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BMJ Open Barriers to and facilitators of a just-in-time adaptive intervention for respiratory illness in cerebral palsy: a qualitative study

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ABSTRACT

Objective To understand caregiver, healthcare professional and national expert perspectives on implementation of a just-in-time adaptive intervention, RE-PACT (Respiratory Exacerbation-Plans for Action and Care Transitions) to prevent respiratory crises in severe cerebral palsy.

Design Qualitative research study.

Setting Paediatric complex care programmes at two academic medical institutions.

Participants A total of n=4 focus groups were conducted with caregivers of children with severe cerebral palsy and chronic respiratory illness, n=4 with healthcare professionals, and n=1 with national experts.

Methods Participants viewed a video summarising RE-PACT, which includes action planning, mobile health surveillance of parent confidence to avoid hospitalisation and rapid clinical response at times of low confidence. Moderated discussion elicited challenges and benefits of RE-PACT's design, and inductive thematic analysis elicited implementation barriers and facilitators.

Results Of the 19 caregivers recruited, nearly half reported at least one hospitalisation for their child in the prior year. Healthcare professionals and national experts (n=26) included physicians, nurses, respiratory therapists, social workers and researchers. Four overarching themes and their barriers/facilitators emphasised the importance of design and interpersonal relationships balanced against health system infrastructure constraints. Intervention usefulness in crisis scenarios relies on designing action plans for intuitiveness and accuracy, and mobile health surveillance tools for integration into daily life. Trust, knowledge, empathy and adequate clinician capacity are essential components of clinical responder-caregiver relationships.

Conclusions RE-PACT's identified barriers are addressable. Just-in-time adaptive interventions for cerebral palsy appear well-suited to address families' need to tailor intervention content to levels of experience, preference and competing demands.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Focus groups were conducted with a wide range of multidisciplinary perspectives, including caregivers of children with severe cerebral palsy, healthcare professionals and national experts in the fields of implementation science, respiratory care quality and family-centred care.
- ⇒ We collaborated with parent partners throughout the design, data collection, interpretation and dissemination of the study.
- ⇒ Our study applies a user-centred design process that reveals provider and patient needs for adaptive interventions prior to implementation in a clinical trial.
- ⇒ Participants were recruited from complex care programmes where they already receive interdisciplinary care and care coordination, and expanding the research to families outside of these programmes may provide additional perceptions of barriers and facilitators.
- ⇒ The study was conducted in two regions within the USA and in two languages, and the results may not reflect those from other settings or cultures.

INTRODUCTION

Cerebral palsy (CP) is the leading cause of motor disability in childhood.^{1,2} Children with more severe CP, for example, levels 4–5 in the gross motor function classification system (GMFCS), are especially prone to recurrent acute illness, including respiratory, gastrointestinal and seizure disorders.^{3,4} Respiratory illness in this population leads to significant morbidity and mortality, accounting for 25% of hospitalisations and 59% of deaths in children with severe CP.^{4–7} Although considered modifiable, improvements in respiratory outcomes in severe CP have been challenging to achieve.^{6–11}

Respiratory illnesses often emerge at home, and families report a need for interventions focused on crisis management and self-efficacy.^{11 12} Potential strategies have included care coordination, accessible care plans and management of comorbidities.⁴ However, caregivers addressing emerging health crises can face challenges with implementing highly sophisticated respiratory care routines or managing the breadth of comorbid triggers that lead to respiratory illnesses in severe CP.¹³ Emerging respiratory illness may also be difficult to recognise, leading to conditions progressing to a point where an emergency department visit or hospitalisation is inevitable.¹¹ An intervention that allows families to easily signal discomfort with their child's health status while also reinforcing caregiver skills and confidence could be key to improving respiratory health outcomes in severe CP.¹¹

To achieve these goals, we designed a prototypical just-in-time adaptive intervention, Respiratory Exacerbation-Plans for Action and Care Transitions (RE-PACT).¹⁴ Just-in-time adaptive interventions (JITAI) aim to deliver the right amount of support at the right time and in the right way given the individual's changing status and context. RE-PACT was conceived from two prior interventions, Plans for Action and Care Transitions (PACT) and Assessing

Confidence at Times of Increased Vulnerability (ACTIV), and consists of three core activities: respiratory illness action planning, mobile health (mHealth) surveillance of parent confidence to avoid hospitalisation and rapid response to periods of low confidence (figure 1).^{15 16} RE-PACT action plans are created with a child's clinical provider and include content to recognise and manage known contributors to respiratory illness. Next, RE-PACT uses caregiver confidence as an indicator of hospitalisation risk, with each participant receiving a weekly text asking, 'How confident are you that your child can avoid an unplanned hospitalization over the next month?'¹⁶ In our previous study, caregiver-reported confidence levels lower than 5 out of 10 were significantly associated with hospitalisation within 2 weeks. Therefore, RE-PACT's rapid response is triggered for confidence ratings <5, in addition to family outreach to the clinical team and hospital discharge, and consists of a designated clinical responder contacting the family within 24 hours and guiding the family to resolution.

