Electronic Communication between Children's Caregivers and Health Care Team: a scoping review on parental caregiver's perceptions & experience

Mary J Gamper, Rebecca Singer Cohen, Maryam Esperanza Razaz, Elaina Parrillo, Clifton Thornton, Aleksandra Wec, Kathryn McDonald, Kelly T. Gleason

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Abstract

Background: Asynchronous communication via electronic modes (e-communication), including patient portals, secure messaging services, text messaging, and e-mail, is increasingly used to supplement synchronous face-to-face medical visits; however, little is known about its quality in pediatric settings.

Objective: To summarize contemporary literature on pediatric caregivers' experiences with and perspectives of e-communication with their child's healthcare team to identify how e-communication has been optimized to improve patient care.

Methods: A scoping review following Arksey and O-Malley's methodological framework searched PubMed, CINAHL, Embase, and Web of Science using terms such as "Electronic Health Records" and "Communication" spanning 2013-2023 that discussed caregiver experiences and perspectives of e-communication with their child's healthcare provider. Studies were excluded if they were abstracts, non-English, non-scientific papers, systematic reviews, quality improvement initiatives, and pertained to synchronous telemedicine. We conducted a two-step screening process involving title and abstract scans and full-text reviews by two independent screeners to confirm eligibility. From an initial 903 articles identified via database search, 23 articles fulfilled all inclusion criteria and are included in this review.

Results: Of the 23 articles meeting inclusion criteria, 11 used quantitative methods, 7 used qualitative methods, and 5 used mixed methods. Caregiver sample sizes ranged from 51 to 3339 in quantitative studies and 8 to 36 in qualitative and mixed-method studies. A majority (n=17) used the patient portal as self-categorized by the study. Secure messaging through a portal or other mobile health application was used in 26% of the studies (n=6), while non-secure messaging outside of the portal was used 17% of the time (n=4) and e-mail was used one-third (n=8) of the time. In 19 of the studies, parents reported positive experiences with and a desire for e-communication methods.

Conclusions: The literature overwhelmingly supported caregiver satisfaction with and desire for e-communication in healthcare, but no literature intentionally studied how to improve the quality of e-communication, which is a critical gap to address.

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Keywords: Electronic Communication, Patient portal, E-mail, Provider-Patient Relations, Parental caregiver, Relational coordination theory

Introduction

In pediatric healthcare, effective communication within the caregiver-clinician relationship is pivotal to enhancing illness understanding, promoting treatment adherence, and fostering improved experiences.[1-4] Asynchronous electronic communication (e-communication), through patient portals, secure messaging, email, and text messaging, is increasingly used to supplement synchronous face-to-face medical visits.[5] However, little is known about the quality of e-communication in pediatric settings.

Despite acceleration of e-communication following the COVID-19 pandemic and the 21st Century Cures Act mandating the sharing of clinical notes with patients, there is limited evidence on best practices, and what evidence does exist may not be applicable to the specific needs of caregivers of patients with complex needs, of children, or of both.[6-10] Limited research exists on how parental caregivers (hereinafter "caregivers") perceive e-communication, particularly concerning its quality and perceived impact on care delivery.[2,6]

The theory of Relational Coordination is particularly applicable to exploring e-communication between parental caregivers and the healthcare team. It has been shown to be generalizable across teams performing highly interdependent work, such as caring for a child, mediated through seven domains: relationships of shared goals, shared knowledge, and mutual respect, supported by frequent, timely, accurate, and problem-solving communication.[11,12]

This review was undertaken to synthesize contemporary literature on pediatric caregivers' perspectives of e-communication with their child's healthcare team. We aim to: (1) identify modes of caregiver-healthcare team e-communication; (2) assess caregiver perspectives on e-communication experiences or expectations; and (3) map findings from such studies to Relational Coordination domains to better understand its role in effective e-communication and how it may be leveraged to alter delivery of care systems and patient and caregiver satisfaction. The overall purpose of our study was to characterize the objectives, therapeutic elements, and delivery characteristics of e-communication as a step toward informing intervention development, healthcare practices and policies, and caregiver and healthcare team

workflows.

Methods

We conducted a scoping review that followed Arksey and O-Malley's[13] methodological framework and the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA)[14] extension for a scoping review checklist. We used the communication domains of the Relational Coordination Theory to guide article synthesis.[11,12]

Study Identification

The search strategy was iteratively developed in consultation with an experienced medical librarian (Supplement 1) and conducted in February 2023. We searched PubMed, CINAHL, Embase, and Web of Science using relevant search terms and MeSH headings (Supplement 2).

We included studies within a 10-year timeframe that discussed caregiver experiences and perspectives of e-communication with their child's healthcare provider. E-communication was defined as web-based technology that allows for asynchronous communication between a caregiver and provider, such as patient portals tethered to electronic health records (EHR) with or without access to clinical notes, secure messaging, non-secure messaging (personal mobile, non-secure short text messages (SMS), WhatsApp), and e-mail. We defined caregiver as the child's primary caregiver and decision-maker. Healthcare team was defined as medical professionals from various disciplines who provide comprehensive care to children, including registered nurses, nurse practitioners, physician assistants, and physicians. We limited the children's age to 0 through 13 years due to legal, access, and privacy issues for older, adolescent patients.[10,15]

Studies were excluded if they were abstracts, non-English, non-scientific papers, systematic reviews, quality improvement initiatives, or pertained to synchronous telemedicine.

Article Selection

We used Covidence literature review software to conduct a two-step screening process involving title and abstract scans and full-text reviews by two independent screeners to confirm eligibility.

