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Internet Accounts of Serious Adverse Drug Reactions

A Study of Experiences of Stevens-Johnson Syndrome and Toxic Epidermal Necrolysis

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Abstract

Background: Life-threatening adverse drug reactions (ADRs) such as Stevens-Johnson Syndrome (SJS) and Toxic Epidermal Necrolysis (TEN) continue to affect patients' lives long after the event. Survivors and their relatives rely heavily on Internet sources for support and advice, but narratives of their experiences posted on patient websites have not been explored previously.

Objectives: The aim of the study was to illuminate patient experience by analysing Internet narratives of drug-induced SJS and TEN and considering the reasons for postings on patient websites, and the concerns they reflect. We also aimed to compare these experiences with a previous study of survivors of SJS and TEN conducted by face-to-face interview.

Methods: We searched for unsolicited personal narratives or descriptions of drug-induced SJS and TEN posted on the Internet between February 2009 and June 2010, and analysed them using a thematic qualitative approach.

Results: We analysed 208 Internet descriptions. Motivation for posting on the Internet included a desire to share experiences and to seek advice from others. Patients and their relatives expressed concern that the ADR may be hereditary, worries about effects on fertility and a fear of recurrence. They also wished to increase awareness of the potential harms from medicines and to inform others of the suspected cause of the ADR.

Conclusion: Individuals experiencing SJS or TEN had many unanswered questions and concerns long after the event. Our findings could guide health professionals in the management of survivors of the ADR, and in communicating more effectively with patients and their relatives. Internet forum postings of patient experiences of ADRs provide insight into patient concerns and supplement findings from detailed face-to-face interviews.

Background

Drug-induced Stevens-Johnson syndrome (SJS) and Toxic Epidermal Necrolysis (TEN) are rare but serious and acutely life-threatening cutaneous adverse drug reactions (ADRs), with a high mortality rate of up to 40%.[1,2]

They are characterized by epidermal necrosis, leading to extensive epidermal detachment, mucous membrane erosion and severe constitutional symptoms, and their complications are similar to those of thermal burns; extensive skin loss leads to massive transdermal fluid losses, with associated electrolyte imbalance and pre-renal failure. Bacterial colonization of the skin and decreased immune responsiveness increase the likelihood of sepsis.[3]

We recently conducted an interview-based qualitative study of 14 survivors of SJS and TEN, and found that these ADRs continued to affect patients' lives long after the event.[4] Along with long-term physical complications, such as scarring and visual impairment, survivors described the psychological effect of the ADR, including symptoms of depression, and 'flashbacks' to the event. The experience of a serious ADR also had a profound impact on their relationship with health professionals, so that many survivors avoided medicines altogether, or avoided seeking medical attention when ill, regardless of the effect on their health.

Survivors and their families in our previous study relied heavily on Internet resources, including online SJS and TEN support groups, to obtain more information about the condition, and found these useful. Other recent studies have shown that patients experiencing serious illness, use the Internet to access support group websites, both to share their experiences and to obtain further information and advice on managing their illness.[5-11] We therefore considered that an analysis of Internet descriptions posted by those who have experienced drug-induced SJS or TEN would be helpful in further exploring the impact of these ADRs and the concerns of those who have been directly affected by them. It would also provide a larger study sample, allowing triangulation of our earlier results as well as extending our findings. We also considered whether Internet searches, which are easier to conduct than face-to-face interviews, could usefully guide patient-centred care when information from interview studies is not available.

Here we analyse unsolicited Internet narratives or postings of those who have identified themselves as having personal experience of these serious ADRs, and aim to interpret the reasons for individuals posting on such Internet sites. We also aim to explore the concerns of survivors and their relatives, and to determine whether issues discussed by patients and their relatives in their Internet descriptions differ from those we found through interviewing survivors of the condition face-to-face.