The objective of this study was to synthesise multidisciplinary perspectives about anticipated barriers to and facilitators of implementation of the RE-PACT JITAI for children with severe CP. The study results will guide implementation and subsequent testing of RE-PACT in a multisite clinical trial. Findings may inform other JITAI

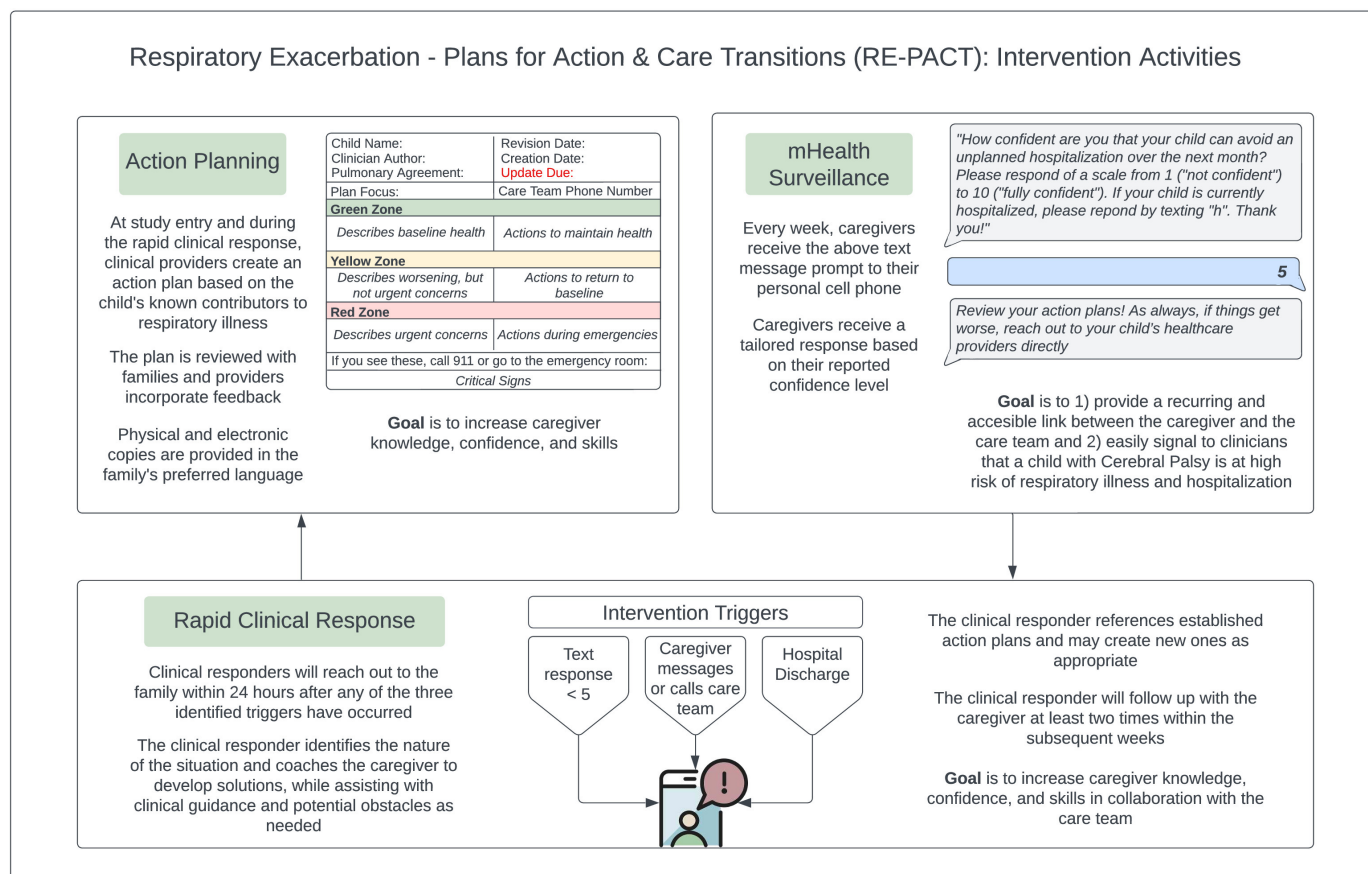


Figure 1 Respiratory Exacerbation-Plans for Action and Care Transitions (RE-PACT): intervention activities. mHealth, mobile health.

focused on managing chronic conditions with acute exacerbations.

METHODS

Study design, setting and sample

This qualitative study was conducted at the University of Wisconsin – Madison (UW) and the University of California – Los Angeles (UCLA) to evaluate barriers to and facilitators of the RE-PACT intervention. Focus groups were chosen for data collection to support synergistic growth of ideas through group dialogue.

Caregivers of children with severe CP were recruited through each site's complex care programme from August to September 2021. The previously described programmes deliver comprehensive interdisciplinary care and care coordination to reduce unmet needs, achieve family-identified goals and lower use of higher-acuity health services.^{17 18} The programmes have similar enrolment criteria based on numbers of affected organ systems, subspecialists and past health services use.

Study eligibility criteria for caregivers included having a child <18 years old enrolled in the complex care programme with a caregiver-reported GMFCS of 4–5 CP and care from a pulmonologist or daily respiratory treatments.³ Additionally, caregivers were ≥18 years of age with English or Spanish language proficiency and a mobile phone capable of sending/receiving text messages.

