LECTURE SUMMARIES
by Christine Totri - San Diego
Realization: Fondation pour la Dermatite Atopique

DAY 2
The Patient and the Disease

ATHENS
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2014
THE PATIENT AND THE DISEASE

SESSION 3: PATIENT DIVERSITY: THE INFLUENCE OF BELIEFS, CULTURE, AND BEHAVIOR ON TREATMENT ADHERENCE

Food allergy – « fact or fantasy »? Linda De Raeye, Brussels (BEL)
What responses when faced with Corticophobia? Hélène Wastiaux, Nantes (FRA)
Use of traditional Chinese medicine in atopic dermatitis and its impact on treatment adherence
Chia Yu Chu, Taipei (TWN)
Discussion, Chair: Sébastien Barbarot, Nantes (FRA)

SESSION 4: ADAPTING THE APPROACH ACCORDING TO THE PATIENT

Therapeutic education and patient personality. Alain Golay, Geneva (SWI)
Using Internet in the management of chronic disease. Peter Lio, Chicago (USA)
Discussion, Chair: Carlo Gelmetti, Milan (ITA) – Christine Bodemer, Paris (FRA)

COFFEE BREAK

SESSION 5: DIVERSE ASSESSMENT MODELS

TPE in children with atopic dermatitis. A multicenter randomized controlled study of 580 cases in China. Lin MA, Beijing (CHN)
Therapeutic Patient Education in Atopic Dermatitis and evidence-based medicine.
Fiona Cowdell, Hull (UK)
A medico-economic model for the care of AD patients.
Doris Staab, Berlin (GER)
Discussion, Chair: Jean-François Stalder, Nantes (FRA) – Masaki Futamura, Tokyo (JAP)
Session 3: Patient Diversity: The Influence of Beliefs, Culture, and Behavior on Treatment Adherence

Food allergy- fact or fantasy?

Linda De Raeve, Brussels (Belgium)

Department of Dermatology of the Brussels University hospital
Clinical Professor and responsible for the training in Dermatology of the students in Medicine and the residents in Dermatology

Food allergy (FA) is a serious public health problem affecting people of all ages (effects about 8% of children in the USA). There has been a true rise in the prevalence of food allergy, although food allergy is overly reported by patients. Several studies report co-occurrence of other allergic conditions in patients with food allergies. Specifically, the prevalence of food allergies in patients with moderate to severe AD is 30 to 40%. Filaggrin mutations may increase the risk for transcutaneous allergic sensitization.

Currently, there is no cure for food allergy. The diagnosis and management of food allergy varies a lot among physicians. Furthermore, there are many misconceptions that exist among physicians regarding the topic. Many primary care doctors do not provide patients with the means to manage their food allergies.

To help with this variation, the National Institute of Allergy and Infectious Diseases established a consensus for the diagnostic criteria of food allergy.

Most children with FA will tolerate milk, egg, soy and wheat. Far fewer will tolerate tree nuts and peanuts. The time course of FA varies by food. Risk factors for FA include family history of FA and presence of AD (25-33% of individuals under 5 years of age with moderate to severe AD had IgE mediated FA). FA should be considered if a patient has anaphylaxis, if a patient has symptoms followed by ingestion of a specific food on more than one occasion, and in infants and children with moderate to severe AD. FA is diagnosed utilizing an appropriate medical history and identification of the causative food. In order to manage food allergy, the patient must avoid the allergen. Furthermore, food allergen avoidance may reduce the severity of AD in patients. Currently, however, there is no evidence available on whether food allergen avoidance will alter the actual course of AD. Avoidance of potentially allergenic foods for managing AD patients without documented or proven FA is not recommended as it puts the patient at risk for nutritional deficiency.

Oftentimes, parents have the following misconceptions about FA: FA causes gastrointestinal symptoms, AD can be due to cow’s milk allergy, cow milk must be replaced by soy, children cannot be tested for food allergy before the age of 5 years, and food allergy is a lifelong condition. Some of the consequences of these misconceptions include the fact that infants and young children with AD are put on a certain diet without any allergy testing being done.