Methods

We knew of the existence of one website (www.sjsupport.org) that contained unsolicited narratives or postings of those with personal experience of SJS and TEN. We then identified other websites in the public domain containing narratives or postings by using popular search engines Google, Google Blogs, Bing, Yahoo and Ask Jeeves. We also searched social networking sites Facebook, Twitter, Bebo and MySpace. Searches were performed using the keywords [*Stevens Johnson syndrome* OR *Toxic Epidermal necrolysis* OR *SJS* OR *TENS* OR *Lyell's syndrome* OR *adverse drug reaction(s)* OR *medication(s)* OR *side-effect(s)*] in combination with keywords [*patient experience* OR *personal experience patient illness* OR *personal illness* OR *blog*

OR *patient story(ies)* OR *patient account(s)* OR *patient narrative(s)*].

Data were collected during February 2009, and again in June 2010, to look for additional data available since the period of first data collection. Having identified relevant websites, we then examined the patient descriptions.

Inclusion Criteria

We defined 'narratives' as first-person descriptions by a patient, relative or friend; and 'Internet postings' as contributions made to a 'thread' of discussion on an Internet site. Each contribution to the thread was counted as a unique Internet posting. We use the term 'Internet description' to encompass both narratives and Internet postings. Only Internet descriptions written in English and where there was evidence of self-identified personal experience of SJS or TEN (either as a patient or as the relative or friend of a patient) were included in the study.

All Internet descriptions that met the selection criteria on the identified websites were downloaded, and each was assigned a numeric code. Internet descriptions were copied and pasted in their entirety into Microsoft Word® (Microsoft Corporation, Redmond, WA, USA); they were not edited for spelling or grammar or otherwise. Descriptive information was then entered into a Microsoft Excel® spreadsheet.

Exclusion Criteria

We excluded non-written accounts, such as video presentations, accounts written in languages other than English, and accounts that did not reflect the experiences of the patient, relative or friend.

Analysis

Descriptive data extracted included the role of the author if provided (i.e. patient, relative or friend of patient), the sex and age of the patient at the time of the reaction, country of origin, an indication from the Internet description of whether or not the author understood or believed the reaction to be drug-induced, and the medicine responsible if mentioned. Each Internet description was also analysed to interpret the apparent reason or motive for posting the description on the website, as perceived by the researchers (TFB/ARC).

We undertook a qualitative analysis of Internet descriptions using NVivo 8.0® (QSR International [UK] Ltd, Warrington, UK). This allowed us to map themes from the current study onto themes identified from our previous qualitative analysis of interviews with survivors, using a 'top-down' thematic approach[12] (see figure 1).

We were also able to identify novel themes not previously found in our face-to-face interviews. Novel themes and subthemes were then grouped together using an inductive, 'bottom-up' approach.

All narratives were analysed by one of us (TFB). Consistency in mapping of pre-existing or novel themes was ensured through masked dual coding of a randomly selected subset of twenty narratives with a second researcher (ARC); any variations in coding were resolved by discussion to achieve consensus. A third researcher (REF) also analysed emerging new themes to ensure rigour and plausibility of the new emergent themes. The final coding scheme was elaborated by TFB and refined by a fourth researcher (JRO).

Results

Identification of Internet Descriptions

We identified two major websites[13,14] and two blogs[15,16] containing relevant Internet descriptions. A total of 228 Internet descriptions relating to personal experiences of SJS and TEN were identified and downloaded, of which 20 were excluded (see figure 2), leaving 208 descriptions for analysis. No Internet descriptions meeting the inclusion criteria were found by searching the social networking sites Facebook, Twitter, Bebo or MySpace.

