Evolution of a patient education website

“CAH Pep Talk.com”

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Pfizer have not had any input into the material within this presentation.

I accept full responsibility for the contents of this presentation. The views expressed should not be taken as representative of Pfizer Australia.
Session objectives

“A passionate idea leads to something amazing”

• Learn the process of developing & facilitating patient education using multimedia technology

• Learn the process of adapting patient education materials & resources to meet the needs of families in developing countries

• Learn the value of running with an idea: “CAHPepTalk.com” now has international exposure

Follow your dreams & never give up!
Session Outline

• The evolutionary path taken
  • The concern for patients with CAH
  • The needs of the CAH community
  • Moving from an idea to reality

• Outcomes: validation of content
  • Results
  • Moving with technology
  • Translation
  • The website
  • The mobile App.

• Clinician to researcher!
Congenital Adrenal Hyperplasia (CAH)

CAH is an recessively inherited “condition” resulting in:
- Cortisol deficiency ... adrenal crisis
- Aldosterone deficiency ... electrolyte imbalance
- Androgen excess ...
  - Ambiguous genitalia in the newborn (gender determination)
  - Virilisation & early puberty, short stature, infertility

Rare & unique “condition” affecting a small number of families.
Incidence 1:10,000 - 1:15,000, high carrier status high 1:50, 1:6000 in SEA
CAH: the issues

• Significant physical & psychosocial issues
  • Vulnerable: child & family
    • Life threatening, inherited condition (Illness, injury, procedures)
    • Treatment: life-long, multiple daily meds & regular follow-up
    • Compliance essential to prevent poor outcome
    • Sick day management: essential

• Parents need a good understanding of the condition & treatment & sick day management procedures.
Management Issues

• Social support/ counselling
  • Standard education: medical consult
  • Review: frequent: 1-2 weekly, then 3/12

• Education: timing is critical to be effective
  • needs to be ongoing, limited resources
  • Information: simple, clear, concise, consistent

• Expertise: limited to specialist centres
  • No formal education processes available.
Impact of Chronic illness

Parental Adjustment and learning...

- Impact of a sick child
  - the diagnosis, inherited condition, long term care
  - risk of adrenal crisis & fear of death

- Grief process
  - shock, denial, anger, disbelief, loss, delayed attachment

- Literacy
  - cognition, comprehension, culture & religion.
Initial Aims

Improve patient access to education

a) Develop a psychosocial education program (PEP) for families with Congenital Adrenal Hyperplasia (CAH)

b) Develop the program into an audio-visual DVD
   • for use as a patient & family resource
   • program able to be facilitated by one health professional in outreach areas
A research journey

Multi-staged project
Stage 1: Semi-structured interviews
Stage 2: Development & validation of CAHKAQ
Stage 3: Development of the Psychosocial Education Program (PEP)
Stage 4: Development of the DVD
Stage 5: Transcript translation
Stage 6: “CAHPePTalk.com”
Stage 7: Emergency Hydrocortisone mobile App.
“Beginning at the end”

• The Planning & evaluation process guided the idea

• What did we aim to achieve: (increased knowledge & coping)
• What did the population want
• What I thought they needed
• What change in health-related behaviours could we measure
• Evaluation process: what did they think?
Solution focused:
  - parent interviews, focus groups, development of CAHKAQ,

  - “Psychosocial Education Program”
    - Development
    - Implementation
    - Evaluation

“Health Education: consciously constructs opportunities for learning for individual target groups”
Stage 1: Parent interviews

• Thematic analysis: “within & between” case analysis
  • Impact of an inherited “condition”:
    • Cognitive paralysis, shock, grief, fear, confusion
    • Overwhelmed by medical interventions, terminology, staff reactions
    • Frightened, burden, responsibility
  • The emotional distress:
    • Unable to manage episodes of illness appropriately
    • Cannot give emergency hydrocortisone
    • Anniversaries- reminders
  • Manage the “here and now” ...hope for the future!
Parent interviews (cont)

• Past: Devastating and emotionally traumatic.

