Problems Associated with Inadequate Treatment for Atopic Dermatitis

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Abstract: Widespread confusion currently exists in Japan with regard to the treatment of atopic dermatitis, creating a difficult social problem. As a background to this confusion, the mass media have been highly critical of topical steroids and have given the general public the idea that steroid ointments are dangerous, although proper use of these ointments is essential for the treatment of atopic dermatitis, as is commonly recognized throughout the world. A so-called “atopy industry” has sprung up in which alternative remedies are used to treat atopic dermatitis, creating large numbers of patients with severe problems resulting from inadequate methods of treatment. In 1998, the Japanese Dermatological Association (JDA) organized a committee to survey the health damage caused by inadequate treatment of atopic dermatitis, and the committee published its final results in 2000. Among 310 severe cases, a surprisingly high 140 cases (44%) were worsened by inadequate treatment, whereas only 3 patients suffered from side effects of steroid ointment treatment. The JDA organized a new committee in June 2000, to examine the problems of treatment in atopic dermatitis. One of the major activities of this committee is direct consultation with patients via e-mail and facsimile. After the initiation of this system, the committee has received 1,504 requests for consultation within 9 months. Dermatologists need to exert much greater effort to solve this social problem.

Key words: Atopic dermatitis; Atopy industry; Topical steroids; Inadequate treatment

Introduction

The phrase “atopy industry” (lit. “atopy business”) is well recognized in Japan, where widespread inadequate treatment of atopic dermatitis in this country has been widely reported by the mass media. It is astonishing that inadequate treatment of atopic dermatitis is so widespread in Japan, despite the fact that atopic dermatitis is a common disease for
which a global standard of treatment has been established.

Why are such large numbers of patients suffering from severe health problems induced by inadequate treatment, to the extent that normal social life is sometimes interrupted? Why do patients still blindly believe that their problems are part of the natural process of healing or are created by the use of topical steroids, instead of recognizing them to be the result of inadequate treatment?

It is the task of dermatologists in clinical practice to clearly educate patients who are suffering the health hazards of inadequate treatment. This is also a problem to be addressed by the Japanese Dermatological Association (JDA), to reach the increasing numbers of patients who refuse to visit a medical facility and instead withdraw from society.

Inadequate Treatment of Atopic Dermatitis

A variety of information and misinformation about the medical treatment of atopic dermatitis is currently flooding Japan, creating a great deal of confusion throughout the society. During the past decade, the adverse effects of topical steroids, essential medicaments in the treatment of atopic dermatitis, were repeatedly exaggerated by the mass media, including the press, TV, and periodicals, creating confusion and anxiety among patients with atopic dermatitis who were receiving orthodox treatment in a medical facility or who were about to receive such treatment. In parallel with this phenomenon, a booming industry that advocates folk remedies and special alternative therapies has developed. This industry is referred to by many as the “atopy industry”. Consequently, increasing numbers of patients have developed an irrational fear of topical steroids, while choosing to depend solely on folk remedies or alternative methods of healing, thereby markedly worsening their symptoms and creating difficulties in leading a normal social life.1–4)

Although folk remedies and alternative therapies cannot necessarily be equated with inadequate treatment, the numbers of patients who have markedly worsened symptoms or who have complications after treatment by a non-specialist or unqualified care provider are continuing to increase. “Inadequate treatment” used here refers to treatment such that its aggressive implementation results in a worsened clinical picture for the patient.

This situation in which patients request folk remedies and alternative therapies at the expense of topical steroids is unique to this country. In other developed countries, medical care by specialists who prescribe topical steroids is well accepted by the general population. For the treatment of bronchial asthma, which is categorized as an atopic disease like atopic dermatitis, a worldwide consensus has been reached as to the usefulness of inhaled steroid therapy, i.e., local administration of a steroid aimed at early relief of airway inflammation. In contrast, it is highly unusual that the similar use of topical steroids aimed at the early relief of skin inflammation has been the focus of a number of criticisms in Japanese society.

Behind this social confusion, lies a prosperous “atopy industry” that targets patients with atopic dermatitis. The actual situation of this industry is also discussed in this paper.