Countering of beliefs

- Explain
  → What FA is
  → How to recognize symptoms
  → Importance of allergy testing
  → Treatment
    - Avoidance FA specific
    - Education
      - Diet
      - Label reading (European law 2011)
    - Periodic re-evaluation
    → improve dietary adherence

There is little information regarding: (1) what dietary advice is provided to families, (2) who gives this advice and whether there is adherence to the dietary advice, (3) and impact on quality of life. There are specific reports that demonstrate increased anxiety in families of children with FA to egg and peanut. It has also been shown that 25% of patients and care givers do not recall basic dietary advice correctly and that non adherence is more common in children with more than one FA and with weak social support. In conclusion, FA plays an important role in patients with moderate to severe AD. Consultation with a dietician is needed because it is not easy for the patients; the dietician should provide a written plan and the advice must be repeated. Finally, if there is a history of if anaphylaxis, a prescription of EpiPen should be provided.
Topical Corticosteroids (TCS) are the mainstay of AD treatment and are required for months or years to control the disease. However, poor adherence may lead to poor outcomes. Many factors can lead to poor adherence including the patient’s psychological profile, the relationship between the patient and doctor, and fears about treatment.

In AD, therapeutic adherence is an issue. AD treatment is complex as the patient and caregivers require skills: how to apply the topical treatment, where to apply it, how much to apply and when to apply.

TCS phobia has a prevalence of 40 to 70% in studies depending on the way you ask the question. Many questions remain regarding steroid phobia including its origins, management, prevalence, identity, impact, and nature. TOPICOP is a TCS phobia study designed to better define the phenomenon. The first part of the study was the construction of a questionnaire that was distributed to patients, with 208 individuals filling it out. It was found that TCS phobia is correlated with the need for reassurance. The study also found that TCS phobia is correlated with the need for reassurance, TCS passing through the blood, a prior adverse event, inconsistent information about the quantity of cream to apply, and a lack of desire to apply the TCS. It was shown that TCS was unrelated to AD severity or the duration of AD.

From this, it is clear that a score assessing TCS phobia can be important to screen and consider phobia in the management of patients as well as to assess the impact of TPE.

The next step is the validation of TOPICOP in other countries and cultures, with the goal of better understanding the variation of phobia among patients depending on the clinical setting.

How can we currently manage TCS phobia in everyday clinical practice? It is important to provide clear, targeted information and advice about AD and its treatment (with written action plans). Patients must also be able to express their beliefs. When counseling patients, the health care provider must also avoid negative words (e.g. a little, not too much, unfortunately, be careful). It is also important that other health care providers are properly trained.

Provide clear information

• Target information

• Explain clearly and honestly
  – Principles of action, systemic effects (metaphor)
  – Risks
  – The quantity of cream to apply
  – Treatment areas
  – When to start and stop the cream

• Care demonstration
  • written action plans
  • Anticipate pharmacists warnings
In addition to yin and yang, there is a five phase theory: wood, fire, earth, metal, and water. These five elements must be in balance to keep the body healthy. Depending on the five elements, there are different manifestation of a disease.

There are also six excesses: wind, cold, fire/heat (aversion to heat), dampness (oozing in eczema), dryness, and summertime.

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The limited evidence that does exist includes the efficacy of using acupuncture to treat severe AD in which after 1 month and 1 year the patients improved significantly. Recently in Taiwan, a randomized, double-blind trial using xiao-feng-san showed some dramatic effects in AD outcomes. Furthermore, one study showed that ⅔ of patients in Taiwan used TCM, an important finding because many patients do not inform their health care providers about what they are doing at home.
The top ten single herbs for AD have been identified. Xiao-feng-san (eliminate wind powder) is the most commonly prescribed herbal formula for AD patients. It is thought to disperse wind, eliminate dampness, clear heat, cool blood, nourish the blood, and stops itch. The most commonly used herb is bai-xian-pi (cortex dictamni).

However there are some negative components to TCM use. For example, infections after using TCM in AD (impetigination and eczema herpeticum) can occur. In this situation, it is important to convince the patient to use western medicine (e.g. antibiotics and TCS). The reason for this is illustrated in a tragedy in July 2012, when a doctor used an illegal agent with a lot of arsenic, which lead to the death of a patient in Taiwan.