Demographics of Internet Description of Authors

A total of 139 Internet descriptions were posted by those who had directly experienced SJS or TEN and 69 by relatives; one was jointly

Understanding of SJS/TEN
Awareness of:
- Drug cause
- Name of condition
- Rarity
- Seriousness and potential fatality
- Spectrum of disease
- Treatment limitations

'Why ADR occurred'
- Ignoring existing allergies
- 'Too high a dose' of the drug
- Failure to monitor blood tests
- Culprit drug unnecessary
- Chance/'A fluke'

Experiences of the condition
- Circumstances leading to ADR
- Symptoms and initial presentation
- 'Confused for another condition'
- Reaction of others
- Support and communication
- Healthcare professionals' awareness of SJS/TEN

Impact of ADR on current life
- Fear or avoidance of medicines
- Views towards culprit drug
- Views on safety of medicines in general
- Irrational fears
- Trust in healthcare professionals
- Precautions
- Long-term physical (e.g. scarring) and psychological effects

Views on information sources
- Internet sources
- Patient information leaflets
- Healthcare professionals
- Views on patient reporting of ADRs

Hindsight
- Views on warning prior to the event

Fig. 1. Previous themes and subthemes identified through interviews with survivors of Stevens-Johnson Syndrome and Toxic Epidermal Necrolysis.[4] **ADR** = adverse drug reaction; **SJS** = Stevens-Johnson Syndrome; **TEN** = Toxic Epidermal Necrolysis.

submitted by a patient and a relative. Of those posted by relatives, 30 were posted by mothers.

Overall, 128 of the Internet description authors indicated that they were female and 68 that they were male. 125 authors (88 patients and 37 relatives) indicated the age at which the reaction occurred. The mean age at the time of the reaction was 17.5 years, with a range of 3 weeks to 77 years, and bimodal ages of 3 and 8 years. Many patient-authors had developed the condition as children and described their experiences retrospectively.

Fewer than half of the authors indicated their country of residence (97/208); the majority of

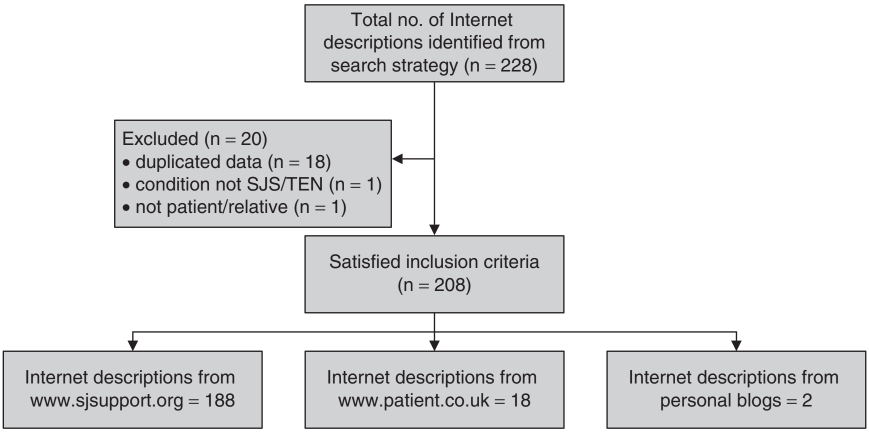

Fig. 2. Identification of Internet descriptions. **SJS** = Stevens-Johnson Syndrome; **TEN** = Toxic Epidermal Necrolysis.

these lived in the US (52/97), and a further 21 indicated that they were from the UK.

Causes of Stevens-Johnson Syndrome and Toxic Epidermal Necrolysis

We reviewed all Internet descriptions to determine whether authors indicated a likely cause for the condition. 152 Internet descriptions indicated that the condition was likely to be drug-induced; in 38 descriptions the cause was not absolutely clear. The condition was unlikely to be related to drugs in 18 descriptions (viral causes, including *Herpes simplex*, and mycoplasma infections were mentioned in five cases), and we did not analyse those descriptions further.

The specific culprit drug was mentioned in 135 descriptions and, of these, 60 referred to the possible culprit drug by its brand name. Eight descriptions mentioned only the general drug class implicated (e.g. ‘antibiotics’). Multiple drugs were implicated as causes of the ADR in 12 descriptions.

