CLOUD CARE: A FEASIBILTY STUDY OF CLOUD-BASED CARE PLANS FOR CHILDREN WITH MEDICAL COMPLEXITY

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STRUCTURED ABSTRACT

Purpose: To determine the feasibility, acceptability, and outcomes associated with use of Cloud Care, a cloud-based longitudinal care plan system, among parents and providers who care for children with medical complexity (CMC) with high utilization.

Scope: Emerging HIPAA-complaint cloud computing technologies provide information systems that support team-based content management through on-demand access for authorized users, multi-user editing, and flexible content formatting. Critical gaps remain in our understanding of how to optimize the use of these cloud-based platforms to support team-based content management within the healthcare sector.

Methods: We conducted a 3-year, single-center, mixed-methods cohort study in which parents received access to their child's Cloud Care profile and were able to share access with their child's healthcare providers. We measured study outcomes using web analytics, surveys, and interviews.

Results: We enrolled 29 child-parent dyads and 473 providers. Feasibility (i.e., perceptions of ease of use of Cloud Care) was high among parents, and more mixed among providers. Acceptability, in terms of completeness, accuracy, and usefulness of information within Cloud Care, was mixed among parents and providers. Adoption rates were 78% and 47% among parents and providers, respectfully. A primary barrier for using Cloud Care was having to access the care plan outside of the child's primary electronic health record or patient portal, and the lack of integration between the child's primary EHR and Cloud Care.

Key Words: Chronic Disease; Health Information Exchange; Health Information Interoperability; Hospital Medicine; Patient Care Planning; Patient Portals; Pediatrics; Transitional Care; User-Computer Interface

PURPOSE

The overall goal of this research proposal was to determine the feasibility, acceptability, and outcomes associated with use of Cloud Care, a cloud-based longitudinal care plan system, among parents and providers who care for CMC with high utilization. To achieve this goal, we conducted a 3-year, single-center, mixed-methods cohort study in which parents received access to their child's Cloud Care profile and were able to share access with their child's healthcare providers. We measured study outcomes using web analytics, surveys, and interviews.

The specific aims of this project were:

Aim 1: Determine the (a) feasibility and (b) acceptability of Cloud Care among parents and providers who received access to their child's Cloud Care profile during the study period.

Aim 2: Determine associations between Cloud Care usage and (a) patient/family-centered outcomes from baseline to 6-months post-enrollment.

SCOPE

Background

The absence of a centralized health information system is a fundamental reason patients in the United States (US) experience fragmented care.[1-3] The fragmented healthcare system leads to high caregiver burden, ineffective communication between members of the care team, and patient safety issues.[4-6] These outcomes are particularly worse for children with medical complexity (CMC) who receive care from multiple specialty physicians, home health providers, therapists, school staff, and community services who do not have access to a centralized record of the child's health status and plan of care.[7-8] Given that the population of CMC continues to grow, it is imperative we prioritize finding solutions to address these gaps in care.[9-10]

A strategy to circumvent these information gaps for CMC is the use of a multidisciplinary care plan.[4,11-13] A care plan is intended to be a portable medical summary that is continuously updated to reflect the needs and goals of the child, family, and their healthcare team.[5,13] Care plans should be developed in partnership with families and should be readily accessible to all those engaged with the child and family.[13] As components of multifaceted interventions, care

plans have been associated with improved care experiences and patient-reported outcomes in pediatric and adult populations.[14]

However, qualitative studies exploring the use of care plans by CMC families highlight several limitations in the design and implementation of existing care plans that diminish their utility for facilitating care coordination.[5,15-17] Existing care plans for CMC are typically a static document either printed on paper or scanned into the electronic health record (EHR) by an individual provider or provider team.[18] This setting-specific format and ownership model results in care plans that are not comprehensive, up-to-date, or readily accessible to all of the child's care providers.[5,15,19]

While leading health information exchange (HIE) platforms are attempting to address one of these barriers by expanding on-demand secure access to these care plans,[20-21] these platforms still do not support a family-centered, team-based approach to create and maintain care plan content in real-time.[22-23] Team-based practices in primary care settings have been associated with higher rates of care plan documentation and improved chronic disease management.[24-26] However, these benefits will only be fully realized for CMC if health information systems can support team-based content management beyond a single practice setting and include families as equal partners.[5,22,27]