A systematic review exists for the use of Chinese herbal medicine for the treatment of AD. In conclusion, patients can potentially reduce their steroid use if TCM is used in combination with western medicine.
**Session 4: Adapting the Approach According to the Patient**

**Therapeutic education and patient personality**

Alain Golay, *Geneva (Switzerland)*

Professor in Medicine and head of the Service of Therapeutic Education for Chronic Diseases, diabetes and obesity at the Geneva University Hospital

*A patient is neither wrong nor right*

*He thinks differently!*

*He is different!*

Communication is dependent on actions but behind actions are emotions/thoughts, values/priorities, and fundamental interpersonal needs. The focus in this lecture is regarding fundamental/interpersonal needs. The audience was asked to take a personality evaluation with the outcome being categorized as one of four personality types:

- Promoter
- Facilitator
- Controller
- Analyzer

When you have a patient, you have to assess the power (dominant or reserved) of the patient and the emotion (extrovert or introvert) of the patient. The promoter and facilitator are expressive and the controller and analyzer are reserved. The following table highlights some of the key differences between personality types:

<table>
<thead>
<tr>
<th>Promoter</th>
<th>Facilitator</th>
</tr>
</thead>
<tbody>
<tr>
<td>- always looking in the future, open minded, not reliable/always late.</td>
<td>- anytime, accepting + (“yes man”), authenticity - (we don’t know what they like)</td>
</tr>
<tr>
<td>- needs impact/strong personality</td>
<td>- needs friends/membership</td>
</tr>
<tr>
<td>- learning mode: identification</td>
<td>- therapeutic attitudes: support the patient and his/her environment</td>
</tr>
<tr>
<td>- therapeutic attitudes: in denial, have to focus on longer term</td>
<td>- compliance: dependent on family</td>
</tr>
<tr>
<td>- compliance: bad adherence</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Controller</th>
<th>Analyzer</th>
</tr>
</thead>
<tbody>
<tr>
<td>- authenticity, not accepting (they say what they think), in the present</td>
<td>- not open mind, reliable, thinks about past</td>
</tr>
<tr>
<td>- needs challenge/achievement</td>
<td>- needs security</td>
</tr>
<tr>
<td>- learning mode: experience/practical learning</td>
<td>- learning mode: reading</td>
</tr>
<tr>
<td>- therapeutic attitudes: propose a lifestyle which does not interfere with their professional life</td>
<td>- therapeutic attitudes: prescribe in detail</td>
</tr>
<tr>
<td>- compliance: dependent on results</td>
<td>- compliance: dependent on health care provider</td>
</tr>
</tbody>
</table>

A patient is neither wrong nor right. He thinks differently! He is different!
Technology in eczema

Peter Lio, Chicago (USA)
Assistant Professor Clinical in the Department of Dermatology and Pediatrics at Northwestern University, Feinberg School of Medicine.
Co-founder and co-director of the Chicago Integrative Eczema Center

The internet is a passive instrument for learning. It can be an important tool to connect to our patients. It can also be an active tool so we can engage with our patients. Dr. Lio’s Chicago Integrative Eczema Center has a website which has a lot of information about eczema. Patients can go and click on resources: there are videos (collection of speakers’ power point presentations), words (articles/editorial pieces), and links (AD Associations such as Foundation pour la Dermatite Atopique). Most of us have this for our patients.

The other part Dr. Lio is trying to work on is a more interactive part. The Chicago Integrative Eczema Center has a facebook page so that patients can communicate with the center. Via the facebook page, the center is able to connect with other groups such as the National Eczema Association. He also has a twitter page where he can put ideas out to the public in a quick way. He has about 80-90 followers (mostly allergists, dermatologist) who re-tweet his posts. With social media there is a new level of connection with patients.

The next level of technology will be the “quantified self.” Individuals can now track their sleep, weight, etc. with activity monitors. For AD, in the future, patients can report their disease progress and medication use with a real time daily app, for example. Furthermore, a potential future direction may be with actigraphy, an activity monitor that measures movement. For example, it can monitor, in real time, the scratching behaviors and sleep of patients. There is preliminary evidence to suggest that actigraphy wristband monitoring can be used to continuously assess disease. Dr. Lio is currently conducting a pilot study with Galderma to evaluate scratching behaviors and sleep in eczema over time in both patients and mothers.
What are your thoughts on using technology in clinical research so that patients can self assess themselves?

This is a great point so that the patient can monitor themselves. Also the doctor can follow them before the patient even comes in. I think we are going to enter whole new level of research and understanding of disease.