Reasons for the Spread of Inadequate Treatment

Why has the inadequate treatment of atopic dermatitis spread to this extent? The following factors were noted in an analysis of the background of the situation.

(1) Medical firms that were targeting various chronic diseases entered the area of atopic dermatitis in large numbers, deeming it a good market because information was confusing.

(2) Patients and the mass media, believing atopic dermatitis to be an intractable disease, sought alternative remedies and eschewed the standard treatment.
(3) The adverse effects of topical steroids were exaggerated, and symptom aggravation caused by inadequate treatment was taken to be an adverse effect of topical steroid therapy.

(4) Medical facilities touting nonsteroidal treatments increased as a result of mass media portrayal as “patient-oriented medical providers”.

(5) In some cases, the combined use of topical steroids was covered up when the therapy was publicized by the mass media, even though steroids were actually part of combined treatment (e.g., Isodine therapy, Bihadasui therapy).

(6) Disagreement between dermatologists and pediatricians in regard to their views on the pathogenesis and treatment caused anxiety among patients, leading them to seek inadequate, alternative treatment, even those that deviated from the recommended treatments of both disciplines.

Survey of Health Damage from Inadequate Treatment

To prevent the increase of adverse health consequences owing to the use of folk remedies and alternative therapies in the treatment of atopic dermatitis, JDA in October 1998 organized a committee, headed by the author, to survey the actual situation resulting from inadequate treatment of atopic dermatitis. The nationwide survey was carried out over one year in 11 university hospitals. Inadequate treatment was defined as treatment that caused worsening of the clinical picture of the patient after its active use. The survey was not intended to evaluate the usefulness of individual treatments. Details of the final results of the survey were published in the June 2000 issue of “Nippon Hifuka Gakkai Zasshi (Journal of the Japanese Dermatological Association)”.

The one-year survey revealed 349 severe cases that necessitated hospitalization at the 11 facilities. Excluding 30 patients who were admitted for educational purposes, the remaining 319 patients included 140 (44%) patients in whom the condition was aggravated because of inadequate treatment. In addition, 127 (40%) patients had spontaneous aggravation, 32 (10%) patients were reluctant to receive treatment, and only 3 (1%) patients suffered adverse effects of topical steroids.

Inadequate treatment was given to 52 (37%) patients by physicians other than dermatologists, and to 37 (26%) patients by dermatologists, accounting for 63% altogether.

Issues involved in inadequate treatment included:

- Prevalence of alternative therapies administered by non-specialists
- Mass media reporting of prescriptions being given by physicians in the absence of any medical examination
- A tendency toward excessive dependence on Chinese medicine
- Persistence of highly restricted diet therapy
- Increased use of nonsteroidal therapy by non-dermatologists.

The consequences of inadequate treatment were found to include a number of cases of withdrawal from society, reflected in 40 (29%) cases in which a leave of absence was taken from school or work or in which the individual quit school or a job, and 21 (15%) cases of withdrawal by staying at home.

Survey of Alternative Therapies by the Department of Dermatology, Kanazawa University School of Medicine

A survey was carried out in 191 patients with atopic dermatitis who were being treated at our atopic outpatient clinic, to examine their experience with alternative therapies. An outline of the survey is given below.

(1) Patients who had used an alternative therapy accounted for 84% of all subjects.

(2) The average number of sessions of alternative therapy experienced per patient was 5.1.

(3) Table 1 summarizes the patients’ impressions of such therapies. The majority of patients
reported that their condition was “unchanged” or “aggravated”. In particular, aggravation was conspicuous for the use of cosmetics, water therapy, and alternative therapy by a medical institution. Only anti-mite therapy held potential benefit.  

(4) About half of the patients replied that they were victims, in one way or other, of the alternative health care industry.  

(5) To the question of whom should be blamed for the current prevalence of ineffective alternative therapies, the mass media was most often mentioned (31%), followed by dermatologists who did not provide sufficient information (19%).

What is the “Atopy Industry”?  

