

Differences in how bronchial asthma patients transmit experience about adverse reactions and usability of inhaled steroids to others: A qualitative focus-group study

Fuki Kurimoto¹, Satoko Hori^{2,3}, Yasufumi Sawada^{3,*}

¹ Faculty of Pharmaceutical Sciences, The University of Tokyo, Tokyo, Japan;

² Faculty of Pharmacy, Keio University, Tokyo, Japan;

³ Graduate School of Pharmaceutical Sciences, The University of Tokyo, Tokyo, Japan.

Summary

Patients' experience of adverse reactions (ADR) and usability of drugs is important for proper use and post-marketing development of drugs, but it remains unclear whether and how patients are transmitting such information to others. The aim of this study was to explore differences in the ways in which bronchial asthma (BA) patients transmit experience of ADR to inhaled corticosteroids and usability of inhalers to others, including the reasons for these differences. A qualitative study involving focus-group interviews was conducted. Participants were fifteen Japanese BA patients treated with inhaled steroids who belonged to an association for BA patients. Data were analyzed using the constant comparative method. Almost all participants reported behavioral differences concerning ADR and usability. Participants actively expressed their doubts and anxieties about ADR to members of a patients' association and their attending physician. In contrast, information about patients' needs, including opinions and questions about the usability of steroids inhalers and anxieties regarding potential ADR to prolonged use of inhaled steroids, was shared only with members within the association and not disseminated outside, with some participants even choosing to keep it personal. Underlying this behavior was a mindset of perceiving efficacy and ADR to be more important than usability, and thinking "it is useless to inform anyone." In conclusion, behavioral differences of how BA patients transmit experience about ADR and usability was obvious, because benefit to inform usability was not perceived. It is necessary to make patients aware that transmitting their experience and comments about drugs is beneficial.

Keywords: Inhaled steroids, dissemination of information, usability of inhalers, adverse reactions

1. Introduction

Post-marketing information about efficacy and safety, as well as feedback about the usability of drugs are important not only to improve compliance, but also to facilitate proper use of drugs and post-marketing development (Ikuyaku, in Japanese; the phrase meaning fostering drugs). In recent years, systems to collect

information regarding adverse drug reactions directly from patients have been investigated in many countries (1,2). However, it seems that such information from patients is not collected enough, and patients are less conscious that information transmitted by them will lead to proper use of drugs or effective post-marketing development (3). In addition, it is not clear whether patients actively transmit information about the usability of drug preparations and their preferences related to drugs. Therefore, in order to encourage the proper use of drugs and to enable effective post-marketing development, it is important to ascertain whether and how patients are transmitting such information, and to understand the background of patients' perceptions about such actions.

With respect to treatment of bronchial asthma,

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*Address correspondence to:

Dr. Yasufumi Sawada, Graduate School of Pharmaceutical Sciences, the University of Tokyo, 7-3-1 Hongo Bunkyo-ku Tokyo 113-0033, Japan.

E-mail: sawada@mol.f.u-tokyo.ac.jp

Table 1. Characteristics of the participants

Group	Sex	Age group (years)	Asthma history	Asthma condition	History of inhaled steroid	Current inhaled steroid	History of current Inhaled steroid usage
A	F	60–69	40 years	Less than once a week	20 years	Symbicort®	8 months
A	F	60–69	11 years and 6 months	Less than once a week	11 years 6 months	Symbicort®	1 year 3 months
A	F	50–59	20 years and 9 months	Less than once a week	18 years	Symbicort®	1 year
A	F	70–79	35 years	Less than once a week	about 20 years	Alvesco®	3 years
B	M	40–49	30 years	Less than once a week	13 years	Pulmicort®	13 years
B	M	70–79	25 years 2 months	Not every day but more than once a week	10 years	Symbicort®/60	9 months
B	F	60–69	about 20 years	Less than once a week	About 20 years	Advair®	3 months
B	F	50–59	31 years 9 months	Less than once a week	More than 10 years	Symbicort® Alvesco®	9 months
B	M	60–69	6 years 8 months	Less than once a week	6 years 8 months	Symbicort®	8 months
B	M	60–69	35 years 5 months	Less than once a week	20 years	Symbicort®	1 year 10 months
B	M	30–39	35 years	Less than once a week	6 years	Advair®100	6 years
C	M	80–89	37 years	Less than once a week	unknown	Advair®250	2 years
C	F	60–69	23 years 4 months	Less than once a week	18 years 2 months	QVAR®100	3 years
C	F	60–69	28 years	Less than once a week	18 years	Alvesco®200	10 years
C	F	30–39	7 years	Not every day but more than once a week	7 years	Advair®500	5 years 6 months