Are you manipulating the patient by assessing their personality?

No, this is a tool to help me work with patients and people in general. One has to deal differently with different people.

How long does it take to define the personality of a patient?

Sometimes several visits, but sometimes right away. The most important thing is to assess the power of the patient and the emotion of the patient.

Does this personality assessment work for adolescents?

Yes, very well.

While all this technology is great, isn’t there something to be said about the patient physically being seen by the doctor?

It is just complementary but not a replacement with the physical doctor patient relationship.
TPE in children with AD: a multicenter randomized controlled study of 580 pts in China

Yuan Liang, Beijing (China)
Department of Dermatology
Beijing Children’s Hospital, Capital Medical University

Background:
In 2008, a guideline for the treatment of AD in mainland China was established. In 2011, the AD Foundation was founded in China. The study objective was to evaluate the validity of TPE on treatment and long-term management of AD as well as to evaluate the effects of TPE on quality of life.

Methods:
The study included 6 educational centers and included patients from 2-14 years of age who were randomized to either the educational group or the non educational group. The form of education utilized included an educational DVD, educational class, and dermatology consultation. The educational DVD had four parts that included the treatment and management of AD, food allergy, psychology of AD patients, and how to take care of the skin of AD patients.

Results:
- SCORAD: in the test group: score decreased 45.11 to 15.47 while in the control the SCORAD from 41.97 to 17.93 at 6 months
- QOL: At 6 months, the score decreased from 9.55 to 3.65 in the test group while in control it was 9.19 to 4.61.
- At the end of study, the patients knew the significance of emollient use and how to use it correctly and how to choose effective emollients

Conclusion:
Compared to the control group, the dryness of skin, lichenification, SCORAD, quality of life, and the knowledge of emollient use improved significantly in research subjects who received TPE.

Conclusions:
- Compared with control group, the dryness of skins, lichenification of lesions, SCORAD, quality of life and the knowledge of emollient use improved significantly from baseline to 6 months
- TPE is a feasible, effective and very important measures in AD management.
The aims of this talk are the following:

- summary of cochrane review update 2014
- evidence base for health behavior change
- application of this evidence to an intervention for AD
- planning future research

The original cochrane review was published in 2007 and an update has been published this year. The review only includes randomized controlled trials. For the AD intervention programs, 10 studies were included: 9 were educational and one was psychological. The interventions varied greatly and were conducted by various individuals including medical students, professional teams, and nurses. All were adjuncts to conventional therapy rather than alternative to therapy.

The review had several limitations including methodological weaknesses in selected studies, heterogeneity of outcome measures, and the heterogeneous nature of the interventions. There were, however, many large and robust studies. The inclusion of new studies, however, did not substantially alter the conclusion of the original review. From the original review it was shown that among the studies, there is a lack of detail about the intervention’s design, the studies did not use a complex interventional framework, few studies used an explicit theoretical base, and there was no standard outcome measure.

For the future, researchers need to think about the theoretical basis of the studies along with the outcome measures being used. For interventions to work best, we need to assess individual barriers - do the patients have the skills, beliefs, knowledge, capabilities, motivation and goals? We also need to tailor our strategies according to our patients and we need a theoretical approach to assessment and the intervention.

In regards to the outcome measures being used, the Harmonizing Outcome Measures for Eczema (HOME) initiation has looked at the core outcomes in eczema including clinical signs, symptoms, long term control of fares, and quality of life. Although self efficacy measures are not in HOME, they are an important outcome too.

An uncontrolled study was recently conducted called the Eczema Education Programme (EEP), the first large scale eczema education intervention in the United Kingdom. The EEP included 1,800 referrals received in the first 3 years of the study. The intervention, based on social learning theory, was nurse led and nurse delivered. Each group had 5-10 people. The program was a total of 6 hours delivered over 2-3 weeks. The sessions were conducted at local children's centers, community health clinics, and specialist clinics. A range of teaching techniques were used and content covered included an overview of eczema, infections, treatment, triggers, and how to use topical therapies. Everyone also received individualized action plans. A total of 257 parent child dyads participated.

From the study, there was statistically significant improvements in various measures. In conclusion, EEP is a feasible option as an adjunct to usual care and can be delivered on a large scale. A large, multi-centered RCT is still needed to test the efficacy of the intervention.