The most common culprit drugs detailed in descriptions included sulfonamides, penicillins and antiepileptics, similar to findings from other epidemiological studies[17] (see tables I and II).

Motives for Submitting an Internet Description

We categorized Internet descriptions according to our perception of the motive for submission to a website, on the basis of statements made by authors within Internet descriptions. We identified four major reasons. The first was individuals wishing to share their experiences of the ADR and provide support for others (164). Secondly, patients or their relatives asked for advice from others regarding the condition and its complications (33). The third category both asked for advice and wished to share experiences (10). Finally, one requested funds to treat the complications of SJS/TEN (1).

Table I. Culprit drugs cited in Internet descriptions

Most common culprit drug	No. of Internet descriptions
Sulfonamides	31
Penicillins	19
Ibuprofen	8
Carbamazepine	7
Macrolides	7
Cephalosporins	7
Phenytoin	7
Lamotrigine	7
Tetracyclines	5

Table II. Estimates of excess risk with drugs associated with Stevens-Johnson Syndrome and Toxic Epidermal Necrolysis (adapted from Roujeau et al.[17], with permission from the New England Journal of Medicine)

Drug	Relative risk	Excess risk
Sulfonamides	172	4.5
Trimethoprim-sulfamethoxazole	160	4.3
Aminopenicillins	6.7	0.2
Tetracyclines	8.1	0.2
Carbamazepine	90	2.5
Phenytoin	53	1.5

Qualitative Analysis

We were able to map several themes directly onto those found in our earlier analysis of face-to-face interviews with survivors of SJS/TEN. These included their experiences of the condition, its impact on their current life, and long-term physical complications such as visual impairment.

Experiences of the Condition

Many described how the ADR was initially misdiagnosed and confused for another condition by health professionals:

> *Internet description 133:* “The fever comes and goes. I asked her [the doctor] to check my genital area as no other doctor has. She ran a full battery of tests and reviewed the lab results from my ER visit the night before. The blisters are now covering my lips and mouth, down my throat, in my ears, nose, and vagina. She tested me for every known STD. After enduring an extremely painful vaginal exam, she told me she wanted to treat me for Herpes. As you can imagine, this has caused great stress on my marriage.”
>
> *Internet description 136:* “… the doctor diagnosed me with things like chicken pox, measles, and flea bites …”

Patients also described how they felt that they had ‘turned into a monster’, and how others reacted to the change in their physical appearance as a result of the ADR.

> *Internet description 73:* “I could see the look of disgust on the face of my aunt and my wife and the visitors for what was happening to me. Everyone who saw me could not believe the way I looked like. Even my kids when they visit me could not recognise me as if I was turned into a monster.”

> *Internet description 124:* “ … and the day when I’ll be released from the hospital finally came … after 1 ½ months. What I looked like that time made people a little disgusted and scared. I still have scars, I didn’t have nails, and only a little hair were left. I had no friends in elementary [school] …”

Impact of the ADR on Current Life

Many of those who had experienced the ADR stated that they now avoid medicines in general due to a fear that they may cause a recurrence.

> *Internet description 92:* “… in the mean time, we live one day at a time, suspicious of all meds, suspicious of all foods, and even suspicious of the air that James breathes … why, why, why???”

Some felt that better warnings might have allowed them to avoid the offending medication in the first place, as in this extract:

> *Internet description 204:* “I just wish the FDA [Food and Drug Administration]/Doctors would warn consumers. If I had known that such a horrible syndrome existed I would have done anything in my power to avoid medications.”

In addition, six further major themes and three marginal themes were identified from the Internet descriptions (see figure 3). Many of these relate to Internet authors seeking advice from others who have experienced the condition, and the concerns that patients and their relatives have regarding SJS/TEN and its complications.

