Co-creating an Adrenal Insufficiency Patient Toolkit using Human-Centered Design

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Introduction

Human Centered Design (HCD) is a framework focused on the user (i.e., patient) and their context. The user is recognized as a content expert and is highly involved in an iterative process of design and evaluation.[1,2] With rising application in healthcare, HCD has been applied in the development of shared decision-making tools, interventions, and safety assessments.[3,4] One advantage to HCD is that it facilitates a sense of shared responsibility with patients and clinicians, and by extension it fosters a patient-centered approach to care.[5]

Adrenal insufficiency (AI) requires a patient to be an active participant in their management. They must be well-informed of their condition and know how to navigate their hormone replacement needs, especially in the context of sick-day management.

In partnership with the Physician Learning Program through the University of Alberta, the Division of Endocrinology and Metabolism identified AI as a clinical area of focus. Through collaboration with Designers and patients, we sought to explore how we could enhance patient care at our clinical site.

Methods

1. Discovery

The first step was to understand the patient context and experience, in addition to the clinician perspective. A team of endocrinologists, a Human-Centered Designer, and patient partners collaborated in an exploration of the challenges of living with adrenal insufficiency and areas for improvement in the local context.

2. Ideation

Qualitative surveys were developed for endocrinologists and patients with adrenal insufficiency followed through the U of A to further gauge local practices and experiences. Ultimately, the development of a patient toolkit to standardize patient education, clinical practices, and information resources was determined to be a priority.

3. Prototyping & co-creation

The priorities of the toolkit content and layout were clarified with endocrinologists and patient partners. Afterward, the toolkit prototypes were developed.

4. Iteration

Multiple sessions were held to review the toolkit prototypes, with recommendations from both physicians and patients guiding further iterations of the toolkit. This process was repeated until the toolkit was determined to be acceptable with both the physicians and patient partners.

5. Usability testing & implementation

Patients with adrenal insufficiency were invited to take part in a review and feedback of the toolkit in real-world application. Those who consented reviewed the toolkit documents with their endocrinologist and were provided a copy to take home. Afterward a qualitative survey was distributed to gauge ease of use, intuitiveness, and for further feedback on the layout, content, etc.

Results

Ultimately 2 documents were produced for the toolkit, including:

1. A patient education resource with basic information on adrenal insufficiency/crisis, treatment, circumstances to seek healthcare, and additional web resources.
2. A personal treatment plan with individualized information on stress dosing of adrenal hormones and common scenarios with suggested dosages.

The team also developed an emergency carry letter and an emergency wallet card (not included in this poster presentation).

13 patients were involved in the usability testing process for the toolkit, and 11 of 13 patients completed the usability testing survey. Questions consisted of both multiple choice and open-ended long answers. Open-ended responses were organized through an inductive approach, and themes that arose from these responses are outlined in table 1. Some of the insights obtained from the survey included:

- Most participants felt that the toolkit was intuitive and easy to use.
- Some respondents preferred a more prescriptive document while others preferred using it as a supplementary resource.
- Some (n=4) respondents felt that the toolkit was missing information, while other (n=3) respondents felt that it was comprehensive.
- All (n=11) respondents commented that they would use the toolkit to guide decision-making for stress dosing.

Example responses included:

- "The tool kit is the perfect resource to eliminate any self doubt. It provides more independence when dealing with these scenarios."
- "This is a snapshot of how the patient should handle things. The other platforms provide the soft side, this is an easy black and white to the point document. Patients and healthcare providers will find this easy to use and functional "

Feedback from the survey was incorporated into the most recent toolkit version shown in Figure 1 below.

Themes/questions	Responses/codes (number of responses)
Overall impressions	"Good." (3) User-friendly (2) Enhances patient autonomy (2) Perceived utility: Primer for newly diagnosed patients (2), prescriptive instructions (3), supplementary resource (4)
Toolkit layout	"Good" (6) Easy to follow (7) Visually appealing (1), Dull (1) Concise (1), too lengthy (1), too condensed (2) Did not like the adrenal crisis graphic (1)
Toolkit content	Comprehensive (3) Accurate (2) Informative (3): learned something new (2) Trustworthy (1) Incomplete (4): symptoms of adrenal insufficiency (3), more specific dosing examples (2)
Comparison to other resources	Convenient (1) User friendly (3) More comprehensive (2) Less information (1)

Table 1: themes developed from the survey responses, with corresponding codes listed on the right.

