



Parental Knowledge of Congenital Adrenal Hyperplasia (CAH) Vietnam & Indonesia



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Introduction

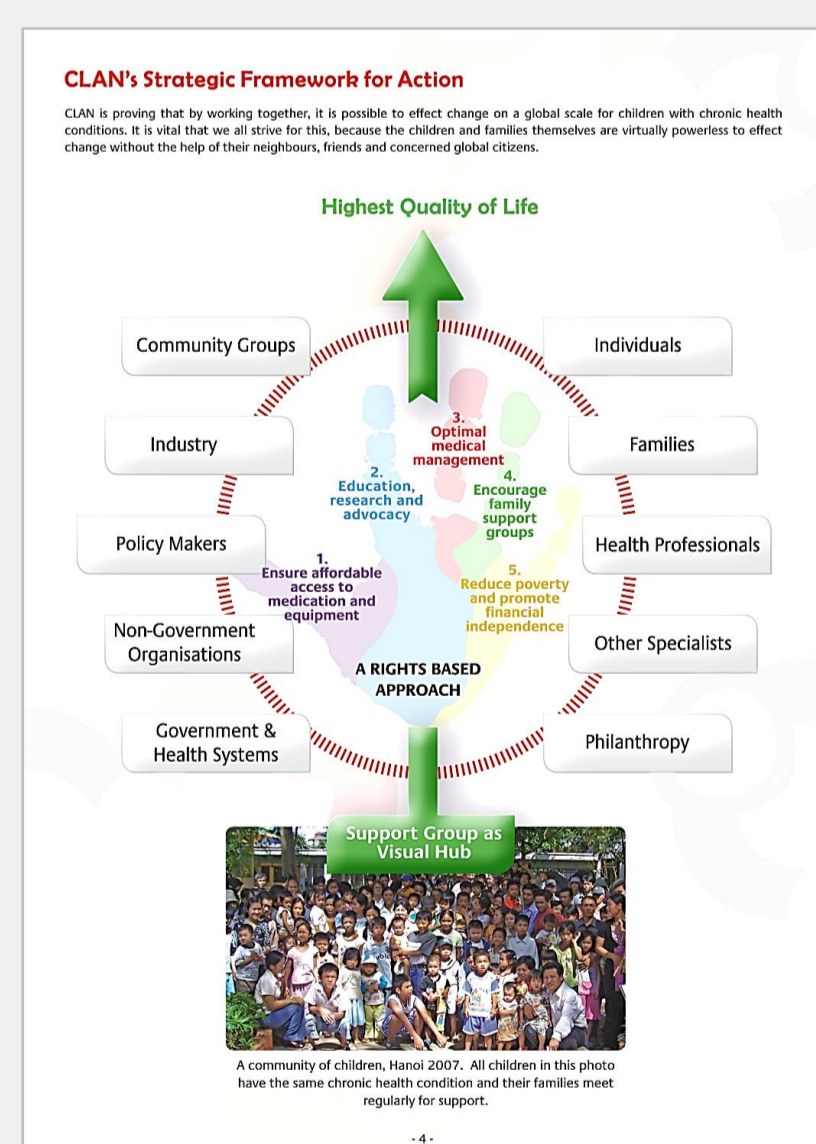
- CAH is associated with significant physical and psychosocial consequences for affected children and families where access to treatment is suboptimal
- The Incidence of Congenital Adrenal Hyperplasia (CAH) in some Asian countries is far higher than in Australia (e.g. 1:6000 Filipino Newborn Screening Program)
- Necessary resources for families in LMICs in Asia are limited:-
 - Reliable access to affordable essential medicines is problematic
 - Medical expertise is usually centralised in major tertiary referral hospitals
 - Families often lack confidence in the care provided by local practitioners
 - Educational resources on CAH in local languages (hard copy and online) can be limited
 - Many families living remotely travel long distances for medical care and to purchase medication
 - Low income families struggle to afford health care

Children in low- and middle-income countries (LMICs) are at especial risk of preventable morbidity and mortality associated with CAH.