Healthcare professionals providing care to children with CP were recruited from each health centre. National experts were recruited from RE-PACT's Design and Implementation Strategy Group, which included experts in implementation science, digital health interventions, respiratory care quality, family-centred care, self-efficacy and JITAI. With their comparable experiences and perspectives, healthcare professionals and national experts were considered as a single group in the qualitative analysis.

We planned a priori to conduct n=4 focus groups with family caregivers, n=4 with healthcare professionals and n=1 with national experts, and to analyse all data together. Prior research suggests that three to five focus groups are typically sufficient to reach thematic saturation; however, we had the option to conduct additional focus groups if iterative analyses suggested new data continued emerging with each focus group.¹⁹ We did not design the study to conduct subgroup analyses.

Procedures

Focus groups were conducted to guide the adaptation and implementation of components from two previous acute illness response interventions for children with medical complexity, PACT and ACTIV, into the novel intervention RE-PACT, for primary caregivers of children with severe CP.^{15 16} Participants viewed a synopsis video describing the RE-PACT intervention along with visuals of each intervention component, for example, respiratory illness action planning, mHealth surveillance of parent confidence

and rapid response to periods of low confidence. The focus group guide (online supplemental appendix 1) was designed to apply the Centers for Disease Control and Prevention's Replicating Effective Programs framework with specific prompts drafted from the team's expertise in qualitative methods and paediatric complex care.²⁰ Focus group guides were reviewed/revised by parent partners for clarity and relevance. Moderators elicited perspectives on the potential challenges or improvements of each component's design and implementation, as well as feedback on a future clinical trial.

Focus groups were 60–90 min in duration, conducted via video conferencing software, and completed in September 2021. Moderators included a clinician from each site's complex care programme, parent partners and trained research coordinators. Spanish-speaking caregivers were recruited from a single site (UCLA), all study activities and materials were presented in Spanish, and focus groups were moderated by native Spanish-speaking team members. Focus group audio and video feeds were recorded, transcribed verbatim and translated as needed, before transfer to Dedoose V.9.0.46 for analysis. All participants also completed a brief demographic survey, reporting their age, gender, race/ethnicity and child's health characteristics or, in the case of healthcare professionals, their professional experience. As previous studies have underscored disparities in healthcare access and trust resulting from systemic and structural racism, we reported race and ethnicity in our participant descriptive statistics.²¹ All participants provided consent before enrolling in the focus groups and family caregivers received a US\$50 honorarium.

Analysis

Respondent characteristics were summarised with descriptive statistics. We performed an inductive thematic analysis to elucidate barriers to and facilitators of implementing the RE-PACT JITAI.²² Two researchers (KDS-V and HMK) independently read through and inductively coded five transcripts, including caregiver, healthcare professional and national expert focus groups. Code prevalence and salience were discussed between independent coders. Through iterative, consensus-seeking discussion including a third researcher (RJC), a codebook was developed, and coding was then repeated for all transcripts. Iterative refinement of the codebook and themes occurred throughout the coding process and findings were shared with the entire research team for review. Intercoder consistency was assessed at the midpoint and end of the coding process.

Patient and public involvement

Patients were not involved in the design, conduct, reporting or dissemination plans of our research. However, our study team collaborated with parent partners throughout the design, data collection, interpretation and dissemination of the study. Parent partners reviewed focus group guides, moderated focus groups,

assisted with data analysis and critically revised the manuscript. Once the manuscript has been published, participants will be informed of the results through a dedicated 'Research Takeaways For Families' website.

RESULTS

Participants

Among n=45 participants recruited for the nine focus groups, caregivers (n=19) were 84% women and from a range of education and income levels (table 1). Nearly half of caregivers reported 1–10 hospital days for their child in the past year, and 21% reported the child's use of a mechanical ventilator. Healthcare professionals and national experts (n=26) included physicians, nurses, respiratory therapists, care coordinators, social workers, researchers and others. Additional participant characteristics are summarised in table 1.

Thematic analysis

Caregivers, healthcare professionals and national experts generated key insights about the structure, implementation and maintenance of RE-PACT, a prototypical JITAI for respiratory illness in severe CP. The four key themes, definitions and representative quotes are available in table 2. The barriers, facilitators and modifications for each theme are illustrated in figure 2. Application of the themes to RE-PACT's theorised causal model is illustrated in figure 3.

Theme 1: families should have the ability to tailor intervention content to match their needs and preferences

All focus groups acknowledged the potential that a wide array of comorbidities could trigger respiratory illness in children with CP, and several caregivers expressed the need for broadly focused action plans that include 'other services as well because our son, his GI [issues] could cause a respiratory issue' (Participant #22). Healthcare professionals and caregivers, recognising the child's social context and changing needs for illness management, also supported modifying the intervention to have families guiding the creation and determining the focus of action plans in collaboration with the clinical team.