• Present: Manageability easier with time, in control

• Future: positive, hope for future, concern for surgery, fertility
What do families want?

• Hope! there is life after this and its normal
  – Social support & counselling
  – Access to support group: not initially, but later.
  – See other kids coping normally
  – Information at different ages and stages

• Health professional issues
  – be careful not *paint a negative picture!*
  – Help parents to be alert .... but not alarmed.... when illness occurs
Stage 2: Development of the CAHKAQ

*(CAH Knowledge Assessment Questionnaire)*

- Phase 1 - Constructing test items
- Phase 2 - Delphi Technique: used to establish “content validity”
- Phase 3 - Pilot test CAHKAQ: “reliability & construct validity”
Questionnaire validation

- *Cronbach alpha = 0.72*

**Questions with greatest error rate:**

<table>
<thead>
<tr>
<th>Question</th>
<th>Incorrect/Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q17 - If a person is pale and drowsy ...</td>
<td>(44%)</td>
</tr>
<tr>
<td>Q21 - Medical follow up is generally recommended...</td>
<td>(44%)</td>
</tr>
<tr>
<td>Q19 - A person is at risk of adrenal crisis ...</td>
<td>(31%)</td>
</tr>
<tr>
<td>Q12 - Not taking hydrocortisone causes ...</td>
<td>(31%)</td>
</tr>
<tr>
<td>Q2 - In CAH the body makes ...</td>
<td>(29%)</td>
</tr>
<tr>
<td>Q8 - Fludrocortisone helps regulate ...</td>
<td>(29%)</td>
</tr>
</tbody>
</table>
Test Your Congenital Adrenal Hyperplasia Knowledge

For each question, circle one answer only.

1. CAH is a condition of the:
   a) pituitary gland
   b) adrenal gland
   c) ovaries or testes
   d) unsure

2. In CAH the body makes:
   a) too much cortisol and too much androgen
   b) too little cortisol and not enough androgen
   c) too little cortisol and too much androgen
   d) unsure

3. CAH is caused by:
   a) a virus
   b) a faulty gene
   c) a harmful environmental agent
   d) unsure

4. The chance that CAH will recur in a family is:
   a) one in four with every pregnancy
   b) with every pregnancy
   c) never
   d) unsure

5. To have CAH the child must inherit the gene from:
   a) both the mother and father
   b) the mother only
   c) the father only
   d) unsure

6. Cortisol is:
   a) an essential vitamin
   b) essential for decreasing blood sugar
   c) a hormone essential for life
   d) unsure

7. Too much androgen may:
   a) slow growth
   b) cause rapid growth and early puberty
   c) delay pubertal development
   d) unsure

8. Hydrocortisone (Fludrocortisone) helps regulate:
   a) salt balance
   b) blood sugar levels
   c) growth
   d) unsure

9. The main reason for treating CAH is to:
   a) promote normal growth and development
   b) prevent an adrenal crisis
   c) both a) and b)
   d) unsure

10. Treatment for CAH is required:
    a) until you grow out of it
    b) until adulthood
    c) lifelong
    d) unsure

11. In an Adrenal Crisis someone urgently needs:
    a) Paracetamol (Pendale)
    b) salt, sugar and rest
    c) hydrocortisone injection and fluids via a drip
    d) unsure

12. Not taking hydrocortisone causes:
    a) low blood sugar & blood pressure
    b) lack of energy & drowsiness
    c) both a) and b)
    d) unsure
Stage 3: Development of the PEP

Preliminary work in this research program informed the Psychosocial Education Program (PEP): titled “The CAH Family Workshop”

- Overview of CAH
- Adolescent transition & adult issues
- Psychological aspects of CAH
- Practical aspects of Sick Day Care
- Hands on injection technique
- Discussion groups & a personal story
Results of the PEP

- 4 CAH Family Workshops held over 2 years
- 140 families from 3 children’s hospitals (*multiple participants*)

