits may be more accessible than video or in person visits and can potentially be another means of increasing care. For a few patients, neither telemedicine (telephone or video) nor in person may be feasible, and home care models such as Medicare's Independence At Home and VA's HBPC may be necessary.

This study has several strengths. A strength of our study is that it specifically assesses an older, functionally dependent, HNHR population with complex needs and social isolation. We used a novel VA set of HNHR older adults and surveyed them about their attitudes toward telemedicine and their physical, emotional, and social determinants. In addition to characterizing the willingness, access, and ability to use video visits for health care, in the context of their physical, emotional, and social characteristics, as has previously been done [9,11-13], we correlated it to frailty status and the neighborhood they reside in.

However, this study does have several limitations. One of the limitations is that technology access was only asked for those who were willing. Had we surveyed our total study sample regarding access, the proportion of those lacking access would likely be higher, given the lower use of email and internet and lower education level and health literacy among the unwilling veterans. Moreover, we did not explore the reasons driving the unwillingness to use video visits, explore the subgroup that has the technology but is unwilling, or include an *uncertain* response category for willingness in our survey. Understanding their barriers and facilitators might provide important insights beyond affordable access to devices and connectivity and digital skills [34]. Previous reports suggest that in addition to poor technology access and literacy, technology unwillingness may be driven by several other factors, including sensory or memory impairment [9,12], which we did not assess. The ADI does not explicitly incorporate neighborhood availability of affordable broadband, which may be a big factor in whether or not people use it; however, it may reflect digital redlining [34].

We also did not ask about or compare willingness among those who had versus did not have prior telehealth visits. Some of the constructs are somewhat narrowly assessed: specifically, the social support measure that assesses caregiver presence with an unvalidated question. However, this was supplemented by the Berkman–Syme Social Network Index, which takes into account marital status, frequency of meeting and talking to close friends and relatives, and participating in religious and club meetings. Similarly, mental health is assessed with a validated 2-item depression scale and is therefore supplemented by the 5-item Self-Perception of Aging scale. Another limitation is that our population was US veterans and overwhelmingly male. The gender demographics here reflect that of the VA, where 89.6% of all veterans are male [35], and not of the general older adult population. Older female HNHR patients may have different needs and access challenges than those described in this study. Moreover, our study was urban and limited geographically to the Miami area and, thus, may not represent regional variations. In addition, we did not assess the availability of the caregivers who may be willing and able to help with the video visit and may have access to the needed devices. Adjustment for multiple comparisons tends to increase type II error [36,37]; therefore, we did not adjust for multiple comparisons. Other limitations include a relatively low survey response rate. The survey was also conducted for patients in an integrated health care system, which may make the findings less generalizable to patients from other types of systems.

Conclusions

Our results underscore the well-recognized fact that older adults, a group that uses health care at one of the highest rates, face significant barriers to accessing needed care, whether it be in person or telemedicine. Certain characteristics put individuals within this group at an even higher risk for barriers to care. Future research is needed to urgently explore ways of mitigating the identified obstacles to telemedicine among HNHR patients at a system level and study and address potential barriers such as concerns about care quality and relationships with physicians at the patient–provider level [38,39]. Programs for HNHR patients should address the specific factors identified here to pave the way for equitable access to health care among high-risk patients. It is recognized that individuals' characteristics, as well as the surrounding social and health care system, are the most important factors that affect telemedicine adoption [40], and some may also serve as barriers. Thus, it was difficult to make a distinction. However, it is important to recognize that only some of the factors are modifiable; thus, the need to make a distinction may be less pertinent. These respondents completed the survey before the COVID-19 pandemic, and it is possible that the COVID-19 pandemic may have significantly changed patients' video acceptance and technology availability as they may have adopted video for personal and health reasons [2]. Thus, the development of innovative, sustainable strategies to support and improve care access for this vulnerable population will help during the COVID-19 pandemic; however, it will also help better manage HNHR patients and keep them healthy in their homes for as long as possible after the COVID-19 pandemic.

Acknowledgments

This work was supported in part by funding from the Health Services Research & Development Service of the US Department of Veterans Affairs (VA; SDR 18-313 under Grant HX-18-015), the VA Office of Geriatrics and Extended Care (GEC; VA GEC SP3E-GREA160) and by the Veterans Integrated Service Network 8 GEC Office. The authors also gratefully acknowledge the support of the sponsors and of the Miami VA Geriatric Research, Education, and Clinical Center; Bruce W Carter, Department of VA Medical Center; and the Miami VA Research. The authors also wish to thank the project staff for their help with various aspects of the project. This quality improvement project registration number is ClinicalTrials.gov NCT04846049.

The data presented here were presented partly in a poster at the Gerontological Society of America Annual conference in 2019, in Austin, Texas, titled, *Age- and Ethnicity-Related Disparities in Technology Use Among High-Risk Veterans*.

Authors' Contributions

All authors contributed to the concept, preparation, and revision of the manuscript and approved its final version. The investigators retained full independence in the conduct of this research. The views expressed in this paper are those of the authors and do not reflect the position or policy of the Department of Veterans Affairs or the US government. The authors assume full responsibility for the ideas presented.

Conflicts of Interest

None declared.

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Abbreviations

ADI: Area Deprivation Index
ADL: activities of daily living
CMS: Centers for Medicare and Medicaid Services
HBPC: home-based primary care
HNHR: high-need, high-risk
IADL: instrumental activities of daily living
JFI: JEN Frailty Index
VA: Veterans Affairs
VVC: Veteran Video Connect

Edited by A Mavragani; submitted 03.08.21; peer-reviewed by K Possemato, P Yellowlees, T Jamieson, A Sheon; comments to author 01.10.21; revised version received 20.12.21; accepted 25.01.22; published 08.04.22

Please cite as:
Dang S, Muralidhar K, Li S, Tang F, Mintzer M, Ruiz J, Valencia WM
Gap in Willingness and Access to Video Visit Use Among Older High-risk Veterans: Cross-sectional Study
J Med Internet Res 2022;24(4):e32570
URL: https://www.jmir.org/2022/4/e32570
doi: 10.2196/32570
PMID:

Original Paper

Social Networking Service, Patient-Generated Health Data, and Population Health Informatics: National Cross-sectional Study of Patterns and Implications of Leveraging Digital Technologies to Support Mental Health and Well-being

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Abstract

Background: The emerging health technologies and digital services provide effective ways of collecting health information and gathering patient-generated health data (PGHD), which provide a more holistic view of a patient's health and quality of life over time, increase visibility into a patient's adherence to a treatment plan or study protocol, and enable timely intervention before a costly care episode.

Objective: Through a national cross-sectional survey in the United States, we aimed to describe and compare the characteristics of populations with and without mental health issues (depression or anxiety disorders), including physical health, sleep, and alcohol use. We also examined the patterns of social networking service use, PGHD, and attitudes toward health information sharing and activities among the participants, which provided nationally representative estimates.

Methods: We drew data from the 2019 Health Information National Trends Survey of the National Cancer Institute. The participants were divided into 2 groups according to mental health status. Then, we described and compared the characteristics of the social determinants of health, health status, sleeping and drinking behaviors, and patterns of social networking service use and health information data sharing between the 2 groups. Multivariable logistic regression models were applied to assess the predictors of mental health. All the analyses were weighted to provide nationally representative estimates.

Results: Participants with mental health issues were significantly more likely to be younger, White, female, and lower-income; have a history of chronic diseases; and be less capable of taking care of their own health. Regarding behavioral health, they slept <6 hours on average, had worse sleep quality, and consumed more alcohol. In addition, they were more likely to visit and share health information on social networking sites, write online diary blogs, participate in online forums or support groups, and watch health-related videos.

Conclusions: This study illustrates that individuals with mental health issues have inequitable social determinants of health, poor physical health, and poor behavioral health. However, they are more likely to use social networking platforms and services, share their health information, and actively engage with PGHD. Leveraging these digital technologies and services could be beneficial for developing tailored and effective strategies for self-monitoring and self-management.

(J Med Internet Res 2022;24(4):e30898) doi: 10.2196/30898

KEYWORDS

patient-generated health data; social network; population health informatics; mental health; social determinants of health; health data sharing; technology acceptability; mobile phone; mobile health

Introduction

Background

Mental health issues such as depression and anxiety disorders are severe psychiatric diseases with high prevalence and elevated risks of recurrence and chronicity [1]. There are >260 million people of all ages who have experienced mental illnesses worldwide, which are a leading cause of disability worldwide and a major contributor to the overall global burden of disease [2]. Studies have demonstrated that mental health issues are a strong indicator of poor general health, unhealthy alcohol use, and sleep problems [3,4]. Poor sleep quality has been linked to an increased motivation to drink, especially for young adults [5]. It is critical for patients with mental health issues to receive appropriate health care and social services.

In recent years, there has been increasing acknowledgment of the important role that mental health plays in achieving improved population health. Understanding how these fundamental factors (physical and behavioral health, mental health, and technologies) relate to one another may yield important insights for novel approaches to designing prevention programs and enhancing services for mental health support. Digital health technologies such as smartphone apps and social media provide opportunities to continuously collect objective information on behavior in the context of people's real lives, generating a rich data set that can provide insights into the extent and timing of mental health needs in individuals [6].

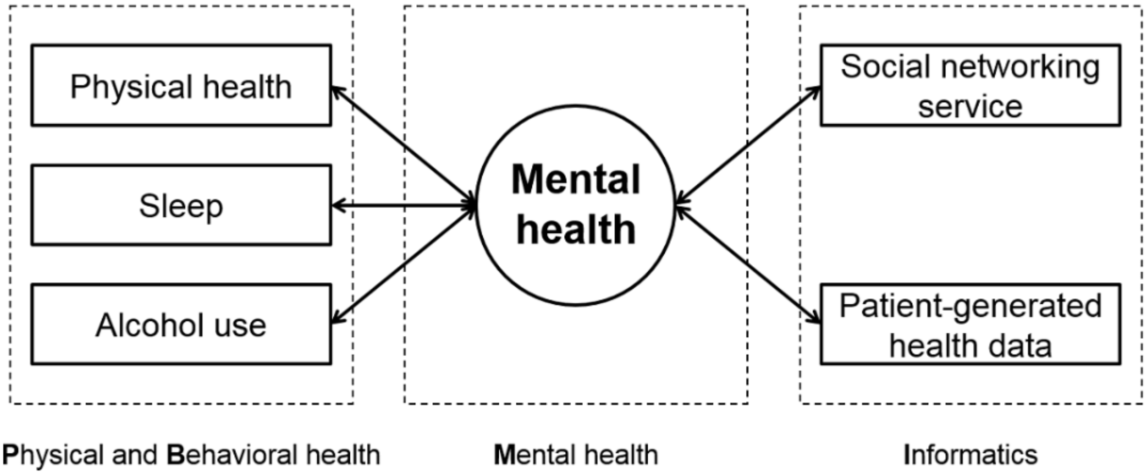
However, long-standing problems have hampered the efforts to improve mental health care delivery, quality of care, and social support. For example, if mental health conditions are assessed exclusively on patients' self-reporting, it may be burdensome to collect and subjective for clinical decision support. Currently, mental health services are mainly provided at times chosen by the practitioner rather than at the patient's time of greatest need [7]. The ideal way of providing support is to conduct regular assessments, which is useful for capturing the temporal dynamics of symptoms and crucial for both diagnosis and treatment planning [8]. However, this could contribute to burnout among health care providers and patients [9].

The emerging health technologies and digital services provide effective ways of collecting human behavior information, gathering patient-generated health data (PGHD), and sharing health-related information outside clinical settings in a systematic way, thus making interventions timely. Coupled with population health informatics tools, these technologies can track people's digital exhaust, which includes PGHD and social networking platform use [10]. Social networking services are web-based platforms that people use to build social networks or social relationships with other people who share similar personal interests, activities, backgrounds, or real-life connections [11]. The rich real-time data enable researchers to gain insights into aspects of behavior that are well-established building blocks of mental health and illness, such as mood, social communication, sleep, alcohol use, and physical activity.

Objectives

This study had 2 aims. The first aim was to provide a conceptual framework that will be used to describe the relationship between physical and behavioral health, mental health, and informatics. Figure 1 demonstrates the conceptual framework—Physical and Behavioral Health, Mental Health, and Informatics (PBMI)—for this study. The results could provide a comprehensive understanding of the relationship between health, behavior, and informatics, which could be useful for developing tailored and effective strategies to support mental health management. The second aim was to describe and compare characteristics of populations with and without mental health issues (depression or anxiety disorders), including physical health, sleep, and alcohol use, based on the proposed PBMI framework. We also examined the patterns of social networking service use, PGHD, and attitudes toward health information sharing and activities.

Figure 1. Physical and Behavioral Health, Mental Health, and Informatics (PBMI) framework.



Methods

Study Design

Data for this study were drawn from the 2019 Health Information National Trends Survey (HINTS) of the National Cancer Institute. HINTS is a nationally representative survey administered every year by the National Cancer Institute that provides a comprehensive assessment of the American public's current access to and use of health information [12]. The HINTS target population is civilian, noninstitutionalized adults aged ≥18 years living in the United States. In this study, we investigated the relationships between mental health, physical health, behavioral health, and social networking service use. Social networking services include sharing health information, writing online diary blogs, participating in online forums or health-related groups, and watching health-related videos.

Study Participants

The data used in this study were from the third round of data collection for HINTS 5 (cycle 3), which was conducted from January 22, 2019, to April 30, 2019. Cycle 3 received 5590 questionnaires, of which 5438 (97.28%) were determined to be eligible after excluding blank, incomplete, and duplicate surveys.

In this study, the primary outcome was the presence of mental health issues, which was determined by the participant's status of depression or anxiety disorder based on the results of the question *Has a doctor or other health professional ever told you that you had depression or anxiety disorder (yes/no)?* Of the 5438 eligible respondents, 1139 (20.95%) reported *yes*, 4168 (76.65%) reported *no*, and 131 (2.41%) were missing and omitted from our analyses.

Measures

Social Determinants of Health

The sample was divided into 2 groups according to mental health status. Participants with depression or anxiety disorders were classified as the group with mental health issues, and the others were classified as the group with no mental health issues. We used the participants' self-reported information on age, sex, race, ethnicity, level of education, annual income, and usual source of care as our sociodemographic variables. We transformed the continuous variable of age into a categorical variable by classifying age into four groups: (1) 18 to 34 years, (2) 35 to 49 years, (3) 50 to 64 years, and (4) ≥65 years. Education level was recategorized as less than college (including post–high school training), some college, college graduate, and postgraduate degree. Annual income level was recategorized as ≤US $20,000, US $20,000 to $35,000, US $35,000 to $50,000, US $50,000 to $75,000, and >US $75,000. We examined the participants' history of chronic conditions using four questions (all with yes or no responses): *Has a doctor or other health professionals ever told you that you had (1) diabetes, (2) high blood pressure, (3) a heart condition, and (4) chronic lung disease?*

Health-Related Information

To assess the participants' general health, we considered their answers to questions related to physical health and mental status, including the ability to take care of their health, emotion control by changing the way of thinking, and future consideration. We also included the Patient Health Questionnaire–4 (PHQ-4), which was a derived composite from the participants' responses to questions on lack of interest in doing things, presence of depressed feelings, nervousness and anxiousness, and uncontrolled worry [13].

PGHD and Social Networking Service Use

We examined the participants' use of the internet for health-related reasons using the following five survey questions (all with yes or no responses): *In the past 12 months, have you used the internet to (1) visit a social networking site, such as Facebook or LinkedIn, (2) share health information on social networking sites, such as Facebook or Twitter, (3) write in an online diary or blog, (4) participate in an online forum or support group for people with similar health or medical issue, or (5) watch a health-related video on YouTube?*

We also inspected the first source of health information of the participants using their responses to the following question—*The most recent time you looked for information about health or medical topics, where did you go first?*—where the respondent could select one of 12 options. We further grouped the options into five main categories: internet, health professionals, family and friends, print materials, and others. In addition, we investigated the participants' attitudes toward sharing health information, such as avoidance of physician visits and talking about health with family and friends.

Alcohol Consumption and Sleep

We examined the participants' alcohol consumption using two questions: the number of days with at least one alcoholic drink per week and the average number of drinks per day. We assessed the participants' sleep hours and quality using two questions: the average number of hours of sleep per night and the self-rated overall sleep quality. We transformed the continuous variable of average sleep per night into a categorical variable by classifying sleep hours as (1) 0 to 6 hours, (2) 7 to 8 hours, and (3) ≥9 hours.

Statistical Analysis

We used the survey package in the R programming language (version 4.0.5; R Foundation for Statistical Computing) to account for the complex sampling design used in HINTS and incorporated the Taylor series (linear approximation) [14] to generate accurate variance estimation. All analyses used weighted data based on the Taylor series method to calculate population estimates. Pairwise deletion was used to deal with missing data to preserve more information.

To assess sociodemographic characteristics, general health, chronic diseases, social networking service use, alcohol consumption, and sleeping variables, we generated weighted 2-way cross-tabulation tables, which were tested with a Pearson chi-square test of association [15].

A univariate logistic regression was built to examine the association between each predictor and mental health. We then performed multivariate logistic regression analyses using a survey-weighted generalized linear modeling function in R [16].

The variables included the participants' sociodemographic and clinical characteristics. Odds ratios (ORs) and 95% CIs for both models were calculated. All reported *P* values were 2-tailed, and a cutoff of *P*<.05 was used to determine statistical significance for all analyses.

Ethics Approval

The data for this study are publicly available.

Results

Population Characteristics

Table 1 reports the sociodemographic and clinical characteristics of the participants. Respondents with mental health issues were significantly more likely to be younger (*P*=.004), White (*P*=.005), and female (*P*<.001); have a lower income (*P*<.001); and have a usual source of care (*P*<.001). They were also more likely to have a history of diabetes (*P*=.001) and lung disease (*P*<.001). There were no significant differences between the 2 groups regarding the characteristics of history of hypertension (*P*=.10), heart condition (*P*=.40), and cancer (*P*=.13).

Table 1. Unweighted and weighted prevalence estimates for sample sociodemographic characteristics, Health Information National Trends Survey 5, cycle 3.

Characteristic	Overall (n=5438), unweighted %	Overall (n=252,070,495), weighted %	Having mental health issues (n=57,953,433), weighted %	No mental health issues (n=189,456,090), weighted %	*P* value
Age (years)					.004
18 to 34	13	24.3	28.1	23.1	
35 to 49	18.3	24.5	26.3	24.2	
50 to 64	31.6	31.1	32.8	30.7	
≥65	37.1	20.2	12.8	22	
Sex (male)	42.1	48.8	37.9	52.5	<.001
Race[a]					.005
White	73.9	77	82.9	75	
Black	16.5	13	9.9	13.9	
Asian	5	5.8	3.4	6.7	
Others	4.7	4.2	3.9	4.4	
Ethnicity (Hispanic)	14.9	16.7	13.9	17.6	.07
Education					.41
High school diploma or less	54.4	70.5	72.5	69.7	
College degree	26.5	17.3	16.1	17.8	
Postgraduate degree	19.1	12.2	11.4	12.5	
Income (US $)					<.001
<20,000	18.8	18.5	26.2	15.6	
20,000 to 34,999	12.8	11	11.6	10.7	
35,000 to 49,999	13.1	13.5	14.2	13.4	
50,000 to 74,999	17.7	17.4	16.8	17.7	
≥75,000	37.6	39.6	31.3	42.6	
Insurance					.18
Public	44.1	35.2	38.9	33.5	
Private	42.3	48.9	44.8	50.8	
Uninsured	4.8	7.7	7.2	7.8	
Others[b]	8.8	8.2	9.2	8	
Has a usual source of care	69.8	64.5	73.7	61.7	<.001
History of cancer	16.1	9.5	7.9	9.7	.13
History of lung disease	11.8	11.2	2	8.2	<.001
History of heart condition	16.1	8.1	9.2	7.8	.40
History of diabetes	21.7	17	22.4	15.2	.001
History of hypertension	45	36	39.1	34.9	.10

[a] Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, and other Asian were collapsed into the *Asian* category. Race categories other than White, Black, and Asian were reclassified as *Others*.

[b] *Others* include coverage under the spouse, coverage under parents, and low-income beneficiary.

Health Information and Social Networking Service

Table 2 shows the characteristics of health information source, health information sharing, and social networking service use. Participants with mental health issues were more likely to have a worse general health status (*P*<.001), less confidence in taking care of their own health (*P*<.001), and a higher PHQ-4 score (*P*<.001). Individuals with mental health issues were also less likely to control emotions by changing the way they thought about situations (*P*<.001) and try to influence things in the future with day-to-day behavior (*P*<.001). In addition, Table 2 shows that those with mental health issues were significantly more likely to visit social networking sites (*P*=.04), share health information on social networking sites (*P*=.001), write online diary blogs (*P*=.007), participate in an online forum or support group (*P*<.001), and watch health-related videos (*P*=.009). There were no significant differences between the 2 groups in the first source of health information (*P*=.23), using wellness apps (*P*=.33), avoidance of physician visits (*P*=.15), and talking about health with family or friends (*P*=.08). Multimedia Appendix 1 shows the results of the multivariate logistic regression of health information and social networking service use.

Table 2. Prevalence estimates for characteristics of health information and social networking service use.

Characteristic	Overall (n=5438), unweighted %	Overall (n=252,070,495), weighted %	Having mental health issues (n=57,953,433), weighted %	No mental health issues (n=189,456,090), weighted %	*P* value
Source of health information					.23
Internet	42.9	46.1	50.2	45.2	
Health professionals	48.9	44.6	39.9	45.9	
Family or friends	4.1	5.2	4.6	5.3	
Print materials	2.3	2.2	2.4	2.1	
Others	1.8	2	2.9	1.5	
Use of health apps					.33
Yes	52.4	54.8	57.7	54.2	
No	42.2	39.6	35.9	40.6	
Do not know	5.4	5.5	6.4	5.2	
Good health status	47.9	49.4	33.7	54.2	<.001
Have ability to take care of health	72.2	71.5	56	76.3	<.001
Avoid visiting physician	25	30.6	33.9	29.6	.15
Talks about health with family or friends	81	78.5	81.9	77.4	.08
PHQ-4[a]					<.001
0	50.3	45.6	13.6	54.9	
1	12.3	13.2	9.3	14.4	
2	9.9	9.6	11.5	9.1	
≥3	27.6	31.6	65.5	21.6	
Can control emotions	85.1	84.5	77.6	86.7	<.001
Consider future	84.5	84.7	79.2	86.6	<.001
Visit social networking sites	65	71.5	76	70.8	.04
Share health information	11.9	14.6	19.7	13.1	.001
Write online diary blog	3.6	5	8	4	.007
Participate in online forum or health-related group	7	8.1	13.3	6.6	<.001
Watch health-related videos	32.8	37.3	42.5	35.9	.009

[a] PHQ-4: Patient Health Questionnaire–4.

Alcohol Consumption and Sleep

Table 3 shows the characteristics of behavioral health, including sleep and alcohol use, of the 2 groups. Individuals with mental health issues were more likely to sleep <6 hours or >9 hours (*P*=.01), have worse sleep quality (*P*<.001), and consume more alcohol per day (*P*=.03). There was no significant difference in the number of days of alcohol consumption per week between the 2 groups.

Figure 2 illustrates the difference in sleep quality among individuals who slept ≤6 hours, 7 to 8 hours, and >9 hours per night between the 2 groups. For individuals with mental health issues, 52% of those who slept ≤6 hours per night had a poor sleep quality. Among individuals without mental health issues, only 9.1% of those who slept 7 to 8 hours per night had a poor sleep quality, which is significantly less than that of individuals with mental health issues who slept the same hours.

We examined whether sleep quality was the same for populations with and without mental health issues separately within the 3 sleep hour categories (0-6 hours, 7-8 hours, and ≥9 hours). As the normality assumption is unjustified, we conducted the Mann-Whitney *U* test. For people who slept 0 to 6 hours (*P*<.001) and 7 to 8 hours (*P*<.001), there was a significant difference in sleep quality between the 2 groups. There was no significant difference in sleep quality for people who slept >9 hours (*P*=.14) between the 2 groups. We found that individuals without mental health issues slept 7 to 8 hours with higher quality, whereas patients with mental health issues slept <6 hours or >9 hours with poor quality.

Figure 3 illustrates the difference in the amount of alcohol consumed per week between the groups stratified by sex and mental health status. Approximately 43% (38,696,406/89,991,643) of women without mental health issues consumed one or more drinks per week, whereas 44.8% (16,123,109/35,989,082) of women with mental health issues consumed the same number of drinks per week. We found no significant difference in drink amount between women (*P*=.66) and men (*P*=.23) regardless of mental health status. However, for individuals without mental health issues, men drank significantly more than women (*P*<.001).

Table 3. Prevalence estimates for characteristics of sleep and alcohol use.

Characteristic	Overall (n=5438), unweighted %	Overall (n=252,070,495), weighted %	Having mental health issues (n=57,953,433), weighted %	No mental health issues (n=189,456,090), weighted %	*P* value
Sleep hours per night					.01
0 to 6	38.9	38.9	41.4	38.2	
7 to 8	53.3	54.1	49	55.7	
≥9	7.8	7	9.6	6.1	
Overall sleep quality					<.001
Very good	20	18.8	10.5	21.1	
Fairly good	58.2	58.7	55.7	59.8	
Fairly bad	17.8	18.3	25.7	16.1	
Very bad	4	4.2	8	3	
Days consuming alcohol per week					.52
0	50.5	51.3	54.2	50.3	
1 to 2	26.5	27.3	25.6	27.9	
3 to 4	10.8	11.1	9.8	11.5	
≥5	12.2	10.3	10.5	10.3	
Alcohol drinks per day					.03
0 to 1	43.2	37.7	29.3	40.1	
2 to 3	43.9	45.3	51.4	43.6	
≥4	12.9	17	19.3	16.4	

Figure 2. Sleep patterns between the 2 mental health groups.