Additionally, most caregivers appreciated the ability to quickly initiate communication with the care team, with one caregiver referring to the clinical response component as a natural 'next step' for healthcare teams after action planning (#19). However, many noted that they would like to vary their use of the clinical responder based on their years of caregiving experience, the time of year (eg, start of school or 'flu season') or post-hospitalisation. Almost all caregivers expressed desire for this intervention early in their caregiving journey, 'not only for the medical questions, but maybe to ease anxiety, fear, concern' (#16). Although not feasible in the current iteration, future RE-PACT modifications may include the ability to allow caregivers to select their preferred frequency of mHealth

Table 1 Demographic, familial and professional characteristics of focus group participants

	Family caregivers	%	Experts and healthcare providers	%	Total	%
Focus groups, n	4		5		9	
Participants, n	19		26		45	
Participant characteristics						
Age						
18–30 years	0	0	3	11	3	7
31–40 years	4	21	7	28	11	24
41–50 years	11	57	7	28	18	40
51–60 years	2	11	3	11	5	11
60+ years	0	0	3	11	3	7
Prefer not to answer	2	11	3	11	5	11
Sex						
Woman	16	84	15	58	31	69
Man	1	5	8	31	9	20
None of the above describe me	0	0	0	0	0	0
Prefer not to answer/missing	2	11	3	11	5	11
Race and ethnicity						
White, non-Hispanic	11	58	19	73	30	67
Black, non-Hispanic	0	0	0	0	0	0
Hispanic	6	31	2	8	8	18
Asian, non-Hispanic	0	0	2	8	2	4
Other	0	0	0	0	0	0
Prefer not to answer/missing	2	11	3	11	5	11
Education						
Less than 12th grade	2	11				
GED/some college	7	36				
Bachelor's degree	4	21				
Advanced degree	4	21				
Not reported	2	11				
Household income, 2020						
<US\$35 000	4	21				
US\$35 000–49 999	2	11				
US\$50 000–74 999	1	5				
US\$75 000–99 999	5	26				
>US\$100 000	2	11				

Continued

Table 1 Continued

	Family caregivers	%	Experts and healthcare providers	%	Total	%
Prefer not to answer/missing	5	26				
Rurality*						
Urban	9	47				
Suburban	5	26				
Rural	3	16				
Prefer not to answer/missing	2	11				
Child characteristics						
Age						
Less than 1-year old	0	0				
1–2 years old	1	5				
3–5 years old	0	0				
6–12 years old	8	42				
13–18 years old	8	42				
Prefer not to answer/missing	2	11				
Days hospitalised in the past 12 months						
None	6	32				
1–4 days	6	32				
5–10 days	3	16				
11–20 days	0	0				
>20 days	2	10				
I do not know	0	0				
Prefer not to answer/missing	2	10				
Use of mechanical ventilator						
Yes	4	21				
No	13	68				
Prefer not to answer/missing	2	11				
Healthcare professional characteristics						
Clinical role†						
MD/DO—pulmonary		2		8		
MD/DO—general		8		31		
Nurse practitioner		2		8		
Registered nurse		3		11		
Respiratory therapist		2		8		
Other		4		15		
Prefer not to answer/missing		5		19		
Years of professional experience						
Less than 1 year		0		0		
1–5 years		5		20		

Continued

Table 1 Continued

	Family caregivers	%	Experts and healthcare providers	%	Total	%
6–10 years			6		23	
11–15 years			1		4	
16–25 years			4		15	
26+ years			4		15	
Prefer not to answer			6		23	

*Participants were asked how they would describe the area where they live.
 †MD: Doctor of Medicine, DO: Doctor of Osteopathic Medicine.
 ‡Includes social workers, care coordinators and more.
 §GED, General Educational Development, equivalent to a high school degree.

messages or the inclusion of a dynamic frequency that is tailored to recent user input (ie, confidence levels).

Theme 2: action plan structure and maintenance determine its use and usefulness

Action plans were met with universal enthusiasm from caregivers and healthcare professionals; however, participants from each focus group noted that the value of the plan hinged on how well it was constructed and maintained. Healthcare professionals identified outdated, bulky or inconsistent plans as barriers to action plan efficacy, but offered practical suggestions. Intervention modifications included indicating ‘expiration dates’, defaulting to 1 year, to ensure timely review and ‘owners’, defaulting to the clinician who created the plan, to lead updates, plan focus and harmonisation between medical specialties who may create separate action plans (#1,2). Caregivers focused on elements improving ease of use in a time-sensitive scenario, leading to intervention modifications such as using an intuitive template, including doses for rescue medicines or providing multiple copies to keep on their refrigerator, their child’s wheelchair, or with all caregivers.