- Ethics & informed consent - pre & post test measures (*knowledge, QOL, & filming for DVD*)
- Group knowledge was gained overall & maintained over time
- Sick day management was challenging
- Psychological evaluation was positive for this clinical group.
  - Social competence/Internalising/externalising (CBCL), Parental perceptions (CHQ)
- Process evaluation: 88% +ve: (*content, useful, time*)
Stage 4: Development of the DVD

- **Aim**
  - Develop components of the Psychosocial Education Program (PEP) into a DVD
  - facilitated by one experienced health professional
  - for patients and families living with CAH in isolated country regions.

- Improving access to education resources is essential.
- Use of multimedia addresses access to information
  - Visual, auditory & psychomotor domains
Value of Multimedia formats

Gaining popularity

- accessible
- watch, read, listen, review & repeat
- learning at own pace
- addresses literacy issue pitched at correct level
- allows reflection (*Krishna, et al. 2003*)
- an interactive component keeps interest.
- *Should not stand alone*
Stage 4: Moving with Technology - DVD

- Development of the DVD
  - Filming recording & editing PEP content
  - Key presenters: “image of trust & experience”
  - Transcribed verbatim for verbal clarity

  - Process
    - Video editing of presentations
    - Total length of DVD = 1.5 hours in 20 min sessions
    - Evaluation: 4 families reviewed final content

  - Launched 2011

- Translated: Vietnamese & Indonesian
Stage 5: DVD translation

• Approached by “Caring Living as Neighbours” (CLAN)
  • NGO: improve health of children with chronic illness in resource-poor countries (Sth East Asia: Vietnam, Indonesia, Phillipines, Pakistan).
  • Incidence is high (1:6000), populations large, resources poor.
  • Limited access to essential medications, medical expertise, resources.
  • Works under a 5 Pillar structure to optimise: medication, medical care, resources, family support, reduction in poverty.
CLAN's Framework for Action

Our mission is to maximise quality of life for children (and their families) who are living with chronic health conditions in resource-poor countries of the world

HIGHEST QUALITY OF LIFE

1. Ensure affordable access to medication and equipment.
2. Education, research and advocacy.
3. Optimal medical management.
4. Encourage family support groups.
5. Reduce poverty and promote financial independence.

A RIGHTS BASED APPROACH

Community Groups
Individuals
Industry
Families
Policy Makers
Health Professionals
Non Government Organisations
Other Specialists
Government & Health Systems
Philanthropy

Support Group as Visual Hub

A community of children, Hanoi 2007. All children in this photo have the same chronic health condition and their families meet regularly for support.
# Demographics

<table>
<thead>
<tr>
<th>Total No. Analysed</th>
<th>Female</th>
<th>Male</th>
<th>Ave Age Years</th>
<th>Average time to diagnosis</th>
<th>Classical CAH</th>
<th>Non Classical CAH/Unsure</th>
<th>Hydrocortisone &amp; Florinef/Hydrocortisone only</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hanoi</td>
<td>155</td>
<td>79</td>
<td>76</td>
<td>8 (1-19yr)</td>
<td>&lt;1 yr (1 @ 4yr)</td>
<td>102</td>
<td>19/12 Unknown</td>
</tr>
<tr>
<td>HCMC</td>
<td>66</td>
<td>33</td>
<td>33</td>
<td>5 (19mth-15yr)</td>
<td>&lt;1 yr</td>
<td>34</td>
<td>6/14 Unknown</td>
</tr>
<tr>
<td>Jakarta</td>
<td>24</td>
<td>14</td>
<td>10</td>
<td>5 (4mth-15yr)</td>
<td>&lt;1 yr</td>
<td>16</td>
<td>2/4 Unknown</td>
</tr>
</tbody>
</table>
Translation needed

• The PEP: a comprehensive resource
  – Transcripts & slides translated: 2 medical professionals (each language)
    – translated word for word, line by line.
    – both English & Vietnamese / Indonesian (tracking translation)
  – Edited for cultural & lay understanding
  – transcripts narrated by Health services interpreter

