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The Emotional Consequences of Corticosteroid Use in Hematology: Preliminary Findings

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This article presents the findings from a pilot study conducted as a first step in understanding the myriad psychological and psychiatric sequelae stemming from the use of steroids for hematology patients. Descriptions of the side effects experienced by 10 hematology patients undergoing steroid treatment are documented and discussed. Steroid usage can have a range of physical and emotional side effects on patients, including hematology patients. The insights are a serious reminder to all who care for hematology patients that the psychological and psychiatric side effects of steroids need to be taken seriously.

KEYWORDS *steroids, hematology, psychological, psychiatric, emotional, side effects*

INTRODUCTION

Steroids are used in treatment regimens for diagnostic groups ranging from asthma (Koh et al., 2002), systemic lupus erythematosus (Chau & Mok, 2003; Mok, Ying, Mak, To, & Szeto, 2006), myocardial infarction (Alisky, 2006), orthognathic surgery (Fleming & Flood, 2005), autoimmune disorders (Weiss, Dyrud, House, & Beresford, 2005), severe acute respiratory syndrome

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(Sheng, Cheng, Lau, Li, & Chan, 2005), dementia (Sacks & Shulman, 2005), Churg-Strauss syndrome (Ismail & Lyster, 2002), and inflammatory bowel disease (Buchman, 2001). The potential for steroid treatments to cause severe emotional and even psychiatric disturbances, ranging from mood disturbances to (florid) psychosis, are well documented (Hong, Cho, Kang, Chung, & Chung, 2006; Ruiz, Dabi, Matusevich, & Finkelsztejn, 2002). From the literature, we know that common side effects of steroid treatments can include symptoms of insomnia, euphoric moods, mood disorders (with depressive, manic, and mixed features), mania, visual hallucinations (Hong et al., 2006; Nabar, Sand, & Heigl, 1996; Patten & Neutel, 2000), severe depression, irritability, violence (Beshay & Pumariaga, 1998), neurophysical deficits, and psychotic states (Naber et al., 1996). However, there is a dearth of literature documenting the emotional and psychiatric side effects of steroid use for hematology patients (McGrath, Pun, James, & Holewa, 2007) and a related lack of comprehensive recommendations for the management, education, and support of patients undergoing steroid treatment and their families. The psychosocial research conducted to date is limited to three case studies (Ducore, Waller, Emslie, & Bertolone, 1983; Nakame, Yamane, & Aoyama, 2002; Sutor, Wells, & Rummans, 1996) and one exploratory empirical study of paediatric leukaemia patients (McGrath & Pitcher, 2002).

The findings presented in this article are from a pilot study conducted as a first step in understanding the myriad psychological and psychiatric sequelae stemming from the use of steroids for hematology patients. Descriptions of the side effects experienced by 10 hematology patients undergoing steroid treatment are documented and discussed. Further published findings from the study explore related issues such as coping strategies (McGrath, Patton, & Leahy, 2009) and the fact that psychological and psychiatric disturbances associated with corticosteroid use are directly related to the drugs used and not a symptom of the individual's prior mental health (McGrath, Patton, & James, 2009b). It is hoped and expected that the results from the study will be considered a start to putting this important topic on the hematology research agenda. The insights in this article provide much-needed information for patients, their families, and the health professionals who care for them about side effects experienced during steroid administration and withdrawal. This is especially important as further findings from the study indicate that the majority of the participants reported that they were not given adequate information on the psychological and psychiatric impacts of steroids nor about the reasons for steroid treatment.