In summary, there is a relative lack of rigorously designed trials and there is limited evidence of the effectiveness of psychological and educational intervention in childhood AD. Future interventions need to use complex interventions guidance, robust and explicit theoretical based outcomes. Consideration should also be given to duration and frequency of intervention.

Therapeutic patient education in atopic dermatitis and evidence-based medicine

Fiona Cowdell, Hull (United Kingdom)
Senior Research Fellow
Graduate Research Director
Faculty of Health and Social Care

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A medico-economic model for the care of AD patients

Doris Staab, Berlin (GER)
Medical Director of the Children’s Department, Charité CBF asthma and eczema trainer
Professor of Neurodermatist, management of academies and training

There are specific problems in AD such as the multiple hypotheses that exist on the genesis of the disease, its chronic and recurrent course, and its stigmatizing appearance. One of the issues with judging the effectiveness of AD treatment is the recurrent course of the disease with relapse. Therefore, the pre and post design of many studies make it difficult to assess the true efficacy of an intervention.

There is essentially four different ways to education patients: information: informed patient promotion of compliance: obedient patient training: the capable patient empowerment: the responsible patient

The last one, “empowerment” is the basis on which we design our programs. The objective of the AD educational programs include improving self management skills and promoting a better outcome of eczema.

In Germany, the cumulative incidence of AD in school children is 15.6% with about 3 million children with AD in Germany. The direct costs of AD in Germany is 1 billion euro, the indirect costs are 1 billion euro, making the total cost equal to 3.5 billion euro per year in Germany. There are a variety of educational programs, which all vary in time and size. All have been shown to be effective, but evaluation instruments and the time differ widely, making direct comparison between the different programs impossible.

A few years ago, a German AD intervention study was conducted which entailed 2 hour weekly sessions for a total of 6 sessions. Each group consisted of 6-8 families with an interdisciplinary team of trainers (pediatricians/dermatologists, psychologists, nurses and dieticians). The topics discussed included basic medical information along with dealing with stress and itching, basic skin care, dietary issues, skin treatment, and overall daily management. Over 1000 patients were recruited, all of whom were randomized to either the intervention group or the control group. Changes in skin condition (SCORAD) were assessed. The children’s subjective severity score improved greatly in the intervention group as did the “itching cognition.”

A cost benefit analysis was also performed one year after the start of the study. There was about 278 Euro in savings of the therapeutic cost in the intervention group and only 70 euro in the control group. The intervention, however, cost 612 euro per family. Therefore, after one year the intervention had no economic benefit. However, the cost benefit analysis has limitations in that the evaluation time was too short. Dr. Staab was convinced economic benefit would be seen for a longer time point such as at 5 years. A cost efficacy analysis was also done which showed that the costs per quantity of improvement in the intervention group was 865 euro and 882 in the control group.

In summary, patient and family education for AD is effective in all age groups. The program conducted in Germany is very well accepted by parents, child and adolescents alike. There are similar programs that are run in France and Italy and the evaluations in these countries have shown similar results. The cost efficacy analysis shows a slight effect of the intervention. We should aim for funding by the health care systems (better outcome for less money). Importantly, the interventions in various countries vary significantly and the big question is: “how much is enough?”

Epidemiologic background in Germany

- Cumulative incidence in school children (7 y) 15.6%
  - Fartasch et al Hautarzt 2000
- Prevalence in 5-6y old children 10.2%
  - Fartasch et al Hautarzt 2000
- 3 Million AD patients in Germany
  - German Neurodermitiker-Bund (www.bnb-ev.de)
  - 60% start in infancy
  - 20-30% at age 1-5y
  - 10-20% between 6 and 20y
  - Szucs, 1995
If I give you one million dollars, what kind of therapeutic study would you study?

There is not a one intervention fits all. What works in the UK, for example, will not work in the US. This is also a question of how much is enough? Giving only information is not enough. It highly depends on the trainer, resources, and the health care system as well.

How effective is the adherence in these programs? Is there a high drop-out rate?

In China, adherence is very good. In Germany, it is the same (once the patients and their families are enrolled, they stay enrolled). The problem in Germany is how do we reach the people who really need it but don’t want to participate. In the USA, adherence is very poor. The patients and the families will maybe attend the first one, but after they are unlikely to attend any sessions.

In Mexico, the adherence is great. The patients really want to come.