F, female; M, male.

treatment based on inhaled steroids is generally the first-line choice (4). In order to control asthma, continued treatment is essential, and the patient's medication compliance affects the efficacy of the treatment (5). Since inhaled steroids are administered using special devices, not only efficacy and safety, but also patients' preferences regarding the inhaler's operability, portability, and preferred usability are important factors influencing medication compliance (6,7).

Patients' associations, which are formalized non-profit patient-interest organizations, promote self-help (8), through group activities such as exchanges between members, regular events, and medical lectures, providing a sense of mental security, as well as information about diseases and drugs. In addition, the associations enable patients to face the disease through exchange, sharing, and accumulation of "experience-based knowledge" that only patients can engage in (8,9). Although the members of patients' associations may have a greater tendency to actively seek information regarding drugs as compared to patients who do not belong to any association, their role in information dissemination about drugs is not clear.

The purpose of this study was to explore differences in the ways in which bronchial asthma patients transmit experience of adverse reactions to inhaled corticosteroids and usability of inhalers to others, including the reasons for these differences. Since there have been few previous studies in this area, we adopted focus-group interview (FGI) methodology, which is an exploratory qualitative technique, for the present investigation.

2. Methods

2.1. Design

In this study, the FGI was adopted as a qualitative

technique, because interactive discussion among multiple participants has the potential to develop greater insights and to clarify perspectives that cannot necessarily be derived from one-on-one interviews (10). To validate the results, FGIs were conducted with three groups, a follow-up questionnaire was conducted after the FGIs to confirm the participants' remarks, and the results were discussed and confirmed with other researchers who had participated in the interviews.

2.2. Subjects

Members of two associations for bronchial asthma patients in the Kanto district (the megalopolis of Tokyo and its suburbs), who were undergoing treatment with inhaled steroids, were invited to participate in the interviews by post and e-mail. Fifteen patients responded (Table 1). A financial incentive was provided to the participants.

2.3. Data collection

Focus groups were conducted in September 2011. The total duration of one interview was approximately 1.5 hrs, and the interviews were conducted in community centers or community meeting rooms. The groups were moderated by an academic staff member and an undergraduate student who were research team members (Hori and Kurimoto) and were both women. The moderators were not acquainted with the participants and were familiar with this research theme. An independent note taker was present. The basic FGI guide used in this study was prepared based on common guidelines for conducting focus group research (10,11). This guide consisted of an introduction, stimulus questions, probes, and a conclusion. The interview was conducted

Table 2. Topic guide used for the focus groups

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- 1) Remarks on doubts and anxieties regarding adverse reactions to inhaled drugs
 Do you consult someone when you have doubts or anxieties about adverse reactions to inhaled drugs? or Do you not consult anyone?
- Do you use the internet?
- Do you make inquiries to companies?
- Do you ask the physician or the pharmacist about drugs based on your doubts and anxieties?
- Is there any advantage in being a member of a patient association when you have doubts and anxieties?
- Or, do you do nothing and leave it as is?
- 2) Thoughts driving behavior related to doubts and anxieties regarding adverse reactions to inhaled drugs
 Why do you consult the person?
- Why do you not consult persons around you?
- When you consult someone, why did you decide to talk to that person? Why did you not select someone else?
- 3) Remarks about worries about usability
 Do you consult someone when you have trouble understanding the method of operation or perceive that usability is poor?
 or Do you not consult anyone?
- Do you use the internet?
- Do you make inquiries to companies?
- Do you ask the physician or the pharmacist about drugs based on your worries?
- Is there any advantage of being a member of a patients' association when you have trouble understanding the method of operation or perceive that usability is poor?
- Or, do you do nothing and leave it as is?
- 4) Thoughts driving the behavior related to usability
 Why do you consult the person?
- Why do you not consult persons around you?
- When you consulted someone, why did you decide to talk to that person? Why did you not select someone else?
- 5) The reasons behind the differences in behavior
 5-1. Comparing the persons you consult when you have worries about adverse reactions and usability, is there any difference?
 5-2. Why do you consult different persons?
-

using an interview guide consisting of five open-ended questions, as shown in Table 2. The survey items for the interview were behavior when the patients had doubts or anxieties after experiencing adverse reactions due to inhaled steroids or felt that the usability of the inhalers was poor, and their reasons for these feelings. Information regarding differences in behavior and the corresponding reasons was also collected. If the topics shown in italics in Table 2 did not emerge during FGIs, these areas were probed by the moderators. A video camera and digital voice recorder were installed in the room used for the interview to record the proceedings, after participants' consent had been obtained. Each interview was conducted by one interviewer and one sub-interviewer, with an observer watching and recording the proceedings. The subjects were divided into groups of four to seven members.