Steroids in Hematology

Steroids are an important component of treatment in many hematological diseases (de Fraine, Diekman, & Gaynor, 1986). As single agents they are useful

in suppressing the immune response in disorders such as immune thrombocytopenia (Gernsheimer, Stratton, Ballem, & Slichter, 1989) and autoimmune haemolytic anaemia (Meyer, Stahl, Beckhove, Huhn, & Salama, 1997). They are also useful in managing some of the local and systemic effects of malignant hematological disease (myeloma, lymphoma, leukemia) including pain, depression, hypercalcaemia, fatigue, nausea, and anorexia (Hanks, Trueman, & Twycross, 1997). In high doses steroids have cytotoxic effects on cells of the lymphoid lineage and are thus very useful when combined with standard chemotherapeutic agents such as cyclophosphamide and adriamycin in the management of non-Hodgkin's lymphoma and acute lymphoblastic leukemia (Rowe, Buck, & Burnett, 2005). High-dose dexamethasone and other steroids are valuable as single agents in the management and palliation of multiple myeloma and other hematological malignancies (Facon, Mary, & Pegourie, 2005). However long-term use of low- and high-dose steroids is associated with a wide range of side effects including immunosuppression with predisposition to infection, weight gain, diabetes, cataracts, osteoporosis, and avascular necrosis of the hips (Saag, Koehnke, & Caldwell, 1994).

METHOD

Given the scant existing research in this area a pilot study was conducted. As a preliminary study, open-ended, exploratory, qualitative methodologies are appropriate (Holloway, 2008; Sirois, 2003). A qualitative approach is also important in ensuring that the outcomes of the research are informed and driven by the voice of the consumer (Liamputtong, 2009). The methodological framework adopted was one of descriptive phenomenology, which is interested in the "lived experience" of people's conscious experience of their life world, that is, their everyday life and social action (Merriam, 2009; Schram, 2003). A phenomenological approach is particularly suited to exploring affective or emotional human experiences (Merriam, 2009) and is thus directly relevant to a study of the psychological and psychiatric experience of steroid use in hematology treatments from the patients' perspectives. This methodological approach is deemed particularly appropriate where, as here, there is scant existing literature surrounding the issue under consideration (Polit & Hungler, 1995). As inductive, phenomenological, qualitative work, the reporting of findings is based on a commitment to the participants' point of view with the researcher playing the role of coparticipant in the discovery and understanding of what the realities are of the phenomena studied (Daly, 2007; Liamputtong, 2009).

The research was conducted by a senior research fellow at the Central Queensland University (University) in association with a liaison psychiatrist and hematologist at Princess Alexandra Hospital, Brisbane,

Queensland, and a hematologist at Fremantle Hospital, Perth, Western Australia. Ethical consent to conduct the study was obtained from the University Human Research Ethics Committee and the ethics committees of both hospitals participating in the study. Participants were verbally informed of their rights in research, and written consent was obtained for participation in the research.

Target Group

The findings presented in this article are from the interviews with 10 patients undergoing hematology treatments in two major public hospitals in two different states in Australia (Princess Alexandra Hospital, Brisbane, Queensland and Fremantle Hospital, Fremantle, Western Australia). The criteria for identifying patients who had experienced problems with steroids was as follows:

1. The recruitment strategy relied on the clinical assessment of the treating hematologist. The hematologist's clinical assessment that the patient was experiencing difficulties with steroids was based on their trained clinical knowledge of symptoms (physical and emotional) associated with steroid use.
2. For a patient to be referred there needed to be evidence that the negative symptoms began at the time of steroid use and ceased after completion of steroids.
3. The symptoms had to be considered by the hematologist to be seriously affecting the patient's emotional well-being.
4. The psychiatrist involved in the study was available to the hematologist for clarification of psychological and psychiatric criteria based on his professional clinical knowledge/experience and understanding of psychiatric *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.) (DSM-IV; American Psychiatric Association, 1994) classifications.
5. The patient interviewed was deemed sufficiently recovered from the negative sequelae of steroids to be able to give full, rational, informed consent.