Reviewers discussed discrepancies as a group to reach consensus. Figure 1 shows the study selection process in a PRISMA diagram.[14]

Study Synthesis

The approach to summarizing and reporting on findings from identified articles varied by research question (RQ). We first compiled articles that assessed caregiver-healthcare team e-communication (RQ1) by focusing on key parameters, such as year, setting, population, and mode of e-communication.[16] We then performed a thematic analysis to synthesize information from articles that reported on caregiver satisfaction related to e-communication (RQ2) and the seven Relational Coordination domains (RQ3). Analysis pertaining to RQ2 and RQ3 involved mapping findings of mode of e-communication onto the Relational Coordination domains, under the hypothesis that the higher the number of Relational Coordination domains identified per article, the higher the caregiver satisfaction.[11]

Results

In total, 903 articles were identified via database search. After duplicates were removed, 658 articles remained for title and abstract screening. Eighty-seven percent (571/659) of the articles were excluded, resulting in 87 full-text studies assessed for eligibility. During full-text review, 74% (64/87) of the articles were excluded, which resulted in 23 articles included in this review.

Basic Characteristics of the Literature

Characteristics of included articles are summarized in 21 and individually presented in Supplement 1. Of the 23 articles included in this review, 11 used quantitative methods, 7 used qualitative methods, and 5 used mixed methods. Sixteen studies were conducted in the United States and one-third (8 [34.7%]) were published after 2020. Half of the studies were conducted in an ambulatory setting (13 [56.5%]) with the next most frequent location being an inpatient setting (8 [34.7%]), of which two were in the neonatal intensive care unit. Only four (17.4%) were conducted in the community setting. One-third (7 [30.4%]) of the studies involved populations with chronic illness or complex medical needs. Half (12 [52.2%]) of studies included participants in addition to caregivers, such as healthcare providers, adult

patients, and teachers. Caregiver sample sizes ranged from 51 to 3339 in quantitative studies and 8 to 36 in qualitative and mixed-method studies. Over half of the 11 caregiver-only studies were comprised of 80% or greater female participants.

Modes of Communication

The studies were assessed for mode of e-communication utilized for caregiver-healthcare team communication and may include more than one mode (Table 2; Supplement 3). A majority (n=17) used the patient portal as self-categorized by the study. Secure messaging through a portal or other mobile health application was used in 26% of the studies (n=6), while non-secure messaging outside of the portal was used 17% of the time (n=4) and e-mail was used one third (n=8) of the time. Healthcare team phone messaging services and facsimiles were cited at 13% (n=3) and 4% (n=1), respectively. Notably, secure messaging was not described in studies prior to 2016, however, patient portals and e-mail were actively referenced throughout the entire study time period and could have included secure messaging. Correspondingly, SMS did not appear in studies after 2021.

Caregiver Experiences and Expectations for E-Communication in Pediatric Healthcare

Overall, when studies are evaluated for positive versus negative caregiver experiences with e-communication use, a majority (87%, n=20) identified positive experiences, with three studies finding more negative impressions of e-communication primarily due to cumbersome electronic system interface, not specifically the quality of communication. [17-19]

Caregiver utilization of e-communication methods varied widely between different studies, but some common themes about experience emerged. Satisfaction with enhanced access to patient information was identified in 18 studies. For example, in a national cross-sectional survey of parents' perspectives on the use of patient portals for their children's health care, over half the participants reported using a portal for their child for patient care tasks such as viewing labs.[20] An added benefit was that the interface could perform business tasks such as scheduling or requesting referrals. In another, mothers of newborns in the NICU reported that portal messaging, email, or texting aided in connecting

with their infant, understanding their infant's health condition and ability to provide care after discharge, and improved the speed, clarity, and anxiety around communication with the healthcare team; however, almost half still preferred face-to-face communication.[21] In a qualitative study involving semi-structured interviews, caregivers who were provided with clinical information via an inpatient portal during their child's hospitalization reported improved ability to remember their child's care plan, to understand their child's health condition, and to better prepare themselves for in-person conversations with the healthcare team in advance of rounds.[22]

Other studies more explicitly looked at the exchange of, rather than receipt of, information in e-communication. In a qualitative interview study, parents of children with chronic illnesses found that e-communication through secure messaging within a portal was advantageous because it eliminated barriers to getting answers to questions.[23] It also fostered feelings of control and independence, alleviated anxiety, and offered reassurance. A drawback of e-communication for parents in this study was the access to information that might be "worrisome" without face-to-face explanation.

Three studies focused on the caregivers' perceptions of reading their child's electronic progress notes.[24-26] One survey found that access to their child's clinical progress note positively impacted caregivers' level of "confidence and trust" in their healthcare and enabled caregivers to feel like a "part of that team."[26] In qualitative focus groups, an inpatient-facing study found that caregivers believed that communication via access to clinical notes would "enhance the partnership and collaboration" between caregivers and the healthcare team and support higher standards for communication accuracy and accountability.[24] A survey on the impact of clinical notes being made available online to patients on the patient-physician relationship demonstrated that a parent's perception of their child's physician was generally positive with access to notes and 15% of parents used the ability to contact their provider about something they read in the note.[25]

Three studies focused on the impact and satisfaction that SMS has on parental caregivers. An intervention focused on sending updates to parents via SMS regarding clinical updates significantly

improved parental satisfaction with the medical treatment, the information provided, and the communication with their NICU-admitted infants' medical staff. Parents also indicated perceived improvements in medical staff's availability, patience, approachability and trust, post-intervention. In a recent mixed-methods study evaluating the use of a non-EHR tethered secure messaging system compared to emails and phone calls, caregivers enjoyed the "laid-back, casual quick messages" of SMS; however, they felt email was most convenient because they were already logged into their email and they could "communicate with multiple providers at the same time."[27] In a study involving an intervention of Web-based chat consultation with resident physicians, caregivers felt their concerns and questions were "well handled" by the extra time with providers via the Web-chat, despite it not being face-to-face.[28]