In order to make it easier for the participants to recall their own experiences about inhaled steroid drugs, placebo samples of steroid inhalers were placed on the table, and were available for practice.

2.4. Data analysis

The interviews were recorded with permission of the participants, and then transcribed verbatim and used along with observation data. Transcripts were independently analyzed by the first and second authors using the constant comparative method. This method

combines inductive category coding with simultaneous comparison of all units of meaning obtained. First, open-coding was used to develop categories based on commonly recurring themes, and each new unit of meaning was compared with all other units and subsequently grouped with similar units of meaning. Categories were continuously refined until saturation of themes and subthemes was reached after three focus groups. Saturation of themes was determined when the range of ideas was identified and no new information was being obtained.

The focus groups and analysis were conducted in Japanese. The statements in italics were then translated into English with the aim of capturing the meaning of the statements, rather than literal translation. Regarding remarks related to each code, a four-stage weighting was adopted based on the method proposed by the previous literature (12). In the weighting scheme, A was assigned when "similar remarks were heard from three groups", B was assigned when "similar remarks were heard from several members from two groups", C was assigned when "similar remarks were heard from one member each, from two groups, or several members belonging to one group", and D was assigned when "similar remarks were heard from only one member from one group". Letters in parenthesis in the Results section and in Tables 3-5 show the results of weighting. In addition, numbers given in the Results section correspond with the sub-themes shown in Tables 3-5.

Table 3. Behaviors of participants when they had doubts or anxieties after experiencing adverse reactions of inhaled steroids, or when they felt that the usability of the inhaler was unsatisfactory

Main Themes	Sub-themes
Behaviors taken	<i>Consulting</i>
#1. when they had doubts or anxieties after experiencing adverse reactions to inhaled steroids	<i>Members of a patients' association (#1-1, A) (#2-1, B)</i> <i>An advising physician of a patients' association (#1-2, C)</i> <i>An attending physician (#1-3, A) (#2-2, B)</i> <i>A pharmacist (#1-4, D) (#2-3, C)</i>
#2. when they felt that the usability of the inhaler was unsatisfactory	<i>A nurse (#1-5, D) (#2-4, D)</i> <i>Getting information from the bulletin of a patients' association (#1-6, A)</i> <i>Attempting to deal with their doubts and anxieties themselves without consultation (#1-7, B) (#2-5, C)</i> <i>Gathering information from the internet (#1-8, B)</i> <i>Devising measures for lessening adverse reactions on their own (#1-9, B) (#2-6, B)</i>

Numbers and letters in parenthesis represent the sub-theme numbers and the results of weighting, respectively.

Table 4. Perceptions and reasons to consult someone or not to do

Main Themes	Subthemes
#3. Perceptions and reasons to consult members or a advising physician of a patients' association	<i>Tremendous reliance on an advising physician (#3-1, C)</i> <i>Past experience of success (#3-2, B)</i> <i>Achieving peace of mind (#3-3, C)</i> <i>Understanding of suffering (#3-4, B)</i> <i>Atmosphere encouraging free speech (#3-5, C)</i> <i>Not being able to communicate with asthma patients in their hospital (#3-6, C)</i> <i>No understanding of asthma from general public (#3-7, C)</i>
#4. Perceptions and reasons to consult medical staff	<i>Possessing specialized knowledge (#4-1, A)</i> <i>Providing appropriate information on asthma (#4-2, C)</i> <i>Encouragement from medical staff (#4-3, A)</i> <i>Specified to an attending physician;</i> <i>Positive response from the attending physician (#4-4, C)</i> <i>Good relationship with the attending physician (#4-5, C)</i> <i>Specified to a pharmacist;</i> <i>A similar footing between physician and pharmacist (#4-6, D)</i>
#5. Perceptions and reasons not to consult medical staff	<i>Patient's pride in possessing correct information (#5-1, C)</i> <i>Related to attending physician;</i> <i>Distrust of attending physician (#5-2, A)</i> <i>Hesitation regarding communicating with the attending physician (#5-3, A)</i> <i>Related to pharmacist;</i> <i>Perception of lack of specialized knowledge (#5-4, A)</i> <i>Poor response from a pharmacist (#5-5, D)</i> <i>Insufficient information-sharing by a pharmacist (#5-6, C)</i>

Numbers and letters in parenthesis represent the sub-theme numbers and the results of weighting, respectively.