Theme 3: digital health tools should be designed to promote consistent use by families and integration into daily life

Although most caregivers reported having an overwhelming schedule, many expressed that a weekly check-in text ‘wouldn’t be something that gets lost’ (#19) and ‘would make us feel important’ (#13). Several caregivers reported already having monthly or quarterly check-in calls with their providers, and felt that a weekly text would improve the continuity of care when ‘you’re not quite sure if this means emergency room’ (#19). Ease of response and perceived benefit were cited as important facilitators for consistent use, along with an ability to repeat text messages without becoming ‘obnoxious’ (#2), as several healthcare professionals noted. A pivotal modification to the intervention structure included the ability for the clinical team to receive mHealth text messages

Table 2 Definitions and representative quotes for focus group themes on just-in-time adaptive intervention design and implementation

Theme	Definition	Caregiver quote	Healthcare professional/expert quote
Families should have the ability to tailor intervention content to match their needs and preferences	Families with different levels of experience or caregiving demands have varied needs for intervention components. Allowing caregivers to trigger creation of action plans and clinical response as often or sparsely as needed, as well as guide the action plan and clinical response focus, ensures these intervention components add value.	'So, for us, the action plan...is very thorough. Like, we've got folder upon folder upon folder for, you know, everything from the breathing to if his g tube came out, overheating, choking, seizures, all of that jazz. But we've got this one big pertinent piece action plan that was, goes to every room...and stays on his wheelchair...Um, but having that check in, that coaching, for me, I don't think I don't see any benefit right now, but that's just for us.'	'I think these families, some of these families, know their child so well, and they're very unique. And so, I think having, talking with the parents and filling it out together would be ideal... There might be very specific vital signs for when they reach that threshold of the yellow zone or the red zone that might be helpful for you know, healthcare providers, nurses that are triaging that don't normally know that patient.'
Action plan structure and maintenance determine its use and usefulness	To facilitate use in a crisis scenario, action plans require focused, succinct, easy-to-understand, accurate and regularly updated information in the family's preferred language. Redundancy should be avoided, and plans should be consistent across specialty providers caring for the patient.	'So, you have the medicine, and the doctor is telling you: if he is coughing, you should start with albuterol. So, it's like a-ha you know that he is in the yellow zone, and you can start giving him the albuterol. And it makes you feel confident, you don't get scared, you don't run to the doctor. Things that we didn't have in the beginning. But with time doctors also started to specify the symptoms better, and as parents, we started taking action.'	'I think some of the issues we've run into with our action plans, a provider might have made one 2019, and then perhaps, for whatever reason, when the patient followed up in their visits in 2020, maybe it was a really busy clinic day, or they, the provider, just totally forgot about the action plan. So, when we go back to look at it during a sick call or if the family is referencing it, the meds are, we've changed them. We've changed the plan. That's not actually their yellow zone anymore.'
Digital health tools should be designed to promote consistent use by families and integration into daily life	For a digital health intervention to work, the tool must be designed to allow easy, consistent use by families that is not intrusive to day-to-day life. Additionally, digital health interventions need to support a wide range of caregiver abilities; and families need to have reliable access to any needed devices, software and internet service for the intervention to work.	'In general, text is pretty easy. It's immediate. And so, I think for most of us, it's not hard to participate. But if you're looking at a broader target population, if not everyone has a phone, can text, is text savvy, there may be some frustrations with technology that would hinder the process.'	'We'd also have to be very trusting of the text technology. If the family sends back a low number, we need to feel very confident that we will get that text and be able to recognize it and send it to someone within that 24-hour timeframe that we've set up that expectation with the family, so they continue to trust in that too.'
Real-time clinical response should meet the relational and structural needs of patients, families and clinicians	Efficacious clinical response depends on meeting the interpersonal and clinical needs of the caregiver, encompassing trust, timeliness, knowledge and empathy.	'It's literally just, I want that certain nurse's opinion, because that's who's always been there for my son. So, I feel like there's a relationship there...I don't want to sound rude, but if it was just some random person, or hasn't met my son in person, I feel like the coaching would kind of be pointless.'	'I think you can have the best plan in the world, but if the family is not buying into it or thinking that that's something that they can actually achieve at home, then it's not going to be very helpful.'
Subtheme: Trust and relationship development are fundamental caregiver-identified needs		'It preferably would be the same person that is assigned to my child, rather than a rotation, which is hard...And I think that timeliness, obviously, is the last component that has to be there because if it's not there for you when you need it, then it's not going to work.'	'I think manpower might be challenging. You know, it sounds like the coach would be a specific person hired, so they would have the bandwidth to address all the messages. I think if this was presented to clinical teams, they might say, we're getting so many patient calls as it is. We can't handle any more.'
Subtheme: Strong infrastructure is imperative to support an effective and timely response			

