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Patient Experiences of Serious Adverse Drug Reactions and Their Attitudes to Medicines

A Qualitative Study of Survivors of Stevens-Johnson Syndrome and Toxic Epidermal Necrolysis in the UK

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Abstract

Background: Adverse drug reactions (ADRs) cause significant morbidity and mortality and account for around 6.5% of hospital admissions. Patient experiences of serious ADRs and their long-term impact on patients' lives, including their influence on current attitudes towards medicines, have not been previously explored.

Objective: The aim of the study was to explore the experiences, beliefs, and attitudes of survivors of serious ADRs, using drug-induced Stevens-Johnson syndrome (SJS) and Toxic Epidermal Necrolysis (TEN) as a paradigm.

Methods: A retrospective, qualitative study was undertaken using detailed semi-structured interviews. Fourteen adult survivors of SJS and TEN, admitted to two teaching hospitals in the UK, one the location of a tertiary burns centre, were interviewed. Interview transcripts were independently analysed by three different researchers and themes emerging from the text identified.

Results: All 14 patients were aware that their condition was drug induced, and all but one knew the specific drug(s) implicated. Several expressed surprise at the perceived lack of awareness of the ADR amongst healthcare professionals, and described how the ADR was mistaken for another condition.

Survivors believed that causes of the ADR included (i) being given too high a dose of the drug; (ii) medical staff ignoring existing allergies; and (iii) failure to monitor blood tests. Only two believed that the reaction was unavoidable. Those who believed that the condition could have been avoided had less trust in healthcare professionals. The ADR had a persisting impact on their current lives physically and psychologically. Many now avoided medicines altogether and were fearful of becoming ill enough to need them.

Conclusions: Life-threatening ADRs continued to affect patients' lives long after the event. Patients' beliefs regarding the cause of the ADR differed, and may have influenced their trust in healthcare professionals and medicines. We propose that clear communication during the acute phase of a serious ADR may therefore be important.

Background

Approximately 6.5% of hospital admissions in the UK are related to ADRs, with an associated mortality of 0.15%, costing the National Health Service £466 million annually.[1]

Drug-induced Stevens-Johnson syndrome (SJS) and Toxic Epidermal Necrolysis (TEN) are rare but serious and acutely life-threatening cutaneous adverse drug reactions (ADRs). SJS and TEN are considered to be part of a single spectrum of disease; SJS affects <10% of body surface area (BSA), with a mortality rate of 1–5%, whereas TEN affects >30% of BSA, with a higher mortality rate of 30–40%. Cases involving between 10% and 30% of BSA are classed as SJS-TEN overlap syndrome.[2,3]

Although over 100 drugs have been implicated, a limited number of drugs, including sulfonamides, anticonvulsant agents, and allopurinol, are most consistently associated with SJS and TEN.[4] Thought to be immune-complex-mediated hypersensitivity disorders, they are characterized by epidermal necrosis, leading to extensive epidermal detachment, mucous membrane erosion and severe constitutional symptoms.[5] The complications of SJS and TEN are similar to those of extensive burns, and survivors of SJS and TEN may therefore suffer lasting morbidity that impairs their quality of life.

Despite their impact on patient morbidity and mortality, the experiences of patients who have suffered the effects of serious ADRs such as SJS and TEN have not been previously explored. We present the findings of a novel retrospective study of adult survivors of SJS and TEN. In order to generate hypotheses regarding experiences of serious ADRs, we explore their experiences and understanding of the condition, and how these influenced their current attitudes towards medicines and ADRs.

Methods

We employed a qualitative approach derived from grounded theory due to the exploratory nature of the study. Our aim was to generate new hypotheses regarding patients' experiences and beliefs about serious ADRs such as SJS and TEN rather than to test them.[6]

We identified survivors of SJS and TEN, aged 18 years and over, admitted over a 10-year period to one of two teaching hospitals in Birmingham, UK. One hospital contained a specialist burns unit, which admitted patients with the condition, and a number of patients had therefore been transferred from other hospitals in the UK.

As SJS and TEN are very rare (estimated annual incidence of 1–2 per million population) and are associated with a high mortality rate, purposive sampling was not feasible.

Patients were identified either from an existing dermatology database of patients diagnosed with drug-induced SJS and TEN, or from medical records through diagnostic codes assigned to them. Forty-eight survivors were identified and contacted by letter, and 18 agreed to participate in the study. Of these, four were excluded: one died from an unrelated condition, two were subsequently uncontactable and one patient had no recollection of being diagnosed or admitted to hospital with the condition. Participants were contacted by telephone to arrange interviews.