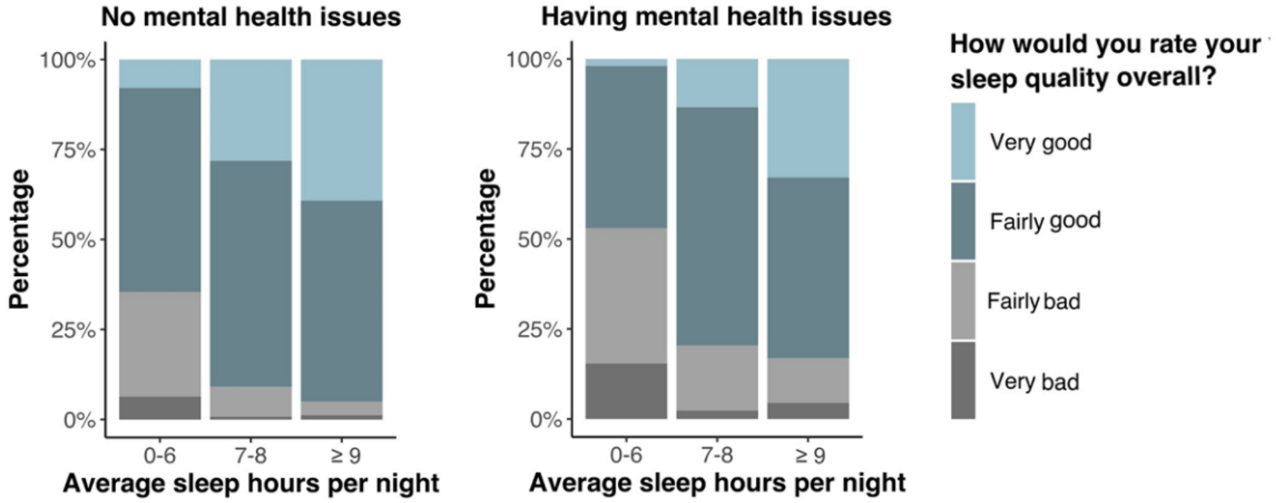
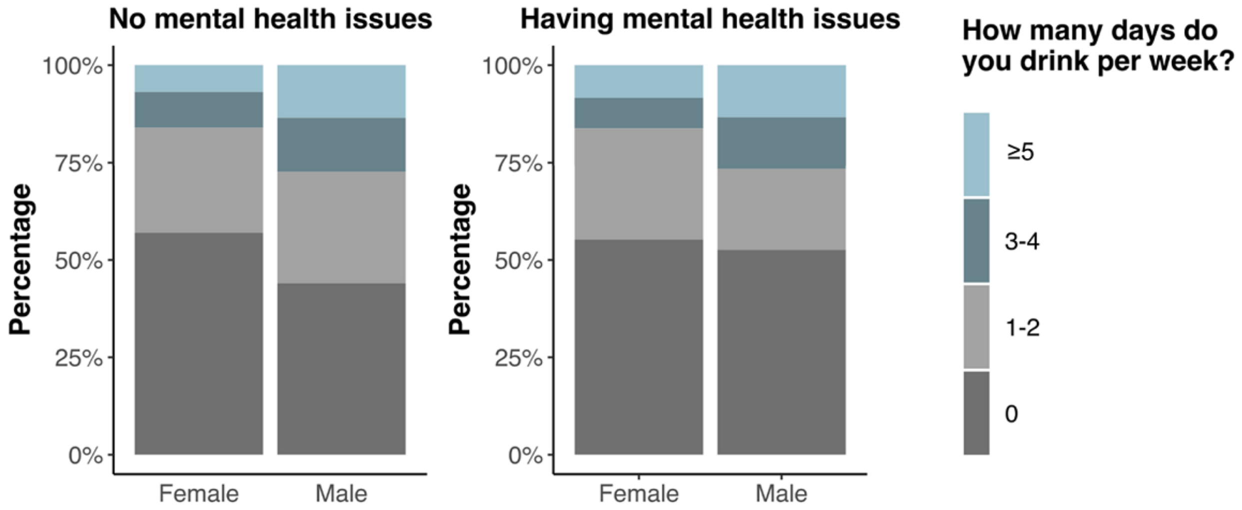


Figure 3. Alcohol use patterns stratified by sex and mental health status.



Social Determinants of Health and Mental Health

Table 4 shows the results of logistic regression analyses. In the unadjusted logistic regression model, most covariates were associated with mental health. In the adjusted model, those aged ≥65 years had a reduced likelihood (OR 0.20, 95% CI 0.11-0.35) of having mental health issues compared with those aged 18 to 34 years. Men were less likely (OR 0.52, 95% CI 0.40-0.68) to have mental health issues. The Black population had a reduced likelihood (OR 0.41, 95% CI 0.27-0.63) of having mental health issues compared with the White population.

Individuals who had an annual family income <US $20,000 were more likely (OR 2.39, 95% CI 1.48-3.84) to have mental health issues than those whose income was >US $75,000. Those having a usual source of care were more likely (OR 1.72, 95% CI 1.24-2.39) to have mental health issues. As expected, those with a history of lung disease (OR 2.17, 95% CI 1.54-3.05), diabetes (OR 1.42, 95% CI 1.03-1.95), and hypertension (OR 1.40, 95% CI 1.07-1.84) were more likely to have mental health issues. The results also indicated that ethnicity, education, insurance type, history of cancer, and history of heart condition had no association with mental health status.

Table 4. Crude and adjusted odds from logistic regression analyses of associations between social determinants of health and mental health.

Predictor	Unadjusted		Adjusted	
	OR[a] (95% CI)	*P* value	OR (95% CI)	*P* value
Age (years)				
18 to 34	Reference	Reference	Reference	Reference
35 to 49	0.89 (0.61-1.31)	.56	0.99 (0.64-1.54)	.98
50 to 64	0.88 (0.60-1.29)	.51	0.60 (0.38-0.96)	.04
≥65	0.48 (0.32-0.71)	<.001	0.20 (0.11-0.35)	<.001
Sex (male)	0.55 (0.43-0.70)	<.001	0.52 (0.40-0.68)	<.001
Race				
White	Reference	Reference	Reference	Reference
Asian	0.46 (0.25-0.86)	.02	0.51 (0.25-1.03)	.06
Black	0.64 (0.46-0.90)	.01	0.41 (0.27-0.63)	<.001
Others	0.79 (0.48-1.32)	.37	0.52 (0.25-1.08)	.08
Ethnicity (Hispanic)	0.76 (0.56-1.02)	.07	0.73 (0.48-1.11)	.14
Education				
High school diploma or less	Reference	Reference	Reference	Reference
College degree	0.87 (0.68-1.12)	.28	0.91 (0.64-1.31)	.63
Postgraduate degree	0.87 (0.65-1.17)	.37	0.92 (0.59-1.42)	.69
Income (US $)				
<20,000	2.29 (1.65-3.17)	<.001	2.39 (1.48-3.84)	<.001
20,000 to 34,999	1.48 (1.00-2.19)	.05	1.59 (1.00-2.55)	.05
35,000 to 49,999	1.44 (0.97-2.14)	.07	1.34 (0.83-2.15)	.23
50,000 to 74,999	1.29 (0.89-1.86)	.18	1.32 (0.88-1.98)	.19
≥75,000	Reference	Reference	Reference	Reference
Insurance				
Public	Reference	Reference	Reference	Reference
Private	0.76 (0.59-0.98)	.03	0.71 (0.47-1.07)	.11
Uninsured	0.79 (0.48-1.31)	.37	0.56 (0.29-1.09)	.09
Others	0.99 (0.65-1.51)	.98	0.94 (0.59-1.51)	.81
Has a usual source of care	1.74 (1.36-2.24)	<.001	1.72 (1.24-2.39)	.001
History of cancer	0.81 (0.61-1.07)	.14	0.88 (0.61-1.28)	.51
History of lung disease	2.99 (2.21-4.04)	<.001	2.17 (1.54-3.05)	<.001
History of heart condition	1.19 (0.79-1.80)	.40	0.94 (0.60-1.47)	.79
History of diabetes	1.61 (1.23-2.10)	<.001	1.42 (1.03-1.95)	.03
History of hypertension	1.20 (0.97-1.48)	.10	1.40 (1.07-1.84)	.01

[a] OR: odds ratio.

Discussion

Principal Findings

This study aimed to describe and compare the characteristics of populations with and without mental health issues (depression or anxiety disorders), including physical health, sleep, and alcohol use. We examined the patterns of social networking service use, PGHD, and attitudes toward health information sharing and activities. We found that participants who were younger, White, and female; had a lower income; had a history of chronic disease; and had a higher PHQ-4 score were more likely to have mental health problems, which is consistent with previous findings [17]. Overall, social determinants of health such as age, race, income, insurance status, and chronic diseases, including lung disease, diabetes, and hypertension, were associated with mental health. Participants with mental illness were more likely to visit social networking sites, share health information on social networking sites, write online diary blogs, participate in online forums or support groups, and watch health-related videos. We also found that participants with mental illness slept less with worse sleep quality and consumed more alcohol per day.

Health disparities exist between women and men and among different races with regard to mental health. Mental health issues result in less sleep with poor quality and unhealthy alcohol consumption behaviors. Individuals with mental health issues are more likely to use social networking platforms, share their health information, and actively engage in PGHD. The results provide important insights into the interplay between three vital health-related domains—physical health, behavioral health (sleep and alcohol use), and social networking service use and their patterns in populations with mental health issues.

In recent years, there has been increasing acknowledgment of the important role that mental health plays in achieving improved population health. Understanding how these fundamental factors (physical and behavioral health, mental health, and technologies) relate to one another may yield important insights for novel approaches to designing prevention programs and enhancing services for mental health support. Digital health technologies such as smartphone apps and social media provide opportunities to continuously collect objective information on behavior in the context of people's real lives, generating a rich data set that can provide insights into the extent and timing of mental and physical health needs in individuals [6].

Social Networking Service

Individuals who have depression and anxiety are more likely to use social networking platforms, especially younger people. They also tend to be less likely to control emotions by changing the way they think about situations and try to influence things in the future with day-to-day behavior. Social networking plays an important role for this population to find ways to reduce loneliness or symptoms of mental health problems.

We also found that women had a higher level of vulnerability to poor mental health compared with men, which aligned with previous findings [18]. There is an ongoing debate on whether the use of mobile health technologies such as social media is detrimental to mental health [19]. Interestingly, those with depression or anxiety disorders were significantly more likely to visit social networking sites, write online diary blogs, participate in an online forum or support group, and watch health-related videos. These social networking platforms could potentially provide effective strategies to intervene in mental illness. We acknowledge that safe limited use of social media is beneficial, but it could introduce harmful influences if people spend too much time in this digital and internet-based world [20]. Further research is needed to understand the quantitative and dynamic patterns of social media use to measure its benefits and harmful effects and inform evidence-based approaches to clinical interventions, practices, policy, education, and regulation [21]. If we take advantage of the social networking services and data-gathering functions of digital platforms in the right ways, we may achieve breakthroughs in the technologies' ability to support mental health and well-being.

Mental Health and PGHD

This study found that individuals with depression or anxiety disorders were willing to share health information on social networking sites, which offers an opportunity to provide interventions that are timely, personalized, and scalable. Coupled with telehealth or remote management platforms [22-24], practitioners could provide mental health services and support in a timelier manner and at each individual's time of greatest need. Digital health platforms and PGHD are facilitating the development of a wave of timely interventions for mental health care and support [7]. Big data technologies are facilitating the integration of PGHD and electronic health records, which will encourage the use of predictive analytics and artificial intelligence such as natural language processing and machine learning on structured and unstructured data to help health care providers, hospitals, and patients make their data more meaningful [25,26]. These findings may be useful for stakeholders such as health care providers, researchers, public health practitioners, and mobile health and social media companies and encourage them to work jointly to design and provide *precision social networking service* with higher personalized and participatory levels, thus improving population health [27].

Mental Health, Alcohol Use, and Sleep

This study found that individuals without mental health issues slept 7 to 8 hours with higher quality, whereas patients with mental health issues slept <6 hours or >9 hours with poor quality. Scientific guidelines for sleep suggest that ≥7 hours of sleep per night are appropriate for adults aged 18 to 60 years, 7 to 9 hours are appropriate for adults aged 61 to 64 years, and 7 to 8 hours are appropriate for adults aged ≥65 years [28,29]. Although the amount of sleep is important, other aspects of sleep also contribute to health and well-being. Good sleep quality is also essential. We found that patients with mental health issues were more likely to sleep too much, which is not recommended by health professionals. Previous studies have shown that adolescents and young adults are prone to both mental health and sleep problems [30]. Sleep quality may be particularly important for young adults such as college students with poor mental health who, compared with their peers, tend to lack protective social support networks [31].

Among individuals who are already susceptible to alcohol use, inadequate sleep may further weaken their cognitive capacity to make safer drinking-related decisions or their self-protective behaviors irrespective of consumption levels. Further investigations are needed to examine how poor mental health relates to both alcohol consumption and consequences as well as the extent to which alcohol consumption may mediate the relationship between mental health and consequences. Digital social platforms play a vital role in educating people on alternative coping or harm-reduction skills to use in drinking contexts.

Given the important role of different types of drinking motives in the connection between mental health and drinking outcomes, it is important to examine drinking motivations as mediators of this relationship [32]. Furthermore, event-level methods that simultaneously account for individuals' sleep and alcohol use behaviors may be helpful for future longitudinal research.

Limitations

The sample consisted of missing data regarding health outcomes and covariates, which may not be missing completely at random. Those who did not respond to questions may be less active and, thus, our estimates may be subject to bias. As the survey was cross-sectional, we could not examine causality among the variables. Meanwhile, given the limitations of the data set, we did not have information about the use frequency and duration of social networking platforms. Despite these limitations, this study provides a better understanding of the effects and patterns of social networking service use, PGHD, social determinants of health, and mental health.

Conclusions

This study provided a conceptual framework—PBMI—that could be used to describe the relationship between physical and behavioral health, mental health, and informatics. With this framework, we described the health disparities that existed between women and men and among individuals of different races with regard to mental health, patterns of using social networking platforms, sharing health information, and engagement in PGHD. Leveraging digital platforms and population informatics such as mobile health and social media along with PGHD could offer unique opportunities to develop effective self-monitoring and self-management strategies for supporting patients with mental health issues.

Authors' Contributions

JY conceived and designed the study and contributed to the analyses. ZW contributed to the analyses. JY, ZW, and JH contributed to the interpretation of the results and drafting and revision of the manuscript. All the authors read and approved the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Multivariable logistic regression of health information and social networking service use.
[DOCX File , 14 KB-Multimedia Appendix 1]

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Abbreviations

HINTS: Health Information National Trends Survey
OR: odds ratio
PBMI: Physical and Behavioral Health, Mental Health, and Informatics
PGHD: patient-generated health data
PHQ-4: Patient Health Questionnaire–4

Edited by R Kukafka; submitted 02.06.21; peer-reviewed by W Tang, F Mughal; comments to author 14.10.21; revised version received 14.03.22; accepted 21.03.22; published 29.04.22

Please cite as:
Ye J, Wang Z, Hai J
Social Networking Service, Patient-Generated Health Data, and Population Health Informatics: National Cross-sectional Study of Patterns and Implications of Leveraging Digital Technologies to Support Mental Health and Well-being
J Med Internet Res 2022;24(4):e30898
URL: https://www.jmir.org/2022/4/e30898
doi: 10.2196/30898
PMID:

Review

Patient-Generated Health Photos and Videos Across Health and Well-being Contexts: Scoping Review

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Abstract

Background: Patient-generated health data are increasingly used to record health and well-being concerns and engage patients in clinical care. Patient-generated photographs and videos are accessible and meaningful to patients, making them especially relevant during the current COVID-19 pandemic. However, a systematic review of photos and videos used by patients across different areas of health and well-being is lacking.

Objective: This review aims to synthesize the existing literature on the health and well-being contexts in which patient-generated photos and videos are used, the value gained by patients and health professionals, and the challenges experienced.

Methods: Guided by a framework for scoping reviews, we searched eight health databases (CINAHL, Cochrane Library, Embase, PsycINFO, PubMed, MEDLINE, Scopus, and Web of Science) and one computing database (ACM), returning a total of 28,567 studies. After removing duplicates and screening based on the predefined inclusion criteria, we identified 110 relevant articles. Data were charted and articles were analyzed following an iterative thematic approach with the assistance of NVivo software (version 12; QSR International).

Results: Patient-generated photos and videos are used across a wide range of health care services (39/110, 35.5% articles), for example, to diagnose skin lesions, assess dietary intake, and reflect on personal experiences during therapy. In addition, patients use them to self-manage health and well-being concerns (33/110, 30%) and to share personal health experiences via social media (36/110, 32.7%). Photos and videos create significant value for health care (59/110, 53.6%), where images support diagnosis, explanation, and treatment (functional value). They also provide value directly to patients through enhanced self-determination (39/110, 35.4%), social (33/110, 30%), and emotional support (21/110, 19.1%). However, several challenges emerge when patients create, share, and examine photos and videos, such as limited accessibility (16/110, 14.5%), incomplete image sets (23/110, 20.9%), and misinformation through photos and videos shared on social media (17/110, 15.5%).

Conclusions: This review shows that photos and videos engage patients in meaningful ways across different health care activities (eg, diagnosis, treatment, and self-care) for various health conditions. Although photos and videos require effort to capture and involve challenges when patients want to use them in health care, they also engage and empower patients, generating unique value. This review highlights areas for future research and strategies for addressing these challenges.

(J Med Internet Res 2022;24(4):e28867) doi: 10.2196/28867

KEYWORDS

patient engagement; patient-generated health data; consumer-generated health data; personal health information; patient empowerment; mobile phone

Introduction

Background

There has been a growing interest in patient-generated health data (PGHD) in recent years, where patients create and collect personal information about some aspects of their own health outside the health care setting [1]. This interest has been spurred by technological developments, most notably by sensors embedded in smartphones and wearable devices that allow people to automatically generate a wide range of health data, from physical activity to heart rate to sleep [2-4]. At the same time, patient perspectives are progressively changing from passive recipients of health care to active agents, with an emphasis on proactive well-being, rather than reactive clinical care [5].

Current evidence suggests that for patients, PGHD support the self-management of disease, promote partnership with providers, enable people to gain social support within the peer network, and facilitate the creation of different types of value [6-9]. Health service providers are also increasingly interested in assessing patient health outside the health care setting, for example, through patient-reported outcome measures (PROMs) [10]. In contrast to PROMs, PGHD can be initiated by patients rather than by health care providers. Not only are patients responsible for capturing personal data but they can also direct the sharing of this information and retain ownership of their data [1]. Furthermore, PROMs are often survey-based, whereas PGHD can be diverse, including sensor data, personal diaries, photos, and histories [1,8,11].

This paper focuses on patient-generated photos and videos because they are more accessible and meaningful for patients than other forms of PGHD. First, accessibility stems from the widespread availability of cameras in smartphones, which allows patients to capture photos or videos of their bodies, lifestyles, and experiences relevant for their health and well-being [12]. Photos are also accessible as a medium that patients can readily use and understand across different languages and cultures, without requiring in-depth medical or technical expertise. For example, patients tracking their diet may find it easier to take a photo of each meal consumed than to keep a diary of the ingredients and nutritional value of each meal [13]. In writing that “seeing comes before words,” Berger [14] highlights that photos and videos are accessible on a more fundamental level, because we experience the world, and thereby our health, primarily through our senses, including our visual sense. Second, photos and videos are meaningful for patients because they can communicate something that they cannot directly express, as suggested by Haines et al [15]: “photographs can reveal the gap between ‘what we see and what we know’, and show aspects of experience not easily captured through words alone.” Videos allow patients to discuss and record what they see and experience. Both photos and videos can aid patients in capturing and discussing unique information during consultations, and conversely, they offer prompts to health care professionals to ask questions that may not be asked otherwise. Furthermore, social media (eg, YouTube and PatientsLikeMe) allow patients to share not only data but also personal experiences and knowledge through photos and videos, which make them interesting resources for other patients, health care professionals, and health care organizations [6,16].

During the current COVID-19 global pandemic, the accessibility and meaningfulness of photos and videos are especially relevant. With unprecedented stress on health systems and risk of infection spread, patients and health care providers are looking for tools that are easy to use and accessible for diagnosis and ongoing care via telehealth [17]. However, current systematic reviews on the use of photography and videos for health and well-being concerns have been limited to specific populations [18], a single clinical assessment [13], or one type of content [19]. A comprehensive assessment of the extent of research evidence and the potential scope of patient-generated photos and videos in different areas of health and well-being is lacking.

Objectives

The overarching objective of this review is to synthesize the literature on patient-generated photos and videos across health and well-being contexts. Specific objectives include (1) providing an overview of the different contexts in which photos and videos are used, (2) examining the value gained for patients and health care professionals, and (3) examining the challenges experienced by these groups in creating, sharing, and examining photos and videos. Throughout the review, we examine the differences between photos and videos. On the basis of these insights, this study seeks to offer practical implications for patients and health care professionals, as well as future research directions for medical informatics researchers.

Methods

Overview

This study was guided by the 5-step framework for scoping reviews by Arksey and O’Malley [20]. Scoping reviews aim to comprehensively assess the size and scope of available research literature to convey the breadth of a nascent field. Similar to systematic reviews, scoping reviews aim to be systematic, transparent, and replicable [21]. However, a scoping review protocol has not yet been published. In contrast to systematic reviews, scoping reviews do not assess the quality of included studies because of the paucity of randomized controlled studies [22], and the review also requires analytical reinterpretation of the literature [23]. In the following sections, we describe each of the 5 steps taken to conduct a scoping review of patient-generated photos and videos for health and well-being. For a succinct summary via a scoping review checklist, see Multimedia Appendix 1 [24]. Although the steps are presented in a linear order, it is important to note that the scoping process is iterative and requires a back-and-forth within and between steps as researchers gain a better understanding of the literature [20,22].

Step 1: Identifying the Research Question

The research questions for this review were as follows: (1) *In which health and well-being contexts are patient-generated photos and videos used?* (2) *What value and challenges do patient-generated photos and videos hold for patients and health care professionals?* These questions were based on our shared interest in photos taken by patients for health, also known as *medical selfies* [12,25]. We refined the questions over time as we became acquainted with the literature to focus on patient-generated photos, rather than selfies, to align with the widespread use of the term *PGHD* in the literature [7,26,27]. Videos were also included because they were similarly captured through smartphones and used in ways similar to photos. Our primary concern has always been with the experiences of patients and their caregivers, as well as their photo-mediated interactions with health care professionals (eg, clinicians, allied health, and nurses) and peers (eg, via social media), rather than a health system or pure technology perspective. On the basis of the literature reviewed, we refined the research question from experience to the more specific study objectives of (1) contexts, (2) value, and (3) challenges.

Step 2: Identifying Relevant Studies

We devised a systematic search strategy to identify relevant studies. The strategy was based on the literature review of the PhD thesis of the third author (KB) and the support of a librarian. The search terms described in Textbox 1 were based on keywords in the research question and were developed in consultation with a research librarian. Full search strings with particular terms for each database can be found in Multimedia Appendix 2.

Textbox 1. Search terms.

Search terms

(image* OR pictur* OR photo* OR video* OR selfie* OR portrait* OR snap* OR shot* OR depict* OR data* OR info*)

AND

(patient* OR consumer* OR care* OR customer* OR veteran* OR client* OR self* OR crowd*)

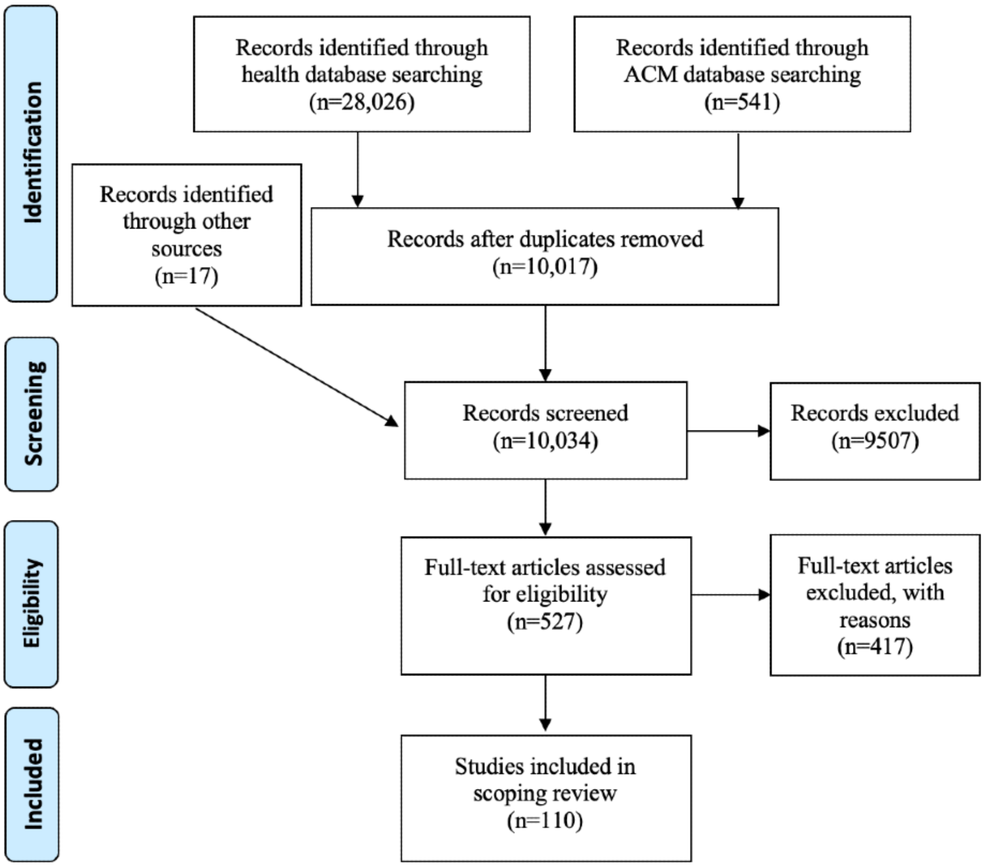
AND

(generate* OR record* OR creat* OR captur* OR document* OR evidence* OR story OR report* OR track* OR initiat* OR monitor* OR take*)

The search included articles from January 2008 to January 31, 2021, written in the English language. The start date was chosen because the major brands of smartphones—iPhone (Apple Inc) and Android (Open Handset Alliance)—were first released in 2007 and 2008, respectively, which provide the platform for patient-generated photos and videos. Articles written in other languages were excluded because of the cost and time required for translation. Only peer-reviewed articles that included primary research were selected to ensure that the conclusions were supported by an evidence base.