Fortunately, emerging HIPAA-compliant cloud computing technologies provide information systems that support team-based content management through on-demand access for authorized users, multi-user editing, and flexible content formatting.[28-30] However, critical gaps remain in our understanding of how to optimize the use of these cloud-based platforms to support team-based content management within the healthcare sector.[28,31] In Aim 1 of the proposed research, we determined how to ideally engage parents and providers in collaboratively-maintaining care plans for CMC. In Aim 2, we determined whether this collaborative engagement was associated with improved outcomes.

Population and Settings

Study participants included child-parent dyads and providers of CMC who received care at a tertiary care children's hospital in the pacific northwest region of the United States. CMC were

identified to be eligible if they met the following eligibility criteria: (1) child receives care at Seattle Children's Hospital (SCH), is categorized as having medical complexity using the Pediatric Medical Complexity Algorithm (PMCA),[32] has technology dependence (e.g., feeding tube, tracheostomy), and had >2 ED visits/hospitalizations in the past year or had >8 clinic visits in the past year. Parents were identified to be eligible if they were English-speaking, were the child's legal guardian, used personal email daily, and had daily access to the Internet.

Providers were identified to be eligible if the parent identified them to be on their child's care team or there was evidence in the child's electronic medical record that the provider was actively involved in the child's care during the study period. Providers included: healthcare providers (e.g., primary care provider, sub-specialists, care coordinators, therapists, school nurses, home nurses, etc.), and others (e.g., other adult caregivers, school staff).

Context

Child-parent dyads were enrolled in the study in-person or by telephone using a standardized recruitment protocol. The research team, which included a complex care physician and nurse, then built the child's Cloud Care profile based on information in the child's electronic health record. Once the profile was created, parents automatically received an email with instructions on how to access and use the Cloud Care system. The research team shared the child's Cloud Care profile with providers if they were identified to be eligible as noted above. Once added to the profile, providers automatically received an email in real-time describing Cloud Care with a link to review an informational consent and instruction on how to withdraw from the study if desired. This email invitation also contained a link to access the child's Cloud Care profile.

METHODS

Study Design

We conducted a 3-year, single-center, prospective, mixed-methods cohort study of CMC child-parent dyads and providers who received access to the Cloud Care system during the study period: May 2019 to August 2022.

We used Bowen et al.'s feasibility study framework[33] to assess seven areas of focus: practicality, acceptability, demand, implementation, limited efficacy testing, integration, and adaptation as described in Table 1.

TABLE 1. Areas of Focus to Examine the Feasibility of the Cloud Care System

	Area of Focus	Data Source
Practicality	Parent and provider perceptions of ease of use of Cloud Care and potential time savings	Surveys
Acceptability	Parent and provider perceptions of the quality of information within Cloud Care	Surveys
Demand	Parent and provider use (i.e., adoption) of the Cloud Care system	Cloud Care web analytics
Implementation	Parent and provider access of Cloud Care profiles when notified to do so	Cloud Care web analytics
Limited efficacy testing	Association of Cloud Care use and patient/family-centered outcomes	Cloud Care web analytics + surveys
Integration	Identification of facilitators and barriers to integrate Cloud Care into existing infrastructure, programs, and clinical care	Surveys + informal feedback from participants
Adaptation	Identification of necessary adaptation to optimize the use of Cloud Care	Surveys + informal feedback from participants

Data Collection and Analysis

We used a combination of data from web analytics and surveys to assess the feasibility of the Cloud Care system as described in Table 1. Surveys were administered electronically to families at enrollment (prior to receiving access to Cloud Care) and 6-months after receiving access to Cloud Care. Families received a $25 gift card after they completed a survey. Surveys were administered to providers 1-3 months after receiving access to Cloud Care. Surveys included free-text responses to collect qualitative data regarding facilitators and barriers to use.

Web analytics were captured from the Cloud Care system into an electronic database in which each user and user activity was recorded with a timestamp. Analysis of each area of focus was conducted separately as described below.