A point of limitation in terms of the participants referred by the clinicians to the study, however, is that they were predominantly diagnosed with myeloma. The findings from the current study indicate that the individuals with myeloma gain disease-specific benefits from steroid use in terms of the pleasure gained from increased ease of mobility. This difference is not documented in the literature, not does it represent a statement of clinical experience of the participants' treating professional, but rather is a direct artifact of the differences in participants' statements from the two different diagnostic groups represented in the study, multiple myeloma and acute

immune thrombocytopenia purpura (ITP). It is important to note, however, that this was the only steroid-related difference recorded in the findings between these two diagnostic groups.

Thus, a recommendations from the current study is the need for further research to include a broader range of hematological diagnostic groups to explore whether other groups report greater difficulties coping with steroids without this disease-specific positive.

Demographics

As detailed in Table 1, ten patients were interviewed for the study between January and June 2007. Eight patients had a diagnosis of multiple myeloma and two had a diagnosis of acute ITP. At the time of interview, the length of time since diagnosis ranged from 2 months to 6 years. The steroids taken by the patients during treatment were dexamethasone and prednisolone.

Seven of the participants were married. Eight of the participants had children, ranging in age from preschoolers to adults, and some had grandchildren. As indicated in the findings, all 10 patients described feeling well supported, either by partners, adult children, parents, friends, or siblings.

Interviews

The data collection was conducted through an iterative, phenomenological, qualitative research methodology using open-ended interviews conducted at the time and location of the participant's choice. The interviews were conducted by an experienced qualitative researcher with a background in haematology employed by the University and thus independent of the hospitals. The interviews were informed by the principles of "phenomenological reflection" as outlined in the work of Van Manen (1990). The line of questioning included the techniques of probing, paraphrasing, and silence to explore each participant's experience.

TABLE 1 Demographics of Participants

Age	Gender	Condition	Date of Diagnosis
23	F	Immune thrombocytopenia purpura	2004
42	F	Multiple myeloma	2000
43	F	Multiple myeloma	2003
50	M	Multiple myeloma	2006
56	F	Multiple myeloma	2004
56	F	Multiple myeloma	2004
61	M	Immune thrombocytopenia purpura	2006
67	M	Multiple myeloma	2003
69	F	Multiple myeloma	2005
72	M	Multiple myeloma	2002

The interviews lasted for approximately 1 hour and were audio-recorded. The interviews were transcribed verbatim by a research assistant independent of the hospitals.

Analysis

The language texts were then entered into the QSR NUD*IST (N6) computer program and analyzed thematically. All of the participants' comments were coded into "free nodes" that are category files that have not been pre-organized but are "freely" created from the data. The coding was established by an experienced qualitative researcher and completed by a research assistant with extensive experience coding qualitative data. There was complete agreement on the coding and emergent themes. The list of codes was then transported to a Word computer program (Word XP) and organized under thematic headings.

The findings in this article are from the following free nodes: F4 (Sleep disturbance), F7 ("High" disturbing), F9 (Depression), F23 (Agitation and irritability), F26 (Hyperactivity), F29 (Mind wandering/forgetfulness), F48 (Anxiety and panic), F53 (Language difficulties), F61 (Loss of self), F77 (Disconnected from reality), F79 (hallucinations), F90 (Psychosis), F6 (Benefits of "High"), and a summary of the free nodes on the physical side effects of steroids.

RESULTS

The focus of this article is on describing the experience associated with the psychological and psychiatric sequelae of steroid use in hematology as this topic is not addressed in the literature. However, it should be noted that the participants also spoke about the emotional distress of coping with the physical side effects of steroid use.

Following is a list of physical symptoms mentioned by the participants:

- Weight gain and excessive hunger and craving for "junk food"
- Fluid retention, swollen face
- Reflux needing medication
- Cramping of fingers
- Dizziness and light-headedness
- Visual side effects such as fuzziness in vision, development of cataracts
- Skin problems (flaking and bruising) and skin sensitivity to sun.

For all of the participants the physical side effects were described as distressing and challenging. The participants made statements to indicate that from their perspective the physical side effects exacerbated the psychological difficulties associated with the steroid drugs.