• Other resources: translated
  – CAHKAQ, evaluation, injection instructions, school & healthcare plans
## Summary of knowledge deficits:

<table>
<thead>
<tr>
<th>Knowledge difficulties</th>
<th>Percentage incorrect or unsure &gt; 3\textsuperscript{rd} tertile</th>
<th>n=155 Hanoi %</th>
<th>n=66 HCMC %</th>
<th>n=24 Jakarta %</th>
<th>n=187 Australia %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q4 The chance CAH will recur in a family is</td>
<td></td>
<td>44.20</td>
<td>39.39</td>
<td>41.66</td>
<td>17.3</td>
</tr>
<tr>
<td>Q9 The main reason for treating CAH</td>
<td></td>
<td>30.20</td>
<td>40.90</td>
<td>20.83</td>
<td>17.7</td>
</tr>
<tr>
<td>Q11 In an adrenal crisis someone urgently needs</td>
<td></td>
<td>16.10</td>
<td>30.30</td>
<td>2.94</td>
<td>3.8</td>
</tr>
<tr>
<td>Q12 Not taking Hydrocortisone causes</td>
<td></td>
<td>36.24</td>
<td>54.54</td>
<td>54.16</td>
<td>31.7</td>
</tr>
<tr>
<td>Q14 If a person misses a medication... they should</td>
<td></td>
<td>41.61</td>
<td>45.45</td>
<td>70.83</td>
<td>30.8</td>
</tr>
<tr>
<td>Q16 If a person has slight cold .... they should</td>
<td></td>
<td>48.99</td>
<td>34.84</td>
<td>66.66</td>
<td>19.8</td>
</tr>
<tr>
<td>Q17 If a person is pale &amp; extremely drowsy...</td>
<td></td>
<td>54.36</td>
<td>51.51</td>
<td>79.16</td>
<td>31.4</td>
</tr>
<tr>
<td>Q18 A person with persistent diarrhea &amp; vomiting</td>
<td></td>
<td>45.63</td>
<td>37.88</td>
<td>29.16</td>
<td>13.0</td>
</tr>
<tr>
<td>Q19 A person with CAH is at risk of an adrenal crisis</td>
<td></td>
<td>61.74</td>
<td>65.15</td>
<td>37.5</td>
<td>24.9</td>
</tr>
<tr>
<td>Q20 Hydrocortisone injection should be given into</td>
<td></td>
<td>68.45</td>
<td>71.21</td>
<td>75.0</td>
<td>24.3</td>
</tr>
<tr>
<td>Q21 Medical follow-up is recommended</td>
<td></td>
<td>61.74</td>
<td>91.21</td>
<td>37.5</td>
<td>38.9</td>
</tr>
<tr>
<td>Q22 Main reason for wearing a medical alert</td>
<td></td>
<td>44.96</td>
<td>51.51</td>
<td>37.5</td>
<td>4.9</td>
</tr>
</tbody>
</table>
Stage 6: CAHPePTalk.com

- Multimedia in health:
  - driven by patient need, advocacy groups “immediate & ready access” to information.
  - In this era of “multimedia hype” information must be factual, validated & pitched for the lay population.

- Multimedia learning methods:
  - structured, patient specific & culturally appropriate
  - appeal to all learners & those with literacy or language difficulties.

- Internet access is worldwide: “CAHPePTalk.com” is accessible
  - developing countries lead the way
Welcome to the CAH Family Workshop website. This website contains a Psychosocial Education Program developed for families with a diagnosis of Congenital Adrenal Hyperplasia (CAH). This program has been developed to provide families with information to assist in understanding and managing the condition. The program is provided in a DVD format.
What is CAH

Introduction

Congenital Adrenal Hyperplasia (CAH) is a condition, which affects the ability of the body to produce the hormones from the adrenal gland. "Congenital" means present at birth: "Adrenal" means adrenal gland.