Seeking Advice from Others

Many of the description authors explicitly sought information and advice from others who might read their posts. The topics on which they sought information were varied, and included seeking advice about the immediate cause, symptoms and treatment of the ADR.

Authors also queried whether the reaction might be hereditary and described the fears they had for their children:

> *Internet description 216:* “I’m totally clueless about SJS though. Am I now a carrier? I’m aware of the fact it was due to an allergic reaction to the drugs prescribed to me. I think I was extremely lucky as it only affected my mouth and not the rest of my body… Could anyone update me on what happens now with regards to SJS and me being a carrier? I’m aware I shouldn’t use that medicine ever again though!”

> *Internet description 70:* “I gave birth to our son September 13, 2002 and am looking for information on heredity and drugs known to cause SJS, as everything I’ve read says it is genetic and blood relations have a greater chance of developing SJS. I cannot imagine anyone having to go through that, and need to protect my son. If anyone has any information please email me …”

Others asked for advice on obtaining compensation for the drug-related event, implying a belief that the ADR should not have occurred and could have been prevented.

> *Internet description 171:* “In the early eighties I suffered from this syndrome because of drugs that I was given during an operation. I was never told that I could die. My parents told me after 4 weeks of quarantine. The doctors took pictures. I was so upset and could not see my eyes were closed. The doctors pulled something from my eyes every day. I have just been informed that I should be compensated because I still have problems and I am looking for help.”

Fears and Concerns

Many authors expressed fears, for example, that the condition may recur, or that the term ‘syndrome’ meant that the condition was permanent:

> *Internet description 34:* “I will never forget. I feel traumatize[d] and sometimes I feel very afraid that this might happen again.”

Theme	Subthemes
Seeking advice from others	• Am I a carrier of SJS/TEN? • Could his death have been prevented? • Did doctors miss telling me anything? • Effects on fertility • Is there a food cause? • Information regarding ADRs in general • Is this symptom due to SJS? • Is there a specific test for ADRs? • What can I do to prevent recurrence? • Could I get compensation?
Fears and concerns	• Is my other condition related? • Fear of effect on pregnancy • Fear of recurrence • Fear of sterility • Concerns that specific drug cause unclear
Physical complications	• Blindness • Genital involvement • Hearing loss • Photophobia
Desire to raise awareness	• Amongst healthcare professionals • Amongst the general public
Helping others by sharing story	
Support from the stories of others	
Marginal themes	• Self-diagnosis of condition • Reporting a new drug cause • Social complications

Fig. 3. Novel themes and subthemes identified from Internet description narratives. **ADRs** = adverse drug reactions; **SJS** = Stevens-Johnson Syndrome; **TEN** = Toxic Epidermal Necrolysis.

> *Internet description 71:* "I am still quite confused by this syndrome. Will it stay in her system forever? Since it is a syndrome, does it always come back and never go away? I don't know anymore and I am scared for my daughter, please help."

Other authors were concerned that the ADR was linked with the development of other illnesses:

> *Internet description 40:* "Three weeks ago my son got Stevens Johnson syndrome and now he has developed diabetes type 1. He is 22, 6ft 7 inches and very fit. Has anyone heard of a correlation between the two?"

> *Internet description 37:* "I have suffered from depression which now it turns out may be as a result of the hypoglycemia which may be a result of a unfavorable reaction with a sulfa drug … I am concerned that the health problems I am having now are something that could be related to my SJS from 11 years ago."

Finally, a number of female authors had fears connected with future fertility and pregnancy:

> *Internet description 25:* "My parents told me the doctors expected side effects to be along the lines of blindness, deafness, or sterility. Thus far I can see and hear just fine, but I'm a

> 19 year old virgin, and I still live with this fear in the back of my mind that I might not be able to have kids when I'm ready to …"

Physical Complications

In addition to extensive scarring, those experiencing the condition described other physical complications, including severe visual impairment and sexual dysfunction:

> *Internet description 11:* "I was finally mainstreamed into the public school system in the first grade where I was taught Braille, cane travelling skills, and many other important skills to being a functional and successful blind person. SJS damaged my eyes quite severely."