A caveat to the following discussion is that participants reported that steroids have different effects on different people ranging from manageable symptoms to florid psychotic episodes. As one participant summed up: "Because everybody's side effects are different ... it does different things to different people."

THE STEROID "HIGH"

Hyperactivity

One of the dominant emotional states associated with steroids noted by the participants was a sense of hyperactivity: "very hyper. Um, quite hyper!"

The hyperactive state is reported to start immediately and to last while the individual is on the steroids: "It's an instant change from what we've been up to that stage ... And yes you do feel like you've got to get up and go."

The changed behaviour is obvious to the patient and their family, as the following statement exemplifies: "The day I took them I was high. And then the days when I was taking them my daughter would say 'Oh you've taken your tablets again haven't you?' Because I wouldn't shut up. I'd talk nonstop."

The hyperactive state would force the person to engage in excessive behaviors, as the following vignette illustrates: "I'd walk, then I'd walk around the property, or I'd go outside and I'd walk, and walk ... And how can I put it ... the dexamethasone ... I knew it wasn't me, I said: 'it's the drugs that are doing that'."

Positives for Myeloma Patients

An exception to the following discussion that outlines the emotional difficulties associated with the hyperactive aroused state caused by steroids was noted by participants diagnosed with myeloma. For some of those individuals with myeloma, the relief that steroids provide was welcome: "Found the steroids a positive experience as they gave energy when very tired from the effects of myeloma."

However, even this high was, at times, problematic, as the following statement illustrates: "I felt as though I don't know what to do with myself, sort of thing. How can I explain it? I think like the world's come to an end and I don't know what to do with myself."

Although the steroid experience may be positive for the person with myeloma, it is important to note that close family may have to deal with associated negative consequences such as mood swings and temperamental behaviors, as the following statement reveals: "My wife did tell me that

my temperament changed—like apparently mood swings and that—but I certainly felt good.”

Agitation and Irritability

Accompanying the sense of hyperactivity, participants reported that there is an associated sense of agitation and irritability, as can be seen by the following statement: “I would, oh, just get agitated.”

Others indicated that the agitated feelings translated into an increased sense of aggressiveness and lack of patience:

- “Come over a bit more aggressive. No patience at all.”
- “Makes me . . . I just . . . I get wild angry at times.”
- “Sometimes you get the [...]. You go and ‘just leave me alone’ sort of thing.”
- “And yes, I think I tried not to do. But I was a bit ‘bitey’ with everybody.”

The important issue is that steroids can generate strong agitated and aggressive feelings that can lead to serious problems for some people: “I have to be a bit careful. I think if you were a young person and you were on it, you’d be in trouble. Yes, because it takes a great deal of self control to deal with those difficult feelings.”

Individuals on steroids are not always aware that family members have to deal with the aggressiveness and mood swings that result from these drugs, as can be seen by the following statement: “They weren’t as noticeable with me as much as with her [wife]—because I’d get snappy apparently. But I am high strung anyway so that sort of added to that.”

Anxiety and Panic

Part of, or paralleling, the hyperactivity is a sense of anxiety and panic, described in the following terms by participants: “The anxiety and the panicky and the dizziness” and “I’d get so . . . um, sort of anxiety, panic type of thing.”

One participant described a type of claustrophobic panic attack: “A little bit of a panic attack. Like I’d get into the shops and I’d think ‘oh I don’t want to be in here’. You know especially in the buildings so long as I was outside I was fine.”

Sleep Disturbances

All of the participants spoke at length about their problems with sleep disturbances while on steroids. The following range of descriptions highlights the seriousness of the sleep disturbances:

- “I couldn’t sleep—I used to sit on the back steps all night, just sit there.”

- “I was really going off my head because I’d been awake sometimes for a week. And it didn’t matter what I did. If I closed or covered my eyes with something, it didn’t matter.”
- “Yes for a few months you were getting very overtired.”