Twenty-eight patients did not respond to the invitation to participate and two patients formally declined. Of those who either declined or did not respond, 19 (63%) were female and 11 were male; age range was 20–89 years (mean 46.8 years).

Data Collection

Semi-structured interviews of patients were undertaken using a standardized interview topic guide devised by TFB, ARC and REF. Patients were interviewed independently by TFB (ten) and ARC (four). All interviews were either conducted at the hospital or at the patient's home, depending on patient preference, and were audio-recorded with the patient's permission. Open questions were asked regarding their experiences of the condition and the circumstances surrounding it, their beliefs regarding the cause or precipitant of the adverse event and their views towards medicines. Patients were encouraged to openly express their own views with minimal intervention from the interviewer. The interview topic guide evolved as interviews progressed, and a final version was developed after the fifth interview (see Supplemental Digital Content 1, http://links.adisonline.com/DSZ/A40, for full interview topic guide).

Analysis

Audio recordings of interviews were transcribed and analysed using an approach based on grounded theory and using the qualitative software package NVivo 8.0 (QSR International, Southport, UK) to manage text and coding. Data analysis was undertaken as the interviews progressed, ensuring that emergent themes were analysed as they arose.

Transcripts of interviews were analysed in five steps: (i) identification of themes; (ii) generation of codes to label passages; (iii) revision of themes and coding scheme in light of newly accumulated data; (iv) application of codes to the final dataset; and (iv) exploration of the relationship of various themes amongst patients.

Interview transcripts were independently analysed and initial coding schemes generated by TFB and ARC; any variations in coding were resolved by discussion to achieve consensus. A third researcher, REF, also analysed the emerging coding framework to ensure rigour in the analysis. TFB elaborated the final coding scheme, and consistency was confirmed through blind dual coding with ARC. After 12 interviews, analysis showed that we had reached theoretical saturation, defined as the point when no new concepts or relevant data regarding a category emerge.[6]

Results

Fourteen adult survivors were interviewed, of whom eight (57%) were women, and age range was 21–82 years (mean 57 years). Data were classified into six main themes: survivors' understanding of SJS and TEN; their interpretation of why the ADR occurred; their experiences of the condition; the impact that the ADR has had on their current life, including their views towards the safety of medicines; views on medicines information sources; and their current views on events leading to the reaction with 'hindsight'.

A number of subthemes were also identified, and the resultant taxonomy is outlined in figure 1.

Circumstances Leading to Adverse Drug Reaction (ADR)

A variety of circumstances led to survivors developing SJS and TEN resulting in hospital admission. The most common causative drugs were antibacterials (nine cases), including penicillins, trimethoprim and cephalosporins; three cases were attributable to antiepileptics (phenytoin and lamotrigine), and the remaining two cases were attributable to allopurinol and sulfasalazine. The majority of events occurred in the community, with a few cases occurring in a secondary-care setting after the patient had been admitted with another complaint.

Understanding of Stevens-Johnson Syndrome and Toxic Epidermal Necrolysis

Survivors had a good knowledge and understanding of the condition. All were aware that their condition was drug-related and all but one knew the specific drug implicated. Most (11/14) survivors knew that the ADR was very rare; they recall either being told this directly by healthcare professionals caring for them at the time of the event or deducing this from the fact that they were treated as a 'novelty' while in hospital.

Most were also aware that it was potentially fatal (13/14) and that treatments were limited and largely conservative. Survivors and their relatives, however, expressed surprise at the seriousness of the reaction. Before the ADR occurred, they were

Understanding of SJS/TEN
Awareness of:
- drug cause
- name of condition
- rarity
- seriousness and potential lethality
- 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 condition
- circumstances leading to ADR
- symptoms and initial presentation
- 'confused for another condition'
- reaction of prescribing doctor
- support and communication
- healthcare professionals' awareness of SJS/TEN

Impact of ADR on current life
- fear of/avoidance of medicines
- views towards culprit drug
- views on safety of medicines in general
- irrational fears
- trust in healthcare professionals
- precautions
- long-term physical and psychological effects (e.g. scarring)

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. Themes and subthemes identified through interviews with survivors. **ADR** = adverse drug reaction; **SJS** = Stevens-Johnson syndrome; **TEN** = Toxic Epidermal Necrolysis.

not aware that such serious reactions could occur as a result of taking medications; this is illustrated by the comments made by patient 7 below.