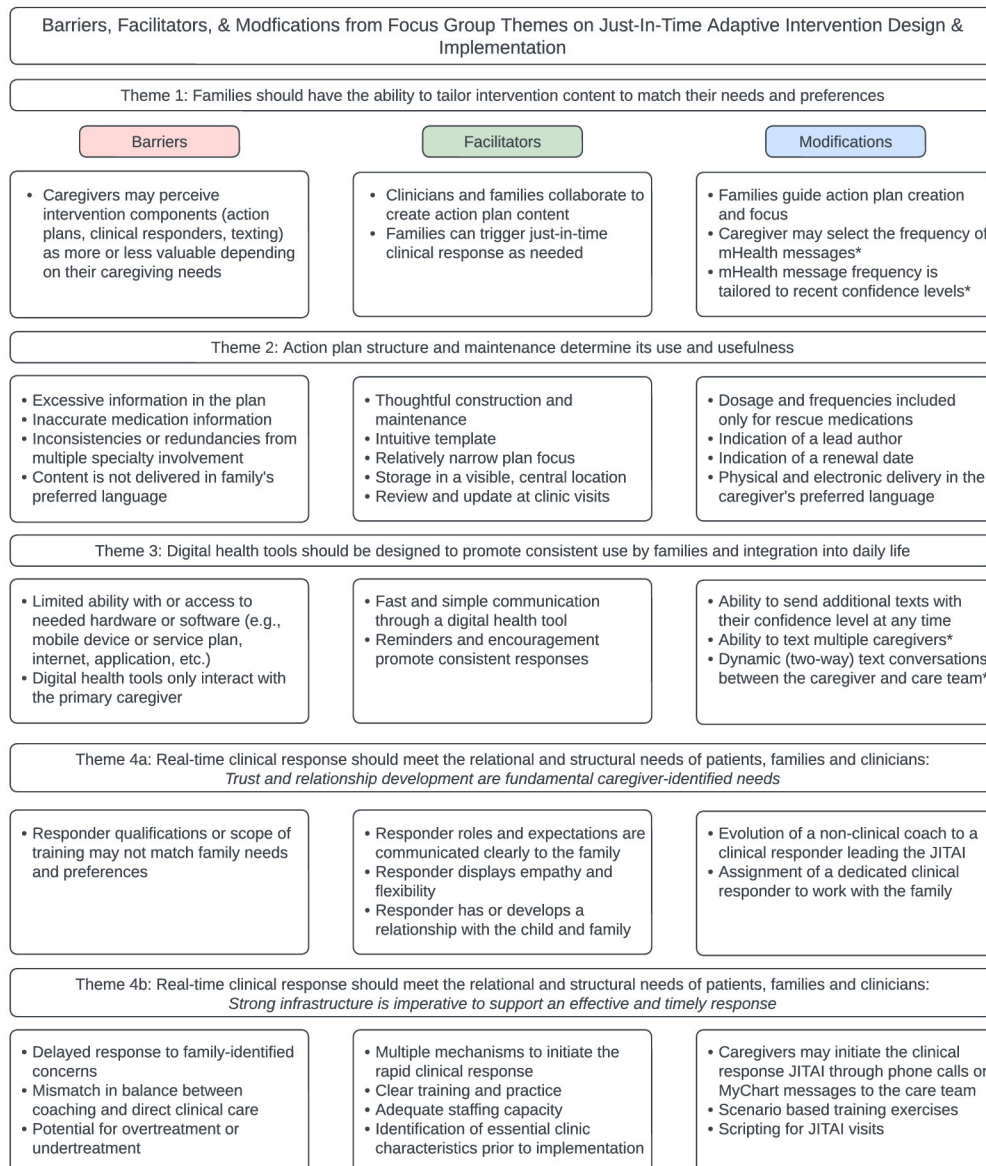


Figure 2 Barriers, facilitators and modifications comprising focus group themes on just-in-time adaptive intervention design and implementation. JITAI, just-in-time adaptive intervention. *Modifications are planned for future iterations of the RE-PACT intervention, but were not feasible at the time of implementation.

from caregivers with reported confidence levels at any time.

However, caregivers and healthcare professionals recognised that the intervention must be mindful of families' abilities and access to digital technology, including mobile phones, text messaging and data plans. Depending on the tools used, future iterations of the RE-PACT intervention should aim to coordinate mHealth communication tools among different family caregivers and support two-way conversations between healthcare teams and families.

Theme 4: real-time clinical response should meet the relational and structural needs of patients, families and clinicians

Caregivers and healthcare professionals voiced concern about real-time clinical response, ranging from responder

qualifications to response timeliness and organisational capacity for implementation.

Theme 4, subtheme 1: trust and relationship development are fundamental caregiver-identified needs

RE-PACT's clinical responder role was initially envisioned as a non-clinical coach, guiding caregivers through their action plans while offering motivational troubleshooting and non-medical support. The vision for this role evolved during focus group data collection to incorporate direct triage and clinical care. Caregivers emphasised that trust in the training, licensure and knowledge of the person guiding care for their child was fundamental to engagement, stating 'there are times when I know more about him medically than the doctors do. So, I don't know if a [non-clinical] coach either would make a difference'