According to the objectives of this study and the focus on patients as technology users, we conducted our search strategy in both health and computing databases. Furthermore, we considered social science databases such as Embase and PsycINFO to cover special studies in psychology and behavioral science. We searched eight health databases (CINAHL, Cochrane Library, Embase, PsycINFO, Web of Science, PubMed, MEDLINE, and Scopus) and one computing database (ACM). To ensure that we did not neglect any relevant articles, we broadened the search by using Medical Subject Headings terms and synonyms to collect a comprehensive pool of relevant articles. As illustrated in Figure 1, the health database search yielded 28,026 results, and the ACM search yielded 541 results. In addition, 2 authors (BP and KB) hand searched the reference lists of related review articles [7,13,18,19,28] and JMIR archives, which returned 17 additional articles. After removing duplicates, 10,017 articles remained.

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram for the selection of studies from the databases.



Step 3: Study Selection

The study selection was performed by 2 authors (BP and KB) based on inclusion and exclusion criteria to ensure consistency and replicability. As illustrated in Figure 1, we followed the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) procedure [29] to ensure systematic selection. On the basis of the literature review and discussion of the research question, we established several inclusion criteria (Textbox 2). Articles needed to fulfill all the inclusion criteria to be included in the review. After screening the titles of articles, 527 remained for review. The 2 authors independently reviewed the abstracts of each remaining article and, if necessary, downloaded the entire article to check if it fit the criteria. Papers that were potentially eligible were discussed during meetings among the authors. Through these discussions, we also established exclusion criteria (Textbox 2) to disambiguate decisions on potentially relevant articles.

Textbox 2. Inclusion and exclusion criteria for study selection.

Inclusion criteria

1. Articles describe patient-generated photography or videos that reflect personal information and experiences to help address a health and well-being concern
2. Photos or videos are taken by patients, carers, or other participants who are not health care professionals or researchers
3. Findings report on photography or videos as a collection mechanism, intervention, or unit of analysis

Exclusion criteria

1. Publications without primary research, such as editorials, opinions, perspectives, reviews, and research protocols
2. Secondary analysis of photos and videos, for example, from social media, that have been shared by individuals without an explicit health or well-being intent
3. Automatic video recordings of consultations or teleconsultations as well as images generated by clinician, surveillance, and patient monitoring systems

On the basis of this process, we selected 110 relevant articles for inclusion in this review. Owing to the large number of papers involved, we only kept track of the number of papers at each stage of the selection process, but we did not record the reason for excluding each paper.

Step 4: Charting the Data

NVivo (version 12; QSR International), a qualitative data analysis software package, was used to store and manage the charted data. Initially, we charted the data in a predefined form (Multimedia Appendix 3 [15,30-138]), collecting publication data to allow numerical coding and extracting qualitative information relevant to our research questions (eg, author information, year published, aims, target group, research methods, results, number of photos or videos, and values). However, with the large number of articles involved, the diversity of studies, and particularly the breadth of qualitative results presented, the spreadsheet became impractical.

To manage the large volume of data generated through charting, NVivo (version 12) was used to code the content from the PDF version of each article. This process also enabled the next step of collating results. Publication data were extracted verbatim from each article by 2 authors (BP and ARA), whereas coding and critical analysis for the research questions was completed by all authors. Extracted information was discussed at regular meetings of all authors to ensure that the research questions were still relevant, and the articles could answer the research questions and to explore any discrepancies to clarify key concepts and identify major gaps.

Step 5: Collating, Summarizing, and Reporting Results

Following the recommendation of Arksey and O'Malley [20], we collated and reported the results based on a thematic analysis approach [139] with an analytic framework [140]. Our thematic analysis followed the steps described by Braun and Clarke [139]. We started by reading articles to familiarize ourselves with the data, recorded notes through the *memo* and annotation features of NVivo, and discussed ideas for coding. One author (ARA) manually coded a subset of the 110 articles to generate an initial list of 102 codes relevant to our research questions of health and well-being contexts, value generated, and challenges. These initial codes gave us an overview of the data, but they also highlighted the diversity of study designs and results, which made the aggregation of findings impossible. Instead, we needed a framework to structure and report the results according to our research questions.

To structure the results around health contexts, we initially coded articles according to the International Classification of Diseases, 10th revision [141], a medical classification established by the World Health Organization consisting of 21 chapters. For example, chapter 1 describes infectious and parasitic diseases, which relates to photos and videos used to describe vaccine information and experiences. However, we found that this framework was limited because it presented a medical perspective and did not fit well with articles that reported well-being outcomes or social media contexts. Hence, we revised the structure around the primary contexts presented in the articles: (1) health care services, where patients share images with a health care professional to observe and treat health and well-being concerns; (2) self-management, where patients use images to independently track and manage health concerns; (3) social media, where patients share personal health information and experiences with peers on the web; (4) education, where images are used for health education in schools and waiting rooms; and (5) service improvement, where patients are invited to take images to reflect on their health service experience and express their needs.

To analyze the value of photos and videos reported in our article collection, we used a health consumer engagement framework [140] that highlights six key values of PGHD: functional, emotional, social, transactional, efficiency, and self-determination. For example, the functional value describes how images are used by health care professionals to support health outcomes through diagnosis, explanation, treatment, therapy, and health promotion. The values from this framework were chosen because they originated from a study of patient-generated photos and allowed value to be considered from the perspective of both patients and providers across different health and well-being domains. We chose this framework over benefit-risk models of the health care value, which aim to promote strategic reform [142,143], because photographs and videos are not routinely used in clinical practice, and quantification of value was not demonstrated in the articles retrieved.

To analyze these challenges, we identified several frameworks that describe data challenges [27,144]. Although none of these frameworks captured the range of challenges identified in our initial codes, we selectively applied relevant concepts from these frameworks for our analysis. For example, accessibility is a key challenge for patients [144], which includes lack of access to camera phones, lack of access due to poor app usability, and difficulty in taking photos of feet or the back. From existing frameworks [27,144], we also included the challenges of privacy, interpretability, and relevancy, and we structured the challenges according to different stages of their use: collection, sharing, and examination of photos and videos. In addition, we inductively coded other challenges that emerged from the articles, such as poor photo quality when photos were not in focus or when they did not clearly show the relevant details.

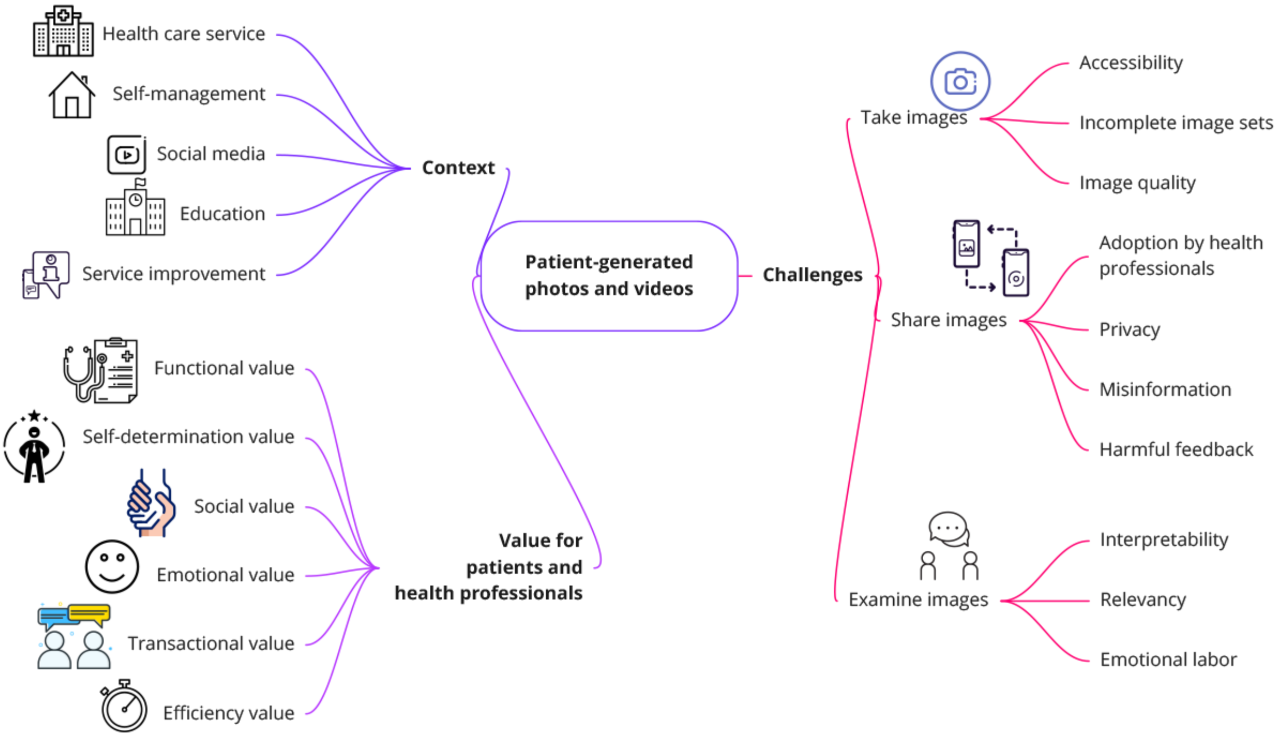
A selection of 15 articles was coded independently by all 3 authors using the chosen frameworks. Regular meetings were held to discuss the suitability of the frameworks for our objectives and to explore any discrepancies in how we applied them in our analysis, especially on how to distinguish between values that appear interrelated (eg, the social and transactional values). Once agreement was reached on how to apply the frameworks and how to structure the challenges, one author (BP) coded the remaining papers. The naming of themes and subthemes was further refined by all the authors while writing the report. The full coding tree is provided in Multimedia Appendix 4. The results present the overall number of articles identified in each theme, as well as the number of articles reporting on photos and videos.

Results

Overview

Of the 110 articles identified in this review, 90 (81.8%) reported on photos, 23 (20.9%) used videos, and 3 (2.7%) used both photos and videos. Figure 2 provides an overview of the key themes revealed in our review, showing the contexts in which photos and videos were used, values gained by patients, and challenges when taking, sharing, and examining photos and videos. The following sections provide further details of each theme.

Figure 2. Overview of key themes identified in this review, presenting the contexts in which patients use health photos and videos, the value gained by patients, and challenges experienced.



Use of Photos and Videos Across Health Contexts

We categorized articles based on the context in which the patient-generated photos and videos were used. As summarized in Table 1, images were largely used in health care services, self-management, and social media contexts. Multimedia Appendix 3 provides a more detailed table that also lists who captured the images (patient or carer), the technologies used to capture and share images, and the audiences receiving them.

Table 1. The use of patient-generated photos and videos across health contexts (N=110 articles).[a]

Context	Description	Articles, n (%)	Photos, n (%)	Videos, n (%)	Image information
Health care service	Patients share images with a health care service to observe and treat health and well-being concerns	39 (35.5)	39 (35.5)	2 (1.8)	Skin photos showing potential cancer [30-34], hernia [35], rash [36-38], and wounds [39-50]; foods and beverages consumed [51-62]; experiences related to mental health (eg, death of a parent) [63], emotions such as hope [64], goals for the near future [65] for therapy; and health equipment [66,67] and medication [68]
Self-management	Patients use images to independently track and manage health concerns	33 (30)	33 (30)	1 (0.9)	Foods and beverages consumed [69-92]; nature, people, and events to reflect on emotions [93,94] and lifestyle [95-97]; and smoking and quitting [15,98-100]
Social media	Patients share personal health information and experiences with peers on the web on platforms such as Instagram, Facebook, Flickr, and YouTube	36 (32.7)	19 (17.3)	17 (15.5)	Foods and beverages consumed [88-92]; disease experience (cancer [101-106], cardiovascular [107], diabetes [104,108], kidney stone [109], and multiple sclerosis [110]); mental health (depression [111-113], suicidal thought [114], and other [93,115,116]); proanorexia images [117-120]; medical procedures [121,122]; smoking and quitting [99]; vaccine information [123-127]; and various health concerns [97,128]
Education	Images are used for health education in schools, waiting rooms, and community centers or at home	7 (6.4)	6 (5.5)	1 (0.9)	Digitally altered selfies showing impact of smoking [129,130] and UV exposure [131,132]; healthy eating ideas [133]; toothbrushing behavior videos [134]; and vagina selfies [135]
Service improvement	Patients are invited to take images to reflect on their health service experience and to express their needs	3 (2.7)	1 (0.9)	2 (1.8)	Children's experiences and challenges in the hospital (eg, needing to process new information) [136,137] and in transitioning to their homes (eg, manage medications) [138]

[a] Several articles reported results on multiple contexts, or they included both photos and videos.

Health care service contexts were described in 35.4% (39/110) of the articles, where patients created photos to document a health concern to share them with a health care professional. The three most common contents in this context were skin photos, food photos, and photos capturing mental health experiences. Patient-generated skin photos were used by dermatologists and general practitioners to review skin lesions and assess potential melanoma [30-34] or rashes [36-38]. Surgeons have also used patient-generated photos to diagnose inguinal hernia [35] and to follow up on surgical wounds or injuries [39-50]. Patient-generated photos showing food and beverages consumed were commonly used by dietitians to support patients with diabetes [54,57,58,60,61], patients with irritable bowel syndrome [53], and pregnant women [51]. Therapists and counselors collaborated with patients to discuss photos capturing events and experiences that affected the patient's mental health (eg, the death of a parent) [63], emotions such as hope [64], and goals for the near future (eg, to go on a holiday) [65]. In addition, of the 110 studies, 2 (1.8%) used wearable cameras that automatically took photos throughout the day to document dietary intake [55,59], which provided the dietitian with more comprehensive data and alleviated the effort required for patients. Only 1.8% (2/110) of the articles in this context used videos either to document intermittent hand twitching for diagnosis [42] or to record feelings and thoughts about mental health issues between therapy sessions [63].

Self-management contexts accounted for almost a third of the articles (33/110, 30%), where patients used images in their day-to-day lives to track and control a health concern. These images had a clinical or therapeutic context; however, the studies did not report any image sharing with health care services. The most prevalent concern that people self-manage through photos is dietary intake. Food photos provide rich information to recall details of the foods consumed, with whom they were eaten, and the context [74]. People can use food photos to provide accurate energy intake estimates, which do not differ significantly from the gold standard, doubly labeled water, over short periods (6 days) [81]. However, over longer periods (6 months), adherence to photographic food diaries diminishes [73]. Several studies have explored the feasibility of photos with children [69,86] and adolescents [70,71,80,83-85]. In addition to dietary intake, people also use photos of nature, surroundings, people, objects (including foods), and past events to reflect on their emotional state [93,94] or their current lifestyle and well-being [95-97]. Photos are also used by smokers to capture places, events, and routines associated with smoking or quitting cigarettes [15,98-100].

Social media contexts featured in a third of all articles (36/110, 32.7%), where patients share videos and photos with an audience of peers on the web. The summary in Table 1 shows 2 key differences with social media, compared with other contexts. First, almost half of the studies in this context report on videos generated by patients, where they talk about personal health experiences on YouTube. A good example is the study by Liu et al [104], which presents insights from 36 video bloggers who share their experiences with chronic conditions that require self-management, such as diabetes and HIV. The findings show that these videos are often used to teach others about self-management or to keep a personal journal to share their physical and emotional updates in their illness journey. Videos (unlike photos or text alone) allow patients to build rapport with their audiences by filming themselves talking, showing emotions, introducing other people, and showing their health care environments and significant events [104]. A second key difference in the social media context is that images are used to present a broad range of health concerns, including cancer experiences [101-106], mental health [93,111-116], and vaccinations [123-127]. This is partly a result of the focus on experience sharing, where people talk about a disease rather than depict a symptom. It also results from social media, allowing patients to find and join web-based communities dedicated to a shared health concern. A poignant example is proanorexia communities on Flickr, Instagram, and YouTube, which use images and videos to promote eating disorders as a desirable lifestyle rather than as a disease [117-120].

Social media contexts overlapped with self-management contexts (8/110, 7.3% articles), where patients used photos predominantly to self-manage a health concern; however, they also shared these photos with peers on the web. Instagram was used to self-monitor diet [88-92] and emotional well-being [93]. Facebook was used to share photos depicting reasons for quitting cigarettes [99]. A bespoke platform (Staccato) was used to capture and share photos of healthy lifestyle choices such as taking steps instead of an escalator [97].

Educational contexts were described in 6.4% (7/110) of the articles, in which the aim was to educate patients about a health concern. In the school context, a face-aging app was used as an educational intervention to promote smoking cessation [129] and sun protection [131,132]. The app allowed students to take a face selfie and to see the potential impact of smoking cigarettes [129] and UV exposure without sunscreen [131,132] on the way that their face will age. A similar educational intervention has been deployed in the context of a physician's waiting room to promote smoking cessation [130]. In a home context, *vagina selfies* were used to let women explore and learn about their own intimate anatomy [135], and patient-recorded toothbrushing videos were used to educate dental residents and to refine their toothbrushing behaviors [134].

Finally, health service improvements were described in 2.7% (3/110) of the articles. In this context, health service providers asked patients and their family members to take photos to better understand their patients' health care experiences with the aim of improving their service delivery. All studies were conducted in pediatric services. Children and parents were invited to take videos or photos to describe their experiences inside the hospital [136,137] and after their transition to their homes [138]. Videos of hospital experiences showed that patients desire better information and ways to share experiences and reflect on feelings [136]. Photos taken at home showed challenges, such as children having to share responsibility for managing medication, and fears and uncertainties, as children adjust to living with a chronic health condition [138].

The Value of Photos and Videos

Patient-generated photos and videos create significant value when used for health and well-being. On the basis of an engagement framework [140], our analysis identified six key values: functional, self-determination, social, emotional, transactional, and efficiency. Table 2 provides a summary of each value and the number of relevant articles.

Table 2. The value of patient-generated photos and videos (N=110 articles).[a]

Value	Description	Articles, n (%)	Photos, n (%)	Videos, n (%)
Functional	Support health outcomes through diagnosis, explanation, treatment, therapy, and health promotion	59 (53.6)	54 (49.1)	7 (6.4)
Self-determination	Empower patient through knowledge, form a personal narrative, and share experiences	39 (35.5)	28 (25.5)	12 (10.9)
Social	Share experience and support with peers, family members, and web-based community members	33 (30)	22 (20)	12 (10.9)
Emotional	Express, understand, and regulate emotions; capture significant moments for therapy	21 (19.1)	18 (16.4)	5 (4.5)
Efficiency	Eliminate unnecessary appointments; replace paper diaries and forms with photographic records	19 (17.3)	19 (17.3)	1 (0.9)
Transactional	Enrich transactions through increased patient engagement and by providing health professionals with a more holistic view of their patients	18 (16.4)	14 (12.7)	6 (5.5)

[a] Several articles reported results on multiple values or on photos and videos.

The most prominent value reported is the functional value (59/110, 53.6%), where photos and videos are used as an aid to support health outcomes through diagnosis, explanation, treatment, therapy, and health promotion. In terms of diagnosis, photos provide important data for health care professionals to diagnose hernias [35], rashes [36], injuries [38], lesions [30,47], and cysts and angioedema [49]. Patients also use photos to self-diagnose skin lesions [32,34] and monitor lesions over time [31]. Photos and videos can provide valuable explanations that lead to new insights for patients about the functioning of their own body [135] and to come to terms with new diagnoses, for example, to cope with cancer [103] and kidney stone disease

[109]. For patients with diabetes, photos and videos provide new knowledge about the impact of lifestyle factors such as diet, alcohol consumption, and exercise on their diabetes management [57,58,60,61,104]. Photos can enhance treatment by showing biopsy sites to decrease wrong-site surgery in dermatology [33], medication monitoring [68], and documentation of the healing of postoperative wounds [41,43,45], ulcers [50], and soft-tissue injuries [44]. The therapeutic value of photos and videos was illustrated in reminiscence therapy in patients with Alzheimer disease, where photos were used to support remembering and reminiscing on personal memories [95], as well as in mental health therapy to reflect on past experiences [113]. Finally, photos and videos support health promotion. This is most common with food photos, which help health professionals and patients create an awareness of patterns of eating, food choices, and portion sizes [55,59,62,73,78,82,84-86]; decide on diet changes to promote healthier food choices [37,51,72,76,87]; and aid in weight loss [52,77].

Functional value often went hand in hand with efficiency value (19/110, 17.3%), where the data provided through photos saved time, money, and effort [140]. Commonly reported with photos of skin conditions, time and money are saved when health professionals assess photos instead of assessing patients in person [41,42,44,45] or when patients can self-diagnose skin lesions and rashes [31,32,34,36,40]. Similarly, patients save time and effort when they are allowed to capture their dietary intake through photos, rather than through pen and paper diaries [56,69,71,76,77,79,80,92].

Several values—self-determination, social, and emotional—come from patients using photos and videos to reflect upon, capture, and share personal health experiences, rather than specific data. Self-determination value (39/110, 35.5% articles) arises when patients “confirm and integrate their beliefs (cognitive, spiritual, or other) into health care services, asserting a degree of control over a health care situation congruent with psychological empowerment” [6]. We identified self-determination value from photos and videos through enhanced knowledge, for example, by examining the personal meanings of smoking and related social influences when quitting smoking [15,98,100]. Health professionals sometimes encourage patients to take on more responsibility by monitoring their condition through photos to shift the power in consultations so that patients become more informed and assertive [33,38,39]. Self-determination also arises when patients use videos to form a personal narrative to make sense of a new diagnosis, such as diabetes [58] or cancer [42,101,102], and what is occurring with their bodies, emotions, and social identity before and after medical interventions. Finally, several studies showed self-determination value from sharing personal health experiences, achievements, resources, and advice with other patients through social media [104,133,136]. This was common for mental health conditions, where negative self-perception is a challenge for many patients. In this context, photos can help empower patients through the expression of emotions and negative self-perception as well as through seeing oneself as part of a (web-based) group with same condition [93,112,113,116,117].

Social value (33/110, 30%) comes from sharing health photos and videos with other patients, family members, and friends. Videos are commonly used to share personal experiences and help with others who manage the same illness, for example, diabetes, HIV, cancer, and multiple sclerosis [58,61,101,103,104,106,107,110,121,136]. Patients report that they were motivated to share personal videos because they could not find the web-based information and guidance they wanted [108] and because they gained additional motivation by being able to help other patients [42]. Photo sharing on social media is also common for general healthy living, for example, to share insights about how to eat healthier meals [88-90,133], stay physically active [97], and give up smoking [98,99]. People with mental health conditions also gain value from posting photos on the web to ask questions, call for help, show empathy, and offer support to others [111-114,118,120]. Many patients reported a sense of community with other social media users who are experiencing similar health challenges [67,104,111,112,115,116,119,133].

Emotional value (21/110, 19.1%) can arise from capturing personal experiences with an illness to better understand and regulate emotions [74,93,94,96]. Emotions reported in the studies include a wide range of emotions: sympathy [97], humor [135], hopefulness [64,101,112], fear [101], hopelessness [112], pain [116], suicidal feelings [114], and ambivalent feelings such as simultaneously feeling joyful and worried [98]. Images also allow patients to express emotions and garner support from family members [138], health care providers [136], and web-based audiences [42,102,108,113,114,116]. Patients report that they feel better when they see other social media users who share similar emotions and that photos are more visually stimulating than written text [88]. Therapies involve patient-generated photos to help clients reflect on coping strategies [64,65] and reminisce about past events and emotions [95].

Finally, photos and videos can enrich transactions between patients and health care professionals (18/110, 16.4%). On the one hand, photos can increase patient engagement. Capturing photos together with personal notes helps patients prepare for consultations and take on a more active role in their interactions with health care professionals, for example, by recalling information about their diet [53], skin lesions [46], and experiences with mental illness [65]. People with aphasia can use photos to support expressive communication with health care professionals [66]. On the other hand, patient-generated photos and videos can empower health care professionals. Reviewing photos during consultation can prompt health care professionals to ask questions about health experiences [42,138], triggers for adverse reactions [53], and adherence to treatment plans [42,138]. Photos used in consultations are not always limited to clinical data, as shown in a study with general practitioners who reported that they also see social images (new babies and holidays) that provide them with insights into the broader lives of their patients that impact their health [38]. Photos and videos help health care professionals gain a more holistic view of their patients and empathize better with their patients, for example, in general practice [38], dementia care

[95], children's hospital [136-138], and cancer prevention and treatment [15,102].

Challenges With Photos and Videos

Overview

The final part of our analysis describes the barriers and challenges faced by patients with health-related photographs and videos. Here, our analysis is structured based on the process of working with photos and videos, starting with challenges that patients face when they take photos, when they share them with peers and health professionals, and when they are examined. These challenges are interrelated, meaning that challenges in taking photos and sharing them, in turn, can also affect examination. Table 3 provides a summary of these challenges.

Table 3. The challenges faced by patients in taking, sharing, and examining images (N=110 articles).