Patient 7 (21-year-old male): "I didn't know people could be ill like that. Being fourteen, I didn't know that … well fourteen to fifteen, I just didn't … (long pause)."

Interviewer: "You didn't think it could happen to someone like you?"

Patient 7: "Yeah, I'm just surprised in a way that allergies of that severity could happen."

Interpretation of Why the ADR Occurred

Survivors held different beliefs regarding the cause of the ADR. Only two survivors believed that the reaction was unavoidable and correctly understood that it could not have been predicted by healthcare professionals, putting it down to 'chance' given its rarity.

The majority, however, believed that the reaction was avoidable. Expressed views of its cause included being given too high a dose of the drug (three survivors), medical staff ignoring existing allergies (three survivors) and failure to monitor blood tests (one survivor). Those with existing allergies, for example, felt that this should have alerted the prescriber that they were 'at risk' and the culprit drug should therefore not have been given to them, as illustrated by the quote below:

Patient 4 (70-year-old female): "Well I felt bitter that I should not have been given cefalexin, but it was on my notes it said I'm allergic to penicillin … and there is a train of thought that cefalexin is closely related to penicillin, and she [the GP] shouldn't have given me that knowing my history, all my notes say no penicillin …. I feel she [the GP] should have looked it up on the Internet, she's got the means, she should have inquired rather than handing out willy-nilly …"

One survivor believed that the drug prescribed was 'unnecessary' for the condition he presented with and hence the reaction could have been avoided. Those who believed that the reaction was avoidable also expressed less trust in healthcare professionals.

Other quotes illustrating survivors' interpretations of why the ADR occurred can be seen below.

'A Fluke'

Patient 8 (82-year-old male): "… Allopurinol …, I mean, it's a standard gout cure I understand … but it went the wrong way … I mean I've no worry about the way the GP dealt with it, so it was a perfectly proper thing to do. It's just a fluke that it hits one in a million."

Ignoring Existing Allergies

Patient 6 (66-year-old female): "I have a history of allergy and I have had two very serious reactions, one when I was 29 and the other about 20 years ago and I had warned the hospital that I was allergic to penicillin and anything associated, but it's a bit of a factory there and everybody gets cephalosporin, I don't think anybody really questioned the fact that there was a relationship between cephalosporin and penicillin … I did make a point of saying to Dr D. I am allergic to penicillin when he came to do the pre-op visit. I don't think he took sufficient notice of that …"

Too High a Dose

Patient 12 (54-year-old male): "I reckon, it's a dreadful thing to say, I reckon my GP had taken his eye off the ball when it came to my blood tests, maybe the doses I was on was too much for me, maybe something a bit more modest would have been a bit more appropriate for me, I mean who knows …"

Patient 2 (44-year-old female): "But the epileptic nurse came by, she did say, ooh this seems a high dose for someone who's only had one fit! … my lips was really sore, they was like all gone black, it was like a crust, it was terrible… but um, perhaps if it had been a lower dose, perhaps it might not have happened."

Experiences of the Condition

Survivors vividly recalled how they first presented with SJS or TEN and the initial symptoms they experienced. The majority of survivors recalled experiencing 'lip swelling', 'blisters' or 'ulcers' affecting the skin and oral mucous membranes, with extensive 'shedding of their skin' and severe pain as a result:

Patient 2 (44-year-old female): "… and they started me on some epileptic tablets which were called lamotrigine … and the tenth day, all my eyes swelled and my lips … it was like blisters, constant diarrhoea really, and severe pain going to the toilet, and generally in a lot of pain, because it was like my skin coming off my body really."

Several expressed surprise at the perceived lack of awareness of SJS and TEN amongst healthcare professionals. Some patients recalled that their signs and symptoms were initially confused for other conditions, including chicken pox, oral thrush, *Herpes simplex* infections and viral upper respiratory tract infections, by both themselves and healthcare professionals:

Patient 1 (75-year-old female): "Well, I'd never heard of it, and when the doctors themselves didn't know anything about it, it was all a bit scary …"

Interviewer: "Do you find it surprising that some people [doctors] didn't know what it was?"

Patient 1: "I am surprised about it, because as I say, I'm not the only one and if they [the doctors] don't know, how do they get on?"

