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Introduction

The move to using multimedia in health education has been driven by patient need and advocacy groups, to have ready access health information.

The process of developing validated educational materials for access via the internet requires careful consideration. In this era of multimedia "hype" and a quest for knowledge, information must be factual, presented clearly and for the average reading age of the population.

What was needed?

Validated comprehensive Psychosocial Education Program (PEP).

Why

- Knowledge and understanding leads to improved health outcomes
- Need for instant access to valid health information
- Limited access to validated resources
- Experienced staff are located in major teaching hospitals located in capital cities. Patients need to travel for specialist care.

Background

Congenital Adrenal Hyperplasia (CAH) is a rare inherited condition with a 1:4 recessive inheritance. Incidence: 1:15,000 with a carrier status of 1:50. Asian population incidence appears higher 1:6000.

An *enzyme defect* leads to glucocorticoid and mineralocorticoid deficiency, leading to salt losing adrenal crisis, shock and death; plus

- **Androgen excess causes:**- ambiguous genitalia, early puberty, short stature and infertility
- **Parental vulnerability:** overwhelmed by diagnosis, medical interventions and terminology
- **Impact of diagnosis:** creates a state of "cognitive paralysis". The shock, grief, fear and confusion that occurs following diagnosis, impairs knowledge attainment.
- **Burden of responsibility:** level of care required, threat of illness and injury, life long management, gender determination: counselling and disclosure
- **Literacy and comprehension:** are always important considerations

Management:

Management of CAH is life long, and requires a good understanding of the condition and its management but more importantly, how to manage clinical problems that arise to prevent an adrenal crisis

Developing effective education initiatives such as the CAHPepTalk website and providing appropriate support are of vital importance in helping families understand and manage the condition and maintain compliance.

Method

A validated Psychosocial Education Program (PEP) was developed via a stringent process of literature review, brainstorming sessions, consultation with family groups and health care professionals. The PEP was implemented and evaluated in 3 NSW Children's Hospitals. It was filmed, recorded and transcribed verbatim. Scripts were edited in line with graphically designed slides and video edited.

The PEP is a comprehensive package of education videos, evaluations and the CAH knowledge questionnaire (CAHKAQ).

The entire "PEPtalk" package has been translated into Vietnamese and Indonesian to address a major area of need in South East Asia. This further led to development of "CAHPepTalk.com" website.



CAHPepTalk.com

The website provides **information, educational resources** and **links** to help families understand and manage CAH. It is a useful resource for Health Professionals.

The "CAH Family Workshop" is a comprehensive psychosocial education program (PEP) in video format containing English, Vietnamese and Indonesian translations.

- What is CAH
- Adolescent and Adult Issues
- Psychosocial Issues
- Sick Day Management
- Emergency Injection of Hydrocortisone



Adrenal Insufficiency

Adrenal Insufficiency is a major dilemma for patients. Appropriate management and compliance with medications is essential. Patients are unable to secrete cortisol from their adrenal glands. The cause is either primary, secondary or iatrogenic. Patients with CAH have primary adrenal insufficiency, and are at risk or an adrenal crisis when unwell, or have poor compliance.

Appropriate management of patients with adrenal insufficiency is critical for preventing a life threatening adrenal crisis, and care plans should include education of the patient, as well as health care teams. To assist in the education process, an Emergency Hydrocortisone APP has been developed for ready access to information in an emergency. **Download it now, it could be life saving for your patients!!**

Emergency Hydrocortisone Mobile APP

The importance of appropriate management of **Adrenal Insufficiency, led to the development of the "Emergency Solu-Cortef Injection (Hydrocortisone) mobile APP** for Iphone and Android devices.

Access to the APP is via the "Pfizer Meds" platform downloaded from the Apple or Google Play sites. This revolutionary site provides a "step by step" video and instruction leaflet on the injection process.

Pfizer Meds

By simply scanning or entering the barcode on your prescription medicine pack, you will be able to access helpful information about your medicine and/or medical condition.



Conclusion

The move to **multimedia learning methods**, which are structured, patient specific and culturally appropriate are appealing to all learners, including those with literacy or language difficulties.

A structured approach to health education has long been recognised to be more effective in improving patient knowledge, than "ad hoc" information.

The use of audiovisual techniques addresses the auditory, visual and psychomotor domains of learning, with participants able to view, listen, read and review information as desired. Providing health information and educational resources via a website and mobile Apps, has become the way of the future. In particular access of what to do in emergency situations.

Transcript filming and recording allowed translation by health professionals and verbal narration by a health services interpreter. Video editing completed the process, to finalise Vietnamese and Indonesian translations, now available on the **CAHPepTalk.com** website for any family or health professional to access.

Comprehension and literacy of the target audience was a primary consideration in deciding the content and the format of this innovative health strategy.

Reference

King, J., Mitchelhill, I., Fisher, M. (2008). Development of a congenital adrenal hyperplasia knowledge assessment questionnaire (CAHKAQ). *Journal of Clinical Nursing*, 17 (13) 1689-1696. ISBN: 978-0-987497-3-3.

Acknowledgements:

CAHPepTalk.com: APEG Nursing Professional Development Grant **Emergency Hydrocortisone Injection Mobile APP:** Pfizer.com