Two additional studies focused on attitudes specifically toward emailing the child's health care team. A majority (78%) of caregivers from a 2013 cross-sectional study in an urban pediatric primary care clinic showed interest in communicating with their child's providers by this method and attitudes were favorable, with three-quarters of email users reporting that it would improve communication with their provider. [29] A mixed-methods study which elicited parents' perspectives on this topic for informing medical student training found that most participants placed high value on a provider's "ability to communicate, respectfully, and empathetically in email."[30]

For the three studies that discussed the needs of parents of children with complex needs, the modes of e-communication involved patient portal, secure messaging, email, and SMS, which were universally believed to enhance the patient/caregiver and healthcare team relationship.[17,18,27] However, a theme of operational barriers emerged from each study. For example, a lack of integration and interoperability of e-communication systems within and across institutions and professions was found to add considerable effort to both the caregivers and healthcare team.[18]

Evidence of Relational Coordination Concepts

Of the seven concepts of the Relational Coordination Theory, "timely" e-communication was identified as a key characteristic in a majority of the studies (n=20),[31] followed by relationships with

"shared knowledge" (n=16) (Table 2). Thematic analysis noted "accurate" communication in approximately two thirds of the studies (n=14), and both "frequent" communication and relationships with "shared goals" were associated with half (n=11). Relationship with "mutual respect" was detected in fewer than half the references (n=10) and "problem-solving" communication was only identified in a quarter of the references (n=6). Four references, each quantitative in design, were only coded for the "timely" Relational Coordination domain.[29,32-34] One reference did not demonstrate evidence of Relational Coordination concepts.[20]

Discussion

This scoping review included 23 articles and identified a small body of literature from the last decade regarding parental caregiver's perspectives on e-communication between themselves and their child's healthcare team. Overwhelmingly parents reported positive experiences with and a desire for e-communication methods. This is particularly relevant to the times as the 21st Century Cures Act[9] has made clinical notes and results, including key laboratory results, much more likely to be shared asynchronously with patients/caregivers outside of face-to-face visits. However, there is sparse data on how parents/caregivers perceive such new platforms of communication, given that only 5 out of 23 studies include analysis of access to clinical notes. Overall, the collective findings did identify that caregivers had generally positive experiences with e-communication. The negative perceptions were due to communication barriers that included workflow and technology malfunctions or underdevelopment, thus they did not explicitly pertain to context or quality of communication between caregiver and clincian.

The literature spans care settings, illness acuity, and includes chronic, primary and specialty care. Female caregivers were the most prevalent among the caregiver populations studied. Most studies examined lived experiences of participants, while a small number addressed anticipated expectations.[21,24,30] Although most studies had aims centered around the theme of caregiver perceptions of communication via various modes of e-communication with their child's healthcare team, it is almost impossible to look across studies in a systematic way for factors to improve the caregiver perception,

given the lack of standardized measures for quality of e-communication.

While the literature holds that patients/caregivers are increasingly using e-communication in the last decade to communicate with their healthcare team, little is known about the characteristics and quality of the conversations that occur and whether the quality of the conversations impacts outcomes.[35,36] In rare examples where content of e-communication has been analyzed, differences have been identified compared to in person communication. For example, e-communication via online portal at a large medical center between adult patients and their providers contained a decreased frequency of language reflecting partnership building or supportive talk compared to in-person conversations (Alpert 2017). This study did not measure the effects of this difference, but it is reasonable to expect it could negatively impact perceived quality. Since evidence exists within non-electronic communication (ie. face-to-face communication) about how specific content affects perceived quality,[6] it is important to determine if those same characteristics and quality preferences apply to e-communication.

Although different modes of communication were studied, trends in preference for mode of e-communication may have changed over time due to increased use of and advances in EHRs and patient portals in the last several years.[37] However, none of the studies necessarily explored whether EHRs and patient portals were the primary modes of communication being routinely utilized. For example, a study may have specifically been asking about patient portals, but the caregiver and healthcare team may actually communicate most often via non-encrypted text messaging. Text messaging a healthcare team member's personal cell phone, as opposed to using secure messaging service through a portal or web-based app, was not evident in this literature search, however, the practice is commonplace.[38]

The seven key domains of the Relational Coordination Theory are present in part in a majority of this literature, though no study specifically used Relational Coordination Theory to aid in conceptualization, measures of communication, or design of tools or interventions to improve e-communication. Yet, Relational Coordination domains are evident in both quantitative and qualitative studies, which is an indication that these communication domains are broadly relevant to the perceived

quality of a child's healthcare across e-communication modalities. Given the applicability of Relational Coordination Theory to parental caregiver communication with healthcare teams, future work which explicitly applies the theory to examine e-communication may shed light on how e-communication methods affect the quality of communication.

There are limitations on our ability to generalize the findings of this review to the national landscape of patient portals, as the majority of studies were conducted at academic healthcare institutes. This introduces a potential bias in the sample, as academic healthcare institutes may have different patient populations, resources to support an EMR/portal, and communication practices compared to other types of healthcare settings (e.g., community hospitals, private practices). There was an absence on literature on nonsecure text messaging despite its widespread use. Further, while not restricting studies by country enhances diversity in the review, healthcare, communication, and e-communication practices vary across countries, which may also affect generalizability.

