HYBRID CLOSED-LOOP TECHNOLOGY AND UNCERTAINTY IN PARENTS OF CHILDREN WITH TYPE ONE DIABETES

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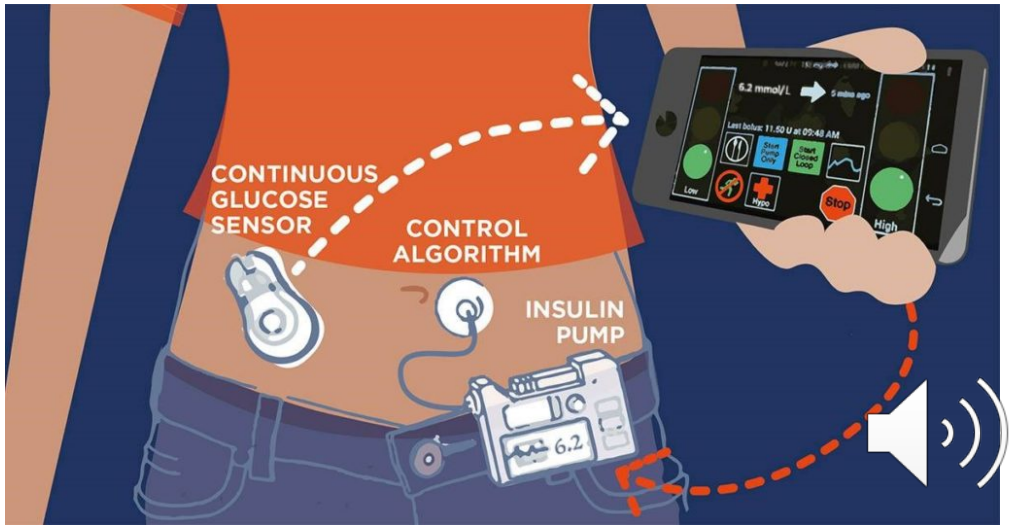
BACKGROUND

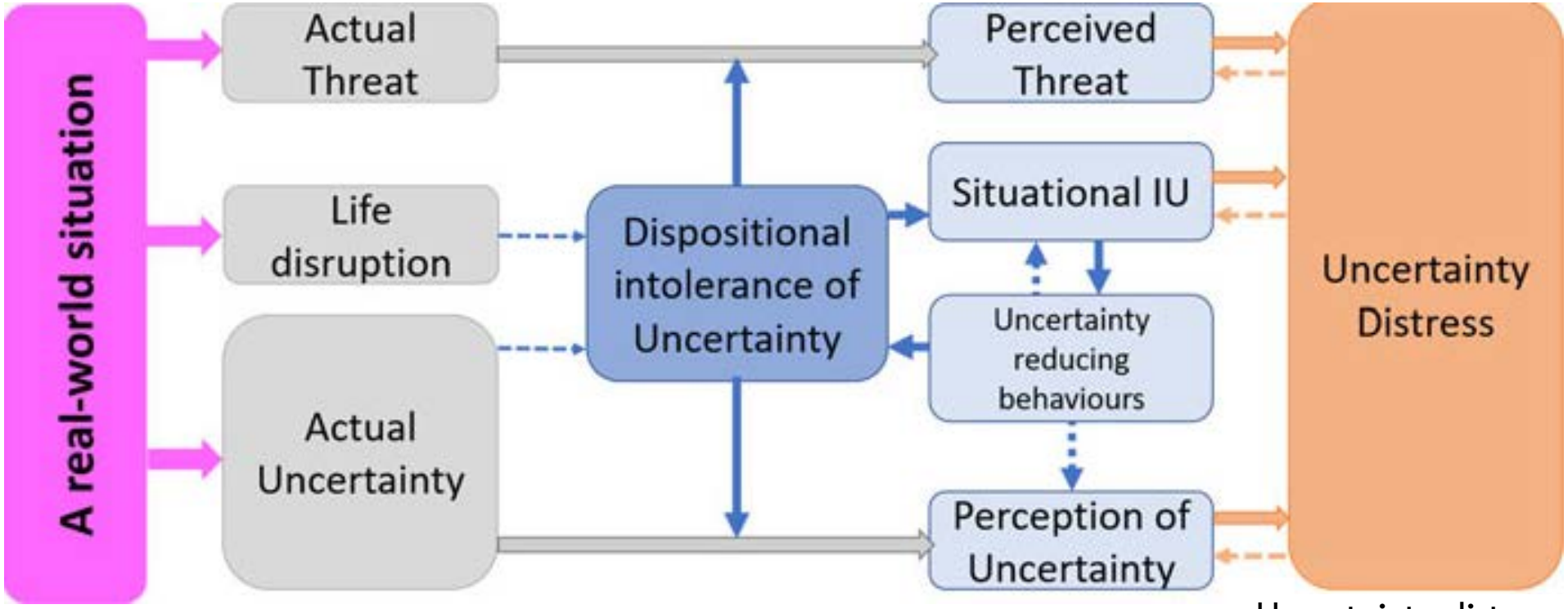
- Diabetes is complex and unpredictable, and getting it wrong has consequences.
- Historically managed by finger-prick blood tests and insulin injections.
- But now… Hybrid closed loop (HCL) technology are rapidly increasing in number.
- Glucose levels measured → sent to control algorithm → algorithm instructs pump to deliver insulin at specific rate.
- Systematic review (2024) found lots of benefits:
  - Better glucose control
  - Aids communication with others
  - Reassurance for parents
  - Reduced life disruption for parents and users
  - Most parents trust HCL