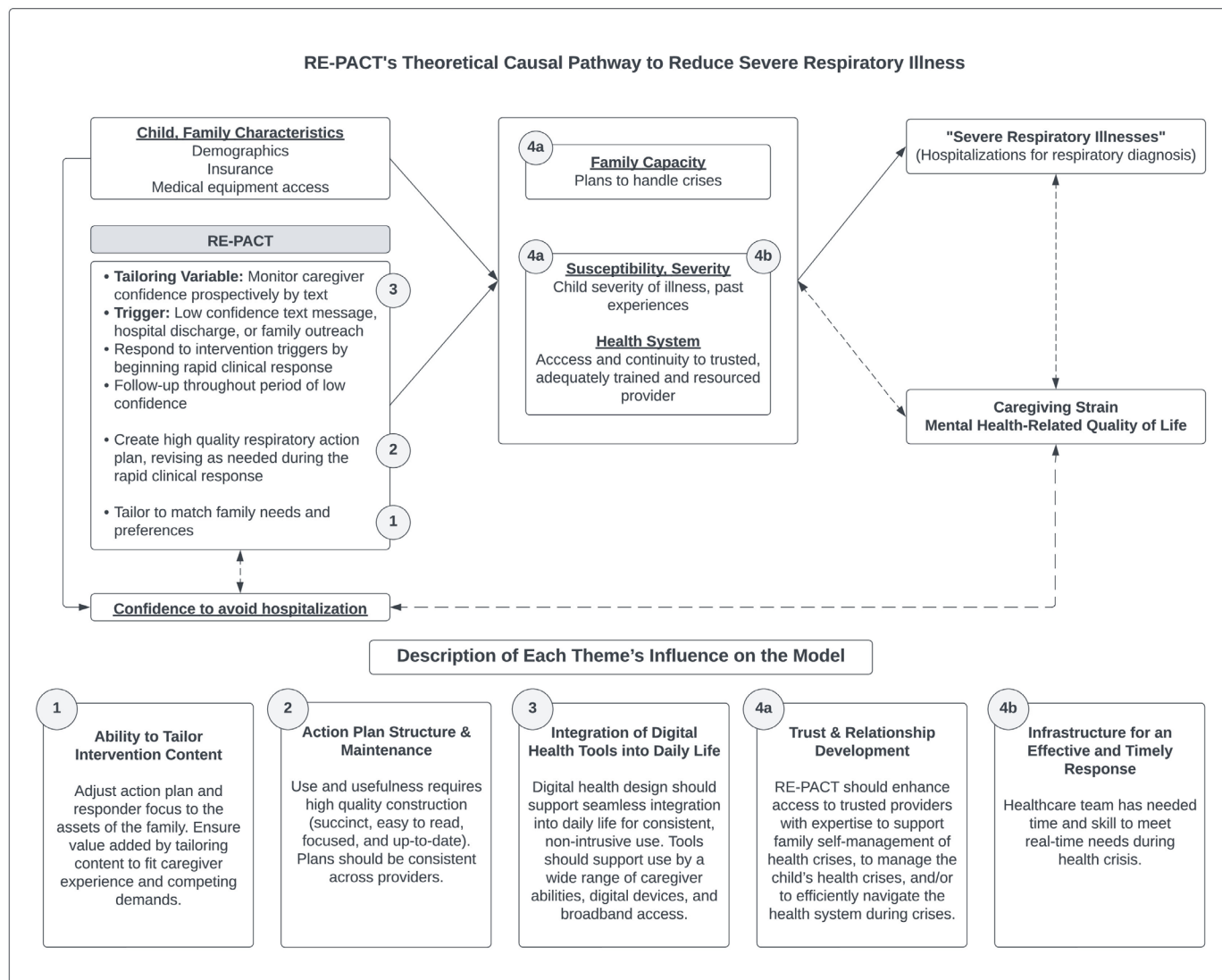


Figure 3 Application of qualitative themes to RE-PACT's theoretical causal pathway to reduce severe respiratory illnesses. RE-PACT, Respiratory Exacerbation-Plans for Action and Care Transitions.

(#16). Healthcare professionals and national experts expressed similar concern about patient complexity, the ability for coaches to identify and escalate issues to clinicians, and the healthcare system's liability. Healthcare professionals without clinical training or credentials (eg, care coordinators, social workers) noted they were 'uncomfortable' with guiding families through action planning and addressing their concerns (#4).

Regardless of the responder's scope of practice, almost all participants emphasised the importance of the family's trust in the responder's empathy and flexibility. Caregivers expressed a strong desire for the responder to already have, or at least develop, a relationship with their child, modifying the intervention to have a dedicated clinical responder assigned to a family for the entirety of the intervention. Additional suggestions included meeting the responder to 'put eyes on the child and see what we would be seeing at home' (#13), having the responder at the 'appointments where you make the care plan' (#20), and ensuring that the responder knows 'that the parent

you're texting with knows their child best and so, if they are concerned, that there really truly is a reason' (#20).

Theme 4, subtheme 2: strong infrastructure is imperative to support an effective and timely response

Infrastructure described by participants as necessary for a reliable, timely and effective intervention included adequate staffing, resources, training and related operational and administrative supports. Healthcare professionals and national experts identified barriers regarding the reliability of technology, the ability for clinical providers to balance triage versus coaching for self-management, and institutions not having 'enough bandwidth to appropriately address the sick calls, and then patients get more frustrated, or perhaps kids are over-treated' (#3). Modifications to the RE-PACT intervention included additional training and scripting to increase the skills needed for clinical response visits as well as event-based triggers to initiate the clinical response JITAI, including caregiver phone calls and MyChart messages to

the care team. As a consideration to future iterations of the RE-PACT intervention, the promotion of safe staffing and adequate capacity were identified as essential infrastructure requirements prior to implementation.

DISCUSSION

This multistakeholder qualitative study synthesised family caregiver, healthcare professional and expert perspectives about the implementation of a JITAI, RE-PACT, comprised of action planning, repeated text messaging and rapid clinical response to prevent respiratory illness in severe CP. Given the significant yet unpredictable impact of respiratory illness on the morbidity and mortality of children with severe CP, novel adaptive interventions such as RE-PACT are needed.^{4-7 11 23} The barriers and facilitators identified through this user-centred design process revealed family needs prior to and when these crises occur and influenced the clinical protocol. For instance, because concerns with a non-clinical coach providing rapid response were common, focus shifted to integrating a clinician rapid responder. Facilitators promoting action plan efficacy and sustainability were built into plan templates and standard operating procedures. Frequent yet simple text communication was endorsed as a desirable tool.