Table 5. Perceptions and reasons not to disseminate information about adverse reactions or poor usability

Main Themes	Subthemes
#7. Perceptions and reasons not to disseminate information about adverse reactions	<i>Is this really an adverse reaction? (#7-1, C)</i> <i>Already having been informed about adverse reactions (#7-2, C)</i> <i>Occurrence of adverse reactions cannot be avoided (#7-3, C)</i>
#8. Perceptions and reasons not to disseminate information about poor usability	<i>Should be solved by oneself (#8-1, B)</i> <i>Useless to talk about it (#8-2, C)</i> <i>Preference for efficacy over usefulness (#8-3, B)</i> <i>Adverse reactions more important than usability (#8-4, C)</i> <i>Not sure whether the information will be forwarded by medical staff to pharmaceutical companies (#8-5, B)</i> <i>Questioning whether an attending physician would take any action (#8-6, C)</i> <i>Usability is acceptable (#8-7, C)</i> <i>Usability has been improved (#8-8, B)</i>

Numbers and letters in parenthesis represent the sub-theme numbers and the results of weighting, respectively.

2.5. Conduct and analysis of the questionnaire survey

We conducted three questionnaire surveys for participants of the FGIs at the timings shown below.

1) Before conducting the FGIs, a self-report mail form pre-survey was conducted to gather information about the participants' sex, age group, asthma history, current asthma status (frequency of attacks), inhaled

steroid usage history, and current inhaled steroid usage. The survey form was collected on the day the FGI was held. 2) On the same day, after completing the FGI, a questionnaire survey on the operability of steroid inhalers was conducted. 3) After analyzing the interview results, in order to evaluate the accuracy and validity of the results, a self-reporting survey form was developed and a mail survey was conducted. The collected survey forms were aggregated and analyzed.

2.6. Ethics

Ethical approval for the study was obtained from the Ethics Committee of Graduate School of Pharmaceutical Sciences, the University of Tokyo. The authors confirm all patient/personal identifiers have been removed so that the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

3. Results

Three FGIs were conducted with 15 participants (6 males, 9 females), who were members of asthma patients' associations. The age of the participants was between 30 and 89 years. Participants' characteristics were summarized in Table 1.

3.1. Behavior of participants

The behavior of the participants when they had doubts or anxieties after experiencing adverse reactions to inhaled steroids, or when they felt that the usability of the inhaler was unsatisfactory could be categorized into "consulting members of a patients' association or an advising physician," "consulting medical staff," "not consulting anyone," and "doing nothing because there was no doubt or anxiety" (Table 3).

3.1.1. Behavior of participants when they had doubts or anxieties after experiencing adverse reactions of inhaled steroids

With regard to the behavior of the participants when they had doubts or anxieties after experiencing adverse reactions of inhaled steroids, most participants mentioned that they firstly consulted members of a patients' association (A) (#1-1). They also put into practice various measures for lessening adverse reactions (B) that they had learned from other members, *via* mutual exchange of information. Some participants also collected information about adverse reactions from an advising physician of the patients' association (C) (#1-2). Even though most of the participants consulted their attending physicians (A) (#1-3), some of them also commented that since one needs to muster enough courage to consult the attending physician after encountering a possible adverse reaction, they would first wish to confirm that the symptom is in

fact an adverse reaction (C) by getting information from members or the bulletin of the patients' association (A) (#1-1, #1-6), and would then report it to the attending physician (C). A few participants said that they consulted a pharmacist (D) (#1-4) or a nurse (D) (#1-5) regarding their doubts and anxieties about adverse reactions. In contrast, some participants mentioned that they did not consult a pharmacist.