Challenge	Description	Articles, n (%)	Photos, n (%)	Videos, n (%)
Image-taking challenges				
Accessibility	Lack of access to camera phone; poor app usability; difficulty in taking photos of feet or back	16 (14.5)	16 (14.5)	0 (0)
Incomplete image sets	Lapses in food photos over long periods or when people (fail to) reach goal; camera error	23 (20.9)	22 (20)	1 (0.9)
Image quality	Image not in focus or not well lit; image not showing relevant details (body part or food)	16 (14.5)	15 (13.6)	1 (0.9)
Sharing challenges				
Adoption by health professionals	Time and effort required; increased sense of responsibility; limited technical support	4 (3.6)	4 (3.6)	1 (0.9)
Privacy	Potential risk to patients and health care professionals captured; lack of safe image transfer; invisible social media audiences	10 (9.1)	8 (7.3)	3 (2.7)
Misinformation	Inaccurate or misleading social media images (vaccination); unhealthy behaviors (anorexia)	17 (15.5)	7 (6.4)	10 (9.1)
Harmful feedback	Web-based feedback harming people who quit smoking or who share stories of depression	7 (6.4)	4 (3.6)	3 (2.7)
Examination challenges				
Interpretability	Not enough information in images to assess dietary intake or to diagnose skin lesions	10 (9.1)	10 (9.1)	1 (0.9)
Relevancy	Clinicians do not examine images; patients stop when food photos show no new information	6 (5.5)	6 (5.5)	0 (0)
Emotional labor	Anxiety about potential infection or cancer diagnosis; stress from revisiting past struggles with surgery or mental illness	7 (6.4)	6 (5.5)	2 (1.8)

Image-Taking Challenges

Image-taking challenges were largely reported with photos. Challenges with capturing videos rarely surfaced in our review, despite the potentially large burden for video (and audio) capture, storage, and editing.

A major challenge in taking images is accessibility (16/110, 14.5%). For example, patients reported difficulty in accessing body parts such as their feet or their backs with a camera phone [30,31] or felt it inappropriate to access their cameras to capture photos of the groin area [31,43,135] and in social situations (to take food photos in public settings such as a restaurant) [54,55,62,74]. Not all patients have access to a camera phone, or they do not know how to use them, particularly children [69] and older patients [33,66]. Usability issues of bespoke apps also limited the accessibility of photos and videos, especially when instructions for taking photos were unclear [33,70,78,135].

In total, 20.9% (23/110) of the articles reported incomplete sets of images as a challenge. This was particularly a concern when patients took photos of their food over long periods [73,74] or when food photos needed to be taken both before and after having a meal to show what has been consumed [55,56,60,69,71,78,79,81,84,85]. Participants reported that the time, effort, and training required to take good images were causes of incomplete sets of data [57,78,82] or simply that they forgot [54,56,57,60,69,71,74,78,82]. People stop taking images when they reach a health goal or when they fail to do so [48,88] or because of life disruptions such as moving to a new home [61].

Patients had difficulties with taking high-quality images (16/110, 14.5%). Photos were not in focus [30,31,33], or photos were too dark to show the relevant body part [31] or food [55,59,82,87]. Often, images did not present all relevant details. For example, photos did not show all ingredients of a meal [60,78,91,133], and videos lacked details on how to complete preparation for a medical procedure [122]. Poor-quality photos of wounds [41,44] and cancer biopsy sites [33] led authors to conclude that patients require further guidance to take high-quality images.

Sharing Challenges

Several challenges arise when patients share photos and videos with health professionals and peers. A first barrier is the lack of adoption by health professionals (4/110, 3.6%). Attending to photos and videos takes time and effort [82], with health professionals indicating that they need support from medical assistants to review and identify relevant photos [53]. Adoption is also limited by an increased sense of responsibility for health professionals, for example, when patients assume that health professionals are available all the time and that they take responsibility as soon as photos or videos have been shared [42]. The institutional environment also prohibits adoption, for example, when electronic medical records do not support images taken by patients [45].

Sharing health concerns through photos and videos introduces various privacy risks to patients and their carers (10/110, 9.1%). There is a risk that people may gain access to images on the patient's phone, for example, patients may accidentally show health photos when showing other images to family and friends [31]. In the context of health services, privacy is at risk when secure and encrypted options for transferring patient photos are not available or when there is a lack of information on who has access to patient photos stored in electronic medical records [45]. Therefore, some clinicians advise their patients to bring photos on their phones instead of sending them, which leaves patients in control and allows them to retain ownership [38]. The privacy of health professionals is also at risk, for example, when patients take images during consultations [38]. Finally, the context of social media introduces privacy risks because the audience is large and unknown, and information can be taken out of context and misinterpreted. For example, videos describing personal experiences with diabetes [108] or memories for people with Alzheimer disease [95] can be seen by not only strangers but also friends and relatives, which can be painful and make them worry.

Misinformation on social media is a common challenge (17/110, 15.5%). This is the only area where videos are more prevalent than photos (10/110, 9.1%, vs 7/110, 6.4% articles). YouTube videos detailing patient experiences can act as a useful source of health information; however, from a medical perspective, these videos can often be inaccurate. For example, patient videos of bowel preparation for colonoscopy often miss important information, such as types of preparation purgatives, disgust, and embarrassment [122]. Videos reporting on breast reconstruction can provide unrealistic expectations [105]. Some videos present unreliable and potentially misleading information about treatments that have no evidence for being effective, such as home remedies for skin cancer [106] and herbal medicines used to treat kidney stone disease [109]. Patient photos and videos posted on social media commonly present vaccinations in a negative light [126], and they receive a higher number of likes than images with positive views toward vaccination [123,124]. Social media are also used to promote harmful behaviors through images of self-injury [116], suicide [114], and eating disorders [117-120].

Patients often share photos and videos on social media to create social value, but such sharing also carries the risk of receiving harmful feedback (7/110, 6.3%). For example, people who quit smoking can gain valuable social support from Facebook groups, but photos posted by current smokers can be counterproductive to quitting attempts [99]. Similarly, people who shared personal experiences with depression [112], rape [115], and thoughts of suicide [114] on social media reported harmful feedback that blamed the victim or even encouraged suicide.

Examination Challenges

When patients and health professionals examine photos and videos, a first challenge is interpretability (10/110, 9.1%). The risk of misinterpretation is related to food photos, where photos and accompanying self-reports did not provide sufficient information to accurately assess intake, that is, items of a meal, portion size, and nutritional value, often remained unclear [52,78,80,82,91]. Health professionals expressed concerns about potential misdiagnosis when they rely solely on photos or videos from patients [38,42], and patients also recognize that this is a possibility [31]. Potential misdiagnosis was raised, particularly in the context of skin lesions. Overestimating the significance of a particular lesion may lead to anxiety, but, more importantly, underestimating its significance carries the risk of missed melanoma [30].

A second examination challenge lies in the relevancy of photos and videos (6/110, 5.4%). Consultation times are limited, and health providers do not always see patient photos as relevant enough to examine them [53]. Patients stop taking food photos and sharing food photos on the web when they think they provide no new information and become irrelevant [61,88]. A lack of gender and racial diversity can diminish the relevance of photos and videos on social media for a particular person or target group; for example, they may fail to encourage human papillomavirus vaccination among African American individuals when they do not see themselves represented on the web [127]. Time delays between capturing and examining images can also diminish the relevancy of photos for patients, for example, when reflecting on diet or mental health [87,94].

Finally, the papers also highlighted the challenge of emotional labor, where examining photos triggers emotions that patients and caregivers find difficult to manage (7/110, 6.3%). Photos can add stress to patients, particularly when they already feel stressed from having to manage a chronic illness [137]. Patients also report anxiety about possible health issues raised by photos, such as infection [42] or a cancer diagnosis [34]. Emotional labor can also result from photos that bring back stressful memories from the past, such as an unpleasant surgery or struggles with mental illness [31,65,96]. Revisiting photos from the past was a challenge for people with dementia, as photos used for reminiscing triggered positive emotions of happiness as well as negative emotions of sadness and distress [95].

Discussion

Principal Findings

This is the first review to better understand how patient-generated photographs and videos are used across different health and well-being contexts, and what value and challenges they hold for patients and health professionals. In many ways, photos and videos reflect the characteristics of other PGHD; that is, they capture data related to medical conditions or general wellness, are generated by patients or their caregivers, and are often shared with health care professionals, peers, and other stakeholders [1,26]. However, our results highlight several key messages that show that photos and videos are not merely a subset of PGHD but are a powerful medium to engage patients as active partners in their health care, which generates unique value and challenges.

First, photos and videos not only are used in health care services, in education, and for self-management at home but also play an important role in social media contexts. According to the traditional notion of PGHD [1], images offer valuable health data to aid with health decisions in health care services, self-management, and health education. The most common areas in our review were skin photos that assist with the diagnosis of melanoma, food photos to help assess dietary intake, and information related to mental health for discussion with therapists. We also observed images used in unique and unexpected ways. For example, under education, we found that women were invited to take vagina selfies to explore their own intimate anatomy, which can be awkward but helps break associated taboos [135]. Very few studies reported on videos to aid with health decisions, but videos are needed for decisions relating to body movement, such as diagnosing twitching [42] and assessing toothbrushing skills [134]. By contrast, in social media contexts, videos were more common. Instead of presenting data, patient-generated videos (and, to some extent, photos) were used as a medium to communicate personal health knowledge, experiences, and stories to social media audiences. This has also been characterized as health video blogging [104] or visual narrative [116]. Both concepts describe when patients use images simultaneously for personal purposes, particularly to keep a journal and to reminisce, and for communicative purposes, particularly to document their health journey and teach others. Such experience videos are not limited to health concerns that can be easily captured using a camera. Hence, we found a broad range of health and well-being topics discussed on social media, including cancer [104], eating disorders [118,119], and vaccination [123,124].

Second, photos and videos do not only offer functional value to aid with diagnosis and treatment but also provide value to engage and empower patients. On the one hand, the functional value was the most mentioned (59/110, 53.6% articles), where photos (rather than videos) primarily aid with diagnosis, explanation, or treatment. This result aligns with traditional notions of photos as data that offer insights to health providers and patients to address a health concern [1] or even for health providers to monitor patients remotely [144]. On the other hand, our results highlighted several different types of value—self-determination, social, emotional, and transactional—that directly benefit the patient. These types of value arise from active engagement with photos and videos, both through personal reflection (self-determination and emotional values) and when patients interact with health professionals (transactional value) and peers (social value). In particular, self-determination value can lead to patients feeling a higher degree of control in their health care, congruent with psychological empowerment [145]. Overall, our review shows that the different types of value described in the framework of Burns et al [140] are applicable across different health and well-being domains.

Third, although reviews of PGHD emphasize that patients benefit from technologies that reduce the effort required by automatically collecting data such as physical activity, heart rate, and sleep [7,8], our review highlights the opposite: active engagement to record and interpret images is important to generate self-determination value (39/110, 35.5% articles), where patients gain a sense of control over their disease and feel empowered in their health care. Only very few studies explored wearable cameras that automatically take images [55,59,95], but even these studies emphasized the importance of active engagement in reviewing images with caregivers and health professionals. Here, we see a parallel between the papers in our review and visual research methods used in public health, such as photovoice [146,147] and photo-elicitation interviews [148], which show that the effort of representing one's health through photos pays off because it gives a voice to people that can be empowering [147]. Moreover, visual research methods [146-149] highlight that images can encourage a critical dialogue between different stakeholders to interpret the meaning of an image in a particular social context (eg, a consultation or an online community) and to achieve mutual understanding, which can result in social (33/110, 30%), emotional (21/110, 19.1%), and transactional values (18/110, 16.4%).

Fourth, challenges with photos and videos largely reflect PGHD challenges; however, there are several unique aspects. On the one hand, our results highlight challenges that are reflective of PGHD as discussed in previous work, such as the time and effort required for patients and clinicians [27], incomplete data [27], privacy concerns [7], and limited interpretability and relevancy for clinicians [8,144]. On the other hand, our review highlighted several unique challenges specific to photos and videos. Photos and videos pose unique challenges for data quality, for example, their quality can be diminished by low lighting, lack of focus, and lack of details [30,31,33]. The privacy risks associated with images are potentially higher than those associated with other PGHD because photographic images are more likely to identify the patient than numerical data of physical activity, sleep, and so on. Furthermore, photos and videos are often posted on mainstream social media where privacy is a particular concern, because unlike that in a face-to-face consultation, information on social media is permanent, searchable, copyable, and accessible to invisible audiences [150]. We also found that photos and videos on social media can lead to problematic discourse either through misinformation presented in these images or through harmful feedback from other social media users. These challenges could also affect nonvisual social media data; however, videos allow patients to create a narrative that connects with audiences in ways that are arguably different from numerical or textual health data. For example, video narratives can be persuasive because they personalize information, create dramatic tension, and foster emotional engagement [102], which explains why misinformation was more commonly reported with videos than with photos, despite the smaller number of video articles overall.

Finally, throughout the results, we identified several advantages and disadvantages of photos compared with videos. Photos were more commonly used than videos (90/110, 81.8%, vs 23/110, 20.9% articles) because photos capture the information required to aid decisions in health care service, self-management, and education contexts. Furthermore, photos generally require less effort for capture and examination than videos. However, videos offer a unique advantage through their richness. As explained in media richness theory [151,152], additional details in videos help reduce uncertainty and equivocality for the task at hand. Videos can address uncertainty by providing additional temporal information, which is required to capture and aid with decisions on body movements [42,134] and to provide education on the different steps in a health care procedure [122]. By contrast, equivocality refers to confusion that cannot be clarified by more information but only through a higher quality or richness of information [151,152]. Our review highlighted that such richness in videos was important when patients captured moments of significance, for example, for personal reflection on well-being [96] and for storytelling in therapy sessions [63]. Likewise, such richness was important when patients shared health experiences on social media, which included not only information but also their emotions when dealing with the challenges of cancer [102,104] and mental health disorders [115]. This is not to say that patients cannot use a series of photos and captions to express rich narratives of health experiences on social media, for example, as illustrated by patients using photos to discuss mental health conditions on the web [112]. However, videos provide more opportunities for rich self-expression, for example, through nonverbal cues such as eye contact, facial expressions, and pausing; by involving other actors with their experiences; or by incorporating the physical and temporal contexts of their health experience [104,153].

Limitations

Our review is subject to several limitations. First, our inclusion criteria limited our review results to only English-language articles and published peer-reviewed literature from 2008 to January 2021.

Second, the articles included in this review comprise diverse study designs, target cohorts, and outcomes. A formal assessment of study quality was not undertaken because this was a scoping review [22], in which most published studies have been pilot or feasibility studies. The review did not find any randomized control trials, which is not surprising because photos and videos are often patient driven.

Third, synthesizing outcomes from a large collection of diverse studies across different contexts was challenging. Only a subset of papers reported health outcomes (reported under the functional value). Many papers presented formative research on the feasibility of introducing photos and videos into a particular context or on the experiences and value gained by patients and health care professionals. Hence, instead of outcomes, we framed the *Results* section more broadly around the various contexts, the value generated for patients and health care professionals, and their challenges. The value for patients and health care professionals was analyzed and collated based on an established framework on the value of PGHD [140]. The analysis of contexts and challenges was largely inductive because existing frameworks for PGHD (eg, the studies by West et al [27] and Abdolkhani et al [144]) did not cover the specifics of photos and videos such as challenges with the photo quality or emotional labor. To ensure consistency, the analysis was conducted independently by 3 members of the research team.

Finally, the broad scope of this review and the large number of articles did not allow for a comparison of effects. On the basis of this scoping review, future work is needed that focuses on specific health domains to critically assess and compare patient outcomes.

Practical Implications

This review shows that photos and videos provide a powerful way for patients to be actively engaged in their health care. For patients interested in their health, photos taken on smartphones are an accessible means of documenting, sharing, and reflecting on their health, particularly in areas that are easy to photograph, such as diet, skin, and everyday life experiences related to mental health. Patients can also use their phone to film themselves talking and reflecting upon personal experiences relevant to their health and well-being, which is often used to share knowledge on managing chronic conditions [104] or to reflect on experiences affecting their mental health [63,96,115]. Both photos and videos are powerful because they allow patients to share aspects of their health and lived experience, which they cannot easily describe through words alone [15]. Although photos require effort to take and examine, our review shows that such an effort can generate self-determination values where patients feel empowered [140] and that sharing photos can create emotional and social values.

Health care professionals interested in participatory health care [154] can empower patients by encouraging them to take relevant photos and discuss them during consultations. Photos and videos often document important details that a health care professional may not consider asking about [38,42,138]. We have seen that such dialogue about photos and videos can provide transactional value as well as functional value to better diagnose and treat conditions. On the basis of our review, such engagement can be effective when health care professionals are genuinely interested in the data and experiences of their patients to make shared decisions about treatments [155].

Health care professionals and patients must be aware of ethical challenges and professional standards to maintain privacy, confidentiality, and trust [156]. On the one hand, our review shows that health care professionals can build trust by taking the images provided by their patients seriously [38]. On the other hand, image sharing introduces privacy and confidentiality risks through a lack of secure transfer and storage [45], accidental access to other images on a patient's phone or social media account [31], and potential recordings of the health professional during a consultation [38]. Hence, health care professionals need to be sensitive to and respectful of any patient images to maintain professional relationships and confidentiality [156]. It is recommended that secure platforms be used, for example, by advising patients to bring images on their own phone instead of sharing them via social media [38]. Finally, clear communication is required to inform patients about privacy protection in place and to establish expectations of how images are used [157].

There are two practical implications for health care services. First, health care provider support is crucial for harnessing the power of health data generated through patient photos and videos. Technology infrastructure, training, and policies are needed to safely transfer, store, access, and integrate patient-generated photos and videos with medical records [11]. In addition, health services need to create an environment where their staff has the time and support needed to review and analyze patient data [27,144]. Second, health care services that engage with patients to share photos and videos can gain crucial insights into the patient experience to help them improve their service delivery [136,137].

Future Research

Scoping reviews are often conducted to determine the value of undertaking a full systematic review [22]. On the basis of the prominent health areas identified in this review, we see value in conducting a narrower review to focus on photos related to skin diseases and to update existing reviews on photos used for dietary assessment [13] and melanoma detection [158]. For dietary assessment, our review identified a large number of recent feasibility studies of food photos with children [69,86] and adolescents [70,71,80,83-85], something that the original systematic review [13] had called for. In addition, our review highlighted that social media play an important role in sharing food photos with peers and gaining social support [88-92]. Similar to an expert review on melanoma detection [158], our results highlighted the importance of patient-generated photos for self-examination and education. In addition, our review also highlighted that patients share melanoma photos and experience videos on social media [101,106]. Finally, our review confirms observations from a professional review on surgical sites [159] that it is feasible for patients to take photos to keep track of wound healing [41,43,45] and that adoption by health professionals remains a challenge due to a lack of time [45].

The breadth of the health areas identified in this review suggests research opportunities to explore patient-generated photos and videos in new health areas. First, in social media contexts, photos and videos are widely used to communicate experiences with diseases that cannot be immediately photographed, such as infectious diseases [123-125,127], Alzheimer disease [95], and myocardial infarction [107]. This breadth suggests that photos and videos can also offer value with other health and well-being contexts that may be invisible to the camera but can be discussed, such as back pain, arthritis, and other musculoskeletal conditions. Second, in the context of education and health promotion, the study of vagina selfies, which allows women to explore their own intimate anatomy [135], as well as the use of videos to share experiences with mammography [121], suggests a broader potential of photos and videos to reflect on women’s health, for example, with pregnancy and childbirth, osteoporosis, or breast cancer. Third, in the contexts of health care services, we see potential for using videos more widely to capture body movements for clinical purposes, similar to the presented studies on capturing toothbrushing skills [134] and an intermittently twitching hand [42]. For example, consultations with physiotherapists could benefit from patient-generated videos that capture rehabilitation exercises and activities of daily living at the patient’s home.

The challenges faced by patients identified in this review highlight the need for further research on technological design. More work is needed to better understand accessibility needs, particularly when capturing videos in a health context. Collaboration between patients and caregivers is needed to ensure that technologies are usable and accessible. To encourage patients to take images, research into protocols and technology designs that train patients to take high-quality photos as well as provide relevant medical knowledge is needed [57,78,160]. To ensure high-quality images, newer smartphone cameras that offer higher sensitivity in low-light settings need to be harnessed together with research into designing visual aids and voice feedback to guide users in taking photos that capture the required content [28,161]. Finally, to retain engagement, patients benefit from technology designs that assist them in examining their images more effectively. This involves highlighting relevant information in photos, as well as integrating photos with other data that might be scattered across other devices, such as vital signs and lifestyle data from mobile and wearable devices, to explore connections and trends across different data sources [8].

The identified interpretability challenges highlight the need for further research to enhance the relevancy of photos and videos for clinicians. On the one hand, empirical research is needed to better understand the goals and priorities of clinicians [8]. On the other hand, sociotechnical studies are needed to explore how emerging technologies such as machine learning techniques can be harnessed to better manage the large number of photographic images. Our review included only 1 study that examined machine learning techniques to aid in melanoma detection in patient-generated photos [34], whereas in medical imaging, machine learning techniques are already used in clinical practice to aid in the diagnosis and prognosis of various health concerns [162,163]. However, even with sophisticated machine learning algorithms, effective integration into clinical practice remains an open question [164,165].

Finally, more research is needed to investigate privacy and misinformation on social media [166]. The privacy of PGHD is a complex issue across many forms of PGHD [1,7,11], which cannot be addressed simply through a more secure technology infrastructure or privacy policies. Inspired by Palen and Dourish [167], we see privacy as a dynamic practice in which patients negotiate access to personal information according to circumstances. More research is needed to investigate how patients manage their privacy under different circumstances: when they capture photos, manage them on their phones, share them in consultations, or post them on social media. Furthermore, our review identified that patient photos and videos shared on social media provide inaccurate and sometimes misleading information on vaccinations [123,124,126]. In light of current efforts to provide COVID-19 vaccines throughout the world, further research is needed to understand the dangers of misinformation on social media and their impact on public health advice on the COVID-19 pandemic and vaccinations, as well as research to harness social media to improve the health literacy of patients [168].

Conclusions

This review showed that patient-generated photos and videos are used across a wide range of health care activities. Similar to other forms of PGHD, photos and videos provide critical information to aid in the diagnosis and treatment of various health conditions. However, going beyond textual and numerical PGHD, photos and videos are powerful media that facilitate rich and meaningful interactions, both in person and on social media. They connect fellow patients and facilitate the exchange of social and emotional support. Photos and videos are also powerful media for enriching transactions with health care professionals. Ultimately, they engage patients with their own health and well-being and empower them in their own care.

On the basis of this review, we present agenda for future research. On the one hand, this review highlighted opportunities to expand the use of photos and videos to other health and well-being areas and to better implement them in clinical practice. On the other hand, this review raised the need for more research to address key challenges such as accessibility for patients, relevancy and interpretability for clinicians, and privacy and misinformation on social media, to fully realize the potential of patient-generated photos and videos for health and well-being.

Acknowledgments

This review was supported by the Queensland University of Technology and the Prince Charles Hospital Foundation (grant INN2018-36).

Conflicts of Interest

None declared.

Multimedia Appendix 1

PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) checklist.
[DOCX File , 63 KB-Multimedia Appendix 1]

Multimedia Appendix 2

Search strategy and keywords for all databases.
[DOCX File , 28 KB-Multimedia Appendix 2]

Multimedia Appendix 3

Data extraction spreadsheet.
[XLSX File (Microsoft Excel File), 70 KB-Multimedia Appendix 3]

Multimedia Appendix 4

Coding tree, exported from NVivo (version 12; QSR International).
[DOCX File , 31 KB-Multimedia Appendix 4]

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Abbreviations

PGHD: patient-generated health data
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROM: patient-reported outcome measure

Edited by A Mavragani; submitted 17.03.21; peer-reviewed by Y Luo, J Chishtie, A Mahnke, N Slabyj; comments to author 27.05.21; revised version received 15.10.21; accepted 28.02.22; published 12.04.22

Please cite as:
Ploderer B, Rezaei Aghdam A, Burns K
Patient-Generated Health Photos and Videos Across Health and Well-being Contexts: Scoping Review
J Med Internet Res 2022;24(4):e28867
URL: https://www.jmir.org/2022/4/e28867
doi: 10.2196/28867
PMID:

Tutorial

Methodological Guidelines for Systematic Assessments of Health Care Websites Using Web Analytics: Tutorial

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Abstract

With the growing importance of communicating with the public via the web, many industries have used web analytics to provide information that organizations can use to better achieve their goals. Although the importance of health care websites has also grown, the health care industry has been slower to adopt the use of web analytics. Web analytics are the measurement, collection, analysis, and reporting of internet data used to measure direct user interaction. Our objective is to provide generalized methods for using web analytics as key performance metrics to evaluate websites and outline actionable recommendations for improvement. By deconstructing web analytic categories such as engagement, users, acquisition, content, and platform, we describe how web analytics are used to evaluate websites and how improvements can be made using this information. *Engagement* is how a user interacts with a website. It can be evaluated using the daily active users to monthly active users (DAU/MAU) ratio, bounce rate, pages viewed, and time on site. Poor engagement indicates potential problems with website usability. *Users* pertains to demographic information regarding the users interacting with a website. This data can help administrators understand who is engaging with their website. *Acquisition* refers to the overall website traffic and the method of traffic, which allows administrators to see how people are accessing their website. This information helps websites expand their methods of attracting users. *Content* refers to the overall relevancy, accuracy, and trustworthiness of a website’s content. If a website has poor content, it will likely experience difficulty with user engagement. Finally, *platform* refers to the technical aspects of how people access a website. It includes both the internet browsers and devices used. By providing detailed descriptions of these categories, we have identified how web administrators can use web analytics to systematically assess their websites. We have also provided generalized recommendations for actionable improvements. By introducing the potential of web analytics to augment usability and the conversion rate, we hope to assist health care organizations in better communicating with the public and therefore accomplishing the goals of their websites.