Populations in this scoping review were not diverse in gender, with possible underrepresentation of male caregivers in a majority of the studies. The rationale for this sex difference in contemporary research was not explained in any of the studies but likely represented convenience sampling. However, fathers, particularly fathers from disadvantaged backgrounds, have historically been underrepresented in pediatric research and their lack of recruitment may impede our understanding of paternal effects on children's health and the development of effective family interventions.[39]

The participants were not diverse in origins, cultures, and native languages which appears to be due to language-based inclusion/exclusion criteria cited in some studies, as well as racial and ethnic disparities in technology needed for patient portal offers, access, and use.[40] Workarounds to language barriers might include use of automated translation software, such as Google Translate, by caregivers or providers to attempt to facilitate asynchronous e-communication; however, the translation is not accurate across languages and only contributes to worsening of health inequity.[41,42] Since the perspectives

identified in the studies reflect English language speakers, caregivers from other linguistic or cultural backgrounds might have different expectations or priorities for e-communication.

Finally, the lack of representation of the independent child voice in the review is a significant limitation. By primarily focusing on caregivers, the review may not fully capture the perspectives and preferences of the primary participant in pediatric care—the patients themselves who may have high digital literacy. Measurement of children's views in communication, particularly in adolescents and young adults, and their impact on outcomes and experiences is crucial for a comprehensive understanding of pediatric e-communication dynamics.

Conclusions

This review provides a foundation for understanding the evidence base regarding how e-communication may be used to drive improved patient outcomes, experiences, or healthcare system workflows. The gap in the literature regarding pediatric caregiver and healthcare team e-communication, specifically the lack of evaluation of the quality of the communication from the caregiver perspective, is urgent to address given the rapid proliferation of e-communication in healthcare.[37] Investigating this critical void can contribute valuable insights to healthcare policy and practice guidelines. As e-communication tools become increasingly integrated into healthcare delivery, understanding the needs, preferences, and experiences of caregivers is essential for optimizing communication quality and enhancing experiences.

Declarations and Statements

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Conflicting Interests

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Figure 1. PRISMA flow diagram showing literature search and study inclusion.

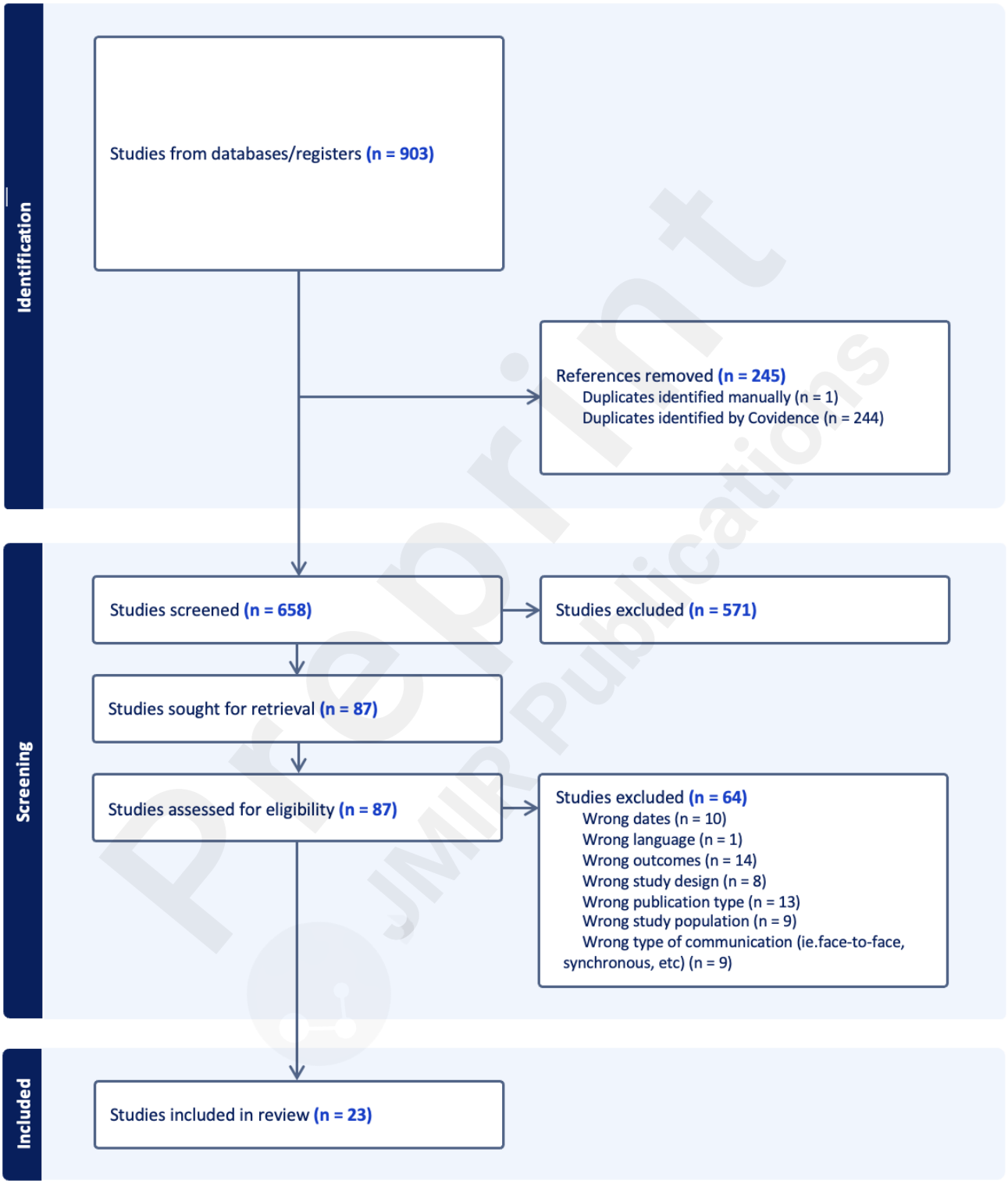

Table 1. Basic characteristics of literature.