Children born with this condition have an enzyme deficiency, which results in the absence of the normal production of the hormones from the adrenal gland. There is both cortisol and aldosterone deficiency, and the lack of these hormones allows the formation of other hormones called androgens, all causing significant health issues for the child. Management is through replacing the missing hormones and suppressing the excess androgen production, with more specific management required during times of illness.

There is a range of challenges faced by parents of children with this diagnosis. A family’s adjustment can be greatly improved by learning about CAH and knowing how to manage this condition effectively.
What is Adrenal Insufficiency?

Adrenal Insufficiency occurs when the adrenal gland is unable to secrete Cortisol, a hormone essential for maintaining blood pressure and normal blood sugar levels. The gland is unable to secrete enough of the hormone to maintain the body's normal function.

Causes: The cause is either 

Primary causes include: Enzyme deficiency (CAH), Adrenal Suppression secondary to high dose steroid treatment for chronic conditions such as chronic renal failure, severe asthma, Crohn's disease of the gut, or as part of oncology or neurosurgical treatment.

Secondary causes: affect the pituitary gland and include: maldevelopment (aplasia or hypoplasia) brain tumours, surgical or irradiation treatments, and head injuries.

What does the hormone Cortisol do?

Cortisol is important in the body for maintaining blood pressure and normal blood sugar levels. It protects the body from harmful illness, and supports the body's function when unwell.
Welcome

Welcome to the CAH Family Workshop website. This website contains a Psychosocial Education Program developed for families with a diagnosis of Congenital Adrenal Hyperplasia (CAH). This program has been developed to provide families with information to assist in understanding and managing the condition. The program is provided in a DVD format.
Chào mừng các bạn đến với buổi hội thảo dành cho gia đình bệnh nhân bệnh Tăng sản thường thân bẩm sinh, một chương trình giáo dục được phát triển dành cho các gia đình bệnh nhân bệnh Tăng sản thường thân bẩm sinh. Chương trình giáo dục này đã được phát triển để cung cấp cho các gia đình những thông tin cần thiết để biết được chẩn đoán và kiểm soát các bệnh nhân bị bệnh Tăng sản thường thân bẩm sinh. Chương trình được trình bày trong 5 phần.

Toàn bộ chương trình kéo dài khoảng 1 giờ rưỡi. Bạn có thể chọn xem bất kỳ phần nào trong 5 phần bằng cách nhấn vào số hiệu của phần đó từ menu chính.

Nếu bạn có bất kỳ câu hỏi nào về những thông tin được trình bày trong chương trình này, xin vui lòng thảo luận với chuyên gia y tế của bạn.

Password Required
If you've got it, enter it below.
Links

What is Adrenal Insufficiency?
Adrenal Alert for EMR
Emergency Letter for CAH
Treatment of Adrenal Insufficiency
Emergency Hydrocortisone Injections: When to give!
Emergency Response Plan
School Health Care Plan
Draft Travel Letter
How to Get Enough Salt
Tablet crushing & administration
Questionnaire
References
Launching mobile technology
Internet reaches all!
No matter where!
Future of medicine
Hydrocortisone Mobile App

- Any patient with “Adrenal Insufficiency”
  - Download “Pfizer Meds App” via “Itunes /Google play”
  - scan the barcode of the vial of Hydrocortisone or enter code
Your Emergency Solu-Cortef™ (hydrocortisone) Injection Kit

Your Emergency Injection Kit contains:
- 1 x 2mL Solu-Cortef™ ACT-O-VIAL™
- 2 x Alcohol Swabs
- 1 x 3mL Single Use Syringe
- 1 x Vial Access Cannula or Drawing Up Needle
- 1 x Injection Needle
- 2 x Cotton Swabs

Preparation:
- Wash your hands thoroughly before preparing the injection.
- Check the label to ensure you have Solu-Cortef™.
- Check the expiry date on the ACT-O-VIAL™.