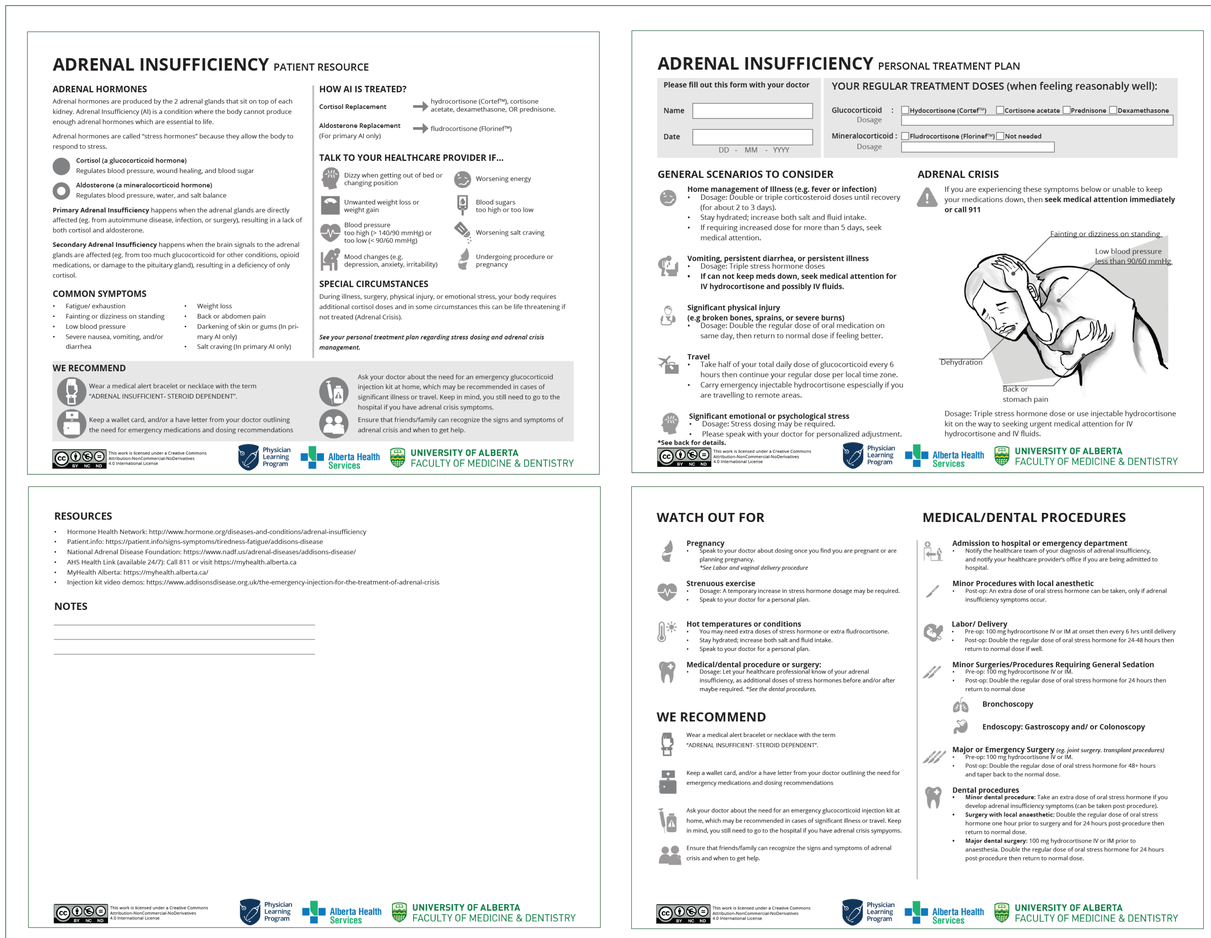

Figure 1: The current toolkit. The two pages on the left comprise the patient information resource, and the two pages on the right are the personal treatment plan.

Conclusions & Next Steps

The implementation of Human-Centered Design (HCD) has great promise in enhancing patient-centered, collaborative care. It is empathy-driven and recognizes the patient as a part of the interdisciplinary team. In this project we have outlined the application of HCD in the development of a patient information toolkit for adrenal insufficiency that is simple, intuitive, and immediately usable for end users.

The toolkit has since been distributed for application within the Endocrinology division (the documents are openly available on the Alberta PLP website), and further feedback will the be obtained to guide future iterations.

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