(J Med Internet Res 2022;24(4):e28291) doi: 10.2196/28291

KEYWORDS

Google Analytics; website usability; conversion rate; website engagement; user demographics; website traffic; website content; internet browsers; healthcare websites; web analytics; healthcare industry; usability

Introduction

Background

With the continually growing global importance of the World Wide Web, websites have become a crucial communication channel for corporations, political groups, and organizations because of their capability to rapidly disseminate information to various audiences at a low cost [1]. Web analytics has become a mainstay of commercial industries and even a commercial industry itself. The web analytics market was valued at US $2.63 billion in 2018 and is projected to reach US $10.73 billion by 2026, growing at a compound annual growth rate of 19.3% from 2019 to 2026 [2]. The field of medicine, however, remains hindered as stakeholders in health care have been slow to adopt digital innovations. Studies have shown that the adoption of digital technologies can improve the performance of health care processes, increase efficiency, and enable the delivery of higher-quality care and reduced response times, with many benefits for several stakeholders, such as national health systems, clinicians, and patients [3]. For organizations to achieve their goals in use and impact, their website's communication capacity is key. A website that cannot effectively communicate is not serving its purpose. Communication capacity can be measured through the usability and conversion rate of a website [1].

Studies have shown a relationship between the usability of health care websites and the credibility ascribed by its users [4]. The International Organization for Standardization defines usability as “the extent to which a system, product or service can be used by specific users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use” [5]. Measures of effectiveness, efficiency, and satisfaction can be viewed as key web analytic metrics and if optimized, can lead to increased website success. By augmenting usability, a website can reach a higher level of engagement and achieve its desired objectives. A lack of design errors, following established design conventions, and ease of navigation are important features emphasized in the literature [6]. When users have difficulty accessing or using a website, they are likely to move on to another resource, while a website that uses usability metrics is more likely to retain users.

Other industries have established user expectations for their respective websites; health care websites are facing the need to conform [7,8]. Studies have been conducted which evaluate usability in areas such as e-commerce, e-government, mobile news apps, and library websites [9-12]. More recently, there have been increasing usability studies focusing on websites within the health care sector, such as websites for emergency medicine residency programs, digital health care centers, hospitals, and cancer centers [13-16]. With the growing importance of website usability and the conversion rate in the health care sector, web analytics can provide health care stakeholders with an easily accessible tool to assist their evaluation of usability and measure conversion rate.

The conversion rate is closely intertwined with usability. It measures the number of users who perform the desired goal of the page (ie, buying a product or filling out a form) relative to the total users [17]. A high conversion rate separates a successful website from an unsuccessful website.

Web analytics refers to the collection, analysis, and reporting of internet data for the purposes of understanding and optimizing web use [18]. On-site web analytics are used to measure direct user interaction, such as the number of visitors, time spent on a website, and click path [19]. Overall, web analytics can contribute to determining a website's usability and conversion rates [1]. This collection of data is used to analyze the performance of a site and can allow websites to improve their persuasion and relevance [20]. It is important to note, however, that web analytics do not provide a comprehensive measurement of website usability. Measurement of usability consists of additional variables that are outside the scope of this publication.

To the authors' knowledge, there is no recent paper outlining how web analytics can be applied broadly to the field of health care. By evaluating the categories of engagement, users, acquisition, content, and platform, we aim to create a universal framework of web analytics that can be applied to health care websites to improve the quality and effectiveness of these websites.

Objectives

This aim of this tutorial is to (1) provide a basic understanding of definitions and methods pertaining to web analytics, (2) create a framework for using web analytics to evaluate the effectiveness of health care websites specifically, and (3) outline the actionable implications of web analytics to assist health care websites in achieving their goals.

Methods

Google Analytics

Google Analytics (GA) is a web analytics service that has been offered by Google since 2005. It is the most widely used web analytics tool, with 84.1% of the market share [21]. It can be used for both websites and apps, across iOS and Android devices. As of August 2013, GA was reportedly used by 66.2% of the 10,000 most popular websites [22]. GA offers a free version that can be used by those with a graphical user interface and without software engineering skills. Any owner of a website or app can sign up for a GA account.

Engagement

An engagement analysis evaluates user activity and is one of the most used analytic tools. It describes how users interact with websites [19]. Factors that are often addressed include how often visitors return to the site, how often new visitors become returning visitors, pages visited per session, and duration of visits [19].

Daily Active User to Monthly Active User (DAU/MAU) Ratio

When evaluating overall engagement, *1-day active users* refers to users who have been active at least once in the previous day, *7-day active users* refers to users who have been active at least once in the previous 7 days, and so on for 14- and 28-day active users. 1-day active users are referred to as daily active users

(DAU) and 28-day active users are referred to as monthly active users (MAU). The ratio of DAUs to MAUs, DAU/MAU, can be expressed as a percentage to understand user engagement; this measure was first popularized by Facebook and has since become a popular key performance indicator (KPI), with some venture capitalists considering a ratio of over 20% favorable and over 50% excellent [23]. Assessing the DAU/MAU ratio can indicate whether a site is attracting users at its intended or expected frequency. For instance, a rideshare website may expect to see a high DAU/MAU ratio. On the other hand, a flight booking site may see a lower DAU/MAU ratio. Regarding health care websites, many sites have goals of continued user involvement. A low DAU/MAU ratio can be used as an indication that the relevancy of the content and usability of a website can be improved. It is important to view this metric in the context of a website's desired goals. For health care websites that do not desire continued engagement, this may not be a relevant metric and therefore would not correlate with usability issues.

Bounce Rate

The *bounce rate* is another metric of engagement referring to the percentage of single-session users (ie, users who visit the site and "bounce" without interacting further, as opposed to users who interact with at least 1 additional page). A session is recorded by GA each time a user visits the site, beginning as soon as the site is first loaded and ending after 30 minutes of inactivity. Using this metric, the website host is provided with insight into the user's engagement with their product. Navigating to other pages of a website or application is typically viewed as an active event triggered by the user. Similar to the DAU/MAU ratio, the bounce rate indicates users who are not achieving the desired interaction with the website. A high bounce rate may suggest a usability issue steering users away from the page. More than simply content, many things can cause users to avoid visiting additional pages. One example is slow loading speeds. If a website is loading too slowly, users may leave the site before viewing any of the content. According to a recent Google study, a website that takes longer than 3 seconds to load on a mobile device loses approximately 53% of its users and the average mobile website speed is around 18 seconds [24]. This issue can be addressed simply by reducing conflicting technology on the back-end server [13,14]. As with the DAU/MAU ratio, web administrators must view this metric in the proper context. If they do not desire continual engagement within a single session, the bounce rate is not a useful metric.

Page Views

The number of pages per session is the number of pages within the site that a user visits during a single session and indicates how thoroughly a user is engaging with a website. A page view is counted every time a website is loaded, and this can be tracked using GA [1]. Similar to the bounce rate, if users are accessing a website but not interacting with additional pages, there may be an issue with its usability. The goal of many websites is for people to view subpages with additional content but various issues could interrupt this, one being front-end web page design. If users are not easily finding links to subpages, they may lose interest and bounce. By working with marketing specialists, web administrators can improve their webpage design and ease user navigation. As with the bounce rate, if continual engagement within a session is not a desired outcome, this metric is not a helpful measure of engagement.

Time on Site

As the name suggests, *time on site* refers to the duration of time a user spends on a website. If the same visitor comes back several hours later or the next day, a new session is counted. This is considered a key indicator of how successfully a website is engaging visitors. It has been suggested that time on site is an indication of website usability. However, this is operating under the notion that the greater the usability of a website, the more time a user will spend on it. A long session duration may suggest that users are spending more time reviewing the detail of a website's content, while a short duration may suggest poor usability. It is important to analyze time on site and page views together to dissect whether users are spending increased time on the site due to difficulty navigating it [1].

Users

Analytics can help health care centers understand who the users of their websites are. GA provides limited demographic information about users, including age and gender distribution and location. If a website has a target audience, they can monitor if they are reaching that demographic. If they are targeting a diverse population of users, they can also use these demographics to monitor their success. Using this information, web creators can better focus their efforts on the population viewing their website or target those who are not using the site. For example, if it is discovered that males over the age of 65 years are primarily accessing a men's health website, the web administrators would know they are reaching part of their target demographic. However, they may want to make efforts in marketing to younger users as well.

Acquisition

By employing use data to understand consumer needs, websites can increase their user acquisition [19]. *Acquisition* refers to the amount of traffic a website receives. *Sources* refer to the origins of a user's traffic to the site. If the overall user volume of a website is low, the method of traffic can be an important variable to address to reach more users. By using acquisition data, administrators can see where there is room for improvement in reaching potential users.

Direct Traffic

Direct traffic refers to visitors who arrive on the site directly by typing the URL into the browser address bar, clicking on a bookmark, or clicking on a link in an email, text message, or chat. Direct traffic can be a strong indicator of brand strength as well as success in email, text message, and offline marketing. If a website is experiencing low volumes of direct traffic, they can increase their efforts in these forms of marketing and in improving their overall brand strength.

Referral Traffic

Referral traffic refers to visitors who arrived at the site via another website. This occurs when outside websites contain links to a given site. If referral traffic is low, websites can place more emphasis on promotion via other websites. For example, if an organization has multiple websites under their umbrella, they can use their content on one website to direct users to their other. Referral traffic also encourages organizations to increase website partnerships that mutually benefit both parties.

Organic Traffic

Organic traffic refers to visitors who arrived at the site via a search result page (eg, Google or Bing) and can be an indicator of strong content or search engine optimization (SEO). SEO is a method for increasing organic traffic that has gained popularity in many industries. Many users find websites by simply entering keywords into a search engine and choosing the website that seems most appropriate. By strategically strengthening a website's content, web administrators can help move their website closer to the top of a search engine results page (SERP) and therefore increase traffic. The nuances of SEO are outside the scope of this publication.

Social Traffic

Social traffic is similar to referral traffic, but it refers to traffic from social media platforms as opposed to traffic from other websites. Websites that are receiving low levels of social traffic can seek to implement, improve, and promote their social media presence on platforms such as Facebook, Twitter, and Instagram. Improved social media presence can also improve overall brand awareness.

Content

Assessments of a website's content can refer to the relevancy of information, the quality of multimedia content, and even grammar and spelling [13,14]. One of the most obvious reasons a website may not achieve its goals is its content not meeting the needs of users.

Relevancy

Concerning relevancy, the following questions should be posed: is a website's information up to date and fact-driven, and does it provide answers people are seeking [13,14]? If the answer to any of these questions is no, users will not engage with a website. If a site is concerned with relevance, a solution may be to increase the frequency of content updates to ensure the information provided is not out of date. Additionally, it is particularly important for health care–related sites to have accurate and fact-driven content. Especially pertaining to health-related information, users will not engage with a website they believe to contain inaccurate information.

Multimedia Content

Multimedia content can be evaluated by quantity and quality of resolution [13,14]. Seeking to further augment their content, websites can use multimedia to make their content more dynamic. Increasing the quality and quantity of videos, graphics, and animations has been shown to increase user engagement [13,14].

Spelling and Grammar

Spelling and grammar are important aspects of content quality. Even if a website's content is up to date and accurate, users still may not trust it if there are obvious spelling and grammatical errors. There are easily accessible spelling and grammar tools available for websites to avoid this issue.

Platform

To better understand potential areas of improvement for a website, engagement can be evaluated on each page. One can also assess the different browsers and devices through which users access a website to identify technical areas of improvement.

Browser

A *browser* is the software application used to access the internet. Common browsers include Google Chrome (Google LLC), Internet Explorer (Microsoft Corp), and Safari (Apple Inc). If a website is not easily accessible on all major internet browsers, web administrators are automatically eliminating potential users. We have already discussed the benefits of SEO to improve the placement of a site on a SERP, but the improvement discussed here is made from a technological perspective. For example, if a website uses Java, a Google Chrome browser will not be able to support it [25]. It is wise for web developers to tailor their websites to the browsers of their users. GA data can provide information about which browsers are being used to access the website.

Device

Users are accessing websites on various devices, namely desktop computers or laptops, mobile phones, and tablets. Similar to browsers, if a website cannot be accessed on all devices, this eliminates an entire category of potential users. Tablets and smartphones are more commonly being used to access the internet; therefore, it is important that websites are mobile friendly. Administrators have the option to make separate mobile websites, but with mobile devices becoming more sophisticated, new methods have developed. One new and simpler method known as responsive design allows for the creation of one web page, then uses multiple sets of CSS rules to adjust formatting of the website to fit the size of the browser window [26].

Discussion

Main Recommendations

By providing detailed descriptions of categories such as engagement, users, acquisition, content, and platform, we have identified how web administrators can use web analytics to systematically assess their websites using tools such as GA. We have also provided generalized recommendations for actionable improvements that can be made to address website weaknesses.

Although web analytics may be at an infant stage in the world of health care, it is very prevalent in other industries. By introducing the potential benefits of web analytics in the health care sector, we hope to continue the standardization of web practices that users have become accustomed to. Using web analytic tools in the proper context, health care website administrators can gain more information on user engagement and use this information to make improvements.

With the health care industry being slow to adapt to standards for website usability, we hope that the outlined methods and recommendations for using web analytics can be directed toward areas in need of improvement and increase the websites' conversion rates. These recommendations can make a significant impact for health care organizations because they are actionable at a low cost. The potential of a website to improve persuasion and relevance has been established and by using web analytics, web administrators can easily expand upon this potential with a smaller financial burden compared to other methods.

Limitations

The approaches outlined in this paper are intended to be broadly generalizable to health care–related websites such that they can be used by a wide spectrum of web administrators in the health care industry. However, each organization should tailor this approach to their unique objectives and considerations. This content serves primarily as an introduction to the potential benefits and methods of using web analytics, and future studies may focus on more specific use cases, such as applications for subfields in health care.

Key web analytic metrics are not a comprehensive method for evaluating website usability. In certain cases, a degree of inference must be made to use web analytics as a reflection of a website's usability. For example, the conversion rate can be used as a measure of a website's effectiveness. However, if those viewing a website are not its targeted users, a poor conversion rate does not necessarily reflect poor usability. This underscores the importance of using various web analytic measures to gain a comprehensive perspective of user interaction. In the given scenario, administrators could examine the demographic characteristics of their websites users to determine if there is in fact an issue with usability. Similarly, metrics like the DAU/MAU ratio, bounce rate, and page views are used as a measure of website engagement, but it remains important to consider these measures within the context of a website's targeted users and objectives. If it is not a website's goal to promote continual access, the DAU/MAU ratio is not a useful measure for usability. Similarly, if it is not a website's goal to foster continual engagement within each session, page views and the bounce rate are not useful.

Finally, these metrics are only one aspect of the overall capabilities of website usability analysis. Other methods to evaluate usability include user interviews and on-page heat mapping. Future studies delving into these methods would help improve our understanding of website usability in health care–related websites.

Conclusions

Websites continue to be a primary method by which health care organizations interact with their consumers; however, the health care sector lags behind many other industries in using accepted and standardized website usability practices. With evidence pointing to the efficacy of using web analytics to augment the usability and conversion rate, health care organizations can benefit from adopting these practices to better accomplish the goals of their websites.

Authors' Contributions

ELF wrote the manuscript. JB contributed to the manuscript revisions. JF contributed to the final version of the manuscript. JC conceived the original idea and contributed to writing the manuscript. DL conceived the original idea and contributed to writing the manuscript. SH conceived original idea and supervised the project. All authors reviewed the final manuscript.

Conflicts of Interest

SH serves on the advisory board of Covid Act Now and Safeter. SH is Cofounder and Executive Board Director of GetUsPPE (unpaid) and ConductScience. SH serves on the American College of Emergency Physicians Supply Chain Task Force. SH has received research funding from the Foundation for Opioid Response Efforts, royalties from MazeEngineers, and personal fees from Withings Inc, the Boston Globe, the American College of Emergency Physicians, ConductScience, Curative Medical Associates, and VIO Med Spa New England. SH is a volunteer at Emojination. The other authors report no conflicts of interest.

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Abbreviations

DAU: daily active users
DAU/MAU: daily active users to monthly active users
GA: Google Analytics
MAU: monthly active users
SEO: Search Engine Optimization
SERP: search engine results page

Edited by A Mavragani; submitted 27.02.21; peer-reviewed by B Chaudhry, J Brooke; comments to author 10.05.21; revised version received 27.05.21; accepted 16.03.22; published 15.04.22

Please cite as:
Fundingsland Jr EL, Fike J, Calvano J, Beach J, Lai D, He S
Methodological Guidelines for Systematic Assessments of Health Care Websites Using Web Analytics: Tutorial
J Med Internet Res 2022;24(4):e28291
URL: https://www.jmir.org/2022/4/e28291
doi: 10.2196/28291
PMID:

Original Paper

Effectiveness of an Internet-Based and Telephone-Assisted Training for Parents of 4-Year-Old Children With Disruptive Behavior: Implementation Research

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Abstract

Background: There is a lack of effectiveness studies when digital parent training programs are implemented in real-world practice. The efficacy of the internet-based and telephone-assisted Finnish Strongest Families Smart Website (SFSW) parent training intervention on the disruptive behavior of 4-year-old children was studied in a randomized controlled trial setting in Southwest Finland between 2011 and 2013. After that, the intervention was implemented nationwide in child health clinics from 2015 onwards.

Objective: The main aim of this study was to compare the treatment characteristics and effectiveness of the SFSW parent training intervention between the families who received the intervention when it was implemented as a normal practice in child health clinics and the families who received the same intervention during the randomized controlled trial.

Methods: The implementation group comprised 600 families who were recruited in the SFSW intervention between January 2015 and May 2017 in real-world implementation. The RCT intervention group comprised 232 families who were recruited between October 2011 and November 2013. The same demographic and child and parent measures were collected from both study groups and were compared using linear mixed-effect models for repeated measurements. The child psychopathology and functioning level were measured using the Child Behavior Checklist (CBCL) version 1.5-5 for preschool children, the Inventory of Callous-Unemotional Traits (ICU), and a modified version of the Barkley Home Situations Questionnaire. Parenting skills were measured using the 31-item Parenting Scale and the shorter 21-item Depression, Anxiety and Stress Scale (DASS-21). The estimated child and parent outcomes were adjusted for CBCL externalizing scores at baseline, maternal education, duration of the behavior problems, and paternal age. The baseline measurements of each outcome were used as covariates.

Results: The implementation group was more likely to complete the intervention than the RCT intervention group (514/600, 85.7% vs 176/232, 75.9%, respectively; *P*<.001). There were no significant differences between the implementation and RCT intervention groups with regard to child measures, including CBCL externalizing score (–0.2, 95% CI –1.3 to 1.6; *P*=.83), total score (–0.7, 95% CI –3.0 to 4.5; *P*=.70), internalizing score (–0.3, 95% CI –1.0 to 1.6; *P*=.64), and ICU total score (–0.4, 95% Cl –1.9 to 1.2; *P*=.64). No significant difference was detected in the Parenting Scale total score (0.0, 95% Cl –0.1 to 0.1; *P*=.50), while DASS-21 total score differed nearly significantly (2.5, 95% Cl 0.0-5.1; *P*=.05), indicating better improvement in the implementation group.

Conclusions: The internet-based and telephone-assisted SFSW parent training intervention was effectively implemented in real-world settings. These findings have implications for addressing the unmet needs of children with disruptive behavior problems. Our initiative could also provide a quick socially distanced solution for the considerable mental health impact of the COVID-19 pandemic.

Trial Registration: ClinicalTrials.gov NCT01750996; https://clinicaltrials.gov/ct2/show/NCT01750996

International Registered Report Identifier (IRRID): RR2-10.1186/1471-2458-13-985

(J Med Internet Res 2022;24(4):e27900) doi: 10.2196/27900

KEYWORDS

parent training; early intervention; implementation; disruptive behavior; behavior problems; preschool children; internet-assisted; child mental health; mental health; behavior; intervention; children; parents

Introduction

Background

There is mounting evidence from randomized controlled trials (RCTs) that parents can be trained to tackle and reduce children’s disruptive behavior and improve their parenting skills [1-3]. These findings are of upmost importance to public health professionals because children who exhibit disruptive behavior face increased risks of adult psychiatric disorders, substance use, crime, suicide, and other adversities [4,5]. Sufficiently strong evidence has been published on the efficacy of parent training to suggest that psychosocial services for children should include evidence-based parent training programs [6,7]. The need for services to tackle childhood disruptive behavior is enormous, but only a minority of families receive them [8]. There are challenges to implementing traditional face-to-face group-based parent training programs in real-world settings. One issue is the large number of barriers such as high cost, poor access, inconvenience, and low fidelity [3,9]. Another is keeping the content of the intervention consistent with the original evidence-based treatment [2].

Digitally assisted interventions are becoming more common, as they can overcome the barriers associated with conventional programs [3,9]. They are also likely to become increasingly popular, as child mental health services struggle to deal with the considerable increase in demand for their services as a result of the COVID-19 pandemic. This unprecedented global health emergency is expected to have major ongoing effects on child mental health owing to factors such as quarantine measures, social distancing, and school closures [10]. The pandemic started at a time when resources were already under pressure, and these are expected to be further affected by manpower shortages and a global recession that puts even greater pressure on health budgets. Digitally assisted interventions are cost-effective solutions that require fewer personnel and can reach geographically remote areas that would otherwise be outside of the reach of specialist services.

RCT studies have shown that remote and digitally assisted parent training programs have worked well in clinical settings [11,12]. We previously reported 12-month and 24-month follow-up studies of the first RCT on the Strongest Families Smart Website (SFSW). This RCT used a population-based sample and provided an internet-based parent training intervention with weekly telephone coaching [13-15]. The development of the SFSW intervention was based on the social learning and cognitive behavioral theories as well as positive parenting practices [16-18]. The target population was 4-year-old children who displayed high levels of disruptive behavior when they were screened during annual health checkups at child health clinics across Southwest Finland. The RCT showed that the children and parents who received the SFSW parent training program derived significant benefits from the initiative. The children displayed significant reductions in their disruptive behavior and other psychiatric symptom domains at their 24-month follow-up assessments. They also demonstrated the same improvements when they were compared with an education control group. The education control group received access to a static website that provided parents with information on how to tackle behavior problems and 1 phone call with a coach. Improved parenting skills were maintained in the intervention group at the 24-month follow-up assessment [14].

There has been growing interest in implementation research during the past 2 decades. Dissemination refers to how knowledge of new practices is actively and passively extended, and implementation refers to how new practices are incorporated into real-world environments. The term *implementation gap* is used to refer to the difference between our knowledge of *what works* and *how it works* [19,20]. Unfortunately, the strong effects that are observed in controlled RCT settings can weaken or become ambiguous when they are implemented in real-world settings [9]. Meta-analyses have shown that effective implementation has been associated with better outcomes, and the magnitude of the mean effect sizes was considerably higher when programs were carefully implemented and when fidelity was confirmed [21]. Successfully converting psychosocial interventions from experimental environments to real-world practice requires a solid framework and a structured implementation plan [22]. Research on evidence-based parent training programs after the RCT stage has often focused on examining the characteristics of an optimal implementation environment rather than maintaining the effectiveness of the intervention. We are not aware of any previous reports on the effectiveness of implementing digital interventions for disruptive behavior so that they can form part of the routine care that children below school age can receive.

Objectives

This was the first study to report the effectiveness of the SFSW internet-based and telephone-assisted parent training program for preschool children when it was implemented in real-world settings. The intervention was put into practice after the population-based screening was used to identify children with disruptive behavior problems during routine visits to Finnish child health clinics at the age of 4 years. The primary aim was to report the changes in the children's psychopathology and functioning level and any improvement in their families' parenting skills. The children and their parents were followed up 6 months after the SFSW intervention was nationally implemented in Finnish primary care child health clinics. We compared the treatment characteristics and effectiveness between the families who received the SFSW intervention in these real-world settings from January 2015 to May 2017 and the families who received the intervention during the RCT from October 2011 to November 2013. Finally, we verified the findings by carrying out the following additional analyses. The first analysis excluded families who did not complete the parent training program. The second analysis excluded the Turku study site from the implementation study group because it was the only site that participated in both the RCT intervention and the implementation phases. In the third analysis, we compared the implementation and the RCT education control group. Our hypothesis was that the effectiveness of the SFSW intervention would be maintained if the protocol used in our previous RCT and the structured implementation plan were strictly adhered to.

Methods

Study Design

This study was a longitudinal comparison of 2 parallel groups. The implementation group comprised 600 families who received the SFSW internet-based and telephone-assisted parent training program in the real-world setting between January 2015 and May 2017. The implementation phase covered 95 child health clinics in 12 administrative regions across Finland. The RCT intervention group comprised 232 families who had been recruited by 42 child health clinics in 7 administrative regions in Southwest Finland between October 2011 and November 2013. The administrative regions in both the RCT and implementation studies contained both urban and rural areas. Turku was the only region that participated in both studies.

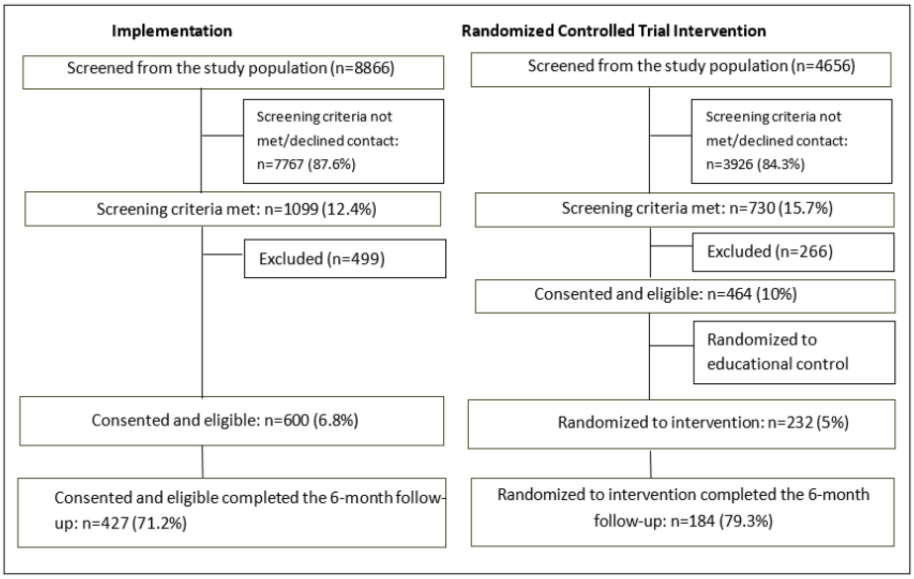
There were both differences and similarities between the implementation and the RCT intervention studies. First, the implementation group received the intervention when it was integrated as a normal practice of the child health clinics, and therefore, all families who met the inclusion criteria were eligible to enter. In the implementation phase, both participants and the health care workers received information that the SFSW parent training intervention has been evaluated as an intervention with strong documented effects by the Finnish national evaluation and classification system for evidence-based interventions [23]. This evaluation was partly based on the results of our previous RCT study [13,14]. In contrast, in the RCT, the intervention was not integrated as a normal practice of the child health clinics. Only those families who were randomized to the intervention group received the intervention. Second, in the implementation phase, an implementation plan, including decision supporting and administration component, was followed. This was important because the implementation phase included increasing number of communities in the whole Finland while the RCT was conducted in a predetermined area of Southwest Finland. Third, the most important similarity was that the content of the SFSW intervention was maintained in the implementation group as identical as possible with that of the original RCT intervention. In both groups, the same psychopathology and parenting measures were collected at baseline and 6-month follow-up. Data on children's daily activities were collected only for the implementation group immediately after the intervention and at the 6-month follow-up. The timeline of the RCT and implementation studies is shown in Figure S1 of Multimedia Appendix 1. The study protocol of the RCT has previously been published [24] and registered at ClinicalTrials.gov (NCT01750996).