Some participants said that they attempted to resolve their doubts and anxieties themselves without any consultation (B) (#1-7). In order to ascertain whether the symptom was an adverse reaction, they gathered information from the internet (B) (#1-8), and to lessen adverse reactions (B), they devised measures on their own (#1-9). Some of the participants mentioned that they did nothing because they had no doubt or anxiety (C).

3.1.2. Behavior of participants when they felt that the usability of the inhaler was unsatisfactory

With regard to the behavior of the participants when they felt that the usability of the inhaler was unsatisfactory, some participants mentioned that they first consulted members of a patients' association (B) (#2-1), and put into practice various measures for improving inhaler usability (B). Many of them also mentioned in this context that they did not consult an attending physician (B) or a pharmacist (D). In contrast, there were some participants who informed an attending physician (B) (#2-2), a pharmacist (C) (#2-3) or a nurse (D) (#2-4).

Some participants said that they attempted to overcome their doubts and anxieties themselves without consultation (C) (#2-5), and devised measures on their own to lessen poor usability (B) (#2-6). Some of the participants mentioned that they did nothing because they have no doubt or anxiety (B).

3.2. Perceptions and reasons underlying behaviors

The following sections describe the perceptions and reasoning underlying the above behaviors (Tables 4-5).

3.2.1. Perceptions and reasons to consult members of a patients' association or an advising physician

One of the patients' associations selected in this study was a branch of a nationwide association with several advising physicians. The participants had tremendous reliance on one physician who was involved in editing the association's bulletin (C) (#3-1). The factors behind this were obtaining the latest information from the bulletin or in exchange meetings (C) and obtaining a specific response to consultation by e-mail or phone (D), which made the advising physician an invaluable partner for consultation and information collection (A).

With respect to the reasons for consulting a member of the patients' association, the responses were

Table 6. Information dissemination by participants only within the patients' association

■Anxiety about the adverse reactions/risks regarding inhaled steroids in the future
<i>"I am worried about what will happen a few years from now"</i> (Participant 5)
<i>"Not sure how the adverse reactions will really emerge after prolonged use. Currently, I do have physical strength to cope with them, but, with time, these will accumulate, and as I grow older and lose physical strength, I am always concerned about what might happen then."</i> (Participant 7)
■Measures taken by the patients to alleviate adverse reactions
<i>"I try to create a thin layer of milk within my mouth before I inhale, and it has always worked for me"</i> (Participant 1)
■Specific opinions about poor usability and measures taken by the patients
<u><i>Regarding ambiguity in gauging the remaining amount of the drug</i></u>
<i>"I always write the date, from the day I actually start inhaling"</i> (Participant 1)
<i>"I write here <on the actual inhaler>, then I write on the calendar, and I also write here"</i> (Participant 14)
<u><i>Regarding difficulty in operation of the inhaler</i></u>
<i>"That is why I write with a color pen myself. First write it once on the right, then go towards the left and using red ink pen when I write here <on the rotation clip of the inhaler>"</i> (Participant 2)

psychological factors, such as achieving peace of mind (B) (#3-2), compassion for the suffering of patients afflicted with the same disease (C) (#3-3), or simply an atmosphere encouraging open dialog (B) (#3-4). Some of the participants also mentioned that they had experience having their doubts or anxieties resolved by advice from the members of the patients' association (C) (#3-5). Some of the participants also mentioned apparently paradoxical reasons, such as not being able to communicate with asthma patients in a hospital where they were visiting (C) (#3-6), and the general public has no understanding of asthma (C) (#3-7).

There were discussions about their concerns regarding possible adverse reactions in the future (C). Table 6 summarizes the information dissemination based on the remarks regarding exchanges between patients' association members only.

3.2.2. Perceptions and reasons to consult medical staff, or not

The participants expected that the persons they consulted would have expertise about asthma, and thus they thought that medical staff having such knowledge would be suitable for consultation (A) (#4-1). At the same time, they also expected that medical staff would provide appropriate information on asthma to patients (C) (#4-2). Some participants said that the reason behind not consulting medical staff was pride that the patient possessed the correct information (C) (#5-1).