Background

CLAN (Caring and Living as Neighbours - an Australian based NGO established in 2004) has been working with families and healthcare teams in Vietnam and Indonesia, to optimise quality of life for children living with chronic health conditions such as CAH.

CLAN works in collaboration with a wide range of partners to support CAH Communities in LMICs so that the children might fulfill their right to health. CAH CLAN, and these have been made freely available to all families in Vietnam and Indonesia.



Aim

Evaluate the knowledge of families attending the CAH Clan Club meetings in Vietnam and Indonesia using the CAHKAQ translated into both languages.

Method

1. CAHKAQ was initially developed and validated in Australia¹. Translation was undertaken by health professionals experienced in CAH from both Vietnam and Indonesian hospitals.
2. CAHKAQ includes demographics and treatment, with 11 questions on pathophysiology and 11 questions on CAH management.
3. CAHKAQ was given to each family at registration for a CAH Club Meeting. Additional clinical data was collected - height, weight and blood pressure.



Results

Demographics of the 3 Centres:

| Total No. Analysed | 245 | Female | Male | Ave Age Years | Average time to diagnosis | Classical CAH | Non Classical CAH/ Unsure/ Unknown | Hydrocortisone & Fludrocortisone only |
|--------------------|-----|--------|------|---|---------------------------|---------------|------------------------------------|---------------------------------------|
| Hanoi | 155 | 79 | 76 | 8 (1-19) ^{yr} | <1 yr (1 @ 4yr) | 102 | 19/12 Unknown = 16 | H&F = 93 H = 50 Unknown = 7 |
| HCMC | 66 | 33 | 33 | 5 (1 ⁹ mo-15 ^{yr}) | <1 yr | 34 | 6/14 Unknown = 12 | H&F = 60 H = 6 Unknown = 3 |
| Jakarta | 24 | 14 | 10 | 5 (4 ^{mo} -15 ^{yr}) | < 1 yr | 16 | 2/4 Unknown = 2 | H&F = 7 H = 7 Unknown = 0 |

CAHKAQ knowledge scores:

| CAH Knowledge | Mean | SD | Minimum score | Maximum score over total | % Less than mean |
|---------------|------|---------|---------------|--------------------------|------------------|
| Hanoi | 30 | +/-7.05 | 7/44 | 44/44 | 41.9% (n=65) |
| HCMC | 31 | +/-7.0 | 9/44 | 44/44 | 45% (n=30) |
| Jakarta | 30 | +/-8.54 | 20/44 | 39/44 | 37% (n= 9) |

Summary of knowledge deficits:

| Knowledge difficulties | Percentage incorrect or unsure > 3 rd tertile | n=155 Hanoi % | n=66 HCMC % | n=24 Jakarta % | n=154 Australia % |
|------------------------|--|---------------|-------------|----------------|-------------------|
| Q4 | The chance CAH will recur in a family is | 44.20 | 39.39 | 41.66 | 17.3 |
| Q9 | The main reason for treating CAH | 30.20 | 40.90 | 20.83 | 17.7 |
| Q11 | In an adrenal crisis someone urgently needs | 16.10 | 30.30 | 2.94 | 3.8 |
| Q12 | Not taking Hydrocortisone causes | 36.24 | 54.54 | 54.16 | 31.7 |
| Q14 | If a person misses a medication... they should | 41.61 | 45.45 | 70.83 | 30.8 |
| Q16 | If a person has slight cold... they should | 48.99 | 34.84 | 66.66 | 19.8 |
| Q17 | If a person is pale & extremely drowsy... | 54.36 | 51.51 | 79.16 | 31.4 |
| Q18 | A person with persistent diarrhea & vomiting | 45.63 | 37.88 | 29.16 | 13.0 |
| Q19 | A person with CAH is at risk of an adrenal crisis | 61.74 | 65.15 | 37.5 | 24.9 |
| Q20 | Hydrocortisone injection should be given into | 68.45 | 71.21 | 75.0 | 24.3 |
| Q21 | Medical follow-up is recommended | 61.74 | 91.21 | 37.5 | 38.9 |
| Q22 | Main reason for wearing a medical alert | 44.96 | 51.51 | 37.5 | 4.9 |

The knowledge base of CAH families across the three Centres appears similar.