Participants

This study focused on the 6-month follow-up assessments of children who displayed a high level of disruptive behavior when they were screened at 4 years of age during routine child health clinic visits. The screening procedure in the implementation study followed the same principles that were used in the RCT study. It was integrated into the standard 4-year-old child health checkups carried out by the child health clinics in the participating administrative regions [13]. All children living in Finland are invited to annual health assessments before they start school at 7 years of age, and attendance rates are just under 100% [25].

In the implementation group, the first 600 eligible parents who agreed to take part in the program received the SFSW parent training intervention. Initially, 8866 children were screened for highly disruptive behavior and 1099 (12.4%) met the screening criteria. The implementation group equated to 6.8% (600/8866) of the initial population-based sample and 54.6% (600/1099) of those who were eligible to take part. The reference group consisted of 232 families who were randomized to receive the intervention during the previous RCT study [13,14]. Information was obtained from 427 (71.2%) of the 600 families in the implementation group at the 6-month follow-up assessments compared to 184 (79.3%) of the 232 families in the RCT intervention group. Figure 1 shows the flowchart of the implementation and RCT intervention groups. The families were typically recruited within 1 month of the child's fourth birthday. They received a study information pack and were asked to bring the completed health questionnaire to the clinic.

Figure 1. Flowchart of the families in the implementation and randomized controlled trial intervention groups.



Inclusion and Exclusion Criteria

The screening measures and enrollment criteria were identical for the implementation and RCT studies [13]. Population-based screening for behavior problems was conducted for all children at the age of 4 years by using the conduct scale of the Strengths and Difficulties Questionnaire [26-28]. The parents were asked if their child had mild, moderate, or severe problems through a single question: “Overall, do you think that your child has difficulties in one or more of the following areas: emotions, behavior, or being able to get on with other people?” About 16.5% of the children (16.7% [1477/8866] and 16.3% [758/4656] in the implementation and RCT groups, respectively) who were screened, scored 5 or more out of 10 corresponding to the 80th percentile cutoff point and reported that the child had difficulties. This indicated a high level of behavior problems. The other inclusion criteria were that the parents perceived that child had at least minor difficulties in emotions, behavior, or social interactions. To participate in the study, the family had to live in an administrative region participating in the study, at least one parent had to speak native Finnish or Swedish, and they needed access to a telephone, computer, and internet connection. We excluded children who were unable to speak in full sentences, had hearing or vision impairments, or were receiving or had received behavior treatment. The exclusion criteria also included children who had been diagnosed with autism, Down syndrome, fetal alcohol syndrome, an intellectual disability, a severe mental disorder such as psychosis or depression, or who had a genetic diagnosis of mental retardation. We also excluded parents whose children did not live with them because they were subject to child protection services owing to child custody, abuse, or neglect issues. Details of the inclusion and exclusion criteria have previously been reported [24].

Procedure

The participants in the implementation and RCT intervention study groups received the SFSW parent training program, which combines an interactive website with weekly telephone coaching [15,29]. One parent was identified for each child and they filled in the web-based questionnaire. However, they were also encouraged to get the child’s other parent involved in the program as much as possible. The program was guided by coaches who were professionals of health care and social services, that is, public health nurses, public nurses, or social workers from the child services. Of note, in the RCT study, there were 6 coaches, and during the implementation study, there were 10 coaches, 6 of whom had not participated in the RCT. The coaches had weekly phone calls with the parents, which were sometimes organized using texts or emails, and they monitored their progress on the website. The intervention consisted of 11 weekly themes that were explored during the interactive web-based program and the associated telephone coaching sessions. After the baseline survey, the coaches called the parents and they agreed to personalize goals tailored to individual behavior problems demonstrated by the child. The program aimed to reduce the problems identified by the parents by teaching them positive and practical parenting skills. During the first 7 weeks, the parent learned positive and practical problem-solving skills and were encouraged to develop an understanding of their child’s emotional development. The primary aim was to reorient the parent so that they noticed the child’s positive, not negative, behavior and reacted with a positive response. The second aim was to apply the skills in everyday situations, to plan daily activities in advance, and to use the methods they were taught to reinforce positive behavior. The final weekly themes focused on reinforcing their new skills and developing sustained positive parenting. The parents practiced the acquired skills with their child, independent of the coach’s support, and learned how to sustain the skills once the program had finished. The content and the conceptual framework of the weekly themes are depicted in Table 1. Each internet-based session comprised an introduction to the weekly theme, session content, video exercises, troubleshooting tips, and a review of what the parent had learnt. Instructional videos and audio clips illustrated the practical applications of the parents’ new skills. The coaches gave the parents feedback about their progress in applying the new skills and encouraged them throughout the program. They only proceeded to the next weekly theme when the parents had mastered the skill-related questions in the current one. This typically took 1 or 2 weeks. The children did not have access to the website or take part in the coaching calls. We are not aware of any potential adverse effects of the parent training in this study or in previous studies [30].

Table 1. The content and the conceptual framework of the skill training process of the Strongest Families Smart Website internet-based and telephone-assisted parent training intervention.

Session	Training components	Key training elements	Parental goals	Coaching elements	Parental action
Introduction to the program	Telephone coaching	Set up the parents for success	Reorient the parents to "How to break the negative circle"	Working alliance Identifying behavior problems Goal setting Present the first weekly theme	Actively start to notice the good
Notice the good	Web-based material (text, videos, audio clips) Telephone coaching	Positive and active parenting	Boost self-esteem of the child and parents and change the parents' views of the child	Working alliance Evaluate the goal setting by modeling, practice such as role play, feedback, support	Notice good behavior often Positive verbal interaction and body language
Spread attention around	Web-based material (text, videos, audio clips) Telephone coaching	Positive, impartial parenting	Strengthen child's empathy skills	Same as above	Learn to spread attention actively Praise the child for interacting positively with others
Ignore whining and complaining	Web-based material (text, videos, audio clips) Telephone coaching	Positive, self-controlled parenting	Teaches parents self-regulation	Same as above	Use positive thinking to stay calm and in control of the situations
Prepare for changes	Web-based material (text, videos, audio clips) Telephone coaching	Positive, proactive parenting	Reinforce good daily routines	Same as above	Warn that behavior must change Use positive "when you do this, then this will happen" statements
Plan ahead at home	Web-based material (text, videos, audio clips) Telephone coaching	Positive, proactive parenting	Reinforce child's active role and involve them in planning	Same as above	Listens to the child's ideas, plans daily situations at home
Reinforce by rewarding	Web-based material (text, videos) Telephone coaching	Positive, active parenting	Involve the child in planning and reinforce good daily routines	Same as above	Understand realistic goal setting and how to use praises and rewards
Plan ahead outside the home	Web-based material (text, videos) Telephone coaching	Positive, proactive parenting	Reinforce child's active role and involve them in planning	Same as above	Listen to the child's ideas Plan situations outside the home
Cooperate with day care	Web-based material (text, videos) Telephone coaching	Positive cooperation and communication between parent and day care	Help child to manage and succeed	Same as above	Set realistic goals and rewards Cooperate
Plan how to use time-out	Web-based material (text, videos) Telephone coaching	Positive, self-controlled parenting	Teach self-regulation and consistency	Reassure and use positive skills How to use time-out	Learn to be consequent Plan how to manage difficult situations
Revise: Problem-solving and future application of skills	Web-based material (text, videos) Telephone coaching	Positive daily parenting in future	Remind parents of positive proactive parenting skills	Ensure that parent is using all the skills and stays on track	Understand how using skills helps to prevent setbacks

Quality Assurance and Implementation Plan

To ensure the integrity of the intervention and the accuracy of the data, several quality assurance measures were in effect during the implementation phase. These were similar to the quality assurance measures during the RCT study [13,14]. The implementation plan is summarized below and has been previously described in detail [15]. The implementation plan was driven by 3 core components [15,19]. First was recruitment, staff selection, and training. Once the coaches were recruited, they received intensive training on the SFSW program and were supervised and regularly monitored to make sure they adhered to the protocol. Together with supervision and staff performance evaluation, this provided systematic quality assurance [15]. The second core component was ongoing supervision and staff performance evaluation. The coaches took part in systematic weekly supervision meetings and group case conferences, where they reviewed and discussed the families they were coaching. Coaches with previous experience of the SFSW program acted as supervisors. After each telephone call, the coaches assessed their own performance on a scale of 4-10. The supervisor received a message from the digital platform about self-assessments that scored 6 or more and discussed the content of the call with the coach. To ensure the fidelity of the data, about 10% of the phone calls was audited by the coach supervisors with the parent's permission and evaluated for competency. Additional training and monitoring of future calls were provided, if indicated. The coaches were required to report any adverse effects such as safety issues, abuse, or neglect to the supervisors, and the case was reported to the child protective services. Of note, 3 cases were reported during the implementation study and none during the RCT. The third core component was the decision supporting and administration. The development, delivery, and implementation process of the digital SFSW parent training intervention were centralized at the Research Center for Child Psychiatry at the University of Turku. The research group and the assisting staff of the Research Center introduced the SFSW intervention and the implementation process to the directors of child and family health services of the primary health care of each administrative region. A jointly funded research contract was signed by both parties. The research group maintained contact with the directors across the study region by organizing regular meetings and providing them with user-friendly monthly progress reports, which included the number of families who had been screened and enrolled. Training was offered to the team leaders of the child health clinics and public health nurses in order to integrate the intervention into primary health care. Moreover, local and national media were involved to increase public awareness of the SFSW intervention.

Measures

Child Measures

The outcome measures were the same in the implementation and RCT studies [13,14]. The main measurement tool used to measure disruptive behavior was the 24-item Child Behavior Checklist 1.5-5 (CBCL/1.5-5) version for preschool children [31]. The CBCL/1.5-5 asks parents to rate emotional, behavioral, and social problems and has an additional section where they can provide extra information. It yields total scores and syndrome scales for the following items: emotionally reactive, anxious/depressed, somatic complaints, withdrawn, sleep problems, attention problems, and aggressive behavior. The first 4 syndromes yield the internalizing score, while the last 2 yield the externalizing score. The CBCL/1.5-5 also includes 5 subscores from the Diagnostic and Statistical Manual of Mental Disorders, fifth edition: affective, anxiety, pervasive developmental problems, attention-deficit/hyperactivity disorder, and oppositional disorder [32]. A large cross-cultural study from 24 countries, including Finland, reported good psychometric properties and good internal consistency for the CBCL preschool version (Cronbach alphas for total, externalizing, and internalizing scores: .94, .88, and .84, respectively) [33,34]. We used the Inventory of Callous-Unemotional Traits (ICU) to measure child psychopathy traits. The instrument consists of 24 items and has been reported to have good psychometric properties for 4-year-old children [35,36]. Cronbach alphas of .93, .81, .88, and .86 have previously been reported for total score, callousness, uncaring, and unemotional scores, respectively, for 4-year-old children [35].

Daily activities were only assessed for the implementation study. Parents were asked to rate the impact of the child´s behavior during daily transitions, including getting dressed, getting ready for day care, during the evening meal, and getting ready for bed. It also covered social interactions, including playing with siblings and other children during a car or bicycle ride and in public places such as the supermarket. A Cronbach alpha of .64 was calculated using our implementation data. The questionnaire was adapted from the Barkley Home Situations Questionnaire, which asks the parent to rate whether the child's behavior causes problems during specified daily routines [37].

Parent Measures

The Parenting Scale, which is a 30-item questionnaire, was used to measure parenting skills [38,39]. Cronbach alphas of .78, .66, .68, and .50 were calculated for total score, laxness, overreactivity, and hostility, respectively, by using our implementation data. We evaluated the parents' stress, anxiety, and depression symptoms with the shorter 21-item Depression, Anxiety and Stress Scale (DASS-21) [40]. The internal consistency of DASS-21 has been reported as 0.93, 0.88, 0.82, and 0.90 for total scale and DASS-21, respectively, in a large study that represented a nonclinical sample [41].

Statistical Analyses

The analyses compared the 600 families in the real-world implementation group to the 232 families in the RCT intervention group. Categorical demographic variables, including the child, parent, and family characteristics, are presented as numbers and percentages. Continuous demographic variables, including the parents' age and duration of child's behavioral problems, are presented as means and standard deviations. We explored any differences at baseline between the 2 groups by using Pearson chi-square test or Fisher exact test for the categorical variables and the two-tailed Student t test for the continuous variables. The primary and secondary outcome variables were analyzed with a linear mixed-effect model for repeated measurements. The within factor was time, namely, baseline and 6-months follow-up, and the RCT intervention group and the implementation group provided the between factor. The covariates in the statistical models were CBCL externalizing scores at baseline, maternal education, duration of behavior problems, and the baseline measurement of each outcome. The statistical model used to analyze the CBCL externalizing score consisted of the group and time main effects, the group-by-time interaction effect, and the following covariates: the CBCL externalizing score at baseline, maternal education, and duration of behavior problems. Meanwhile, the statistical model used to analyze all the secondary outcome variables, namely, the CBCL total and other CBCL subscores, ICU, the Parenting Scale, and DASS-21 consisted of the group and time main effects and the group-by-time interaction effect. It also included the following covariates: the specific secondary variable to be analyzed at baseline, the CBCL externalizing score at baseline, maternal education, and the duration of behavior problems.

The sensitivity analyses comprised the families who had completed the parent training program as well as the treatment comparisons. Turku was excluded from analysis, as it was the only site that had taken part in both the implementation and RCT intervention studies. As the study subjects in the implementation group were recruited from January 2015 to May 2017 and in the RCT intervention group from October 2011 to November 2013, we also tested the effect of the recruitment year on the CBCL externalizing score at baseline. The model included the effects of recruitment year, maternal education, and duration of behavior problems. The effect of the recruitment year was insignificant (*P*=.17). An additional analysis also compared the implementation to the RCT education control group. The model included the CBCL externalizing score at baseline, maternal education, duration of behavior problems, paternal age, and the baseline measurements of each outcome as covariates. A *P* value <.05 was considered to be statistically significant. The statistical analyses were performed using SAS 9.4 (SAS Institute).

Ethics Approval

Ethical approval for the implementation study was received from the University of Turku (approval number: 18/2018). The parents provided written informed consent for both the implementation and the RCT studies.

Results

The number of families who discontinued the program was 86 (14.3%) of the 600 families in the implementation group compared to 56 (24.1%) of the 232 families in the RCT intervention group. This meant that the odds ratio was 1.9 with a 95% CI of 1.3 to 2.8 (*P*<.001), as seen in Figure 2. The 6-month follow-up assessment was completed by 71.2% (427/600) of the parents in the implementation group and 79.3% (184/232) of the parents in the RCT intervention group (*P*<.001), as seen in Figure 1. Table 2 shows that there were no differences between the implementation group and the RCT intervention group when it came to the parent, family, and child characteristics and the factors related to parent training program. However, the mothers in the implementation group had higher educational levels than the mothers in the RCT intervention group (*P*=.046) and the children experienced a longer duration of behavior problems (*P*=.004). The mean duration of the telephone coaching calls was 37 minutes in both the implementation and the RCT intervention groups. The total duration of telephone coaching plus the average time spent on the program website was 13.8 hours in the implementation group and 14.1 hours in the RCT intervention group (*P*=.49).

Figure 2. Kaplan-Meier curves of families completing the program in the implementation and the randomized controlled trial intervention groups. RCT: randomized controlled trial, fixed axes according to editor comments.

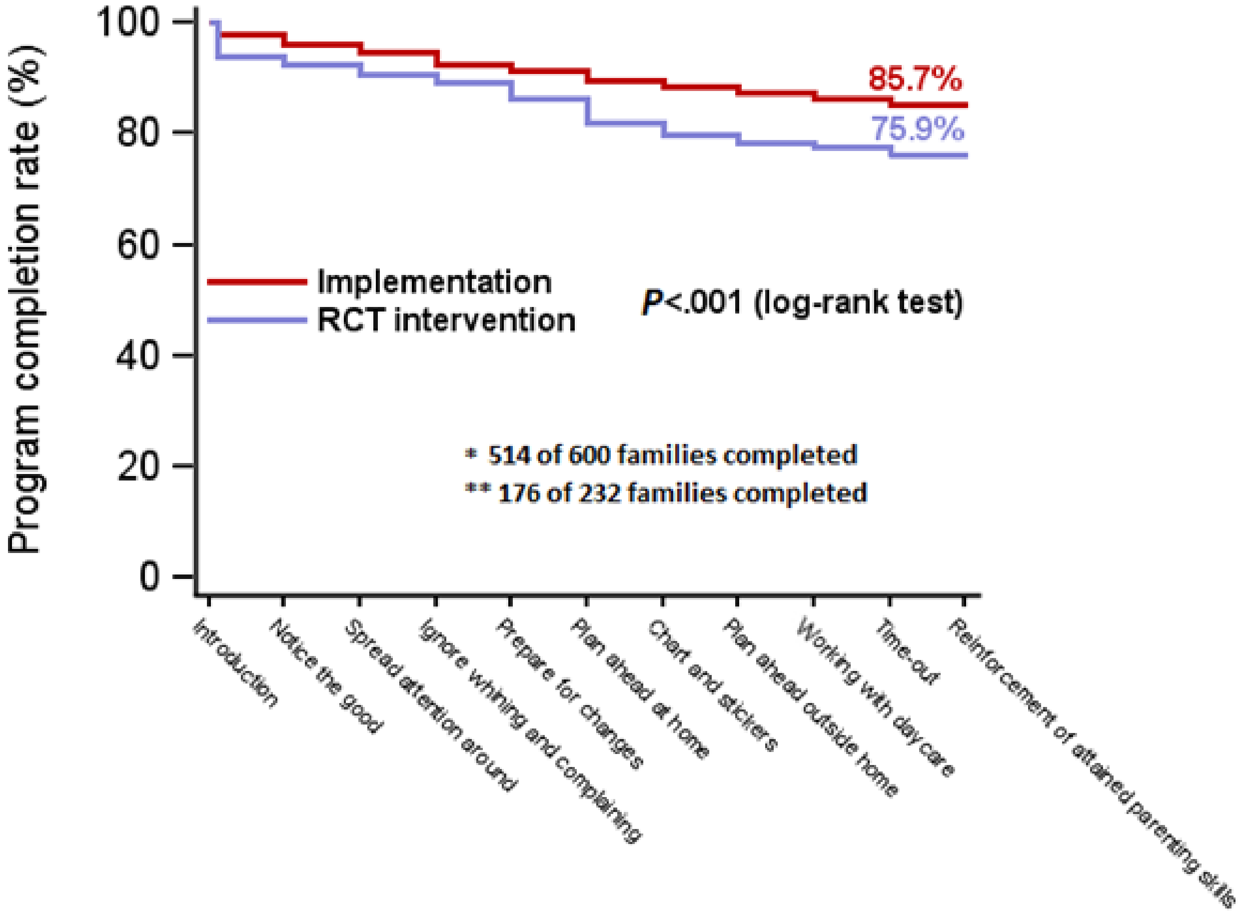


Table 2. Demographic characteristics of the families and treatment factors in the implementation and the randomized controlled trial intervention groups.

Demographics	Implementation group (n=600)	Randomized controlled trial intervention (n=232)	*P* value
Parent and family characteristics			
Family structure[a], n (%)			.54
Two biological parents	489 (81.6)	191 (83.5)	
Single biological parent	82 (13.7)	24 (10.4)	
Biological parent and foster parent	19 (3.2)	9 (3.9)	
Other	9 (1.5)	5 (2.2)	
Age (years), mean (SD)			
Maternal	30.3 (4.8)	30.5 (5.4)	.68
Paternal	32.7 (5.7)	33.2 (5.9)	.28
Maternal education[b], n (%)			.046
Elementary school or less	15 (2.5)	13 (5.7)	
Secondary education	204 (34.2)	85 (37)	
College or university degree	378 (63.3)	132 (57.4)	
Paternal education[c], n (%)			.28
Elementary school or less	27 (4.8)	16 (7.4)	
Secondary education	280 (50.1)	99 (45.8)	
College or university degree	252 (45.1)	101 (46.8)	
Child characteristics, n (%)			
Sex			.82
Female	238 (39.7)	90 (38.8)	
Male	362 (60.3)	142 (61.2)	
Day care outside home[d]			.29
Yes	476 (79.9)	192 (83.1)	
No	120 (20.1)	39 (16.9)	
Behavioral problems			.18
Minor	301 (50.2)	129 (55.6)	
Definite	252 (42)	92 (39.7)	
Severe	47 (7.8)	11 (4.7)	
Duration of problems[e]			.004
<6 months	193 (33)	102 (45.1)	
6-12 months	155 (26.5)	44 (19.5)	
>12 months	237 (40.5)	80 (35.4)	
Program characteristics, mean (SD)			
Total number of calls	10.4 (2.5)	10.1 (3.3)	.20
Duration of calls for the 11 themes (min)	37.3 (11.0)	37.3 (13.5)	.96
Duration of website access per theme (min)	45.3 (19.3)	47.8 (19.9)	.12
Total duration of calls (h)	6.5 (2.4)	6.4 (3.3)	.65
Total duration of website access (h)	7.3 (2.8)	7.5 (3.2)	.56
Total duration of program (h)	13.8 (4.3)	14.1 (5.4)	.49

[a] Missing observations: implementation group (n=1); randomized controlled trial group (n=2).

[b] Missing observations: implementation group (n=3); randomized controlled trial group (n=2). Pairwise comparisons: elementary school or less versus secondary education (*P*=.06); elementary school or less versus college or university degree (*P*=.02); secondary education versus college or university degree (*P*=.28).

[c] Missing observations: implementation group (n=41); randomized controlled trial group (n=1).

[d] Missing observations: implementation group (n=4); randomized controlled trial group (n=1).

[e] Missing observations: implementation group (n=15); randomized controlled trial group (n=6). Pairwise comparisons: <6 months versus 6-12 months (*P*=.003); <6 months versus >12 months (*P*=.01); 6-12 months versus >12 months (*P*=.42).

In the implementation group, there were significant improvements from the baseline to the 6-month follow-up assessment in the primary outcome, which was the CBCL externalizing score. The same was true for the secondary outcomes: CBCL total and internalizing scores and the total scores of the ICU, Parenting Scale, and DASS-21 (Table 3). The sensitivity analysis, which included the participants who completed the whole program (Table S1 of Multimedia Appendix 2), yielded similar estimates of the improvements in all the outcomes. Table 4 shows the mean scores of the primary outcome, CBCL externalizing score, and the secondary outcomes at baseline and 6 months in the implementation and the RCT intervention groups. There were no significant differences between the 2 groups in the CBCL externalizing, total, or internalizing scores. In addition, no significant differences were seen in the total scores of the Parenting Scale or ICU. The estimated difference of 2.5 (95% CI 0.0-5.1) points in DASS-21 nearly reached statistical significance (*P*=.05), indicating better improvement in the implementation group when it was compared to that of the RCT intervention group. Of note, the improvement in DASS-21 showed significantly better improvement in the implementation group (estimated difference 1.1, 95% Cl 0.1-2.2; *P*=.04). When only the participants who completed the whole parent training program in the implementation group were compared to those in the RCT intervention group, the results remained similar (Table S2 of Multimedia Appendix 3).

The additional analyses compared the changes in primary and secondary outcomes between the implementation and the RCT education control groups, as shown in Table S3 of Multimedia Appendix 4. There were significant differences between the groups in CBCL externalizing, total, and internalizing scores, as well as the total scores of the Parenting Scale and DASS-21. However, the total ICU score did not reach statistical significance (*P*=.27). As the city of Turku participated in both the implementation study and the RCT study, we repeated the analyses by excluding the participants living in Turku from the implementation group. This did not show any significant differences in any of the symptom scores between the study groups (Table S4 of Multimedia Appendix 5). Changes in daily activities from the baseline assessment to posttreatment and the 6-month follow-up assessment are shown in the Table S5 of Multimedia Appendix 6. This information was only obtained from the implementation group; therefore, comparisons with the RCT intervention group could not be made. There were significant improvements in all measurements for social interactions and daily transitions from baseline to posttreatment and to the 6-month follow-up. The data for daily activities were obtained from 83% (498/600) of the participants in posttreatment and 66.5% (399/600) of the participants in the follow-up.

Table 3. Change from baseline to 6 months in child psychopathology, parenting skills, and parents' stress in the implementation group.