It is apparent that alternative treatments for atopic dermatitis can cause serious harm to patients. It is therefore worth exploring this industry in detail.  

The “atopy industry” is defined as “economic activities that are involved in the treatment of atopic dermatitis by means of actions not covered under health insurance, targeting patients with atopic dermatitis”.  

Use of the term “atopy industry” rather than “folk remedies” provides a better understanding of the current situation of treatment for atopic dermatitis. Folk remedies originally are extensions of people’s personal experience and the wisdom of ancestors and the elderly. They imply tradition and goodwill. However, most current “folk remedies” are purveyed by commercial enterprises aimed at making profit in a capitalist economy. In addition, in some cases, certain expensive products are sold via medical practices in hospitals managed by a related company, or by doctors who recommend a certain folk remedy that they are advocating. Therefore, the boundaries between folk remedies and medical practice are nebulous.  

The aforementioned definition of the “atopy industry” is intended to include such activities practiced or supported by medical facilities and doctors.

Are Alternative Therapies Effective?  

Alternative therapies that are unlikely to be effective are nevertheless described as “dramatically effective”. The following points indicate how ineffective therapies can be seen in consumers’ minds as effective.  

(1) Extravagant advertising: Exaggerations

<table>
<thead>
<tr>
<th>Therapy</th>
<th>Number of patients who experienced (total 191)</th>
<th>Total number of cases</th>
<th>Effective</th>
<th>No change</th>
<th>Aggravated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health food and related remedies</td>
<td>100 52.4%</td>
<td>228</td>
<td>8.8%</td>
<td>84.2%</td>
<td>7.0%</td>
</tr>
<tr>
<td>Spa and bathing treatments</td>
<td>92 48.2%</td>
<td>151</td>
<td>15.9%</td>
<td>65.6%</td>
<td>18.5%</td>
</tr>
<tr>
<td>Cosmetics and related remedies</td>
<td>83 43.5%</td>
<td>144</td>
<td>4.9%</td>
<td>64.6%</td>
<td>30.6%</td>
</tr>
<tr>
<td>Anti-mite and related remedies</td>
<td>73 38.2%</td>
<td>109</td>
<td>24.8%</td>
<td>74.3%</td>
<td>0.9%</td>
</tr>
<tr>
<td>Water therapy and related remedies</td>
<td>47 24.6%</td>
<td>57</td>
<td>1.8%</td>
<td>75.4%</td>
<td>22.8%</td>
</tr>
<tr>
<td>Medical institution-related alternative therapies</td>
<td>34 17.8%</td>
<td>35</td>
<td>8.6%</td>
<td>20.0%</td>
<td>71.4%</td>
</tr>
<tr>
<td>Other alternative therapies</td>
<td>67 35.1%</td>
<td>101</td>
<td>8.9%</td>
<td>63.4%</td>
<td>27.7%</td>
</tr>
</tbody>
</table>

Patients who experienced more than one type or session of treatment provided their impressions of efficacy of each type or session, and the percentages were calculated over the total number of cases in the population.
and overstatements are the nature of commercial advertising.

(2) Spontaneous remission: Patients may believe that there is no spontaneous remission of atopic dermatitis and therefore view such remission as treatment-related.

(3) Effect of suggestion: The more expensive the therapy, the greater the belief in its efficacy.

(4) Elimination of aggravating factors: When treatment involves aggravating factors, its discontinuation inevitably improves the patient’s condition.

(5) Incomplete data: The efficacy of folk remedies is usually backed by testimonials or personal experience rather than scientific evidence.

(6) Exclusion of aggravated cases: All aggravations tend to be attributed to the adverse effects of previously used topical steroids.

(7) Combined use of steroids: In alternative therapies implemented through medical facilities, steroids tend to be combined with the alternative treatment, and this may not be recognized by the patient.

Problems Inherent in the “Atopy Industry”

The reader may be unaware that a death resulting from alternative therapy for atopic dermatitis has already occurred in this country. An “atopy detergent” developed by a certain metal finishing company was publicized in a community bulletin as a remedy for atopic dermatitis. A 4-year-old boy who used this agent eventually died of methemoglobinemia.