> *Internet description 79:* "… So now, 13 years later [after SJS], I am finally married to a very understanding wife but to be honest, our sex life is not what it could or should be simply because I cannot enjoy sex or achieve orgasm – lack of sensitivity on my part … You know, if my arms, feet, toes, fingers or legs would have blistered and ruptured, I could have dealt with that … I really feel that it has left some long term effects that I will never overcome."

Desire to Raise Awareness

A number of authors discussed their desire to raise awareness of drug-induced SJS and TEN, not only among the general public, but also among health professionals, as their condition had been misdiagnosed, or the diagnosis had been delayed.

> *Internet description 150:* "I don't want people to suffer this complex disease, especially suffer unnecessarily due to ignorance, health money managers, and drug companies… Let's be honest, SJS situation always has the potential for fatality. There is no little SJS case. I personally commit in any way to mobilize this [internet] group to grow, and to unify this community… I will work to raise funds or distribute information to aid the awareness movement."

> *Internet description 195:* "I definitely feel that the medical profession is not aware enough of Stevens-Johnson. Every time I get a chance to tell my story to a medical person, I do. I wish there was a way we could tell our stories. I wrote to Oprah once in the hope that someone there might take an interest in our plight but did not hear anything from them. We need a way to educate the public about this terrible disease."

Self-Diagnosis

Authors described how they researched their symptoms when they developed the ADR, and attempted to reach a diagnosis themselves. In keeping with the views of survivors elicited through interviews, many were surprised at the lack of awareness of health professionals regarding the condition.

> *Internet description 67:* "I started doing my own research and found a description of erythema multiforme in the Merck Manual of Medical Information. By the next evening, I recognized that I was starting to have lesions in my esophagus, eyes, and lips and went to the ER. I told the doctors what I expected and was started on high doses of Decadron [dexamethasone] … I was amazed at the lack of knowledge on the part of the medical professionals. I clearly knew more about this disorder than anyone else I dealt with. I do however credit the ER doctor with listening to me and starting the steroids immediately."

> *Internet description 136:* "… my mom looked frantically through a book of medical problems and came to Steven Johnsons Syndrome. It fit the description perfectly but when she asked the doctor if it could be that he said no, it's too rare …"

Helping Others by Sharing Story

A number of authors demonstrate a degree of altruism and the desire to help others by sharing their story on Internet forums.

> *Internet description 37:* "I feel so incredibly fortunate to not have had to suffer as much as some of these other people. I share my story so that it might help someone else. Until this website I had never heard of another person with this condition and had not ever found any real useful information concerning it."

> *Internet description 78:* "My Father wants other people to know about this deadly syndrome, for people to be cautious of the drugs they take and for people to be aware of erring doctors. This is why I am sharing my brother's story with you. Who knows, this email may save a life."

Support from the Stories of Others

Others indicated their gratitude for the support and comfort they gained from reading the stories of others who had been through similar experiences.

> *Internet description 4:* "I want say that in 1995 I tried to find any information I could on SJS and there wasn't much out there to find. A year ago I noticed that there is much more info on this syndrome. I am greatful [sic] for the info and I read alot of people's stories to Jeff it makes him feel not so alone!!! Thanks for listening to our story."

> *Internet description 90:* "We were later informed that this was a case of Stevens Johnson syndrome. His skin is still falling off and he is in so much pain I want to cry when I see him. I know nothing about this illness and I am thankful for this site. Your stories were heart breaking and I hope my brother's doesn't worsen. Please contact me with any useful information that could put my mom and myself at ease."