SO, WHAT'S THE PROBLEM?

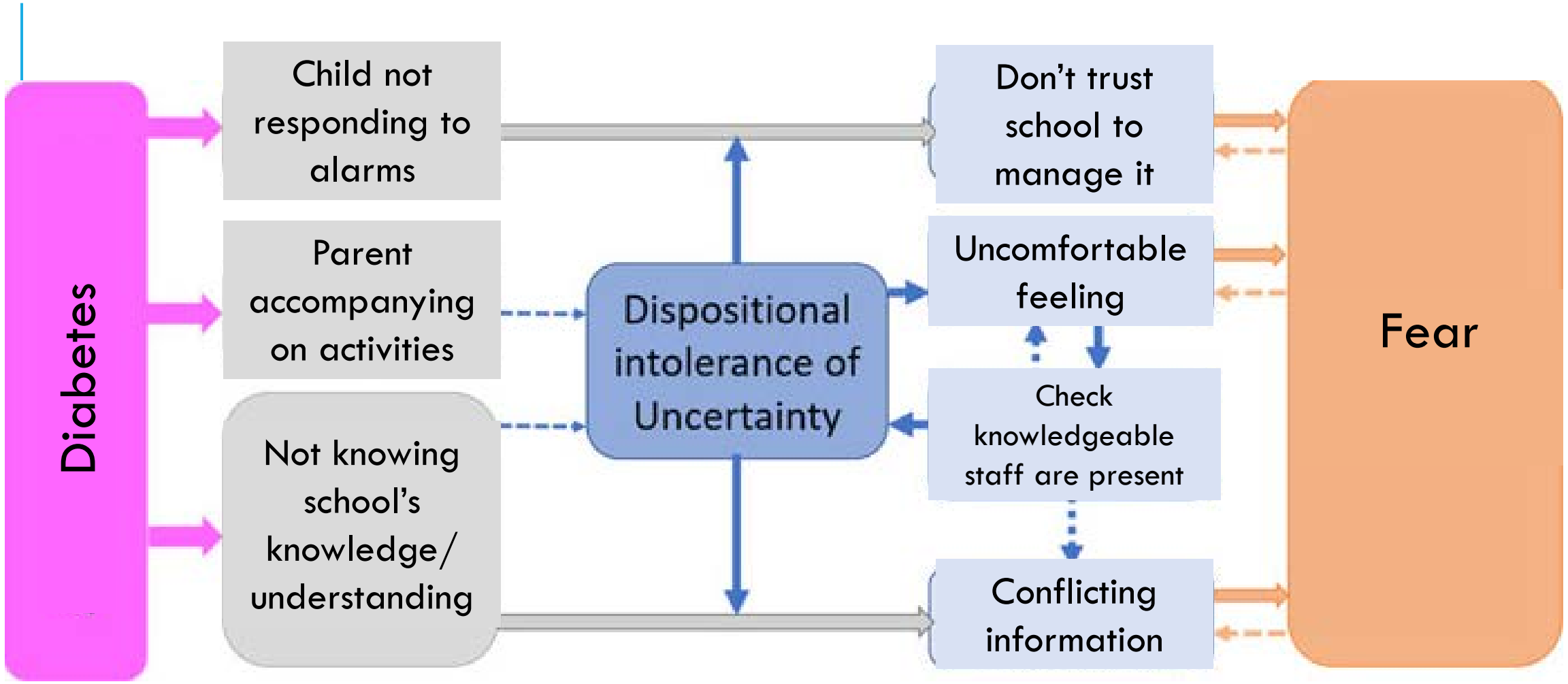
- Newcastle diabetes team found some problems in introduction of HCL.
- Previous research and systematic review on parental experience mention:
  - Takes time to develop trust
  - Overwhelmed by data
  - Constantly checking numbers
  - No 'time-off' from diabetes
  - Over-riding system
- Algorithm needs time to calibrate to child so over-riding system renders it obsolete putting child in medical danger.
- Medical professionals don't know why some parents are more accepting of HCL than others.