The majority of survivors (11/14) were seriously ill with the condition, and around half spent time in an intensive care unit after admission to hospital.

Support and Communication During the Event

Most patients felt well supported both by their GPs and, in particular, by the healthcare staff caring for them during their admission. They recall positive experiences of the medical and nursing care they received and felt that they were given adequate information about the condition, treatment and prognosis.

Survivors who were managed in specialist dermatology centres or burns units felt better supported and managed than those who were not. Those initially managed in non-specialist centres describe feeling under-supported, primarily, they believe, because the hospital lacked the facilities and experience to care for them.

The husband of one survivor, initially managed in a non-specialist centre, contacted the manufacturer of the implicated drug directly for more information as he felt he lacked information at the time of the event. Another survivor said that that the healthcare professionals caring for her could have communicated better, and that she was not allowed to be involved sufficiently in decisions regarding her care. She also felt that the staff were 'overwhelmed' by the severity of her condition and that although they could do little to treat it, they were not honest and open with her about this. These perceptions have damaged the trust and confidence that she now has in the healthcare system many years later:

Patient 14 (48-year-old female): "I did not have any answers whatsoever. Nobody would give me an answer. 'Oh I'll get back to you on that one.' And I didn't have any answers, and yeah, thinking about now, after I'd got through, they didn't know, and they didn't want to admit to not knowing, but I would have had more faith in them if they would admit it … I was asking 101 questions, it would have been nice for them to say 'look, I don't know', but they wouldn't."

Regardless of where they were managed, the majority of survivors and their families relied heavily on Internet sources for more information at the time of the event, with a few contacting patient support groups set up for sufferers of SJS and TEN.

Impact of ADR on Current Life and Views towards Medicines

Fear of or Avoidance of Medicines

The majority of survivors were currently fearful of or avoided taking medicines altogether. Some also expressed a marked fear of becoming ill enough to necessitate their use, implying that they fear that taking any medicine may lead to a similar adverse event.

One survivor, for example, admitted that she will avoid going to see her general practitioner (GP) if she had an infection of any kind, to avoid being prescribed antibiotics.

Patient 1 (75-year-old female): "But the only thing now is, it's made me so scared of taking pills…. I won't go to the doctors if I can help it now … um, you know if you got infections or any thing like that, I won't go, and if I had to go, was forced to go, he gives me tablets, I ask him … I must be the worst person, the worst nightmare they've had! [smiles] … I ask him, then I ask the chemist [laughs], then I think, I'm not taking them! Just in case, you know? It's frightening …"

Another survivor who had developed TEN after taking lamotrigine for newly diagnosed epilepsy, refused to take any antiepileptics after the reaction for a number of years, as she was too frightened to do so, and suffered from at least two serious epileptic fits as a result. She described how her fear also extends to her children when they are ill and require medicines.

Patient 2 (44-year-old female): "… what I found that happened when I came out of hospital, if I had a headache or anything, I was too scared to take any tablets, with C**** [patient 2's son], when he was 3 or 4, if he had a temperature … any other time, I'd just have the Calpol®, but I keep reading the instructions over and over again [laughs] … the one particular night, he did have a sickness bug, I felt as though my legs were shaking because I just couldn't cope … I'd read a Calpol® label, not once but half a dozen times [laughs] … thinking, I hope I'm doing the right thing!"

A few survivors also expressed fears regarding medicated supplements such as 'cough sweets' and certain foods, as illustrated by the quotes below.

Patient 7 (21-year-old male): "… I stopped taking any medication unnecessarily, like paracetamol, penicillin, Nurofen®, and … Lockets® [medicated lozenges], because they're like medicated inside aren't they … and, so I stopped taking all that kind of stuff … and I get really bad migraines as well, that will actually make me throw up, but I still don't take Nurofen® … because of the chance …"

Patient 1 (75-year-old female): "I think it's just made me aware of everything really … um, if er, if new sweets have come on [to the market] or anything … from different foods, you think, knowing that it's stupid! But it does … you think about it!"

Interviewer: "So if you're taking or eating new foods, you worry about it?"

Patient 1: "That's right; it goes through your mind, and I think, God, you're so stupid thinking this, when it's a medicine that's caused it, why should the food cause it? It's just psychological really."