Practicality

Parent and provider surveys contained 3 items to assess ease of: (1) accessing; (2) reviewing; and (3) editing information within the Cloud Care system. The surveys also asked respondents how much time it took to find the information they needed in Cloud Care compared to their usual

information retrieval processes. If a participant completed multiple surveys during the study period, we used their final survey responses. We used descriptive statistics to analyze the categorical distribution of both parent and provider responses.

Acceptability

Parent and provider surveys contained 3 items to assess perceptions of the quality of information in Cloud Care, which captured 3 areas: (1) completeness of information; (2) accuracy of information; and (3) usefulness of information within the Cloud Care system. If a participant completed multiple surveys during the study period, we used their final survey responses. We used descriptive statistics to analyze the categorical distribution of both parent and provider responses.

Demand

We used web analytics to calculate the proportion of participants who accessed Cloud Care at least once among those who were invited (i.e., adoption rate), by parents and providers. We further sub-divided provider adoption rates into participants who are within our organization (internal) versus outside our organization (external) based on user email address.

Implementation

We used web analytics to calculate the proportion of participants who accessed Cloud Care within a specific timeframe in response to a notification to review or edit a child's profile (i.e., fidelity) as described in Table 2.

TABLE 2. Fidelity Metric Specifications regarding Timely Access to Cloud Care

Parents	% of caregivers who accessed Cloud Care within 30 days of receiving a monthly notification to review and edit their child's Cloud Care information.
Providers	% of providers who accessed Cloud Care within 3 days of receiving either: (1) a pre-visit notification to review a child's Cloud Care information, (2) a post-visit notification to edit a child's Cloud Care information based on the visit; or (3) a general notification sent within 48 hours of an emergency department visit or hospital admission to review and edit the child's Cloud care information based on the visit.

All notifications were initially sent manually via email by a research coordinator who tracked healthcare encounters for each child participant daily. The research coordinator recorded the date of each healthcare encounter for a child (e.g., clinic visit, emergency department visit, or

hospitalization) and the primary care team members involved in the healthcare encounter. If a care team member did not previously have access to Cloud Care, they were sent an invitation to access the system as part of this notification. Within 4 months of initiating the study, a feature was added to automatically send pre- and post-appointment notifications to care team members from the Cloud Care system. These notifications were triggered by the research coordinator adding the date of the appointment and care team member into the "appointments" tab in Cloud Care. General notifications for emergency department visits or hospitalizations were still sent manually.

Limited Efficacy Testing

We examined relationships between average Cloud Care adoption rates and fidelity rates among care team members for an individual child and differences in patient/family-centered outcomes from baseline to 6-months after receiving access to Cloud Care. For the independent variable of Cloud Care usage, adoption and fidelity rates were calculated as described above. We then calculated the mean adoption and fidelity rate among all care team members who received access to Cloud Care for each patient. We then categorized adoption and fidelity rates into 20% intervals (scale 0-100% for each child's).

For the dependent variable, patient/family-centered outcomes included items from the Pediatric Integrated Care Survey questionnaire,[34] the University of Washington Caregiver Stress Scale,[35] and a 2-item health-related quality of life measure. All outcomes were parent-reported given many of the children in the study have intellectual or developmental disabilities precluding them from completing surveys on their own. Given the variety of items and response options, we dichotomized each survey item/outcome as a "positive" change or a "negative/neutral" change from baseline to 6-months. Associations between Cloud Care usage and outcomes were analyzed using univariable logistic regression models.

Integration

We qualitatively analyzed open-ended responses from surveys into facilitators and barriers to use of the Cloud Care system to identify future integration opportunities. The study team also received unsolicited feedback and recommendations via electronic mail from participants, which we also incorporated in our analysis. Some of these integration opportunities were also implemented during the study.

<u>Adaptation</u>

Like integration, open-ended survey responses regarding overall impressions of Cloud Care and recommendations for improvement were qualitatively analyzed by the study team using content analytic techniques. The study team then categorized improvement opportunities as design improvements and implementation improvements. Some of these improvement ideas were implemented during the study.

The study was approved by the Seattle Children's Hospital Institutional Review Board.