Reporting a New Drug Cause to Other Users

One author describes developing SJS secondary to Zocor® (simvastatin) and indicates his desire to report to others what he considered a new ADR, although SJS is listed in the Summary of Product Characteristics for Zocor® as an adverse effect:

> *Internet description 194:* "On Thursday I made an appointment with my doctor, and he was smart enough to not only realize my condition was caused by a drug reaction, he also mentioned Stevens Johnson Syndrome, although he didn't make a big deal about it. He took me off the Zocor immediately… It seems, after reading your website, that I was extremely lucky, not only to have such mild symptoms, but also to have a doctor who knew what he was doing. That's my story. I don't know if this helps you at all, but it might help to add Zocor to the list."

Social Complications

Finally, some authors describe the social consequences resulting from disability due to the complications (or treatment) of SJS/TEN, indicating the burden resulting from the disease long after the event.

> *Internet description 1:* "My friends left me alone. They did not want anything to do with me. There was this one word, which was following me every moment. That word was 'Disabled and Handicapped'."

> *Internet description 155:* "He stated that I had SJS and they began giving me prednisone and I have been taking it ever since. Over the past few years many things have been going wrong with my health; diabetes, cataracts, polyperiphial [polyperipheral] neuropathy, weight gain, mooning of the face, mood swings, broken bones and the list goes on. I have been fighting with the VA [Veterans Affairs] and Social Security to get the benefits that I deserve and the fight goes on. I have lost several jobs and it is becoming increasingly difficult to provide for my family."

Discussion

We found unsolicited Internet descriptions to provide a rich dataset of patient experience of ADRs.

The Internet descriptions taken together gave a very clear picture of common concerns shared by patients with life-threatening and life-changing illnesses in general, and SJS and TEN in particular.

We also identified similar themes previously found through solicited means from our face-to-face interview study of survivors, from Internet descriptions of the ADR; up to now, there are few studies examining Internet descriptions of illness, and none have triangulated their findings by comparison with another method.[5-11] We conclude therefore that Internet descriptions of personal experience of the ADR may yield similar data to that found through interviewing survivors face-to-face.

Despite the rarity of SJS/TEN, we identified a large number of Internet descriptions of the ADR. Several new themes that were not found through interviewing survivors were identified from Internet narratives, including fears and concerns of those who had experienced the condition. This emphasizes the potential value of analysis of Internet descriptions of patient experience in rare disorders, where engagement with patients to understand their experiences and views might otherwise be difficult.

As well as constituting an essential part of their narrative, authors indicated that they wished to inform others of the suspected cause of the reaction to increase awareness of the ADR. Our findings therefore support the idea that many members of the public might be motivated to report ADRs on Internet forums. Since underreporting of ADRs is a significant problem,[18] such patient reports could provide useful additional information for health professionals and the pharmaceutical industry. Of note, around two-thirds of Internet descriptions by relatives were made by parents; such information on ADRs in children is particularly valuable since ADRs in children in particular are poorly reported.[19]

The contribution of patient (as opposed to professional) reports of ADRs is shown in a recent review of patient reporting systems from six countries, where possible new ADRs that had not previously been reported by health professionals were identified.[20] The potential of using the Internet as a source of patient reports is also demonstrated by the setting up of a public group in May 2010, focusing on ADRs, on the social networking site Facebook. Use of this site showed that although the ADRs reported were not serious or unexpected, their causal relationship with the suspected drugs was strong.[21] In a number of Internet descriptions in our study, it was not clear whether the suspicion of an ADR was based on medical advice, or on patients or relatives assuming an association themselves. However, a comparison of the most commonly cited culprit drugs in our study with those from previous epidemiological studies shows some congruity.[17]

The reasons why patients report ADRs are only now beginning to be understood.[22] Our study showed that the majority of individuals appear to have posted on websites in a desire to share their experiences with others, and hence provide a source of support for others who had also experienced the ADR. These findings are in keeping with previous work looking at Internet descriptions of personal illness, which showed that some Internet descriptions are primarily constructed to explain the illness and consequent emotional changes, whereas others are constructed to give advice and support to others.[23] Although altruism may be a key factor in people’s decisions to post their experiences on the Internet, sharing their experiences of a serious illness can also be therapeutic for those posting, and writing about important personal experiences in an emotional way has been shown to improve mental and physical health.[24-26]

Patients and their relatives described the concerns and fears they had, including fears of a recurrence of the condition, and their fears of future infertility.