Even those who had previously slept well at night found that on steroids they could only sleep for a couple of hours and mostly not until the early hours of the morning: “I just sit up ‘til 4 o’clock [a.m.]. And then go to bed at 4 o’clock.”

As will be reported in full elsewhere, even the use of sleeping tablets was not effective in reducing this problem. The overtiredness made normal life activities an enormous effort: “It was like a cloud—It was an effort to go anywhere.”

The overtiredness and exhaustion, for some, had the potential to create a paranoid condition as can be seen by the following example: “And she [psychiatrist] said lack of sleep, that’s why I was getting this paranoia. And she prescribed these pills.”

Cognitive Problems: Forgetfulness, Wandering Mind, Language Problems

For some of the participants forgetfulness and an inability to focus the mind were cognitive problems associated with steroids, as the following examples demonstrate: “I have a very bad short term memory” and “I’ve been getting . . . My memory’s pretty stuffed too.”

In some cases the forgetfulness was only minor: “I’ve lost track of a couple of things . . . you know, your mind might wander a little bit at times.” For others it was a significant difficulty that interfered with work:

I would do all the accounts for it. Some days I was a bit sassy with them and I’d forget where I’d put them. And things like that. But I would try and leave it till I wasn’t on the drugs. The days when I wasn’t on the dexamethasone.

Language can also be affected, and some individuals reported difficulties remembering even ordinary words, as the following vignette demonstrates: “And the worst part I found, um, was words. I had trouble with words. Can’t think of words. Like you’ll be talking and quickly . . . um . . . like the kettle will be sitting on the stove and you’ll be looking at it and you’ll think ‘what is that?’”

Hallucinations

Hallucinations can be another distressing psychological sequelae, as the following statements from different participants indicate: “I’d end up

hallucinating” and “Oh yes, I was hallucinating because I saw [name of relative] who was killed in a car crash. And he was talking to me.”

One participant provided a description of a hallucination experience caused by steroids, as follows:

Oh look, there was one I remember, it was just going all night long. But one I remember, someone had put a bag over me and these metal-like ants, their claws crawling all over the back of me. And I was just screaming out for someone to help me, and no one was there to help me. Eventually woke up from that. You felt like you were suffocated. I must have been screaming into the pillow. And from that then you go into another one.

As the nightmares are in the mind the screams are not heard and those close are not aware of the need to offer assistance, as can be seen by the following example: “At home, it always happened when I was at home. My husband was here but he didn’t hear me screaming. He didn’t know I was having these nightmares.”

High steroid dose was mentioned as a factor causing the hallucinations: “Just on the high dose. Told it was the steroids. I wondered what on earth was going on.”

Depression

There were some participants who described a depressed emotional state associated with steroid use, as can be seen by the following statement: “The depression side of it. Because I’m a bubbly and vibrant sort of person. The drug dragged me right down even harder. I tried to sort of not let it affect me, but it did.”

For the women interviewed, the negative changes in body image were a significant contributor to a depressed emotional state. The most difficult change to deal with caused by the steroids was reported to be weight gain: “And the weight is the one thing that really has got me down. I can’t wear the clothing that I like to wear. It’s what I found harder than. It’s that I find tough.”

Another woman explained that there was a depression caused by losing a positive sense of self: “Oh, I sort of look at myself and I think: ‘Oh God I’m ugly.’ With this great big ... I reckon I look like a Brahman bull. With my ‘no chin’ and big in the face, big dinner plate face. And I think: ‘Oh it’d be nice to look decent again’.”

In summary, it is a sense of alienation from the earlier self: “I mean, I look in the mirror and think: ‘Oh who’s that?’ It’s silly but that’s the one thing that you’re actually left with after you’ve gone through a lot of the treatment—It’s not you looking back at you.”