The following is a summary of problems involved in the alternative treatment of atopic dermatitis.

(1) Patients are not given correct information about the disease and its treatment.

(2) Alternative remedies may themselves serve as aggravating factors.

(3) Medical care may be given by unlicensed practitioners.

(4) Unreasonably high prices may be charged.

(5) Liability is unclear in comparison with that for treatment obtained through proper medical channels.

Committee for Treatment Problems in Atopic Dermatitis

To counter the confusion surrounding medical care for atopic dermatitis, JDA, acting on behalf of Japanese society, in June 2000 set up a committee to examine problems associated with the alternative treatment of atopic dermatitis. This expanded committee unified two committees previously established in 1998 (committee on the development of treatment guidelines for atopic dermatitis, committee for the
survey of health damage caused by inadequate treatment of atopic dermatitis), for the purpose of addressing a wider range of issues in the treatment of atopic dermatitis.

The chief activities of the committee are as follows.

• Patient consultation via dial-in facsimile and e-mail (Table 2).
• Extensive survey of health damage resulting from inadequate treatment.
• Review and promotion of treatment guidelines.
• Examination of issues surrounding new therapeutic drugs (e.g., tacrolimus ointment).
• Survey of the current situation of damage through consumer centers.
• Survey of information about atopy on the Internet.
• Publicity activities directed to the general public.

The above activities of the committee are intended to continue until April 2002.

Consultation System for Atopic Dermatitis Patients

In July 2000, JDA began a consultation system for patients suffering from atopic dermatitis. This system was introduced in the July 7, 2000, issues of the Asahi and Yomiuri newspapers. About 200 applications for counseling were received in the following two days, with the number reaching 616 by the end of the month (425 cases by e-mail, 189 by facsimile, and 2 by letter) and 1,504 by March 2001. Problems related to inadequate treatment accounted for about 20% of all requests for consultation.

Emergency Call for Atopy Industry Victims

In response to the increasing number of victims of the atopy industry and occasional lawsuits, a defense counsel for atopy industry victims was organized by a group of concerned young lawyers, and an emergency call system for victims of the atopy industry was implemented by the counsel on August 5, 2000, in a law office in Tokyo, with medical advice provided by dermatologists. Following that, a consultation service was set up via the Internet. In addition, in May 2001, a plaintiff represented by the lawyer Shinnosuke Fukushima, the leader of the above-mentioned defense counsel, won the first lawsuit against the atopy industry by defeating an esthetic service provider. The verdict was widely reported in the mass media.

The Fight Against the Atopy Industry

The greatest responsibility for the spread of the atopy industry rests not with the mass media or patients themselves, but with doctors who deal with the treatment of atopic dermatitis. Medical care providers have been slow to take action against the industry, and more than a few have actually joined forces with it.

What should be done to win the fight against this unscrupulous industry? This is a question that needs to be addressed.

The most important elements are that better, more informative explanations be given to patients and that treatment be carried out with perseverance in daily medical practice. While patients naturally want rapid relief, they need to be told clearly and understandably that atopic dermatitis is a chronic disease characterized by the cardinal symptom of skin inflammation. They need to understand that long-term control of the inflammation is necessary, mainly through the use of topical steroids. This principle should be emphasized, and should be clearly understood by the patient. Doctors who treat patients with atopic dermatitis should not disregard the basics of treatment for skin disease, i.e., to choose topical drugs that suit the pathological condition. If they fear the adverse effects of topical steroids and perform non-steroidal therapy in a careless way, with the excuse that the patient her- or himself has requested it, ultimately they may suffer loss of
the patient’s trust.

It is also necessary for medical care providers to have a thorough understanding of the actual situation and tactics of the atopy industry and to take measures to deal with these tactics. As mentioned previously, the JDA widely publicized through the mass media the results of a survey on the actual damage caused by the atopy industry, and have attempted to correct the public’s rigid and biased attitude that steroids used for the treatment of atopic dermatitis are “evil drugs”. The efforts of JDA are now producing successful results, although more remains to be done.

REFERENCES