Views Towards Culprit Drug

Interestingly, survivors did not appear to have negative views regarding the safety of the culprit drug in general, despite having had a serious reaction to the drug themselves. They are aware that although taking the culprit drug is life-threatening for them, this is not necessarily the case for others, including family members. They believe that the reaction is specific to themselves and their individual circumstances.

Views on the Safety of Medicines in General

The majority of survivors indicated that their views on the safety of medicines in general have not changed since the reaction, despite a change in their own medication-taking behaviour. They are aware that all medicines are associated with benefits and harms, and these have to be taken into account when deciding to take medications, as shown in the quotes below.

Views on using or prescribing medicines only when they are necessary were also discussed by survivors, including avoiding the over-reliance on or over-use of medicines.

Patient 14 (48-year-old female): "They're good as long as you understand the side effects of it. As long as you consciously understand the side effects of them, and again it's down to the individual on whether you want to, I want to … I need to know the worse case scenario so I can make my decision, consciously, because I've got to live with it."

Patient 10 (74-year-old male): "I suppose it depends how many … if you're taking medicines all the time, but suppose sometimes you've got to take it haven't you? As I said at the beginning you do take that risk but if you're taking it for a reason … like at the time I needed that, so that's why I took it …."

Patient 4 (70-year-old female): "Well … in general they're a good thing if they are not abused because there are a lot of patients with illnesses who are kept alive thanks to the medication, they've got to be used with common sense not just dished out willy-nilly …"

Trust in Healthcare Professionals

For some, the experience of a life-threatening reaction to a drug prescribed by a healthcare professional has diminished their trust in healthcare professionals, and advice given to them regarding treatment. A number of survivors described having less trust or 'blind faith' in what they were told by healthcare professionals since the reaction; this was particularly true of those who believed the reaction could have been avoided if the healthcare professional prescribing the drug had acted differently.

Patient 1 (75-year-old female): "… the only thing I feel is, you're scared … well I am, of going to the doctors, and he tells me you've nothing to worry about, and all this and that, but I'm still nervous of taking anything … he gives me antibiotics and he says you 'should' be alright with it, you should, but I said to him, I can't depend on his 'you should', I've got to be certain, if I'm not sure, I just won't take them."

Patient 3 (65-year-old male): "… you see that the public have got a blind faith in the medical world and I'm not so blind now, I'm more challenging …"

Patient 14 (48-year-old female): "I'm reading and since that happened and any medication I take, I'm reading everything before I'm taking it. Whereas previously, previously I was of the school of thought I use to think 'oh the doctor knows what he's talking about'. Now I'm going, 'they ain't got a clue, they can't be …' and that's the impression it's left on me."

Physical and Psychological Sequelae

The main long-term physical complication was cutaneous scarring, affecting survivors both physically and psychologically. Survivors discussed how scarring after the event has, for example, made them less confident, and reminds them of their traumatic experience.

Interviewer: “You mention your skin will never be the same. Has that changed the way you have to behave or live your life?”

Patient 11 (65-year-old female): “Yes, apart from what I wear, I’ve got to sort of think, I can stand that … sleeves, I keep wearing. My legs are a mess; I don’t want to wear …” [struggles to speak, becomes tearful].

One survivor also appeared to exhibit symptoms of post-traumatic stress disorder.

Interviewer: “Do you think it has affected your life psychologically at all?”

Patient 13 (41-year-old male): “Yes … being depressed, yes, because as I said I get flashbacks, your memory goes but you remember certain things like when I’m having a shower or taking my top off or look in the mirror it all comes back again.”

Interviewer: “You remember the events again?”

Patient 13: “Yes because I’m scarred in my mind as well as scarred on my body … I have flashbacks to my illness … the doctors were great and the hospital was great … but what let me down was the aftercare because ok, I got home and had to go back for check ups, but I said what about my scars? And the doctor was great he said you’re a big strong lad, you’ll be able to cope, but really I don’t.”

‘Hindsight’

None of the survivors recalled being warned that SJS or TEN was a possible adverse effect prior to taking the drug. Survivors were rather philosophical, however, when asked whether they felt that they should have been warned, bearing in mind that the ADR was rare. They indicated awareness that many ADRs affect a minority of people. Interestingly, many stated that they would still have taken the implicated drug even if they had been warned, as all medicines are associated with a degree of risk.