Psychotic Behavior

One of the participants in this sample had a series of psychotic episodes when on steroids: "They gave me psychosis, love. I went quite loopy [laughs]. A horrible experience—you can say that again. When I was in hospital I was three different people on the steroids."

A full description of the psychosis will not be given as it might identify the person. It is important to note, however, that the person was not informed that psychotic episodes could be a side effect of steroid use and was unaware as to what was causing the aberrant behavior at first. The individual was referred to a psychiatrist and prescribed medication for the psychotic episode that lasted for months. At the time of writing, the person remained under psychiatric care because of the steroid-related psychosis. As will be reported elsewhere, it was common for those interviewed not to be told of the possibility of a psychotic reaction to steroids.

Long-Term Use

A particularly sobering fact about these psychological and psychiatric side effects is that some individuals are on steroids such as prednisone for long periods of time or, as one person explained, for the rest of their life: "I'm on it for the rest of my life at this stage, on prednisolone for the rest of my life. And I know I wish that I could stop taking it."

DISCUSSION

The findings indicate that there are serious psychological and psychiatric consequences of steroid use in hematological treatments. The insights from the study are important as steroid use is central to treatments for hematological malignancies (Facon et al., 2005; Rowe et al., 2005). As discussed in full elsewhere in further findings from the study (McGrath, Patton, & James, 2009) these emotional sequelae can affect any hematology patient; the psychological and psychiatric side effects do not appear to be caused by previous mental health problems. As noted by Patten and Neutel (2000), education and support about the side effects of steroids are crucial, but as yet neglected, dimensions of care. The need for patient education about the emotional and psychiatric side effects of steroid use is essential in view of the fact that further findings from the current study indicate that it is the exception rather than the norm for individuals to be fully informed about any of the side effects. Patients and their family members should be informed about the possible side effects and referred to a social worker or other mental health professional in order to learn the signs of a psychotic reaction and to prepare in advance how to cope.

For the participants in the current study, the emotional difficulties were exacerbated by accompanying physical side effects such as weight gain, excessive hunger, fluid retention, swelling of the face, reflux, cramping, dizziness, and light-headedness, visual side effects and skin problems. In addition, many experienced significant cognitive difficulties such as forgetfulness, wandering mind, and language problems.

A constant reported by all participants was the hyperactive emotional state that dominates the steroid experience. The hyperactivity starts immediately with steroid administration and continues while the individual is taking the drug(s). The change in behavior is obvious to the patients and their family, usually expressed as a hyperactive/hyperalert emotional state where the individual engages in excessive behaviors such as constant talking or activity. The only point of difference between the experience of the participants from the two diagnostic groups included in the study is that some of the myeloma patients reported benefits from the increased mobility and energy obtained from the steroid "high." However, even for this group there were problems associated with the unpleasant emotional state, mood swings, and temperamental behaviors. As noted elsewhere (Hong et al., 2006; Patten & Neutel, 2000), euphoria, mood disorders, and even mania can be associated with steroid use.

Agitation or irritability is one of the most important negative sequelae of the hyperactive state caused by steroids. Aggressive feelings combined with a lack of patience are described as central to the steroid experience. Participants in the current study indicated that it takes a great deal of self-control to deal with such difficult feelings and thus it is understandable that problems can easily arise for the vulnerable, who are less able to deal with aggressive emotions. This concern is made worse by the fact that individuals on steroids are not always aware of how aggressive they are being to others. Irritability, aggression, and even violence are reported elsewhere as associated with steroid use in relation to prednisone (Beshay & Pumariega, 1998). Indeed, it is documented that aggression and violence can be serious symptoms associated with steroid overuse in subpopulations such as athletes, bodybuilders, and young people where it is used for gains in strength and muscle mass (Trenton & Currier, 2005). Further emotional states associated with the hyperactivity of the steroid experience from the current study are anxiety and panic.