Limitations

We recognize some limitations in this study. First, we only included CMC who receive care from a single tertiary care institution. Our institution's complex care program did not provide outpatient services at the time of the study. Furthermore, 7 months into our study, our institution transitioned to an electronic health record vendor system with a more seamless ability to share information across institutions who used the same vendor and a robust patient portal which open access to notes, appointment information, and secure messaging functionality for families. These contextual elements may have influenced the feasibility of the Cloud Care platform, which limits the generalizability of our findings. Second, our study excluded families with limited English-proficiency; a critical step in future work will be to conduct additional formative studies to understand how to best tailor cloud-computing technologies to support multiple languages. Third, we did not assess the digital health literacy of participants; therefore, future usability and feasibility studies should be conducted to understand how this model should be further adapted to meet variable levels of literacy. Fourth, Cloud Care did not include a secure messaging system for care teams which would help facilitate seamless communication, a key component of collaborative information management. Fifth, survey response rates were low among parents and providers which may have represented a biased sample for some feasibility measures. Lastly, we planned to collect medication accuracy data to assess a patient safety outcome, as well as repeated measures of our patient-centered outcomes after the 6-month assessment; however, due to the COVID-19 pandemic, collection of these outcomes from families proved to be more difficult than we initially anticipated.

RESULTS

Principal Findings

This study uncovered several important findings regarding the feasibility of using a cloud-based care plan to optimize outcomes for CMC. We ultimately enrolled 29 child-parent dyads in our study, which represented an enrollment rate of 69% (29/42 families). We invited a total of 473 providers to access Cloud Care for at least one of these study patients. Principal findings of this study are further detailed by each area of focus regarding feasibility of this intervention.

Practicality & Acceptability

Among parent participants, 29 families were invited to complete these surveys and 15 parents responded (response rate = 52%). Eleven of these respondents reported that they logged into their child's Cloud Care profile at least once (73% of those who responded).

Among provider participants, 473 providers were invited to complete these surveys, and 82 providers responded at least once during the study (response rate = 17%). Forty-five of these respondents reported they logged into a child's Cloud Care profile at least once (55% of those who responded).

Table 3 provides the categorical distribution of parent and provider perceptions of the ease of use of the Cloud Care system (practicality). Table 4 provides the categorical distribution of parent and provider perceptions of the perceived time saved finding information in Cloud Care compared to their usual processes (practicality). Table 5 provides the categorical distribution of parent and provider perceptions of the quality of information in Cloud Care system (i.e., acceptability).

TABLE 3. Perceptions of Cloud Care Ease of Use

	No. of respondents	Not at all easy	Slightly easy	Moderately easy	Quite easy	Extremely easy
Parents						
Ease of accessing	11	0%	0%	18%	18%	64%
Ease of reviewing information	11	0%	0%	9%	18%	73%
Ease of editing information	6	0%	0%	0%	0%	100%

Providers		Not at all easy	Somewhat easy	Very easy
Ease of accessing	42	7%	45%	48%
Ease of reviewing information	42	2%	52%	45%
Ease of editing information	19	0%	47%	53%

TABLE 4. Perceptions of Time Saved Finding Information in Cloud Care Compared to Usual

	No. of respondents	Took more time to find information	Took same amount of time	Took less time to find information
Parents	11	0%	36%	64%
Providers	41	10%	51%	39%

TABLE 5. Perceptions of Information Quality in Cloud Care

	No. of respondents	Not at all	Slightly	Moderately	Quite	Extremely
Parents						
Complete	11	0%	0%	55%	9%	36%
Accurate	11	0%	0%	18%	36%	45%
Useful	6	17%	0%	50%	17%	33%
Providers		Not at all		Somewhat		Very
Complete	39	0%		62%		38%
Accurate	38	0%		34%		66%
Useful	42	5%		60%		36%

Demand

Based on web analytics, Table 6 describes the adoption rates for caregivers and providers. Note: Some enrolled children had more than one guardian identified as a "parent" in this analysis.

TABLE 6. Cloud Care Adoption Rates

	No. of participants	Adoption Rates
Parents	32	78%
Providers	473	47%
Internal	364	49%
External	109	40%

Implementation

The analysis of fidelity rates for parents and providers is ongoing.

Limited Efficacy Testing

The analysis of associations between Cloud Care usage (i.e., adoption and fidelity rates) and patient/family-centered outcomes is ongoing.