	Overall N=23		EHR/ Patient Portal N=17		Other ^ N=13	
	n	(%)	n	(%)	n	(%)
Year						
2013-2016	8	(34.8)	6	(75.0)	5	(62.5)
2017-2020	7	(30.4)	5	(71.4)	4	(57.1)
2021-2023	8	(34.8)	6	(75.0)	4	(50.0)
Study Design						
Quantitative	11	(47.8)	8	(72.7)	6	(54.5)
Qualitative	7	(30.4)	6	(85.7)	3	(42.9)
Mixed-methods	5	(21.7)	3	(60.0)	4	(80.0)
Participants						
Parents	23	(100.0)	17	(73.9)	13	(56.5)
Health care worker	9	(39.1)	5	(55.6)	6	(66.7)
Adult patient	1	(4.3)	1	(100.0)	0	0.0
Teacher	1	(4.3)	0	0.0	1	(100.0)
Setting						
Ambulatory	13	(56.5)	11	(84.6)	7	(53.8)
Inpatient / ICU	8	(34.8)	7	(87.5)	4	(50.0)
Community-based	4	(17.4)	2	(50.0)	4	(100.0)
Web-based	1	(4.3)	0	0.0	1	(100.0)
Mode of e-communication						
EHR/Patient portal	17	(73.9)				
Secure messaging	6	(26.1)				
E-mail	8	(34.7)				
Non-secure text messaging	4	(17.4)				
Phone	3	(13.0)				
Other	2	(9.7)				

Table 1 Legend. Individual studies may have more than one category of Participants, Setting, or Mode of e-communication, so Overall % corresponds to n/23 studies. The columns EHR/Patient Portal and Other (any mode that is not EHR/Patient Portal as described by a study) may add up to more than the number of Overall studies in a row since studies may include more than one mode of e-communication. The % in those columns is the number of studies/number of overall studies in the corresponding row. ^. Other includes secure messaging (n=6), email (n=8), SMS (n=4), phone (n=3), fax (n=1), webchat (n=1).

Table 2. Evidence of Relational Coordination Theory concepts in the literature.

							7 Domains of Relational Coordination						
	Mode of Communication						Relationships with:			Communication with:			
Author, Year	EHR/Portal	Secure messaging	Email	Text messaging	Phone	Other	Shared goals n=11	Shared knowledge n=16	Mutual respect n=10	Frequent n=11	Timely n=20	Accurate n=14	Problem-solving n = 6
Britto, 2013	l						X	X	X	X	X	X	X
Clark, 2015	l												
Fiks, 2015	l						X	X			X	X	
Aldekhyyel, 2018	l										X	X	
Kelly, 2019	l						X	X	X	X	X	X	X
Amirav, 2020	l							X				X	
Bell, 2021	l						X	X	X	X	X	X	
Kelly, 2021	l						X	X	X	X	X	X	
Sarabu, 2021	l							X	X		X	X	
Smith, 2022	l						X	X	X	X	X	X	X
King, 2017	l	n						X			X		
Kelly, 2023	l	n					X	X	X	X	X	X	
Weatherly, 2019	l	n			p						X	X	
Nadia, 2022	l	n	m								X		
Weems, 2016	l	n	m	t			X	X		X	X		
Dudas, 2013	l		m	t							X		
Horsky, 2014	l		m		p	v	X	X			X	X	X
Parpia, 2021		n	m		p		X	X	X	X	X		X
Schiller, 2013			m				X	X	X	X	X	X	X
deJong, 2017			m								X		
Adams, 2021			m	t				X	X	X	X		
Globus, 2016				t				X		X		X	
Kaskinen, 2018						v					X		

l	EHR/portak
n	secure messaging
m	email
t	text messaging
p	phone
v	other

Supplement 1. Studies on electronic communication between parental caregivers and their child's health care providers.

Author	Year	Title	Study Design	Study Aim	Study Participants	Setting	Institution	Duration	Main Findings
Amirav, I[43]	2020	An Asthma Specialist's Consult Letter: What Do Parents Think about Receiving a Copy?	Quantitative	To examine parents' perceptions about receiving a hard copy EMR-generated letter from a pediatric pulmonologist at the end of their child's first asthma consult visit.	Parents of children (n=51)	Ambulatory	Not disclosed	12 months	Parents value and want to receive a hard copy of their child's asthma specialist'sEMR-generated summary letter at the end of the visit, and they would like to receive information of this nature from other clinicians
Bell, S[26]	2021	Tackling Ambulatory Safety Risks Through Patient Engagement: What 10,000 Patients and Families Say About Safety-Related Knowledge, Behaviors, and Attitudes After Reading Visit Notes	Quantitative	Systematically examine the effect of reading notes on patient and family perceptions of safety-related knowledge, behaviors, and attitudes	Parents/ guardians of pediatric patients (n=3339); Adult patients (n=6913)	Ambulatory (1 adult, 1 pediatric)	Not disclosed	4 months	Transparent visit notes can engage patients and families in at least some areas of ambulatory risk
Clark, S[44]	2015	A National Survey of Parent Perspectives on Use of Patient Portals for Their Children's Health Care	Quantitative	To assess parents' current utilization and future willingness to use patient portals to conduct business and patient care activities for their child	Parents of children 0-17 years (n=1420)	Ambulatory	National survey	Not disclosed	Patient portals are not currently a significant mode of parent-provider interactions in the pediatric setting