Parents in Vietnam and Indonesia appeared to have a reasonable knowledge about the basic pathophysiology of the condition (Q1-11), with some uncertainty about the inheritance of CAH (Q 4 & 5).

There was a significant deficit in the area of clinical management, and uncertainty about medication dosing. More than 50% of families did not understand the consequences of not taking or missing Hydrocortisone doses. Sick day management issues were a particular challenge for families in Vietnam and Indonesia (Q12-19), a finding similar to Australian data ². Like families in Australia, families living in Vietnam and Indonesia also struggled to identify features of serious illness and when to appropriately administer stress doses of hydrocortisone.

Questions (Q17, 18, 19, 20) relating to more severe illness had the highest incorrect answers (37.5 - 79.16%) and this was consistent across the three Centres.

In Summary

- These results highlight the importance of providing families of children living with CAH in LMICs with further education in a structured way. Children living with CAH have a right to fulfill their life potential, and we all have a collective responsibility to help them achieve that.
- The diagnosis of CAH can be emotionally devastating for any family, and can greatly influence the attainment of knowledge. Having some understanding about what may influence knowledge about CAH and its management is critical to improving outcomes for these families. These groups had a basic understanding of the basic pathophysiology of CAH except for some uncertainty about inheritance in Q4 & 5. There fact that clinical management seemed to challenge families could be influenced by local issues in relation to adequate supply of affordable medication. Families may be aware of the value of Florinef or the need to triple dose with hydrocortisone during times of stress, but avoid using it because of limited access to affordable supplies. A multi-sectorial approach to improving health outcomes is essential, and this is facilitated by CLAN's strategic "Five Pillar" framework for action.
- Paediatric centres in Vietnam and Indonesia see relatively high numbers of children with CAH compared to Australia, yet the numbers of specialist Paediatric Endocrinologists and specialist nurses are far less available. Many families live remotely and travel long distances to obtain medical care and medications, which can be expensive.
- The data set obtained for the Indonesian group who attended the CAH Club meeting in Jakarta (Kahaki) was indeed small. Indonesia is a country with a large island archipelago, making travel difficult and unaffordable for LMIC families. Attendance at such meetings can also be influenced by a significant need for privacy and confidentiality about health diagnoses. There can also be an element of denial and a reluctance to share experiences which can be culturally significant.
- CAH Support Groups facilitate education and psychosocial support for large numbers of families in a time-efficient way, although limited resources and funding for these activities are a constraining factor.
- Free online access to translated educational resources and psychosocial support for CAH families and health professionals will be an important innovation as Internet access increases in LMICs. Quality, validated educational material in a multimedia format will allow all families and health professionals to view, hear and revise key information as needed. Updating material regularly would be relatively cost-effective.
- The CAH Psychosocial Education Program (CAHPeP) has been developed particularly for this purpose. It has been translated into Vietnamese and Bahasa Indonesian (see Poster P03.20) and is accessible on the Internet at www.CAHPePTalk.com. Promoting use of these education materials amongst families and evaluating subsequent knowledge growth and satisfaction respectively will be an important next step.

Conclusion

Health education is an integral component in any health setting, however it should not occur in isolation. Using the CAHKAQ to evaluate knowledge provides important information on which to focus education strategies, as well as providing baseline data point for evaluating knowledge attainment and understanding. Education and understanding are important for enhancing health outcomes for all patients.

References:

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2. Irene Mitchelhill (2010) Evaluation of a psychosocial education program for Congenital Adrenal Hyperplasia. *Master of Nursing (Hons) Thesis*. University of Technology, Sydney.