Integration

Table 7 provides a summary of the primary barriers to accessing Cloud Care.

TABLE 7. Reasons for Not Accessing Cloud Care

	No. of respondents
Parents	
Didn't know about it	1
Too busy	3

Providers	
Do not know what it is	8
Not beneficial for that clinical encounter	7
Did not have encounter with patient yet	6
Do not know the patient	4
Did not want to log into another system because of time	4
Did not want to log into another system because EHR is sufficient	4
Overwhelmed with clinical work	3
Did not remember it existed	2
Do not recall if they accessed it	1

We also conducted a content analysis of general feedback from users of the Cloud Care system, which is summarized below.

Usability:

- Parents and providers did not read user guide when attached to the email, even when shortened to one page.
- Parents did not know what sections of care plan they could or could not edit in real-time.
- Dieticians recommended that active issues related to nutrition needs should be accessible from the stand-alone "Diet & Nutrition" page.
- Parents and providers noted that standardized documents such as "airway diagrams" or "seizure care plans" should be accessible from sections of the emergency care plan.
- Providers thought that the organization of Cloud Care by active issues resulted in too many clicks and was not as intuitive.
- Parents thought active issues list had too much medical jargon.

Usefulness:

- Sub-specialty provider did not understand the general purpose of care plans and why they are needed if information could be found in EHR.
- Parents and providers thought the care plan may be more useful to individuals who cannot get ready access to this information through the EHR.
- Providers and parents thought it would be more useful if they knew the other care team member was also engaging with the care plan.

- Parents and providers wanted the action items section to be organized in a manner in which it was easy to know which action items were due soon and which care teams were responsible for completing the action item.
- Outpatient providers want access to Cloud Care profile information prior to the patient's discharge so they can adequately prepare for follow-up, especially when outpatient care will occur in rural communities where access to specialty care and medications may be more difficult to obtain.

Accuracy:

- Early intervention therapist and some parents wanted to see the full clinical note versus a curated summary of the encounter.
- Some nursing providers were hesitant to update the care plan because this was not a request from their leadership.
- Providers wanted information that exists in the EHR as discrete fields to be pulled in the care plan to minimize errors.
- Early intervention therapist was hesitant to update the care plan because she would defer to the sub-specialist and did not feel confident she would add information that the sub-specialist would want to know.

Comprehensiveness:

- Some parents noted that the information was overwhelming to look at for the first time, so they needed time to orient themselves.

Efficiency (time-savings):

- Provider did not feel that it saved them time because they did not know what information to review, update, or which information to focus on.
- Sub-specialty provider felt that it was too comprehensive for their role when they only manage one issue for the patient.

<u>Adaptation</u>

Adaptations of the Cloud Care system to address barriers uncovered during the study were categorized as prototype revisions or implementation model revisions as described below.

Prototype revisions:

Revision Type	Description	Revision Date
Usability	Added links between stand-alone sections such as "Diet/Nutrition" or "Developmental and Community Services" and active issues	June 2020
Usability	Added an "About Cloud Care" page with user guide	June 2020
Usefulness	Added print functionality for the "Emergency Care Plan" and "Medication List"	August 2020

Revision Type	Description	Revision Date
Accuracy	Added functionality to directly upload PDFs of clinical notes in "Medical History" section or "Emergency Care Plan" (e.g. seizure care plan)	August 2020
Usability	Building a directory of active issues with family-friendly language.	October 2020
Usability	Reorganizing Cloud Care by "Care Teams" rather than "Active Issues".	January 2021
Usefulness	Reorganized the "Action Items" section to include automatic color-coded status updates (overdue, due soon, in progress, not started, completed) based on start date and due dates of action items.	January 2021
Usability	Implemented care team specific dashboards to improve time in finding information.	February 2022
Usability	Created syncing between "Action Items", "Appointment", and "Medical History" sections to improve work-flow efficiency and reduce double-documentation within the system.	February 2022

Implementation model revisions:

Revision Type	Description	Revision Date
Review/edit notifications	Notifications highlight action items tab and why care plans are an important tool for families	July 2020
Care team orientation	Research team sends a blind copied email to all identified care team members at the beginning of the study to highlight the "team-based" component of the care plan	August 2020
Parent orientation calls	Research team members review Cloud Care with parent at the start of the study after care plan has been built	August 2020
Review reminder notifications	Changed the core team care coordination review reminder notifications from monthly to weekly	August 2020
Review/edit notifications	Review/edit notifications are automated through Cloud Care	August 2020
Care team member access	Provide access to primary care physicians earlier during the hospitalization rather than waiting closer to discharge.	February 2021
Core team	Addition of a "Clinical Curator" (sporadic involvement)	April 2021
Core team	Addition of a "Digital Health Navigator" (sporadic involvement)	September 2021

Outcomes

We present a list of key outcomes from these studies:

- We developed and adapted a proof-of-concept prototype of a cloud-based care plan for children with medical complexity.

- Feasibility (i.e., perceptions of ease of use of Cloud Care) was high among parents, and more mixed among providers.

- Acceptability, in terms of completeness, accuracy, and usefulness of information within Cloud Care, was mixed among parents and providers.

- Adoption rates were 78% and 47% among parents and providers, respectfully.

- A primary barrier for using Cloud Care was having to access the care plan outside of the child's primary electronic health record or patient portal, and the lack of integration between the child's primary EHR and Cloud Care.

- The implementation of cloud-based care plans requires a team of owners, an electronic notification system, and alignment between structured data fields within the care plan and EHR.

- Family-centered outcomes are important to measure in the evaluation of cloud-based health information technology. Our studies provide a list of measures that could be used to assess the effectiveness of health information technologies design to improve care coordination for CMC.

Discussion, Conclusions & Implications

Our research challenges existing clinical practice paradigms by testing a novel cloud-based care plan system to improve care coordination for CMC. The findings of this study demonstrate that designing feasible (easy to use) systems may be possible; however, acceptability of these systems remain limited by lack of integration with existing EHR systems. Although parents and providers found a comprehensive, accessible care plan to be an appealing tool for CMC, feasibility of maintaining curated content in a time-constrained environment resulted in suboptimal adoption. Double documentation continued to pose an insurmountable challenge for many providers, which then necessitates a team of providers to curate such a care plan. In a resource rich environment, or one in which there is a dedicated complex care team, a tool such as this may prove to be more valuable. Future research is needed to understand whether a cloud-based care plan may be most beneficial among providers who are unfamiliar with the child (e.g., ED settings or infants with medical complexity) or among care providers who care for these children in non-integrated settings (no access to the primary hospital's EHR).

Cloud-based care plans also provide families the opportunity to be integral partners in the care team, resulting in a system in which care is happening with them rather than to them. Editing of

Cloud Care content among parents was variable and could have been dampened by testing during a pandemic. Interest in collaboratively managing care plan content also seemed to depend on the engagement of the child's healthcare providers, creating a circular feedback loop. Thus, parents may be more willing to engage in collaboratively management of information that their child's providers routinely use (such as information located in the child's EHR). Future research is needed to test real-time collaborative management of information within a patient portal that is directly linked to a child's EHR.

As interest in care plans continues to grow, these findings will be informative for EHR vendors and technology companies to develop care plans that are consistent with the needs, priorities, and constraints of caregivers and providers who care for pediatric patients, and particularly those with complex chronic conditions. This study also presents several additional research opportunities to better understand the impact of cloud-based health ITs and processes of implementing cloud-based health ITs on meaningful outcomes for CMC families. As cloud-based health ITs become more prevalent, studies such as these are imperative to understand how best to leverage them and integrate them with existing information systems to promote comprehensive, coordinated, and equitable care for patients with multiple chronic conditions across the care continuum.

List of Publications and Products

1. Desai AD, Kinard D, Hawley KD, Lundgren S, Leggett BD, Adams S, Orkin J, Willgerodt MA. A Feasibility Study of a Cloud-Based Shared Care Plan for Children with Medical Complexity. *Manuscript in Progress*.

2. Jenkins A, Kinard D, Tran C, Desai AD. Optimizing the Design and Implementation of Longitudinal Care Plans within the Electronic Health Record for Children with Medical Complexity. *Manuscript in progress.*

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