**STEP 1**
- Place the ACT-O-VIAL™ on a firm surface and invert the bottle and withdraw the correct dose ordered by your doctor.

**NOTE:** If using a drawing up needle, keep the needle tip below the fluid level.

**STEP 2**
- Put the ACT-O-VIAL™ on a hard surface.
- Place the palm of your hand on the lid of the ACT-O-VIAL™.
- Place the vial firmly on the lid to force the liquid into the bottom chamber.

- Gently mix the solution without shaking it.
- Rotate the ACT-O-VIAL™ turning it upside down a number of times.
- DO NOT SHAKE.
- The solution is initially cloudy but will become clear.

**STEP 3**
- Remove the plastic tab that covers the rubber stopper with your fingernail.

**STEP 4**
- Wipe the top of the ACT-O-VIAL™ with an alcohol swab.

**STEP 5**
- Connect the 3mL syringe and the vial access cannula or drawing up needle firmly together.

**STEP 6**
- Do not recap the needle.
- Press the cotton swab firmly over the site for a few seconds.
- The injection will work quickly, but supervision is still required.
- Measure and take the patient to hospital for further care if necessary.

**STEP 7**
- Place the ACT-O-VIAL™ on a firm surface and insert the access cannula or drawing up needle through the rubber stopper.

**STEP 8**
- Withdraw the syringe from the ACT-O-VIAL™.
- Remove the access cannula or drawing up needle and replace it with the injection needle. Use the needle size recommended by your clinic nurse.
- Pick the syringe to remove any bubbles.
- Exert any excess air.

**STEP 9**
- Divide the thigh into 3 sections.
- Clean the leg area with an alcohol swab BEFORE injection.

**STEP 10**
- Holding the syringe firmly, give the injection by quickly inserting the needle fully through the skin surface into the muscle layer.
- Push the plunger until the dose is fully injected. This will only take around 10 seconds.

**STEP 11**
- Remove the needle and place in a SHARPS CONTAINER.
- Do not recap the needle.
- Press the cotton swab firmly over the site for a few seconds.
- The injection will work quickly, but supervision is still required.
- Measure and take the patient to hospital for further care if necessary.

**STEP 12**
- With the access cannula or drawing up needle in the ACT-O-VIAL™, invert the bottle and withdraw the correct dose ordered by your doctor.

**NOTE:** If using a drawing up needle, keep the needle tip below the fluid level.
Finding the “magic fit”

• Finding the balance: Nurse Clinician to Researcher!
  – Prioritising full time clinical work/pursuing part time research
  – Team support and understanding

• Nursing v/s Medical research
  – Qualitative v quantitative analysis
  – Significant psychosocial & educational value

• Follow your dreams and never give up!
  • The value of running with a passionate concept
Grants

- ENSA (CAHKAQ) $5,000
- Sesqui New Staff support (Thematic analysis) $19,400
- Nurses Registration Board (PEP) $5,450
- SCH Douglas & Lola: (DVD development) $10,000

Website funding:
- APEG Nursing Professional Development Grant $10,000
  - Developed in honour of Jenny Nairn (03/01/1959 - 16/04/2010)
  - passionate Endocrine Nurse & a founding member of ENSA
Acknowledgments

CAHKAQ/PEP: patients & families: SCH, CHW & JHCH
  – ENSA – initial research grant: 5 Granting bodies in total.
  – Jennie King, Murray Fisher: Faculty of Nursing- Sydney University.
  – Expert Endocrinologists, nurses & parents for Delphi & focus groups.
  – MN (Hons.) Supervisors: Jackie Crisp & Carolyn Briggs- University of Technology Sydney.
  – Mentor: Late Professor Gabriel Antony

DVD film & editing: - Medical Illustration/Clinical photography: University of NSW, Sydney
Web design: - Nat Jackson: - Jacksonspeed.com
Mobile App: - Dalia Saad & Sonya Owen: Pfizer Australia

My family... Paul, (Hamish), Jessie & Angus.