Discussion

Survivors of drug-induced SJS and TEN generally had a good knowledge of the condition. There are only rare circumstances in which the risk of SJS and TEN can be determined prior to treatment; for example, the increased incidence of carbamazepine-induced SJS in individuals of Han Chinese ethnicity with the human leukocyte antigen *HLA–B*1502* genotype.[7] None, however, was relevant to our cohort. Nonetheless, patients formed their own and varied views of the cause of their ADR.

These beliefs have influenced their current views and attitudes towards medicines and their trust in healthcare professionals. Those who believed that the condition could have been avoided expressed more negative views on the safety of medicines and less trust in healthcare professionals.

The experience of a serious ADR had a profound impact on their current medication-taking behaviour, with many survivors avoiding medicines altogether or avoiding seeking medical attention when ill, regardless of the impact on their health. Some also had unsubstantiated fears, for example, of food supplements or medicated lozenges, possibly related to a lack of confidence in their ability to avoid a recurrence of the reaction.

Our study therefore highlights that clear communication with patients at the onset of life-threatening ADRs may be important, particularly those that could not have been reasonably predicted, such as SJS and TEN.

Patient education after the event may also be valuable. It would be important, for example, to explain to patients that those experiencing idiosyncratic ADRs such as SJS and TEN, are not more pre-disposed to experiencing other unrelated ADRs as far as we are aware; this might be helpful in reducing avoidance behaviour related to necessary medications in the future.

On the basis of this study, it is also apparent that after a serious ADR, patients’ views on medicines and healthcare professionals were more positive if they perceived they had been given clear and honest information at the time of their illness.

Given the rarity of the ADR, it is unsurprising that many healthcare professionals were perceived by patients to know little about it, but interviews with survivors indicate that regardless of this, survivors preferred that healthcare professionals were open and honest about their limited knowledge and the lack of definitive treatments available, and were keen to remain fully informed regarding progress in management and prognosis.

In our survey, survivors who were managed in specialist dermatology centres or burns units felt better supported and managed than those who were managed in non-specialist centres, implying that all patients with SJS and TEN should be managed in specialist centres where the expertise and facilities exist to deal with the condition.

These findings support existing objective evidence that early referral and management of SJS and TEN in a specialist unit leads to better outcomes, with reduced mortality and length of hospitalization.[8,9]

Based on our findings, we hypothesize that psychological support in the aftermath of a life-threatening ADR may be beneficial, and this should be explored. This might include support for sequelae such as loss of confidence due to scarring, and symptoms of post-traumatic stress disorder, which are not uncommon when an individual has experienced a life-threatening condition such as serious burn injuries, where skin loss and scarring sustained is similar to that seen in SJS and TEN, or after a critical illness requiring intensive care.[10,11]

Survivors and their families relied heavily on Internet resources, including online SJS and TEN support groups to obtain more information about the condition, and found these useful. Access to the Internet is increasing amongst the general population and, in particular, health concerns are the most common reasons for subscriptions to online services. Internet use, either directly or via friends or family, is widespread in patients experiencing cancer for example, with patients using the Internet to find second opinions and seek support and experiential information from other patients.[12] Social connections enabled by Internet support groups constitute a new forum of social support, that has largely unstudied potential.[13] The study of online support groups for those who have experienced ADRs such as SJS and TEN would therefore be a potential area for further research.

Finally, survivors are aware that many ADRs, including SJS and TEN, affect a very small minority of people, and believe that they still would have decided to take the drug even if they had been warned of the potential of developing the reaction. This supports the view that it may not always be necessary to warn patients of very rare ADRs, even if they are serious.

Limitations

Because of the rarity of the condition and its high mortality rate, it was not feasible to undertake formal purposive sampling, and hence our cohort may not be representative. Also, our findings cannot be generalized because of the qualitative approach used, although this is accepted as the aim of our study is to generate hypotheses and ideas, rather than test them.

In addition, the views of survivors of life-threatening ADRs such as SJS and TEN may differ from the views of those of other serious or potentially fatal ADRs. It may not be appropriate therefore to extrapolate out findings to patients who have experienced other serious ADRs.

Conclusions

Life-threatening ADRs such as SJS and TEN may continue to affect patients' lives long after the event. Patients' beliefs regarding the cause of the ADR differed, and may have influenced their trust in healthcare professionals and in medicines in general; clear communication during the acute phase of a serious ADR may therefore be important.

Our findings may be used as a framework for the understanding of other serious ADRs, and to improve the future management of patients with the condition.

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