deJong, N[32]	2017	Enhanced Access and Parents' Preferred Contact fora Child's Chronic Condition	Quantitative	To assess whether the perception of enhanced access by parents in their child's primary care and main specialty practices is associated with preference for contacting either practice when problems arise with a child's chronic condition	Parents whose children <18 years use both primary and specialty practices (n=609)	Ambulatory	Tertiary-care children's hospital in southeastern US	2 months	We found that a majority of parents would prefer to contact a specialist with concerns about a child's chronic condition exacerbation and that preference was related to perception of enhanced access at the child's main specialist practice
Dudas, R[29]	2013	Pediatric Caregiver Attitudes Toward Email Communication: Survey in an Urban Primary Care Setting	Quantitative	To document pediatric caregiver attitudes toward and access to these technologies in an urban pediatric primary care clinic	Pediatric caregiver-Child aged 0-21 year dyads (n=229)	Ambulatory	Johns Hopkins University	14 months	Most caregivers in our urban population have access to email and are interested in communicating with their child's providers by this method, although only 11% currently communicate with their provider via email. Overall, attitudes toward email were favorable with three-quarters of email users reporting that email would improve communication with their provider and be satisfying
Fiks, A[45]	2015	Parent-Reported Outcomes of a Shared Decision-Making Portal in Asthma: A Practice-Based RCT	Quantitative	Test the feasibility, acceptability, and impact of an innovative, EHR-linked patient portal with decision support directed at both families and clinicians on asthma outcomes	Parents/legal guardians of children aged 6-12 years (n=60)	Ambulatory (1 urban, 1 suburban)	The Children's Hospital of Philadelphia	12 months	Use of an EHR-linked asthma portal was feasible and acceptable to families and improved clinically meaningful outcomes

Globus, O[46]	2016	The use of short message services (SMS) to provide medical updating to parents in the NICU	Quantitative	To evaluate the impact of using SMS technology for updating parents of preterm infants with medical information on parents and nursing staff to increase parent's satisfaction and parent-staff communication	Parents of infants hospitalized in the NICU (n=91); Nurses (n=47)	NICU	Sheba Medical Center	Not disclosed	SMS updating is an easy and user-friendly technology that enriches the modalities of information delivery to parents of hospitalized preterm infants
Kaskinen, A[28]	2018	Pediatric Web-Based Chat Services for Caregivers of Children: Descriptive Study	Quantitative	To describe chat conversations between caregivers and physicians in a Web-based chat service to determine the factors that should be considered when planning a similar chat service. To evaluate whether caregivers considered the consultations helpful, whether physicians considered they could answer caregivers' questions, and whether further face-to-face medical contact was needed	Caregivers of children (n=98)	Web-based	Private medical center for children in the greater Helsinki area	18 months	Both caregivers and physicians considered that the concerns and questions of caregivers of children were well handled in a external consultation service Web-based chat
Nadia, B[34]	2022	Has Telemedicine come to Fruition? Parents' and Physicians' Perceptions and Preferences Regarding Telemedicine	Quantitative	To evaluate both patient and physician perceptions, preferences, and acceptability regarding the use of the different modalities of telemedicine for various health problems	Parents of children (n=222), Pediatrician (n=45)	Ambulatory	University of Geneva	12 months	Parents preferred the telephone for simple medical advice, discussion of parameters, acute or chronic problems, and psychological support

Sarabu, C[25]	2021	The Value of OpenNotes for Pediatric Patients, Their Families and Impact on the Patient-Physician Relationship	Quantitative	To better understand how pediatric patients and families perceived OpenNotes	Parents of children <12 years (n=159)	Ambulatory	Stanford Children's Health	5 month	Majority of patients and families understood their notes; they largely found them accurate; most did not contact their clinicians after reading a note; and the majority found that reading their notes improved trust with their clinician
Weems, M[21]	2016	Electronic communication preferences among mothers in the neonatal intensive care unit	Quantitative	To assess the use of online and mobile communication platforms among mothers of NICU infants and their interest and preferences in receiving electronic clinical updates during the NICU stay using available technology	Mothers of infants admitted to the NICU (n=217)	NICU (2)	Regional One Health, Le Bonheur Children's Hospital	3 months	Mobile technology is widely used by this population of NICU mothers and could be a powerful tool to help mothers cope and care for infants during and after admission to the NICU
Adams, S[17]	2021	Perspectives on team communication challenges in caring for children with medical complexity	Qualitative	Explore communication challenges and solutions/recommendations from multiple perspectives (parents of children with medical complexity, health care providers, teachers) with a goal of informing patient care	Primary caregivers of a medically complex child (n=17), Health care provider (n=11), Teachers (n=5)	Community	Hospital for Sick Children, Credit Valley Hospital, and Royal Victoria Regional Health Centre	18 months	There were three types of communication challenges described by parents, HCPs, and teachers: 1) Organizational policy and antiquated technology system barriers, 2) Inadequate access to health information and 3) Lack of partnership in clinical decision making