They also described concerns that other conditions they subsequently developed may have developed as a consequence of their previous experience of the ADR, although there is little current evidence in the literature for such associations. Such findings imply that patients and their relatives have many unanswered questions and concerns about the ADR after the event. Our findings may therefore be helpful in guiding health professionals in discussions with patients and their relatives regarding the concerns they may have and allow them to be addressed should they arise.

Authors of Internet descriptions described physical complications that did not feature significantly in the findings of our previous study of survivors, including sexual dysfunction, and severe visual impairment or blindness. This may reflect that survivors may have been more comfortable writing anonymously on the Internet about sensitive issues such as sexual dysfunction than they would have been discussing these face-to-face with an interviewer. In addition, the numbers we were able to recruit in our previous study were small due to the rarity and high mortality rate of the condition. This may have reduced the likelihood of recruiting patients who were significantly visually impaired as they would be unable to read the recruitment literature sent out to them, a limitation we identified in our previous study.

Finally, patients and relatives describe how they attempted to reach a diagnosis themselves when health professionals struggled to determine the cause for their presentation; a few description authors actually reported reaching the correct diagnosis through their own research using medical textbooks. This is unsurprising as self-diagnosis triggers the diagnostic hypothesis in 18% of consultations with general practitioners, and a few studies have shown that a number of conditions such as recurrent urinary tract infection, recurrent anterior uveitis and schistosomiasis can all be self-diagnosed correctly.[27]

Limitations of Our Study

As we limited our search of the Internet using the most commonly used search engines by public users, there is a possibility that we may have missed data available through other less commonly used search providers.

A reporting bias, with elderly patients using the Internet less frequently, must also be recognized.[28] This may explain the large proportion of reports describing the ADR in younger patients. However this may also in part be explained by the fact that many of those who posted on websites were parents of children who had recently experienced the ADR. In addition, the mortality in SJS and TEN increases with age, which may explain why fewer elderly patients submitted reports.[29]

We could not independently verify the data we analysed. There was no corroborative diagnostic information apart from that detailed in the Internet descriptions. We could not therefore independently confirm the diagnosis of a drug-induced event in any of the patients. In some cases – for example, where the subject was not described as being admitted to hospital – the diagnosis of a serious and often life-threatening condition may be in doubt. In addition, we were unable to ascertain whether the descriptions of the ADR accurately reflect the distribution of severity of disease in the underlying population.

However, we analysed narratives where there was evidence of self-identified personal experience of SJS or TEN, regardless of the causation; what the author believed to be true was central to our study.

In addition, the themes that emerged included all those that we had previously identified by direct patient interview. It is likely, therefore, that the experiences described and views expressed were genuine. They may, of course, be unrepresentative of the entire cohort of patients who survive SJS or TEN.

Conclusions

Internet descriptions of drug-induced SJS or TEN by sufferers and their relatives can help to provide health professionals with a deeper insight into patient experience of serious ADRs.

Patients and relatives who have experienced SJS or TEN posted on support group websites or blogs to share their experiences, provide support to other sufferers and obtain advice from others who have had similar experiences.

Internet descriptions indicated that patients and their relatives had many unanswered questions and concerns regarding the ADR, often long after the event.

We hope the study will increase awareness of the many fears and concerns that patients with SJS/TEN may have, and allow health professionals caring for them to provide further information to address them.

We believe our findings could be used to guide health professionals in the management of such patients and also in communicating with their relatives more effectively.

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