Other reasons to consult the attending physician were encouragement from the attending physician (A) (#4-3), positive response from the attending physician (C) (#4-4), or a good relationship with the attending physician (C) (#4-5). In contrast, some participants said that the main reason behind not consulting an attending physician was distrust (A) (#5-2) or hesitation (A) (#5-3). Some of the reasons for distrust were responding with blunt answers when consulted regarding adverse reactions or requests of drugs (B), not being satisfied with diagnosis or instructions (B), insufficient sharing of information or lack of expertise (B), and lack of consensus among medical staff (B). Moreover, not having any

understanding of the pain and suffering of the patient (B), and difficulty in communicating (C) were also mentioned as factors causing distrust. With respect to hesitation, the reasons were limitations of consultation time (B), experience of being offended by the attending physician in the past (C), and the perception of avoiding a situation where consulting may result in being considered a troublesome patient (C).

The participants mentioned that the reasons to consult pharmacists were on a similar footing between physicians and pharmacists (D) (#4-6), and encouragement from the pharmacists (C) (#4-3). With respect to not consulting a pharmacist, the reasons given were the negative perception of pharmacists not having expertise about asthma (A) (#5-4), providing insufficient information (D) (#5-5), or lack of response to questions (C) (#5-6). Because of these factors, some participants said that they had rejected advice from pharmacists (C).

One participant mentioned that the reason to consult nurses was encouragement from a nurse (D) (#4-3).

3.2.3. Perceptions and reasons not to disseminate information about adverse reactions

As a reason not to disseminate information about adverse reactions, the participants mentioned that they did not know whether it was really an adverse reaction or not (C) (#7-1). There were also some participants who had no doubt or anxiety when an adverse reaction occurred, resulted from situations such as already having been informed by the patients' association or the attending physician about adverse reactions (C) (#7-2), or the perception that the occurrence of adverse reactions cannot be avoided (C) (#7-3).

3.2.4. Perceptions and reasons not to disseminate information about poor usability of inhalers

In all the focus groups, participants expressed opinions about usability (A), such as difficulty in inhaling and knowing how much drug remained in an inhaler. The reasons for not disseminating information about usability even under such conditions were that one

should solve usability issues oneself (B) (#8-1), and that it was useless to communicate with others (C) (#8-2). Moreover, based on the experience of improvements in symptoms as a result of inhaling steroids (C), and experience and anxiety concerning adverse reactions (A), the perception was that efficacy (B) (#8-3) and adverse reactions (C) (#8-4) were more important than usability. On the other hand, even if an opinion was expressed, participants questioned whether medical staff would notify the drug manufacturers (B) (#8-5), and even if poor usability was reported, they questioned whether the attending physician would take any action (C) (#8-6).

Some of the participants mentioned that they do nothing because they have no doubt or anxiety (C), because the usability is acceptable (C) (#8-7), or because the usability has been improved (B) (#8-8). Some of the participants with a long history of asthma even favorably evaluated usability as much better than before (C) as a result of successful research and development by pharmaceutical companies.

Regarding voluntary reports to drug manufacturers, neither the patient as an individual, nor the patients' association as an organization took any initiative (B). Some of the participants felt that it would be nice to have measures whereby the patients themselves could report poor usability (C). During the FGI, some of the participants mentioned that they had come to realize that it was desirable to exchange opinions about inadequacies in inhaler usability either as an individual or through the patients' association as an organization (C).

3.3. Results of the follow-up questionnaire

Responses were obtained from all 15 participants. The validity of the analysis was supported by the results of the follow-up.

Among the participants, five reported that their thoughts and behavior had changed after participating in the FGI. Regarding specific changes, participants mentioned the following points.

"It was important for the patients to engage more actively in information exchanges regarding opinions and questions."

"I noted that it was acceptable to disseminate information to pharmacists and pharmaceutical companies, and things such as inferior usability could likely be improved by reporting them as a summary of patients' association members' opinions. Previously, we used to rely only on the attending physician, bulletin, and members of the patients' association."

"When I told the pharmacist that I marked the direction of rotation of the inhaler with a color marker on the clip, she gave me some stickers to place on the clips. I also mentioned about the ambiguity in display of the remaining number of doses. This was significant for me because, based on the experience of the interview, I

was able to take a different action."

4. Discussion

The participants in the study placed tremendous reliance on the advising physician of the patients' association, and in some situations, even preferred the advising physician to their own attending physician for consultation. Sharing the latest information and dealing with the patient with a caring attitude were mentioned as factors promoting dissemination of information to the advising physician, in accordance with patients' perceptions of desirable traits in a physician (13).

For participants who belonged to a patients' association, the members of the patients' association were regarded as peers with the same disease, whom they could safely consult about doubts and anxieties, and exchange information based on their own experience of the disease or knowledge gained in patients' association meetings. These are well known characteristics common to patients' associations and SHGs (14).