Britto, M[23]	2013	Parents' Perceptions of a Patient Portal for Managing Their Child's Chronic Illness	Qualitative	To examine parents' perceptions of the benefits and/or drawbacks of a patient portal for managing their child's chronic illness	Parents of child aged <18 years diagnosed with chronic illness (n=24)	Ambulatory	Cincinnati Children's Hospital	Not disclosed	Reported perceived portal benefits include removing barriers to communication, reducing hassles, maximizing convenience, providing a sense of control and independence, reducing anxiety, and providing reassurance
Horsky, J[18]	2014	Coordination of Care for Complex Pediatric Patients: Perspectives from Providers and Parents	Qualitative	To gather and analyze insights from clinicians, coordinators, and parents of children with multiple chronic conditions to formulate a preliminary model of care coordination intended to inform the design of electronic support tools	Parents of children with multiple chronic problems (n=16), Medical care providers (n=6)	Ambulatory; Community	Two institutions affiliated with a large urban healthcare delivery network	5 hours	The core themes about barriers to effective care coordination that emerged from the interviews showed that lack of integration and system interoperability within and primarily across institutions and professions adds considerable effort to the work of most clinicians, providers of services, and parents
Kelly, M[22]	2019	Parent Perceptions of Real-time Access to Their Hospitalized Child's Medical Records Using an Inpatient Portal: A Qualitative Study	Qualitative	To identify why parents used the portal, their suggestions for improvement, and their perspectives of new features being considered by the hospital	Parents of hospitalized children < 12 years (n=14)	Inpatient	Tertiary care children's hospital in the Midwest	Not disclosed	Providing parents with real-time clinical information during their child's hospitalization using an inpatient portal may enhance their ability to engage in caregiving tasks critical to ensuring inpatient care quality and safety

Kelly, M[24]	2021	Stakeholder Perspectives in Anticipation of Sharing Physicians' Notes With Parents of Hospitalized Children	Qualitative	Elicit stakeholder perspectives on the anticipated benefits and challenges of sharing hospital physicians' admission and daily progress notes with parents at the bedside during their child's hospitalization and identify strategies to aid implementation of inpatient note sharing	Parents of hospitalized children (n=8), Nurses (n=8), Residents (n=5), Hospitalists (n=7), Administrators (n=6)	Inpatient	Tertiary children's hospital in the Midwest	2 months	Parent and healthcare team stakeholders anticipate benefits and challenges of sharing inpatient notes with parents during their child's hospitalization and suggest practical ways that hospitals can implement note sharing to support positive outcomes and mitigate negative consequences
Kelly, M[47]	2023	Parent Perceptions of Real-time Access to Their Hospitalized Child's Medical Records Using an Inpatient Portal: A Qualitative Study	Qualitative	To identify why parents used an inpatient portal application on a tablet computer during their child's hospitalization and identify their perspectives of ways to optimize the technology	Parents of hospitalized children < 12 years (n=14)	Inpatient	Tertiary care children's hospital in the Midwest	Not disclosed	Providing parents with real-time clinical information during their child's hospitalization using an inpatient portal may enhance their ability to engage in caregiving tasks critical to ensuring inpatient care quality and safety

Smith, C[48]	2022	In Anticipation of Sharing Pediatric Inpatient Notes: Focus Group Study With Stakeholders	Qualitative	To investigate the anticipated impact of increasing the flow of electronic health record information, specifically physicians' daily inpatient progress notes, via a patient portal to parents during their child's acute hospital stay—an understudied population and an understudied setting	Parents of children <12 years (n=8), Hospital administrators (n=6), Hospitalist physicians (n=7), Resident physicians (n=5), Nurses (n=8)	Inpatient	Midwest academic children's hospital	2 months	All focus groups identified many potential benefits of inpatient Open Notes inlcuding the enhanced sharing of information between the health care team and absent family members; increasing information for parents to review, thus adding to their knowledge base; providing parents with a sense of structure, enabling them to plan and organize; improving quality assurance for the health care system by involving parents as viewers, commenters, and potential correctors of the record; and illuminating the clinical communication process itself, thus educating and reassuring parents about the care process.

Aldekhyyel, R[49]	2018	Using a Bedside Interactive Technology to Solicit and Record Pediatric Pain Reassessments: Parent and Nursing Perspectives on a Novel Workflow	Mixed-Methods	Study the perspectives of both parents and nurses towards using an interactive patient care tool in the management of pain at our children's hospital	Parent of hospitalized child (n=30), Nurses (n=59)	Inpatient	University of Minnesota Masonic Children's Hospital	6 months	Cohesive agreement among parents and nurses on the perceived usefulness of the pain management tool
King, G[50]	2017	Connecting Families to Their Health Record and Care Team: The Use, Utility, and Impact of a Client/Family Health Portal at a Children's Rehabilitation Hospital	Mixed-Methods	To examine the use, utility, and impact of the connect2care portal from the beginning of portal introduction until the end of data collection	Caregivers of children (n=38); Providers (n=9)	Inpatient; Ambulatory; Community	Holland Bloorview Kids Rehabilitation Hospital	14 months	There was a moderate degree of perceived usefulness of and satisfaction with the EHR and e-messaging features, and evidence that the portal was perceived to provide useful access to the clinical record
Parpia, C[27]	2021	Evaluation of a Secure Messaging System in the Care of Children With Medical Complexity: Mixed Methods Study	Mixed-Methods	To (1) evaluate the use of a secure messaging system, (2) examine and compare the content of messages to email and phone calls, and (3) explore PCs' and CTMs' perceptions and experiences using secure messaging as a method of communication	Parental caregivers of children with medical complexity <18 years (n=36), Nurse practitioners (n=7), Other Hospital and community-based healthcare providers (n=59)	Community	The Hospital for Sick Children, Credit Valley Hospital, and Royal Victoria Regional Health Centre	Not disclosed	Secure messaging was highly used, allowed for diverse topics of conversation, and enhanced the PC-CTM relationship
Schiller, J[30]	2013	What parents want from emails with their pediatrician: Implications for teaching communication skills	Mixed-Methods	To elicit patient preferences about email communication to inform training. To elicit parents' perspectives on physician-parent email communication and compared parent and faculty assessments of medical students' emails	Parents of children (n=19)	Ambulatory	Not disclosed	3 months	Parents place value on medical students' abilities to communicate clearly and convey respect and empathy in email

Weatherly, J[19]	2019	Challenges with Patient Adoption of Automated Integration of Blood Glucose Meter Data in the Electronic Health Record	Mixed-Methods	To understand how AIS would impact patient-provider communication	Patients with type 1 diabetes age 5-20 years or their parents (n=28)	Ambulatory	Stanford Children's Health	6 month	Although integration is technically possible, the patient experience was cumbersome and resulted in low adherence to the technology

Supplement 2. Keyword search and strategy.