All of the participants noted the difficulties associated with sleep disturbance and sleep deprivation caused by steroids. Overtiredness has serious impacts on normal life ranging along the continuum from ennui and exhaustion to the more extreme psychiatric condition of paranoia. The findings from the adult data resonate with previous insights from paediatric hematology research on the steroid dexamethasone, where it was found that children were awake all night eating excessively (McGrath & Pitcher, 2002). There is also evidence of sleeplessness being a problem associated with steroid use

in an adult case study of a patient undergoing an allogeneic bone marrow transplant (Nakamae et al., 2002).

For some, the emotional problems created by steroids include psychiatric conditions such as hallucinations, depression, and psychosis. As described by one participant, the hallucinations can be frightening and solitary experiences. The depression caused by steroids contributes to a sense of a loss of the previous self. The body changes caused by steroids, such as weight gain, add to and exacerbate the depressive state. In the current study, the participant who reported experiencing psychosis from steroids remained in this state for many months while on treatment and required ongoing psychiatric care. Although documented as uncommon, psychosis is noted as a complication of steroids in a number of diagnostic conditions other than hematological malignancies such as myocardial infarction, asthma, and Sheehan's syndrome (Alisky, 2006; Hong et al., 2006; Koh et al., 2002). Depression has been reported elsewhere as a serious side effect of steroid administration in a case study of a 15-year-old girl with acute lymphoblastic leukemia, a common hematological malignancy (Sutor et al., 1996). As Twycross (1994) reported, occasionally patients become hypomanic or profoundly depressed, to the point of attempting suicide.

As reported in full elsewhere, the findings from the study indicate that most patients were unaware of the emotional side effects of steroids and had to seek information after suffering the side effects. The sobering facts reported by these participants need to be contextualized within the understanding that many haematology patients will be on steroids for years, and some will be on steroids for the rest of their lives (Saag et al., 1994).

IMPLICATIONS

The insights are a serious reminder to all who care for haematology patients that the psychological and psychiatric side effects of steroids need to be taken seriously. In view of the fact that further findings from the study indicate that the psychosocial sequelae can affect any hematology patient treated with corticosteroids, not just those with a history of mental illness, the findings are relevant to all hematology patients. Patients need information on the emotional and social sequelae of corticosteroids and their experience normalized. This can be achieved by reassurance that health professionals will acknowledge, understand, and respond to difficult side effects such as hyperactivity; excessive behaviors including constant talking or activity; mood swings; irritability; agitation; aggression; anxiety; panic; sleep disturbance; sleep deprivation; exhaustion; cognitive difficulties including forgetfulness, wandering mind, and language problems; physical side effects; and a sense of loss of self. Some patients will need additional support for psychiatric conditions such as paranoia, hallucinations, depression, and psychosis.

Further findings from the study (McGrath, Patton, & Leahy, 2009) outline a number of strategies that the participants from the study reported assisted them to cope with the difficult emotional impact of steroids. The strategies include accepting that corticosteroids are necessary for disease control, knowing that the negative emotional states being experienced are due to the corticosteroids, stoicism, and self-reliance based on a cognitive-rational approach, keeping busy, remaining fit and active, and, for some, using antidepressants to help with mood swings. The participants indicated that for sleep disturbances it was helpful to accept the sleeplessness, engage in distraction, and when possible to have light sleeps. The understanding and support of family and friends is important. However, counselling was not reported as useful. These strategies can be shared with other hematology patients and their families as suggestions for coping.

CONCLUSION

As outlined in the introduction, to date there is a "loud silence:" in the research literature on the psychological and psychiatric sequelae of steroid administration in hematology treatments. The findings presented in this article are a serious reminder to all who care for hematology patients that the side effects of steroids need to be taken seriously. This is an area where more research is needed as it has very important implications not only for patients but also their families. It is the authors' hope and expectation that the evidence presented here will go some way toward putting this issue on the research agenda and will provide insights useful for patients, their families, and health professionals who provide the care.

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