Identifying how and when to respond to a child's increased hospitalisation risk is a critical gap in implementing JITAI clinical responses. Our conceptual model for reducing hospitalisations for children with medical complexity, derived from prior studies of RE-PACT's components, ACTIV and PACT, posits frequent, proactive elicitation of family-identified concerns as a valuable participant-specific indicator of which/when elements of an intervention should be delivered.²⁴ Findings from these focus groups support our hypothesis that JITAIs such as RE-PACT may prevent hospitalisation by improving family capacity and reducing child susceptibility to severe illness (figure 3). These latter concepts have been identified by families as key determinants of hospitalisation risk.²⁵ This intervention strategy should achieve at least two important goals of our conceptual model, reflected in our study's themes. First, RE-PACT promotes earlier response to illness through text messaging, which triggers clinical teams to systematically troubleshoot, using decision rules from action plans to address immediate clinical problems, and then reinstitute maintenance plans when critical periods have passed. Second, this intervention helps clinicians deliver customised responses matched to family needs in a consistent manner across patient populations, increasing equity in access to crisis response. For example, a recurring, simple-to-understand text prompt that allows caregivers to signal when they may need additional help could alleviate several known healthcare navigation barriers, including difficulties initiating communication, navigating electronic communication portals, coordinating communication among specialists and balancing other caregiving priorities.²⁶

This study's themes also recognise that tailoring variables, such as low-confidence text messaging, should avoid creating excessive new burdens for caregivers or clinicians. Analyses of mHealth engagement illustrate how technology performance and ease of use affect users' perceived value of the intervention.²⁷ RE-PACT's perceived non-intrusive nature, with text messages easily integrated into daily life, is promising and consistent with prior research.^{15 16 28 29} Although our results illustrate that caregivers and healthcare professionals view RE-PACT as a tool to build skill, confidence and adaptability for families at any stage in their caregiving journey, understanding what motivates sustained engagement with RE-PACT will be important since family needs change over time.³⁰ Healthcare professionals and national experts recognised that staff capacity could be challenging, especially if increased family communication demands occur. Future research should determine whether early warning signals (such as our confidence text tailoring variable) help staff save time and resources through intervention before problems are crises. These data are important for return-on-investment evaluations.

The substantial influence that focus group findings had on RE-PACT's design illustrates the value of formative research during intervention planning. For example, participants' emphasis on trust, combined with known links between trust and treatment adherence, follow-up and health outcomes, led to considerable revisions of RE-PACT's personnel and activities prior to a planned trial of RE-PACT.^{31 32} Both families and healthcare professionals noted that hiring new staff to perform coaching, especially if not clinically skilled, could limit trust in the relationship and reduce engagement with the intervention, as well as efficacy. Additionally, trust requires appropriate capacity and infrastructure for RE-PACT to function in an expected and timely manner. In light of these concerns, RE-PACT was reconceived to include complex care clinicians (eg, nurses, advanced practice providers, physicians) as clinical responders given their existing patient familiarity and experience communicating with families during illnesses.

Over the long-term, JITAI such as RE-PACT may have broader public health implications. While meta-analysis of mHealth interventions demonstrates significant improvements in a range of paediatric health behaviours and outcomes, there are relatively few examples that apply adaptive intervention techniques.³³ Studies of asthma and promotion of physical activity provide promising early evidence.^{28 34 35} Where RE-PACT is unique is in the application of a JITAI framework to the complex care clinic, inclusion of both families and care providers in the decision rule algorithm and the deep reliance on user-centred design principles. Since prior studies of RE-PACT's components, ACTIV and PACT, observed high feasibility and acceptability in children with medical complexity, a population with heterogeneous conditions, intervention structures similar to RE-PACT may prove to be generally applicable to other

chronic conditions with acute exacerbations managed by families at home.^{15 16}

This study has several limitations. Participants were recruited from complex care programmes where they already receive interdisciplinary care and care coordination. Expanding research to families outside of these programmes may provide additional perceptions of barriers and facilitators. Caregivers discussed how they would have perceived the intervention at different stages, though enrolling less experienced caregivers might uncover additional perspectives. There was limited representation of the country's racial diversity. Although the study was conducted in two regions within the USA and in two languages, the results may not reflect those from other settings or cultures. A notable strength of the study was the inclusion of parent partners throughout the design, data collection, interpretation and dissemination of the study.

CONCLUSION

Our study provides guidance for designing and implementing JITAI focused on the management of acute illnesses in chronic conditions. The provision of a simple, systematic and recurrent connection to clinical support for caregivers managing emerging health crises at home, concurrent with confidence and skill development, addresses previously identified unmet needs. These interventions may lead to novel approaches to improve historically stubborn health outcomes, including respiratory illnesses and mortality in severe CP. These findings will be applied to a clinical trial assessing RE-PACT, a prototypical JITAI for caregivers of children with severe CP.

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