COULD THE UNCERTAINTY DISTRESS MODEL (UDM) PROVIDE AN EXPLANATION?



(Freeston et al., 2020)

Uncertainty distress: 'the subjective negative emotions experienced in response to the as yet unknown aspects of a given situation'


Diabetes
Child not responding to alarms
Parent accompanying on activities
Not knowing school's knowledge/ understanding
Dispositional intolerance of Uncertainty
Don't trust school to manage it
Uncomfortable feeling
Check knowledgeable staff are present
Conflicting information
Fear

AIM OF RESEARCH

Phase one: What are parents experiences pertaining in uncertainty?

Phase two: To develop a situational specific model of uncertainty distress in the context of parental management of paediatric diabetes, and test the model by:

1. Examining relationships between uncertainty and distress using standardised measures.
2. Explore the internal consistency of the model by examining relationships among factors in the diabetes situational UDM.
3. Explore convergent validity by examining relationships between the diabetes situational UDM and standardised measures of adjustment, intolerance of uncertainty and illness uncertainty.

PHASE ONE METHODOLOGY

- Parents or caregivers of children using HCL technology to manage type one diabetes recruited opportunistically via social media.
- 2-hour focus group with 8 parents to explore the experiences of parents.
- Analysed through stepped approach informed by framework analysis using UDM.
  1) Transcribed the data and checked transcription for accuracy.
  2) Familiarised self with data by reading and re-reading transcript.
  3) Mapped constructs of the UDM as headings to generate categories.
  4) Coded data using constructs of the model.
  5) Mapped quotes from data onto headings.
  6) Developed themes in participant quotes in discussion with team

PHASE ONE RESULTS

Construct and themes	Example quotes
Actual threat • Child not responding to alarms. • Not intervening when previously would have and blood sugar going high.	"She doesn't wake up during the night, she just sleeps through the alarms".
Perceived threat • Not allowed to message child/ child not replying. • Don't trust school to manage it.	"Teaching assistants at the time were getting very insecure about us trusting them to manage it and were like you keep overstepping us, you keep getting involved and like, yeah, of course we're going to get involved. We know more".
Actual uncertainty • Not knowing schools' knowledge/ understanding. • Not knowing whether to intervene or wait.	"We're going into high school and like what is their stance? What will they be like? Will they take it as seriously as they should do?".
Perceived uncertainty • Conflicting information (e.g. app not matching how child is feeling) • Don't know algorithm	"It's like the decision making and what's going wrong because I can see she's not well, but this is telling me she's absolutely fine when she's clearly not."

PHASE ONE RESULTS CONT.

Construct and themes	Example quotes
Life disruption • Improvements to sleep. • Parent accompanying on activities.	"That has been the best thing for me, the sleep, like I had to have time off work because I was just like not functioning at all".
Situational intolerance of uncertainty • Uncomfortable feeling in the moment when don't know.	"I mean, for me that point is more annoyance. It's like at that time, I don't feel any anxiety, I feel annoyance."
Uncertainty reducing behaviours • Seek out further information • Check knowledgeable staff are present	"I almost used to like stalk the carpark before I dropped her off because I'd look for the cars of the teachers that I'd know knew about it".
Uncertainty distress • Fear. • Guilt.	"You still feel guilty, even though it's nothing that you can do and just I think that's what upsets me".