While many of the participants chose to consult the attending physician when they had doubts or anxiety after experiencing adverse reactions, distrust and hesitation about the attending physician were barriers to information dissemination for some of the patients. Since dissatisfaction with the information and treatment provided by the physician and the attitude of the physician may lead to distrust (15), this is likely to be a barrier to communication between the patient and the physician. Moreover, the observations that patients tend to refrain from expressing their opinion when the physician is very busy or because they do not want to be seen as troublesome patients are in agreement with the findings of previous studies (16,17). With respect to pharmacists, the general perceptions of an insufficient volume of information sharing and lack of expertise about asthma acted as barriers to communicating their opinion.

Most of participants in the FGIs actively disseminated information when they had doubts and anxieties after experiencing adverse reactions. However, they did not actively discuss with medical staff any anxieties regarding adverse reactions in the future resulting from prolonged use of inhaled steroids. With respect to poor usability, while information was shared among the members of the association, there was neither any active dissemination of information to medical staff nor any engagement with pharmaceutical companies. In the first place, the participants did not even perceive that it was acceptable to disseminate such information to medical staff or pharmaceutical companies. The factors influencing such behavior were the perception of efficacy being more important, and the mindset that "it was useless to inform someone." However, as a result of participating in the FGI, some of the participants realized that "it was acceptable to actively disseminate

information about usability either as an individual or *via* the patients' association as an organization," and some of them actually practiced it after the FGI.

Although medical staff should ideally capture patients' needs in the field and transmit them to the pharmaceutical companies, in practice that may be difficult to implement considering circumstances such as the busyness of the medical staff and the fact that communication between patients and medical staff is not always smooth. In view of this, a more useful approach may be to implement measures through which the patient's needs can be directly obtained from the patients. Some of the participants evaluated the opportunity to express their opinion in an FGI as highly useful.

Limitations of the study are as follows: This study was conducted with participants who were members of asthma patients' associations. The information dissemination behavior or mindset of asthma patients who belong to different types of patients' associations, or who do not belong to any patients' association, may be different.

With respect to doubts and anxieties after experiencing adverse reactions, the main barriers to dissemination of information by participants were distrust and hesitation about communicating with medical staff. Distrust was reported to stem from insufficient information availability from medical staff and lack of good communication capability. In order to resolve these issues, further education of medical staff is required. Previous studies have indicated that even for questions about the validity of the treatment proposed by the physician, which are difficult for a patient to ask, appropriate words from the physician can encourage patients to ask questions (18,19), and appropriate education of physicians led to better communication between patients and physicians, as well as an improvement of patients' condition (20). According to a structured review, communication between patients and medical staff regarding drugs, guiding patients, and encouraging them to ask questions to pharmacists can be effective measures to encourage patients to express their opinion (15). Moreover, according to the previous survey (21), medication compliance improved for patients who read educational materials on communication with the physician during checkups, as compared to that of patients who did not read such materials. This suggests that, in addition to measures for medical staff, simultaneously educating patients is likely to be a useful strategy. With respect to the medical staff being very busy, which is one reason for the hesitation of patients to communicate with physicians or nurses, there may be no easy solution, but one possibility would be to provide patients with opportunities to disseminate information to the attending physician and the primary care pharmacist by utilizing settings such as patients' associations, which are different from usual checkups or guidance about medication in hospitals. In fact, some hospitals have set

up patients' associations within the hospitals; these hold monthly meetings in which the physicians also take part to facilitate communication with patients.

In conclusion, behavioral differences in how bronchial asthma patients transmit experience about the adverse reactions and usability of inhaled corticosteroids were obvious. Information about the patients' needs, including opinions and questions about the usability of steroids inhalers, was shared only with members within the association and not disseminated outside, with some participants even choosing to keep it personal. Additionally, many patients believed that it was not acceptable to disseminate such information to the outside. Underlying this behavior was a mindset of perceiving efficacy and adverse reactions to be more important than usability, and thinking that "it is useless to inform someone."

The present qualitative study suggests that measures should be implemented to make patients aware that transmitting their needs, experience and comments about drugs is beneficial. In addition, new platforms are needed within which the patients themselves can freely transmit their opinions about improving drugs and delivery devices. Above all, such implementations would also improve awareness that patients are subjectively involved in their pharmacotherapy.

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