PubMed 128 results
"Electronic Health Records"[Mesh] OR "Clinical notes" [tiab:~2] OR "Clinical note" [tiab:~2] OR "Open notes" [tiab:~2] OR "Open Note" [tiab:~2] OR "Physician notes" [tiab:~2] OR "Patient portal" [tiab:~2] OR "Electronic health record" [tiab] OR "EHR" [tiab] OR "EMR" [tiab] OR "electronic medical record" [tiab:~2] OR "Patient portals" [Mesh] OR "electronic mail" [Mesh] OR "electronic mail" [tiab:~2] OR "e-mail" [tiab] AND "Communication"[Mesh] OR "Communicat*" [tiab] AND "Physician-Patient Relations"[Mesh] OR "Professional-Patient Relations"[Mesh] OR "Physician patient" [tiab:~2] OR "doctor patient" [tiab:~2] OR "nurse patient" [tiab:~2] OR "provider patient" [tiab:~2] OR "physicians" [Mesh] OR "nurses" [Mesh] or "physician*" [tiab] OR "nurse*" [tiab] OR "provider" [tiab] AND "Parents"[Mesh] OR "parent*" [tiab] OR "father*" [tiab] OR "mother*" [tiab] OR "patients" [Mesh] OR "patient*" [tiab]
Embase 462 results
'electronic health record'/exp OR 'e-mail'/exp OR 'patient portal'/exp OR (((clinical OR physician OR open) NEAR/2 (note OR notes)):ti,ab,kw) OR 'electronic medical records':ti,ab,kw OR email:ti,ab,kw OR 'electronic health record':ti,ab,kw OR emr:ti,ab,kw OR ehr:ti,ab,kw OR ((patient NEAR/2 portal*):ti,ab,kw)) AND ('interpersonal communication'/exp OR communicat*:ti,ab,kw) AND ('professional-patient relationship'/exp OR 'physician'/exp OR 'nurse'/exp OR (((physician* OR provider* OR nurse* OR doctor*) NEAR/2 patient*):ti,ab,kw) OR physician*:ti,ab,kw OR nurse*:ti,ab,kw OR provider*:ti,ab,kw) AND ('parent'/exp OR father*:ti,ab,kw OR mother*:ti,ab,kw OR parent*:ti,ab,kw)
CINAHL 156 results
((MH "Electronic HealthRecords+") OR (MH"Email") OR (MH "PatientPortals")) OR TI (((clinical OR physician ORopen) N2 (note OR notes))OR electronic medicalrecords OR email ORelectronic health record OREMR OR EHR OR (patientN2 portal*)) OR AB (((clinical OR physician OR open) N2 (note OR notes))OR electronic medical records OR email ORelectronic health record OREMR OR EHR OR (patientN2 portal*)) AND (MH "Communication+")OR communicat* AND ((MH "Physician-PatientRelations") OR (MH"Professional-PatientRelations+") OR (MH"Nurse-Patient Relations")OR (MH "Physicians+")OR (MH "Nurses+")) ORTI (((physician* ORprovider* OR nurse* ORdoctor*) N2 patient*) ORphysician* OR nurse* ORprovider*) OR AB (((physician* OR provider*OR nurse* OR doctor*) N2patient*) OR physician*OR nurse* OR provider*) AND (MH "Parents+") OR TI (father* OR mother* ORparent*) OR AB (father*OR mother* OR parent*)
Web of Science 156 results

(((TS=(“electronic health record” OR “e-mail” OR “patient portal” OR ((clinical OR physician OR open) NEAR/2 (note OR notes)) OR “electronic medical records” OR email OR “electronic health record” OR emr OR ehr OR ((patient NEAR/2 portal*)))) AND TS=((“interpersonal communication” OR communicat*))) AND TS=((“professional-patient relationship” OR “physician” OR “nurse” OR ((physician* OR provider* OR nurse* OR doctor*) NEAR/2 patient*)) OR physician* OR nurse* OR provider*)) AND TS=((“parent” OR father* OR mother* OR parent*))

Supplement 3. Mode of electronic communication, sorted chronologically by year of publication.

Author	Year	EHR / Patient portal n=17	Secure messaging n=6	Email n=8	Text messaging n=4	Phone n=3	Other n=2
Britto	2013	X					
Dudas	2013	X		X	X		
Schiller	2013			X			
Horsky	2014	X		X		X	X (Fax)
Clark	2015	X					
Fiks	2015	X					
Globus	2016				X		
Weems	2016	X	X	X	X		
deJong	2017			X			
King	2017	X	X				
Aldekhyyel	2018	X					
Kaskinen	2018						X (Web chat)
Kelly	2019	X					
Weatherly	2019	X	X			X	
Amirav	2020	X					
Adams	2021			X	X		
Bell	2021	X					
Kelly	2021	X					
Parpia	2021		X	X		X	
Sarabu	2021	X					
Nadia	2022	X	X	X			
Smith	2022	X					
Kelly	2023	X	X				

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