PHASE TWO METHODOLOGY

- Parents or caregivers of children using HCL technology to manage type one diabetes recruited opportunistically via social media.
- Cross-sectional survey design consisting of:
  - Participant demographics
  - Description of child
  - Standardised measures (GAD-2- anxiety, PHQ-2- depression, IUS-5- intolerance of uncertainty, PPUS- illness uncertainty, IADQ- adjustment, and BSFC-s- carer burden)
  - Adapted diabetes specific version of the Responses to Uncertain Situation Questionnaire (scenarios, actual and perceived threat and uncertainty, situational intolerance of uncertainty, life disruption, uncertainty reducing behaviours, and uncertainty distress)
  - Debrief sheet
- Correlation analysis.

PHASE TWO RESULTS

Demographics (N=144)

- Predominately white (94%), educated (68% degree level), working (39%), or middle-class (49%) mothers (95%).
- 78% using HCL <2 years; 34% using HCL <6 months.
- 94% used previous technology to manage diabetes.
- 84.1% of the participants' chosen uncertain situation occurred 'sometimes' or 'quite a lot', indicating RUSQ situations (developed from phase one) were familiar to participants.
- 28.8% of participants met cut-off criteria for Generalised Anxiety Disorder on the GAD-2; 12.8% met cut-off criteria for Major Depressive Disorder on the PHQ-2; and 45.7% of participants met criteria for Adjustment Disorder on the IADQ.

PHASE TWO RESULTS CONT.

Relationship between uncertainty and distress:

Higher intolerance of uncertainty (not specific to diabetes or HCL technology) was related to poorer outcomes, except for anxiety.

Internal consistency of the diabetes UDM:

The internal parts of the model are correlated for this population (i.e. the model has internal consistency).

PHASE TWO RESULTS CONT.

Relationship between the diabetes UDM and standardised measures of adjustment, intolerance of uncertainty and illness uncertainty:

The situational parts of the situational UDM relate to adjustment disorder, intolerance of uncertainty, and uncertainty in illness scores within this population.

As data was not missing at random and the listwise number was 83 participants it was decided not to continue with hierarchical regression analysis as according to a prior power calculation the analysis would be significantly underpowered (required N = 139).

	IADQ	IUS-5	PPUS
Uncertainty Distress	.51	.41	.24
Life Disruption	.64	.33	.33
Actual Threat	.07	.12	.35
Perceived Threat	.61	.30	.48
Actual Uncertainty	.37	.37	.44
Perceived Uncertainty	.69	.31	.44
Situational Intolerance of Uncertainty	.42	.31	.29
Uncertainty Reducing Behaviours	.59	.31	.26

Bold= statistically significant relationship

SO, WHAT DOES THIS MEAN?

- Higher intolerance of uncertainty is related to poorer outcomes within parents of children using HCL: supports the validity of the model in this population.
- An adequate measure of actual threat will be necessary for future testing of the model; however, results suggest that the internal parts of the situational UDM are internally consistent.
- The situational parts of the model relate to adjustment disorder, intolerance of uncertainty, and uncertainty in illness scores within this population.

<u>The UDM could be tested to explain why some parents engage in what can now be known as uncertainty reducing behaviours.</u>

STRENGTHS, LIMITATIONS, AND FUTURE RESEARCH

Strengths	Limitations
Two phase approach: enhanced model specificity and increased validity of survey questions.	Not allowing participants to fully choose uncertain situation for RUSQ.
Included parents of children of all ages, and children using HCL for up to several years: increases transferability of findings.	Sample highly skewed towards white, educated, working or middle-class mothers in professional employment. Also, likely to be highly motivated and over-engagers: self-selection bias.
Including participants with up to 30% missing data per scale through multiple imputation: reduces bias.	Helpful to consider how parental education, child age, length of time using HCL, and previous technology impacted but did not reach enough participants to conduct hierarchical regression analysis. **So:** data collection continuing to look at above variables and perform first test of the model.
Helps explain why some parents' struggle: HCPs can make better decisions and provide intervention to improve physical and psychological wellbeing of child and parent.	

THANK YOU FOR LISTENING

ANY QUESTIONS?

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