Variable	Baseline (n=600), mean[a] (SE)	After 6 months (n=600), mean[a] (SE)	Mean change[b] (SE)	95% CI	P^c value
Child measures					
Primary outcome					
Child Behavior Checklist externalizing score	21.1 (0.5)	14.8 (0.5)	6.2 (0.4)	5.5 to 7.0	<.001
Secondary outcomes					
Child Behavior Checklist Total score	48.8 (1.2)	33.6 (1.3)	15.2 (1.0)	13.3 to 17.2	<.001
Child Behavior Checklist Internalizing score	12.1 (0.4)	8.5 (0.5)	3.6 (0.4)	2.9 to 4.3	<.001
Symptom domains					
Aggression	18.0 (0.4)	12.5 (0.4)	5.5 (0.3)	4.9 to 6.1	<.001
Attention	3.1 (0.1)	2.4 (0.1)	0.7 (0.1)	0.6 to 1.0	<.001
Sleep	4.0 (0.2)	2.5 (0.2)	1.5 (0.1)	1.2 to 1.7	<.001
Withdrawn	2.4 (0.1)	1.6 (0.1)	0.8 (0.1)	0.6 to 1.0	<.001
Somatic	2.9 (0.1)	2.0 (0.2)	0.8 (0.1)	0.6 to 1.1	<.001
Anxious	2.9 (0.1)	2.0 (0.1)	0.8 (0.1)	0.6 to 1.0	<.001
Emotional	3.9 (0.2)	2.8 (0.2)	1.2 (0.1)	0.9 to 1.4	<.001
Diagnostic and Statistical Manual of Mental Disorders, fifth edition subscores					
Affective problems	3.3 (0.1)	2.0 (0.2)	1.3 (0.1)	1.1 to 1.5	<.001
Anxiety problems	4.2 (0.2)	2.9 (0.2)	1.4 (0.1)	1.1 to 1.6	<.001
PDD[d] problems	4.7 (0.2)	3.3 (0.2)	1.4 (0.2)	1.1 to 1.7	<.001
ADHD[e] problems	6.0 (0.2)	4.5 (0.2)	1.6 (0.1)	1.3 to 1.8	<.001
ODD[f] problems	6.5 (0.2)	4.6 (0.2)	1.9 (0.1)	1.6 to 2.1	<.001
Inventory of Callous-Unemotional Traits					
Total	24.6 (0.5)	20.6 (0.5)	4.0 (0.4)	3.2 to 4.7	<.001
Callousness	8.3 (0.2)	6.2 (0.2)	2.2 (0.2)	1.8 to 2.5	<.001
Uncaring	13.2 (0.2)	11.6 (0.3)	1.6 (0.2)	1.3 to 2.0	<.001
Unemotional	3.1 (0.1)	2.9 (0.1)	0.2 (0.1)	–0.1 to 0.4	.30
Parent measures					
Parenting scale					
Total	3.2 (0.0)	2.7 (0.0)	0.6 (0.0)	0.5 to 0.6	<.001
Laxness	2.7 (0.0)	2.2 (0.0)	0.4 (0.1)	0.4 to 0.5	<.001
Overreactivity	3.9 (0.1)	3.1 (0.1)	0.8 (0.0)	0.7 to 0.9	<.001
Hostility	1.9 (0.0)	1.6 (0.1)	0.3 (0.1)	0.3 to 0.4	<.001
21-item Depression, Anxiety and Stress Scale short form					
Total	18.5 (1.1)	12.1 (1.1)	6.4 (0.8)	4.9 to 7.9	<.001
Depression	5.2 (0.5)	3.1 (0.5)	2.1 (0.3)	1.4 to 2.7	<.001
Anxiety	2.4 (0.3)	1.4 (0.3)	1.1 (0.2)	0.7 to 1.4	<.001
Stress	11.0 (0.5)	7.7 (0.5)	3.3 (0.4)	2.6 to 4.0	<.001

[a] Least-squares means.

[b] Change from baseline to 6 months after providing informed consent.

[c] Adjusted with maternal education and duration of problems.

[d] PDD: pervasive developmental disorder.

[e] ADHD: attention-deficit/hyperactivity disorder.

[f] ODD: oppositional defiant disorder.

Table 4. Mean changes from baseline to 6 months in child psychopathology, parenting skills, and parents' stress in the implementation and randomized controlled trial intervention groups.

Variable	Mean (SE) change from baseline to 6 months		Implementation versus RCT intervention, mean (95% CI)	*P*[c] value
	Implementation group (n=600), mean[a] (SE)	RCT[b] intervention (n=232), mean[a] (SE)		
Child measures				
Primary outcome				
Child Behavior Checklist externalizing score	6.3 (0.4)	6.1 (0.6)	–0.2 (–1.3 to 1.6)	.83
Secondary outcomes				
Child Behavior Checklist total score	15.3 (1.0)	14.6 (1.6)	–0.7 (–3.0 to 4.5)	.70
Child Behavior Checklist internalizing score	3.7 (0.4)	3.4 (0.6)	–0.3 (–1.0 to 1.6)	.64
Symptom domains				
Aggression	5.5 (0.3)	5.5 (0.5)	–0.0 (–1.2 to 1.3)	.95
Attention	0.7 (0.1)	0.6 (0.1)	–0.1 (–0.2 to 0.4)	.53
Sleep	1.5 (0.1)	1.5 (0.2)	–0.0 (–0.5 to 0.5)	1.0
Withdrawn	0.8 (0.1)	0.5 (0.2)	–0.3 (–0.0 to 0.7)	.08
Somatic	0.8 (0.1)	0.6 (0.2)	–0.2 (–0.2 to 0.7)	.29
Anxious	0.9 (0.1)	1.0 (0.2)	–0.1 (0.5 to 0.3)	.62
Emotional	1.2 (0.1)	1.3 (0.2)	–0.1 (–0.7 to 0.4)	.58
Diagnostic and Statistical Manual of Mental Disorders, fifth edition subscores				
Affective problems	1.3 (0.1)	1.3 (0.2)	0.0 (–0.4 to 0.5)	.95
Anxiety problems	1.4 (0.1)	1.5 (0.2)	–0.1 (–0.6 to 0.4)	.69
PDD[d] problems	1.4 (0.2)	1.2 (0.3)	0.2 (–0.3 to 0.8)	.41
ADHD[e] problems	1.6 (0.1)	1.2 (0.2)	3.5 (–0.2 to 0.9)	.17
ODD[f] problems	1.9 (0.1)	2.2 (0.2)	–0.3 (–0.7– 0.2)	.26
Inventory of Callous-Unemotional Traits				
Total	4.0 (0.4)	4.3 (0.7)	–0.4 (–1.9 to 1.2)	.64
Callousness	2.0 (0.2)	2.1 (0.3)	–0.1 (–0.7– 0.8)	.83
Uncaring	1.6 (0.2)	1.9 (0.3)	–0.2 (–1.0 to 0.5)	.53
Unemotional	0.2 (0.1)	0.3 (0.2)	–0.1 (–0.6 to 0.3)	.44
Parent measures				
Parenting scale				
Total	0.6 (0.0)	0.5 (0.0)	0.0 (–0.1 to 0.1)	.50
Laxness	0.4 (0.0)	0.4 (0.1)	0.0 (–0.1 to 0.2)	.79
Overreactivity	0.8 (0.1)	0.6 (0.1)	0.2 (–0.0 to 0.4)	.07
Hostility	0.3 (0.0)	0.3 (0.1)	0.0 (–0.1 to 0.2)	.85
21-item Depression, Anxiety and Stress Scale short form				
Total	6.4 (0.7)	3.9 (1.1)	2.5 (0.0 to 5.1)	.05
Depression	2.1 (0.3)	1.0 (0.5)	1.1 (0.1 to 2.2)	.036
Anxiety	1.0 (0.2)	0.8 (0.3)	0.3 (–0.4 to 0.1)	.44
Stress	3.3. (0.4)	2.2 (0.6)	1.1 (–0.2 to 2.4)	.09

[a] Least-squares means.

[b] RCT: randomized controlled trial.

[c] Adjusted with maternal education and duration of problems.

[d] PDD: pervasive developmental disorder.

[e] ADHD: attention-deficit/hyperactivity disorder.

[f] ODD: oppositional defiant disorder.

Discussion

This was the first population-based study to evaluate the effectiveness of an internet-based and telephone-assisted parent training intervention for children with behavior problems when it was implemented in real-world practice. The children's psychiatric problems improved, including externalizing and internalizing problems and callousness. The findings were remarkable from the perspective of the children's social development, as the program had significant effects on daily transitions and activities such as getting dressed, dining behavior, activities outside the home, and interactions with other people. Parents reported that their parenting skills had improved and they demonstrated less distress in dealing with their children at the 6-month follow-up. Most importantly, this study shows that the improvements that had been achieved were similar to those reported for the intervention group in the RCT. There was no difference in the changes in the children's psychiatric problems or parenting skills when the implementation and RCT groups were compared. Furthermore, when changes between the implementation and RCT education control groups were compared, the implementation group showed significantly better improvements in the children's externalizing and internalizing problems as well as in parenting skills and parents' distress. In addition to the effectiveness of the treatment, the ability to engage and retain parents in the program is one of the keys to successful parent training interventions [42-44]. Previously, we reported high parental satisfaction levels in both the RCT and implementation groups [15]. High satisfaction levels and the quality of relationships between parents and professionals have been associated with greater improvements in the effectiveness of interventions [45,46]. The dropout rate in our RCT study was 24%, while previous studies on digital parenting interventions report usually 30%-50% dropout rates [12,47-50]. In general, high dropout rates in digital interventions have been especially associated with nonguided interventions [43,51-54]. The reasons for the exceptionally low dropout rate in the implementation phase (14%) are likely to be multiple. One possible explanation is that in the implementation phase, the SFSW intervention that was offered had gained research-based evidence and the benefits of it were known and communicated to the professionals in the primary health care, especially in child health clinics, and to parents and largely in the media. Thus, the public and the professionals were aware of the intervention and its benefits. It is very likely that this convinced both health nurses at the child health clinics who motivate the parents in engaging in the program and the concerned parents tackling with their child's challenges.

In order to successfully implement interventions, we need to know whether they work and *why* they work [19]. Success can be related to how appropriate the background theory is, the context where the intervention takes place, practical issues such as how easy it is to attend sessions, and specific intervention practices such as practicing specific parenting skills [55]. Our SFSW intervention fulfilled these criteria well. It was based on the social learning theory and the cognitive behavioral theory as well as principles of positive parenting, which provided a sound theoretical framework for the intervention. The context of the program was well-defined, including a clear definition of the population that the program was aimed at, and there were clear inclusion and exclusion criteria. The program also had a clear structure, including a description of the core components, which was practiced through modeling, practice, feedback, and support. It has previously been emphasized that a solid framework and a structured implementation plan are needed to successfully make the transition from evidence-based psychosocial interventions to *real-world* clinical practice [22]. We systematically followed a structured plan during the implementation process [15]. The SFSW program contained the core implementation drivers that facilitated the process when intervention was implemented in the primary health care. The same quality assurance measures were in place during the RCT and implementation phase. These were based on the centralized delivery of the intervention, which used a digital platform and ongoing training, monitoring, and supervision of the program coaches. It is important to note that the primary health care staff were also provided with ongoing training. In addition, the program was effectively administered by including regular meetings with the directors of the child and family services and providing them with user-friendly reports. Media coverage raised awareness, and this made it easier to recruit families and increased the perceived value of the program [15].

Several practical features of the program may have paved the way for positive outcomes during the real-world implementation. First, the program was much easier for the parents than face-to-face interventions because they did not need to leave home or work or make childcare arrangements. Second, the telephone coaching provided immediate problem-solving, which may have been more rewarding for the parents than communicating using emails or text messages. A recent meta-analysis showed that digital interventions that included support and guidance, such as telephone calls, had larger effect sizes on mental health outcomes than smartphone interventions without any personal support [56]. Third, the coaches were well-trained and formed good relationships with the parents [15], which is central to the success of any intervention [57].

There were some limitations in our study. First, although the parental and child outcomes were measured using well-validated questionnaires, they were rated by the same person, namely, the parent. One parent was identified for each child, but they were also encouraged to get the child's other parent involved in the program as much as possible. Further details on the level of parental involvement could have added to the richness of the data, but there were practical limitations to collecting this. To reduce the possibility of the common rater variance, observations by other informants such as day care personnel could have validated our findings. Second, we have discussed mechanisms that could have been responsible for the positive outcomes. However, there is very little empirical evidence on whether the effects of the intervention resulted from the internet sessions, the personal telephone coaching, parental motivation, or a combination of those factors. Further studies need to examine factors that explain these positive outcomes. Personalized medicine is increasingly being used to move away from one-size-fits-all interventions to those that are more tailored to individual needs. This approach could yield useful information on the mechanisms underlying interventions and enable more accurate targeting.

The target group, content, and effectiveness of the intervention were maintained when the implementation group results were compared with the findings of the RCT intervention. Internet-based telephone-assisted parent training interventions may have advantages over traditional group-based treatment approaches when the goal is to identify children at risk in the community at an early stage. This new approach can provide effective parent training for a large number of families, including many who would not normally participate in clinic-based services. Referring families who need parent training to clinical services often results in substantial delays and they need other support while they are waiting. Digitally delivered interventions move child mental health treatment outside traditional clinics and into people’s homes and schools, increasing access and reducing stigma. In addition, they can be increased to help more families, and parents are more likely to stay with the program until the end. There is a global shortage of skilled staff who can address child mental health problems in low- and high-income countries and even in countries with public health care [58,59]. This could become an even greater issue when demand inevitably increases because of the impact of the COVID-19 pandemic on children and the effects of the expected global recession on health care budgets. Our study highlights the positive findings that were demonstrated when our internet-based training and phone coaching initiative provided support for the parents of children with behavior problems, who were identified using population-based screening at primary health care. This initiative made the successful transition from an RCT to real-world settings, and our findings may have potential global implications for addressing the unmet needs of children with mental health issues if the findings are repeated in other sociocultural contexts.

Acknowledgments

We wish to thank the family coaches and Project Engineer Atte Sinokki from the Department of Child Psychiatry, University of Turku, as well as the public health directors and health nurses at the participating municipal child health clinics who made this study possible. This research was funded by the Academy of Finland Flagship Program Inequalities, Interventions, and a New Welfare State (decision 320162), the Academy of Finland Health from Cohorts and Biobanks Program (decision 308552), and the European Research Council under the European Union’s Horizon 2020 research and innovation program (grant 101020767) (author AS).

Conflicts of Interest

AS is the founder and director of Digifamilies, which provides evidence-based treatments to Finnish public health services. The Strongest Families Institute (SFI) is a not-for-profit organization that delivers services to Canadian families. PJM is the cofounder and Chair of SFI Board of Directors. The other authors have no conflicts of interest to declare.

Multimedia Appendix 1

Timeline of the randomized controlled trial and implementation studies.
[DOCX File , 13 KB-Multimedia Appendix 1]

Multimedia Appendix 2

Change from baseline to 6 months in child psychopathology, parenting skills and parents’ stress in the Implementation group for participants who completed the program.
[DOCX File , 31 KB-Multimedia Appendix 2]

Multimedia Appendix 3

Mean changes from baseline to 6 months in child psychopathology, parenting skills, and parents’ stress in the implementation and the randomized controlled trial intervention groups for participants who completed the program.
[DOCX File , 23 KB-Multimedia Appendix 3]

Multimedia Appendix 4

Mean changes from baseline to 6 months in child psychopathology, parenting skills, and parents’ stress in the implementation and randomized controlled trial educational control groups.
[DOCX File , 23 KB-Multimedia Appendix 4]

Multimedia Appendix 5

Change from baseline to 6 months in child psychopathology, parenting skills, and parents' stress in the implementation and randomized controlled trial intervention groups. The city of Turku is excluded from the implementation data.
[DOCX File , 25 KB-Multimedia Appendix 5]

Multimedia Appendix 6

Change from baseline to posttreatment and 6 months in daily activities and social interactions in the implementation group (n=600).
[DOCX File , 26 KB-Multimedia Appendix 6]

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Abbreviations

CBCL: Child Behavior Checklist
DASS-21: 21-item Depression, Anxiety and Stress Scale
ICU: Inventory of Callous-Unemotional Traits
RCT: randomized controlled trial
SFSW: Strongest Families Smart Website

Edited by A Mavragani; submitted 03.03.21; peer-reviewed by Y Perry, A Woolard; comments to author 20.04.21; revised version received 31.08.21; accepted 15.12.21; published 04.04.22

Please cite as:
Sourander A, Ristkari T, Kurki M, Gilbert S, Hinkka-Yli-Salomäki S, Kinnunen M, Pulkki-Råback L, McGrath PJ
Effectiveness of an Internet-Based and Telephone-Assisted Training for Parents of 4-Year-Old Children With Disruptive Behavior: Implementation Research
J Med Internet Res 2022;24(4):e27900
URL: https://www.jmir.org/2022/4/e27900
doi: 10.2196/27900
PMID:

Review

The Efficacy of Health Information Technology in Supporting Health Equity for Black and Hispanic Patients With Chronic Diseases: Systematic Review

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Abstract

Background: Racial inequity persists for chronic disease outcomes amid the proliferation of health information technology (HIT) designed to support patients in following recommended chronic disease self-management behaviors (ie, medication behavior, physical activity, and dietary behavior and attending follow-up appointments). Numerous interventions that use consumer-oriented HIT to support self-management have been evaluated, and some of the related literature has focused on racial minorities who experience disparate chronic disease outcomes. However, little is known about the efficacy of these interventions.

Objective: This study aims to conduct a systematic review of the literature that describes the efficacy of consumer-oriented HIT interventions designed to support self-management involving African American and Hispanic patients with chronic diseases.

Methods: We followed an a priori protocol using the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses)-Equity 2012 Extension guidelines for systematic reviews that focus on health equity. Themes of interest included the inclusion and exclusion criteria. We identified 7 electronic databases, created search strings, and conducted the searches. We initially screened results based on titles and abstracts and then performed full-text screening. We then resolved conflicts and extracted relevant data from the included articles.

Results: In total, there were 27 included articles. The mean sample size was 640 (SD 209.5), and 52% (14/27) of the articles focused on African American participants, 15% (4/27) of the articles focused on Hispanic participants, and 33% (9/27) included both. Most articles addressed 3 of the 4 self-management behaviors: medication (17/27, 63%), physical activity (17/27, 63%), and diet (16/27, 59%). Only 15% (4/27) of the studies focused on follow-up appointment attendance. All the articles investigated HIT for use at home, whereas 7% (2/27) included use in the hospital.

Conclusions: This study addresses a key gap in research that has not sufficiently examined what technology designs and capabilities may be effective for underserved populations in promoting health behavior in concordance with recommendations.

(J Med Internet Res 2022;24(4):e22124) doi: 10.2196/22124

KEYWORDS

chronic disease; minority health; technology assessment; biomedical; self-management; systematic review; mobile phone

Introduction

Background

Nearly half of all adults in the United States are living with 1 or more of the *Big Five* chronic conditions—diabetes mellitus (*diabetes*), cardiovascular disease, chronic respiratory disease, cancer, and stroke [1]. Racial inequity persists for outcomes under these conditions [2]. For example, African American individuals continue to experience greater disease prevalence than non-Hispanic White individuals for hypertension (25%) and diabetes (49%); likewise, Hispanic individuals' diabetes rates are 20% higher than those of White individuals [3]. Furthermore, nearly 5 decades of literature details racial and ethnic inequity in diabetes prevalence and risk factors for diabetes-related complications and following recommended self-management behavior [4].

Chronic disease self-management is challenging because the treatment regimens often demand much from the patient and their families; recommended self-management frequently includes regular meal planning, consistent physical activity, monitoring and tracking (eg, fluid intake and blood glucose), and daily medication behavior [5]. Following the recommended self-management behavior is vital because these behaviors are associated with health outcomes. For example, following the recommended medication behavior, physical activity, dietary behavior, and blood sugar testing are all associated with glycemic control [6]. Comorbidity can exacerbate the burden associated with following self-management recommendations. For example, a cancer survivor with diabetes who must take medication as part of their cancer treatment (eg, prednisone) may experience difficulty in maintaining the recommended glucose levels, which can in turn impact medication behavior [7]. Chemotherapy can also cause adverse side effects, including pain and cognitive impairment. Both can present barriers to following recommended self-management for years following cancer treatment [8], and cancer survivors from racial minority groups experience poorer outcomes for other chronic conditions diagnosed after a cancer diagnosis [9].

Patients with chronic diseases may use information technology (eg, mobile apps) as sources of health information to help answer questions regarding symptoms and treatment options [10-12]. However, racial inequity also characterizes access to information and communication technologies (ICTs). Most White individuals own a laptop or desktop computer (83%), whereas only about two-thirds of African American individuals (66%) reported owning either. There is also racial and ethnic inequity in access to broadband at home, with 78% of the White population reporting access compared with 65% of African American individuals and 58% of Hispanic individuals [13]. African American individuals and Hispanic individuals own smartphones and tablets at similar rates as White individuals; however, smartphones represent the only web-based access for 12% of the African American population and 22% of the Hispanic population, whereas only 4% of White individuals only access the internet via smartphones [13]. Furthermore, African American individuals experience disruptions in access, as they are twice as likely as White individuals to cancel or suspend mobile phone services because of cost [13]. These interruptions are particularly vital because African American individuals are more likely to use smartphones for web-based access than White individuals [14,15]. To use health information technology (HIT) to help support following the recommended self-management health behavior, individuals must both have access to ICTs and possess the requisite skills to use them [16,17]. African American individuals experience barriers to HIT use because of inequitable access and disparities in skills required to use technology designed to support chronic disease self-management [16]. Consequently, the extent to which this technology is effective in supporting Hispanic and African American patients for chronic disease self-management is unclear. Understanding efficacy is imperative given persistent disparities in health outcomes and in HIT access and use.

Sociocultural factors also influence individuals from ethnic minority groups' use of consumer-oriented HIT. Trust, perceived credibility, attitudes, and perceptions predict health technology acceptance and use [17]. For example, over a decade of research describes how African American individuals have different attitudes than White individuals regarding technology innovations in health care, and these factors predict HIT acceptance [18]. Trust is an important consideration in the design of health informatics interventions to promote health and wellness [19]. Sociocultural barriers (eg, unwanted attention) are among the barriers Hispanic populations report for consumer-oriented HIT [20].

Sociocultural factors present barriers that contribute to intervention-generated inequality [21,22]. Intervention-generated inequality occurs when technology-enabled health informatics approaches disproportionally benefit most populations [17]. Therefore, these interventions are less effective for minority populations and can essentially exacerbate population disparities that contribute to health inequity [23]. HIT-enabled health promotion can be enhanced by developing HIT that considers sociocultural factors that influence use (eg, levels of health literacy and digital literacy, lack of access to, or knowledge of digital tools) [24]. Systematic reviews of consumer-oriented HIT to support health and wellness find that articles do not adequately consider sociotechnical factors [25].

Objectives

HIT research describes the potential benefit from the use of technologies designed to track and report health behaviors, along with the acknowledgment of sparse insights to guide researchers concerning specific barriers to use for ethnically diverse populations [20]. However, no systematic review has been published describing the efficacy of consumer-oriented HIT designed to support following recommended self-management behavior for African American or Hispanic patients with chronic diseases. Therefore, we conducted this study of efficacy of consumer-oriented HIT in these patients. For this study, we classify *consumer-oriented HIT* as a technology designed to support recommended chronic disease self-management. It includes a myriad of mobile, tablet, and computer apps designed to support following recommended chronic disease self-management behaviors, such as electronic journals to track physical activity and prompts and reminders to support medication behavior. HIT also includes technology that enables access to health information, such as podcasts and disease-specific discussion boards. Given that ethnic minority populations experience both persistent inequity in chronic disease outcomes and barriers to access of consumer-oriented HIT designed to support following recommended self-management behavior, this study was guided by the following research question: what is the impact on clinical outcomes of consumer-oriented HIT interventions on self-management behavior or health outcomes for Black or Hispanic patients with chronic diseases?

Methods

Overview

After confirming health equity as the focus of this study, we followed an a priori protocol with equity as the focus, the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses)-Equity 2012 Extension was selected as a guideline for conducting systematic reviews that focus on health equity [26,27].

Inclusion Criteria

We developed a rationale for eligible study designs and inclusion of outcomes, per the PRISMA-Equity 2012 Extension for systematic reviews [27]. First, we identified foundational articles based on the refined research question [28-31]. We then reviewed papers from several journals that published the foundational articles and published the foundational articles and journals that published papers that the foundational articles cited. Given the interdisciplinary nature of health equity research, we selected established journals, with an emphasis on health equity (eg, *Social Science & Medicine*, the *Journal of Racial and Ethnic Health Disparities*, and the *Journal of Health Care for the Poor and Underserved*) and from medical informatics (eg, the *Journal of American Medical Informatics Association* and the *Journal of Medical Internet Research*). We chose a systematic review based on the types of articles appearing in these journals. Given that outcomes are germane for describing inequity, we selected journals that reported outcomes.

Information Sources

Next, we crafted themes of interest, again per the PRISMA-Equity 2012 Extension for systematic reviews [26], which formed the foundation of our inclusion and exclusion criteria: health technology designed for patients, Unified Theory of Acceptance and Use of Technology, theme (eg, acceptance, usability, readiness, satisfaction, and preference), self-management (eg, self-management behavior, health behavior, adherence, and compliance), health conditions (eg, chronic disease and physical health), and demographics.

To evaluate and select databases, we again reviewed the 4 foundational articles. We also consulted with a health sciences librarian to evaluate and finalize the databases. We selected seven electronic databases: PubMed, Cumulative Index of Nursing and Allied Health Literature, Web of Science, Cochrane, Compendex, Institute of Electrical and Electronics Engineers, and Computers and Applied Sciences Complete.

Search Strategy

We created search strings based on our themes of interest (eg, acceptance, usability, readiness, satisfaction, and preference), according to the specific database format, to locate articles that met our inclusion criteria. We consulted with health science librarians to ensure adherence to the database string format. Information regarding the search strategy (eg, search strings) is given in Multimedia Appendix 1 [30,32-57]. When the database permitted, all results were limited to peer-reviewed journal articles published after 1990 as the World Wide Web was introduced during this period. All database searches were conducted on November 26, 2018. In addition, PJM hand-searched references of the included articles to ensure all pertinent articles were included.

Study Selection

Articles were included if they met specific inclusion criteria and excluded if they fulfilled the exclusion criteria (Textbox 1).

Rayyan (Rayyan Inc), an internet-based software package, was used to facilitate article screening [58]. CRS and PJM blindly completed the title and abstract and full-text screening. They resolved conflicts together after the blind screening feature in Rayyan was turned off.

Textbox 1. Article inclusion and exclusion criteria.

Inclusion criteria

- Articles included patients with chronic diseases or caregivers who specified they were of Black or African American, or Hispanic origin.
- The patient or caregiver must be the end user or direct benefactor of technology.
- Technology gives personalized information to patients and or caregivers.
- Technology was designed to support self-management recommended for chronic conditions (ie, medication behavior, physical activity, dietary behavior, and attending follow-up appointments).
- The article is in English in a peer-reviewed journal.
- The article has been published since 1990.

Exclusion criteria

- Intervention targets providers.
- No electronic technologies (ie, technology using electricity) examined in the article.
- Technology is not designed to support self-management recommended for chronic conditions (ie, medication behavior, physical activity, dietary behavior, and attending follow-up appointments). Technology designed to prevent falls was not included.
- A systematic review of technology.

Data Collection Process and Data Items

Once conflicts were resolved, we analyzed the included articles and extracted relevant information (Table 1). Given the focus of our review is technology designed for chronic disease self-management for African American and Hispanic patients, we detailed information concerning race or ethnicity and cultural tailoring, type of technology used, behavior targeted, and specific chronic disease and clinical outcomes measured. We used content analysis to classify themes and totaled the frequency of self-management activities reported.

We analyzed the risk of bias in each included article using the Cochrane Collaboration Risk of Bias Tool [59]. The tool was developed in 2005 based on the following seven principles for assessing risk of bias in randomized trials: (1) avoiding use of quality scales (eg, because scales, and resulting scores, are inappropriate appraisals of clinical trials, their use increases risk of bias), (2) focusing on internal validity (eg, a small trial with high internal validity may have high risk of bias, whereas a large trial, while having high precision may have high risk of bias if internal validity is low), (3) assessing the risk of bias in trial results (eg, the quality of the reporting—which may be assessed by evaluating level of detail—helps determine the risk of bias; methodology used in conducting the trial—such as not calculating the sample size with power analysis, not including ethical review board approval, or limiting participants' knowledge of intervention received can all increase the risk of bias), (4) using judgment when assessing risk of bias (eg, omitting bias assessments from aspects of the trail methodology or interpretation of results may increase risk of bias), (5) choosing domains to be assessed (eg, if detail is not described for how incomplete data were accounted for, or aspects of blinding for participants and practitioners, can increase the risk of bias), (6) focusing on the risk of bias in the data as represented in the article (eg, the exclusion of certain participants in trial results who are then reinstated for other results increases the risk of bias), and (7) reporting outcome-specific evaluations of the risk of bias (eg, describing randomized allocation to control or experimental group during participation may influence the risk of bias in other aspects of the trial, such as physicians' knowledge of the specific intervention and its usual effects). The tool contains six domains for assessing potential bias, with sources of bias in each domain: (1) selection bias (inadequate generation of a randomized sequence and inadequate concealment of allocations before an assignment increase the risk of bias), (2) performance bias (inadequate blinding of participants and study personnel increases the risk of bias), (3) detection bias (inadequate blinding of outcome assessment increases the risk of bias), (4) attrition bias (incomplete outcome data for outcomes reported increases the risk of bias), (5) reporting bias (selective reporting increases the risk of bias), and (6) other bias (ie, any bias not included in the other 5 named domains).

Table 1. General characteristics (N=27).

Characteristics[a]	Values, n (%)
Self-management area	
Medication behavior	17 (62)
Follow-up appointment attendance	4 (14)
Physical activity	17 (62)
Dietary behavior	16 (59)
Care setting	
Home (capability to access or use from home)	27 (100)
Hospital[b]	2 (7)
Technology	
Computer, laptop, or tablet[c]	3 (11)
Telephone (landline)	0 (0)
Mobile phone	17 (62)
Mobile app	1 (3)
Text	15 (55)
Web-based	8 (29)
Bluetooth device	2 (7)
Specialized telemedicine device	2 (7)
Nintendo Wii	1 (3)
Voice-enabled device	1 (3)
Social media	1 (3)
Function	
Collecting personal health data[d]	13 (48)
Goal setting and tracking	17 (62)
Integrated survey and assessment	19 (70)

[a] Articles may be included within multiple categories.

[b] We did not include articles in which users could use videos to chat or communicate with providers.

[c] Telemedicine units or devices were included.

[d] Tracking of patient’s personal health data (data logs) and tracking of patient data by providers were included.

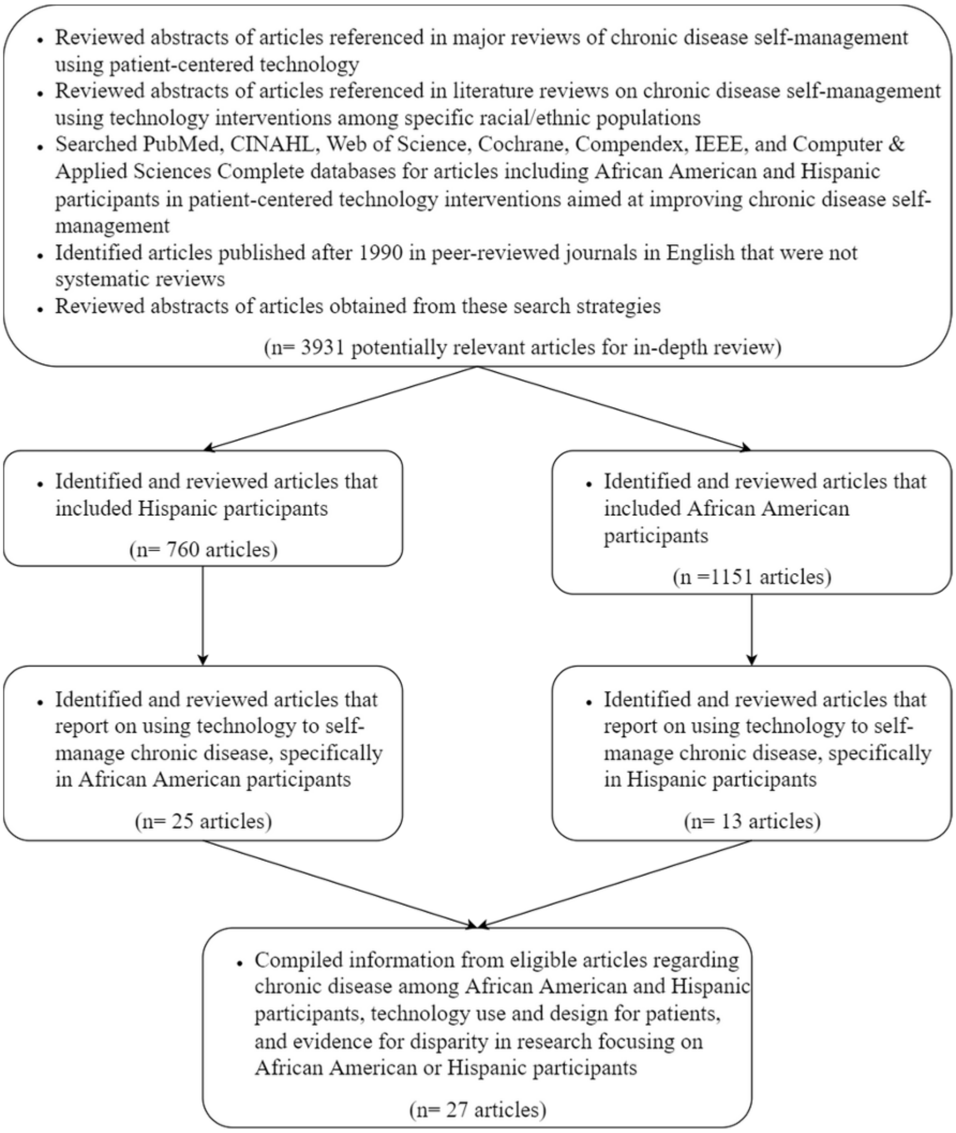
Results

Study Characteristics

A total of 25 eligible articles involving African American participants and 13 articles with Hispanic participants were identified. Of these, only 27 met our final criteria, as not all articles discussed technology use and design for patients (see PRISMA flowchart in Figure 1). All 27 articles were published between 1996 and 2018. The mean participant sample size was 640 (SD 209.5; 26/27, 96% of articles). Of the 27 included articles, 14 (52%) focused exclusively on African American patients, 4 (15%) focused on Hispanic patients, and 9 (33%) focused on both African American and Hispanic patients.

Each of the 27 included articles was examined for the risk of potential bias according to each of the 6 domains (Table 2).

Figure 1. PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flowchart.



- Reviewed abstracts of articles referenced in major reviews of chronic disease self-management using patient-centered technology
- Reviewed abstracts of articles referenced in literature reviews on chronic disease self-management using technology interventions among specific racial/ethnic populations
- Searched PubMed, CINAHL, Web of Science, Cochrane, Compendex, IEEE, and Computer & Applied Sciences Complete databases for articles including African American and Hispanic participants in patient-centered technology interventions aimed at improving chronic disease self-management
- Identified articles published after 1990 in peer-reviewed journals in English that were not systematic reviews
- Reviewed abstracts of articles obtained from these search strategies

(n= 3931 potentially relevant articles for in-depth review)

- Identified and reviewed articles that included Hispanic participants

(n= 760 articles)

- Identified and reviewed articles that included African American participants

(n =1151 articles)

- Identified and reviewed articles that report on using technology to self-manage chronic disease, specifically in African American participants

(n= 25 articles)

- Identified and reviewed articles that report on using technology to self-manage chronic disease, specifically in Hispanic participants

(n= 13 articles)

- Compiled information from eligible articles regarding chronic disease among African American and Hispanic participants, technology use and design for patients, and evidence for disparity in research focusing on African American or Hispanic participants

(n= 27 articles)

Table 2. Risk of bias in individual articles (N=27).

Study	Participants, n	Patients or caregivers involved in the design of technology	Incomplete outcome data[a]	Blinding of participants or personnel[b]	Other bias[c]
Almeida et al [32]	452	High	Low	Low	Not reported
Collins and Champion [33]	15	Not reported	Low	Low	Not reported
Davidson et al [34]	50	Low	Low	Low	Low
Davis et al [35]	51	Low	Low	High	Not reported
Finkelstein et al [36]	30	Not reported	Low	Low	Not reported
Finkelstein and Wood [37]	N/A[d]	High	High	Not reported	Low
Fortmann et al [38]	414	Low	Low	Low	Not reported
Friedman et al [39]	267	Not reported	Low	Low	Not reported
Gerber et al [40]	95	Not reported	Not reported	High	High
Green et al [41]	9298	Low	Low	Low	Low
Grimes et al [42]	12	Low	Not reported	High	Not reported
Heitkemper et al [30]	220	Low	High	Not reported	Not reported
Joseph et al [43]	29	Low	Low	Low	Not reported
Kline et al [44]	123	Not reported	Low	High	Not reported
MacDonell et al [45]	48	Low	High	Low	Low
Lin et al [46]	124	High	Low	Low	High
Mayberry et al [47]	19	Low	Low	High	Not reported
McGillicuddy et al [48]	12	Low	Low	Low	Not reported
Newton et al [49]	97	Not reported	High	Low	High
Nundy et al [50]	15	Not reported	Low	Not reported	Not reported
Reese et al [51]	14	Low	High	High	Not reported
Reininger et al [52]	71	Not reported	Low	High	Not reported
Rosal et al [53]	89	Low	Low	Low	Low
Shea [54]	1665	High	High	Low	Low
Skolarus et al [55]	94	Low	High	Low	Low
Trief et al [56]	1665	Low	Low	Low	Not reported
Weinstock et al [57]	1665	Low	Low	Low	Not reported

[a] Outcome data.

[b] Randomization or blinding of patients.

[c] Any other bias identified by the reviewers.

[d] N/A: not applicable.

Additional Analyses: Qualitative Synthesis

Articles that reported technology interventions and included self-management aimed at improving chronic disease outcomes using either clinical or behavioral outcomes were eligible for systematic review inclusion (Table 3). We chose content analysis for categorizing data into themes and counting their frequency based on our decision to count frequency of self-management behaviors [60]. We reported the following four specific self-management activities: medication behavior, physical activity, dietary behavior, and follow-up appointment attendance. The frequency of each self-management behavior was totaled by analyzing the included articles.

Table 3. Self-management behaviors in the included articles (N=27).

Study	Medication behavior	Follow-up appointment attendance	Physical activity	Dietary behavior
Almeida et al [32]	No	No	Yes	No
Collins and Champion [33]	No	No	Yes	Yes
Davidson et al [34]	Yes	No	No	No
Davis et al [35]	Yes	No	Yes	Yes
Finkelstein et al [36]	No	No	Yes	No
Finkelstein and Wood [37]	No	No	Yes	No
Fortmann et al [38]	Yes	No	Yes	Yes
Friedman et al [39]	Yes	No	No	No
Gerber et al [40]	No	No	Yes	Yes
Green et al [41]	Yes	Yes	No	No
Grimes et al [42]	No	No	No	Yes
Heitkemper et al [30]	Yes	No	Yes	Yes
Joseph et al [43]	No	No	Yes	No
Kline et al [44]	Yes	No	Yes	Yes
MacDonell et al [45]	Yes	No	No	No
Lin et al [46]	No	No	Yes	Yes
Mayberry et al [47]	Yes	No	Yes	Yes
McGillicuddy et al [48]	Yes	No	No	No
Newton et al [49]	No	No	Yes	Yes
Nundy et al [50]	Yes	Yes	No	Yes
Reese et al [51]	No	No	Yes	No
Reininger et al [52]	Yes	No	Yes	Yes
Rosal et al [53]	Yes	No	Yes	Yes
Shea [54]	Yes	No	No	No
Skolarus et al [55]	Yes	No	Yes	Yes
Trief et al [56]	Yes	Yes	No	Yes
Weinstock et al [57]	Yes	Yes	No	Yes

Study Selection

Other data recorded from the articles included the technology functions (Table 4), the type of technology used, the effectiveness of the technology, the number of participants enrolled, and the first author's last name (Multimedia Appendix 1). These were grouped together to reveal findings such as which technology was effective based on population and chronic disease type (Multimedia Appendix 1) [29,30,32-57].

Table 4. Technology functions in the included articles (N=27).

Study	Tracking by a patient or caregiver using technology	Tracking or viewing patient data by a patient or caregiver	Tracking of patient data by providers	Goal setting or tracking	Integrated surveys or assessments
Almeida et al [32]	No	No	Yes	Yes	No
Collins and Champion [33]	No	No	No	No	Yes
Davidson et al [34]	Yes	Yes	Yes	Yes	Yes
Davis et al [35]	No	No	No	Yes	Yes
Finkelstein et al [36]	No	Yes	Yes	Yes	No
Finkelstein and Wood [37]	No	Yes	Yes	Yes	No
Fortmann et al [38]	No	No	No	Yes	No
Friedman et al [39]	No	No	No	Yes	Yes
Gerber et al [40]	No	No	No	No	No
Green et al [41]	Yes	Yes	Yes	No	Yes
Grimes et al [42]	No	No	No	Yes	No
Heitkemper et al [30]	No	No	No	Yes	Yes
Joseph et al [43]	No	Yes	Yes	Yes	Yes
Kline et al [44]	No	No	No	No	Yes
MacDonell et al [45]	No	No	No	No	Yes
Lin et al [46]	No	Yes	Yes	Yes	No
Mayberry et al [47]	No	Yes[a]	No	Yes	Yes
McGillicuddy et al [48]	No	Yes	Yes	No	No
Newton et al [49]	No	Yes	Yes	No	Yes
Nundy et al [50]	Yes	No	Yes	No	Yes
Reese et al [51]	No	No	No	Yes	Yes
Reininger et al [52]	No	No	No	No	Yes
Rosal et al [53]	No	Yes	Yes	Yes	Yes
Shea [54]	No	Yes	Yes	No	Yes
Skolarus et al [55]	No	Yes	No	Yes	Yes
Trief et al [56]	No	Yes	Yes	Yes	Yes
Weinstock et al [57]	No	Yes	Yes	Yes	Yes
Total, n (%)	4 (14)	14 (51)	15 (55)	17 (62)	19 (70)

[a] Coaching of family members via phone was also conducted.

Health Outcomes Described in the Included Articles

Diabetes, hypertension, and heart failure were the three chronic conditions included in the resultant studies (N=27). Diabetes was the most common chronic disease among these studies. Of the total number of studies, 8 specifically tracked hemoglobin A_{1c} (HbA_{1c}) and blood pressure (BP) levels [30,35,38,44,54,56,57]. Only a study by Weinstock et al [57] reported statistical significance for both clinical outcomes. A study by Davis et al [35] reported increases in medication adherence and self-efficacy for diabetes medication behavior in African American patients. However, none of the results were statistically significant, and they did not report any clinical significance. The study by Weinstock et al [57] targeted A_{1c} reduction in Hispanic and African American patients. The intervention included a home telemedicine unit with a web-enabled camera for a videoconference consultation, which provided educational information. Results showed HbA_{1c} improvement for Hispanic patients; however, improvement was not statistically significant and clinical significance was not specified. A study by Shea [54] used a home telemedicine–specialized device for videoconferencing with a nurse to support HbA_{1c} and BP monitoring. The intervention reported clinically significant A_{1c} improvement (8.35%-7.42%), but the results were not statistically significant. A study by

Heitkemper et al [30] used a website and SMS text messages for diabetes management targeting African American and Hispanic patients. Use was low among participants because they rarely used the internet to search for health information; consequently, outcomes were not reported. In a study by Kline et al [44], the intervention was a culturally tailored guide for diabetes management targeting the Hispanic population. It included a telenovela with learning modules and games. However, specific clinical outcomes (eg, A_{1c}) were not reported, as the focus was on the development and feasibility of the intervention.

Hypertension was the next most common condition specified (ie, they focused on hypertension vs BP reporting). Three studies specified the goals of reducing hypertension [39,48,55]. However, none reported statistical or clinical significance. A study by Skolarus et al [55] used an SMS text messaging intervention with a faith-based collaborator and reported both systolic and diastolic BP for African American patients. Half of the participants reached BP targets. A study by McGillicuddy et al [48] used a mobile health intervention that targeted Hispanic patients to promote BP improvement through medication self-management support. The study reported statistically significant increases in medication adherence. A study by Davidson et al [34] reported statistically significant results in systolic and diastolic BP reduction in Hispanic and African American participants. The system used electronic medication dispensers and SMS text messages. It included Bluetooth-enabled BP monitors.

Heart failure was the third chronic disease that was the focus of one of the resultant studies. A study by Finkelstein and Wood [37] assessed the feasibility of an intervention that used a laptop and Nintendo Wii to support medication behavior in African American patients with heart failure. Although clinical outcomes were not reported, participants reported a high level of acceptance of the technology.

Discussion

Principal Findings

Given the development of HIT apps and considerable research in this area, a relatively small number of resultant articles (N=27) investigated associations between the use of HIT and chronic disease outcomes among African American and Hispanic patients. This is a vital gap because of persistent inequity in chronic disease outcomes for racial minority populations and because intention to use HIT designed for chronic disease self-management is most predicted by performance expectancy, followed by social influence [61]. Researchers of HIT acceptance and use for chronic disease self-management should incorporate health outcomes in investigations, particularly outcomes commonly used to report racial inequity. Of the 27 articles, a majority addressed 3 of the 4 self-management behaviors investigated: medication behavior (17/27, 63%), physical activity (17/27, 63%), and dietary behavior (16/27, 59%). However, only a few (4/27, 15%) focused on follow-up appointment attendance. This is an area that warrants investigation and development of capabilities because HIT may be well-positioned to mitigate known causes of missed appointments, which is a persistent issue among racial minority populations who experience persistent inequity, such as Latinx immigrants and low-income African American patients in urban settings: forgetfulness, transportation barriers, family and employer obligations, and anticipated long clinic wait times [62-64]. Investigating and alleviating barriers to appointment attendance is important because ethnic minority patients are more likely to have low income and live in urban areas, two factors that are associated with the frequency of missing primary care appointments [65-67].

All the articles investigated HIT designed with capabilities to access or use at the patient's home, whereas only 2 articles also included use in the hospital. This is concordant with the movement of developing HIT for use in patients' homes versus hospitals [68]. The risk of misuse of HIT is segmented according to environmental, human, and technological factors [69]. The number of different users is associated with the risk of misuse because users may have various levels of education, instruction, or training. Thus, the risk of misuse is higher in home care settings when compared with hospital care settings [68]. Developers should consider the known risks of misuse and the number of users in home care settings for African American and Hispanic patients, given that individuals from racial minority populations have different attitudes than White patients regarding technology innovations in health care, and these factors predict HIT acceptance [18].

Various technologies are included in the resultant articles, except for the landline telephone, in which none of the articles were investigated. This follows the broad trend that more than half of US households are reliant on mobile phones and do not have landlines. In addition, Hispanic and Black adults are more likely than White adults to live in households with only mobile phones [70].

The collecting and tracking of personal health data, which over 10% of users are doing on behalf of someone else (eg, caregivers), and goal setting and evaluation are pertinent capabilities that are closely related to self-management behavior [71,72]. In addition, given the association of social influence with intention to use HIT, caregivers and other members of the patient's network should be incorporated into the design of HIT. This may be especially pertinent for Black women who report feeling responsible for providing emotional and tangible support to homebound parents who may live in the home [73]. In fact, incorporating shared tracking use should inform HIT design, and models have been created that reflect the interplay of social context and health tracking [71].

Insights derived from this study of the 27 resultant articles reveal the potential for future development and evaluation of HIT tools in two distinct areas—known barriers faced by members of ethnic minority groups in using HIT and the unique barriers they may face in following self-management recommendations. For example, in a limited sample size, a mobile phone–based intervention that combined SMS text messaging with nursing care showed improvement in following recommended self-management behavior (ie, medication behavior, glucose monitoring, foot care, physical activity, and dietary behavior) for Black adults with diabetes [74]. In addition, a diabetes self-management education intervention for medically underserved populations showed specific impact on outcomes that are characterized by racial disparities and HbA_{1c} improvement at 6 and 12 months [30].

Despite these important findings, more specific research is needed to elucidate the sociocultural factors that in particular are known to impact HIT acceptance and use [75]. For example, the level of trust is associated with HIT acceptance and use in the context of diabetes self-management [76-78]. Moreover, factors for older adults from racial minority groups should be specifically investigated because they are less likely than individuals who do not belong to racial minority groups to use health management sites and search the web for health information to support chronic disease self-management [79]. Finally, investigations of HIT acceptance, use, and impact on self-management and outcomes should be conducted with larger samples. Despite considerable literature on drivers of inequity and the emergent literature describing the potential for HIT to support chronic disease self-management, the literature suggests that persistent disparities in chronic disease outcomes are in part because of the lack of large-scale, HIT-enabled interventions that support following self-management recommendations and report impact on outcomes [75,80-82]. In addition, given the limited reporting of clinical outcomes that inform equity measures (eg, HbA_{1c}), more research is needed to understand if or how access and then use may impact following recommended self-management behavior and subsequent outcomes. Doing so may reveal critical insights to associate HIT access with outcomes, particularly imperative given persistent barriers to technology acceptability and use [75].

This study has a key limitation. We only examined articles that specified Black and Hispanic users. Specific cultural factors may emerge from a broader examination, given that various cultural factors influence both technology acceptance and use (eg, practices, customs, language, and communication) [82,83]. Understanding cultural factors is essential because they can influence the way an individual interprets health information, how they define symptoms, and if and who they decide should provide them care [75]. Therefore, individuals' sociocultural factors must be considered in the design and use of *culturally informed HIT* [84]. This insight is vital because cultural competence is specified as a critical aspect in developing technology to help reduce health inequity globally; in fact, this has become a popular concept in various countries for improving quality of care, specifically access to respectful and responsive health care [85].

Conclusions

The proliferation of technology-enabled tools designed to support people in following recommendations for chronic disease self-management has outpaced the research describing the degree to which the Black and Hispanic populations use this technology to support self-management behavior. Although factors driving the general use among the Black and Hispanic populations continue to be investigated, little is known about their impact on health outcomes because of their use. In this paper, we have helped to address this important gap because various technology skills are required to use consumer-oriented HIT designed to support recommended self-management and doing so may require considerable effort from the patients [86]. For example, deciphering the vast and growing amount of information requires that individuals access, assess, and organize various health information. To help elucidate gaps in the literature, we conducted this systematic review to understand the extant literature concerning the use of ICTs among Hispanic and Black people to support chronic disease self-management and highlight potential gaps.

Acknowledgments

The authors would like to acknowledge the health sciences librarians from Rutgers University who assisted in refining our search strategy, specifically Lilyana Todorinova.

Conflicts of Interest

None declared.

Multimedia Appendix 1

A list of search strings and their corresponding databases, the care setting and self-management behavior for each included article, and technology effectiveness in managing chronic disease for each included article.
[DOCX File , 29 KB-Multimedia Appendix 1]

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Abbreviations

BP: blood pressure
HbA$_{1c}$: hemoglobin A$_{1c}$
HIT: health information technology
ICT: information and communication technology
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

Edited by G Eysenbach; submitted 03.07.20; peer-reviewed by R Newton, M Peeples; comments to author 18.08.20; revised version received 25.09.20; accepted 23.01.22; published 04.04.22

Please cite as:
Senteio C, Murdock PJ
The Efficacy of Health Information Technology in Supporting Health Equity for Black and Hispanic Patients With Chronic Diseases: Systematic Review
J Med Internet Res 2022;24(4):e22124
URL: https://www.jmir.org/2022/4/e22124
doi: 10.2196/22124
PMID: