Support for A&E nurses caring for patients with sickle cell disease


Abstract

Aim To investigate the supportive work carried out by a health psychologist working with nurses in an A&E department caring for patients with sickle cell disease, some of whom are known to present with difficult and challenging behaviour.

Method A sample of 21 female nurses who had all taken part in the support group completed questionnaires concerning perceptions of the usefulness of the sessions, attitude changes, degree of the perceived benefit derived, degree of perceived comfort in the group and views about whether the sessions should continue.

Results Most nurses found the support group useful and, since attending the group, many reported more sympathetic attitudes towards sickle cell disease patients. The forum was observed to promote reflection in practice and offered a degree of social support, as well as giving the nurses more confidence in dealing with ‘difficult’ patients generally. Most nurses were happy with the format of the support group.

Conclusion The support group was found to provide the nurses with emotional support as well as boosting their confidence in dealing with this patient group. This will have an impact on the quality of patient care they are able to deliver.

Introduction

Sickle cell disease (SCD) is a term used to describe a group of blood disorders. The main genotypes and disorders include HbSS (sickle cell anaemia), HbSC (HbSC disease) and SB Thal (sickle beta-thalassaemia). SCD is inherited and is one of the most prevalent haemoglobinopathies in Northern Europe (WHO 1985). It primarily affects the Caribbean and African population and also small numbers of people from the Mediterranean and the Middle East. Guy’s and St Thomas’ Hospitals Trust serves a sickle cell population within Lambeth, Southwark and Lewisham and has more than 600 adult patients on its patient register. This population is essentially West African and African-Caribbean in origin, with an age range of 19-79 years.

In SCD an abnormality occurs within the amino acids of the beta chain of haemoglobin, causing distortion of the red blood cells and greatly reduced elasticity under conditions of low oxygen tension. Vaso-occlusion caused by sickled blood cells is responsible for chronic and acute damage to tissues and organs, causing the recurrent and unpredictable pain (Brozovic and Davis 1987) commonly referred to as a painful crisis.

Painful crises are the most frequent manifestations of the illness. In the UK and US, they are usually managed in hospital and account for 90 per cent of all emergency admissions in this group of patients (Davies 1994).

SCD, being present at birth, crosses the developmental life-span, and its impact on the individual can be pervasive, affecting physical and emotional wellbeing. Every aspect of life is affected, with a variety of adverse outcomes, including pain, disability, fear and uncertainty about the future (Thomas et al 1999). This often gives rise to feelings of helplessness and depression, which exacerbate the pain and influence the manner in which it is expressed. SCD poses specific challenges to the patient’s internal resources, which when stretched to the limit result in anxiety and depression, dysfunctional coping and negative thought patterns (Thomas et al 1999).

Effects of sickle cell disease

A considerable amount of psychological research has been conducted with the SCD population, looking at the relative risk of psychological disturbance and the effectiveness of different strategies used to cope with pain. For example, research conducted in the US and UK has found that the vast majority of admissions for painful crises occur in individuals who are poorly adjusted, have high levels of distress and
have developed negative patterns of coping (Gil et al 1992, Thomas et al 1998, 1999). These variables can also be seen to contribute to inadequate pain management, since it is well known that these types of emotional states and styles of coping can intensify pain experience (Gil et al 1992, Melzack and Wall 1988, Thomas et al 1995, Tyrer et al 1989). This poorly adjusted group accounts for a small minority, as most people with SCD are extremely well adjusted and resilient and cope very well in full-time employment.

Some of the patients who present to A&E with pain and emotional distress are often unable to understand why they have to wait to get treatment, and can become verbally abusive and refuse to accept reasonable explanation. Part of the reason for this kind of response is the tremendous fear that patients experience, as many believe that they could die in a sickle cell crisis. This fear is not unfounded, as they have heard of other patients, and in some cases their own siblings, dying unexpectedly following admission for sickle cell crisis. In addition, the hidden nature of the illness makes nursing assessment extremely difficult, as there are no clear and consistent physical indications of a painful crisis.

Some of the patients who present to A&E with pain and emotional distress are often unable to understand why they have to wait to get treatment, and can become verbally abusive and refuse to accept reasonable explanation. Part of the reason for this kind of response is the tremendous fear that patients experience, as many believe that they could die in a sickle cell crisis. This fear is not unfounded, as they have heard of other patients, and in some cases their own siblings, dying unexpectedly following admission for sickle cell crisis. In addition, the hidden nature of the illness makes nursing assessment extremely difficult, as there are no clear and consistent physical indications of a painful crisis.

**Sickle cell patients’ use of A&E**

Guy’s and St Thomas’ Hospitals Trust has a large population of approximately 600 sickle cell patients, and the use of A&E is likely to reflect the population size. An audit conducted for a two-month period (November 25 1996 to January 30 1997) saw a total of 135 episodes of patients presenting with sickle crisis pain. However, these episodes only related to 58 patients, of whom 66 per cent were male and 34 per cent female. In addition to confirming that most sickle cell patients are coping adequately in the community (Thomas et al 1999), these figures suggest an average of 2.3 attendances per patient over this period. Most of these attendances (89 per cent) were categorised as triage two, which meant that they were seen by a casualty officer within 20 minutes of arrival, and most (85 per cent) received parenteral opiate medication within 30 minutes of arrival in A&E. This approach supports patient management regarding analgesia and meets national standards (such as the Manchester Triage System) for triaging patients in pain (BAAEM 1997). Triage two is considered a very speedy response to medication needs and is extremely demanding on the resources of all those involved in providing such care.

Within this pattern of repeated presentation by sickle patients, nurses necessarily develop friendly relationships with them and their families. This is a ‘double-edged sword’, however, as it means that these nurses can also be exposed to abuse from such patients. Such relationships can make it difficult for nurses to assert themselves professionally by challenging abusive behaviour.

Nurses usually have to shoulder the burden of the abuse and demands, and frequent exposure to this kind of stress makes it very hard to remain non-judgemental and empathic. From this perspective, they might begin to view SCD patients as ‘difficult’ (Anionwu 1996). The patients on the other hand might perceive nurses to be uncaring and, in their helplessness, become increasingly more angry and display more intense emotional reactions. These reactions, however, can appear to nurses to be ‘over the top’, thus confirming the staff’s preconceived view of ‘difficult problematic patients’.

**Work and stress**

Stress in the workplace is an ever-growing problem in many organisations, and stress associated with caring within the NHS structure is an everyday occurrence. Health care has undergone a period of rapid change in which employees at all levels are experiencing uncertainty, unpredictability and uncontrollability. It is well known from both animal and human research that each of these states can give rise to immense psychological stress (Katz and Wykes 1985). These problems can be compounded when combined with the staff’s own personal, financial and health concerns outside the organisation. A natural consequence of continued high levels of stress is ‘burnout’. Symptoms of burnout include low job satisfaction, poor performance, lack of ability to empathise with patients, increasing ritualisation of tasks, depersonalisation and labelling of patients, intolerance, avoidance of patients, feelings of inadequacy and an increase in absenteeism (Maslach 1997).

Within the A&E department, nursing staff feel particularly vulnerable because of the added stress associated with having to contend with managing serious injuries of severe trauma victims, sudden death, distressed relatives and violent, aggressive and demanding patients and relatives, in addition to other challenging and difficult behaviour. As a protective strategy, nurses might put psychological distance between themselves and their patients by becoming more detached. According to Maslach (1997), this is particularly true if the patient has a condition that is upsetting or difficult, and in this case the patient is seen not as an individual but as a particular case. As discussed, SCD is considered to be one of the most difficult conditions to manage. Nurses working in the emergency care system...
for only a few years are particularly susceptible to the experience of burnout. This stress, in turn, has a negative impact in terms of decreased job performance, lack of social support to other staff members, low morale, negative work attitudes and loss of concern for clientele (Keller 1990, Walsh et al. 1998). Keller (1990) performed a large-scale study on a sample of emergency nurses using questionnaires designed to measure burnout. Results revealed that 65 per cent of the nurses were experiencing high levels of emotional exhaustion and 77 per cent were experiencing depersonalisation, both of which are indicators of burnout.

In considering the risk factors that can give rise to burnout in nurses, the quantity and quality of contact with patients are equal contributors. Burnout is associated with frequency and intensity of contact. A&E nurses at Guy’s and St Thomas’ Hospital Trust have frequent contact and intense interactions with sickle cell patients. In terms of the physical expenditure required to provide frequent analgesic medication, it might seem as if they are required to work harder for patients with SCD than for other patient groups. This becomes particularly acute in the current climate of shortage of trained nursing staff. There is also an increase in the demands made on their psychological resources when patients display emotional reactions such as fear, anxiety and anger. Bureaucratic organisational structures and policies that sometimes give rise to centralised decision making, and lack of support and autonomy, also add to nurses’ stress. The Patient’s Charter (DoH 1995) highlights patients’ rights within the NHS, and healthcare professionals in delivering patient care strongly advocate for their patients. While this is laudable and correct, it does seem that there are few initiatives promoting the rights of the professionals caring for patients.

A supportive forum for nurses

In November 1997, Guy’s and St Thomas’ Hospital Trust created a new post of clinical/health psychologist within the haematology department, primarily to provide support for sickle cell patients and their families. This innovative and much needed post was the first of its kind in the country.

In starting a new psychological service, the psychologist considered that, in addition to supporting patients and their families, an important aspect of the role is concerned with providing a supportive forum for nurses and doctors. The nurses caring for sickle cell patients had no formalised arena in which to ‘safely’ acknowledge the burden of caring. Thus, providing a forum for nurses to speak freely of the burden associated with caring for sickle cell patients would reduce stress and empower them by increasing their level of social support. This empowerment, in turn, would help to reduce the level of detachment and resentment that nurses sometimes felt towards patients with SCD.

The supportive sessions are one hour in length and take place on a monthly basis. The groups operate on the principles of confidentiality, mutual respect and integrity, to ensure that nurses can be at ease when acknowledging the difficulties they experience. In addition, the psychologist advises on strategies and skills to challenge unacceptable behaviour and verbal abuse and to provide boundaries for patients while giving good care. At an appropriate juncture during the sessions, the psychologist provides information about the psychological challenges that sickle cell patients have to contend with. This information categorises abusive behaviour as lack/loss of control: one of the problematic psychosocial consequences of living with SCD. With this insight, nurses are less likely to take such behaviour personally.

The sessions are confidential, and the full details of what is discussed cannot be revealed. However, the general themes emerging from the sessions strongly endorse the fact that nurses in A&E experience significant distress in their daily care of sickle cell patients. The source of the distress is multi-factorial and includes feeling abused by the patients who are sometimes tyrannical, disrespectful, rude, unrewarding and draining. Abusive behaviour is particularly difficult for the nurses to cope with as they are committed to providing good quality care to all their patients, and sometimes it is very hard to achieve this objective in the face of such abuse. In coping with these difficulties, they perceived very little organised support and relied heavily on informal systems of self-support.

As these support sessions became an established...
Fig. 2. Changes in attitude after sessions

<table>
<thead>
<tr>
<th>No</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>24%</td>
<td>76%</td>
</tr>
</tbody>
</table>

Box. 1. Nurses’ quotes from the questionnaires

- ‘Very good to talk through attitudes and aspects of care in a non-threatening environment’
- ‘The meetings have helped me feel more confident in my practice’
- ‘They have offered me a way to learn coping strategies with some difficult situations’
- ‘It draws insight into the psychosocial aspect of sickle cell disease’
- ‘More of an awareness of the psychological implications of the disease’
- ‘To keep us in touch with any changes in care’
- ‘I feel the care I offer is better’
- ‘Useful safe forum’
- ‘Allowing to share thoughts and feelings’
- ‘It’s given me more confidence to tackle difficult behaviour and sometimes verbally aggressive patients’
- ‘To get feedback on what has been happening with patients since we last saw them’

The perceived benefit derived, degree of perceived comfort in the group and views about whether the sessions should continue.

Method of evaluation

A sample of 21 female nurses who had all taken part in the support group completed questionnaires. Of these, seven were D grade, 11 were E grade, one was F grade and two were G grade. All nurses were assured of full confidentiality, and consent was obtained for publishing the findings.

The questionnaire used an analogue rating scale (from 0 to 10) concerning perceptions of the usefulness of the sessions, followed by seven questions assessing attitude change, degree of the perceived benefit derived, degree of perceived comfort in the group and views about whether the sessions should continue.

Results

Usefulness of supportive sessions Figure 1 shows that 70 per cent (n=15) of nurses found the support group extremely useful, with 25 per cent (n=5) finding it moderately useful. Five per cent (n=1) rated the sessions as poor, which might be related to the fact that this group of participants commented that they would have liked the groups to be more structured.

Attitude change Figure 2 reveals that 76 per cent (n=16) of the nurses in the sample feel that their attitudes have changed since the introduction of the support groups. Reasons given for their attitude change included being able to understand the other problems patients experience apart from a painful crisis and ‘...the emphasis on dual responsibility of patients and nurses to communicate effectively is a very useful concept’. One participant reported that the groups enabled her ‘...to think more about sickle cell patients’ and this improved her attitude. Seven others felt that their attitudes had changed because they had gained a better understanding of sickle cell patients’ fears and anxieties when they come into A&E.

Five nurses reported that they had developed more sympathetic attitudes towards the SCD patients, and this was attributed to the fact that they had gained better understanding of the psychosocial reasons that determine why some of the patients behave in a certain manner. It seems from this feedback that nurses’ attitudes have changed through better understanding of the patients’ perceptions of their illness and the physical and psychological factors motivating their behaviour.

Nurses’ perceptions of beneficial effects The nurses were asked to identify the personal benefits achieved through the sessions (Box 1). As can be seen, the answers implied that the forum promoted reflection in practice, which in turn impacted positively on patient care. Comments such as: ‘It’s very good to talk through attitudes and aspects of care in a non-threatening environment’ and: ‘The meetings have helped me feel more confident in my practice’, suggest that the sessions offered nurses a degree of social support and positive reinforcement for good practice. In general, it seems that nurses have gained more confidence in their ability to deal with difficult patients generally as well as in their work with the SCD patient population. Having a safe forum to discuss their problems and for unburdening themselves safely seems to have enabled nurses to feel supported and empowered.

Continuing the sessions Most nurses (90 per cent) were happy with the format and felt it should remain the same (Fig. 3). All participants felt that they could speak freely in the sessions and wanted them to continue. Only 10 per cent of nurses wanted the format changed, and the reasons given included the need for more structure, and more opportunity for one-to-one therapy.

Discussion

It seems from this evaluation that providing a supportive forum for nurses in A&E has enabled them to develop more positive attitudes towards sickle cell patients. The nurses themselves acknowledge that the change in attitude is due to education about the psychological factors that are responsible for motivating behaviour. The perceived benefits achieved by A&E nurses are seen as being derived from social support.
Maslach (1997) has argued that social support and feedback mitigate against burnout and make important differences in enabling health professionals to deal effectively with difficult issues such as ambivalence towards patients. The opportunity to reflect on difficult situations and to consider alternative responses, as well as to share feelings and experiences with colleagues, helps to promote emotional support.

It is well established that staff who experience high levels of work-related stress tend to report less job satisfaction. In contrast, high staff morale leads to better patient functioning, which in turn promotes positive staff attitudes. While the data from this evaluation of the supportive sessions cannot claim to measure either job satisfaction or morale, the positive change in attitudes and the personal benefits achieved, strongly suggest that nurses did experience a reduction in stress associated with caring for patients with SCD. Clinical observation and personal reports from individual nurses support the notion of improved morale.

The framework offered in the supportive sessions is designed to offer nurses emotional support, the permission to acknowledge the difficulties of caring and strategies for coping with stressful situations. This support has led to better nursing assessments being undertaken and marked improvement in communication between A&E staff and sickle cell patients, as well as between the A&E staff and the sickle cell team. Specifically, communication between the specialist sickle cell nurses and the A&E nurses has dramatically improved. This improvement, in turn, has led to patients being more co-operative and consequently to a dramatic reduction in the number of sickle cell patient/staff conflicts.

These sessions are continuing on a monthly basis as most of the nurses found the sessions extremely useful and can see the value of continuing. Another indication of the value of the supportive sessions is the observation that the number of nurses attending the sessions has grown steadily and the discussions are no longer confined to sickle cell issues but are now widened to encompass other kinds of work-related stress.

**Conclusion**

It seems that the emotional support offered by supportive sessions over the past two years as part of the health psychology service has important consequences not just for nurses, but also for the quality of patient care they deliver. The NHS ‘macho’ culture is a huge barrier to healthcare professionals acknowledging their stress and distress, as frequently such disclosure is seen as evidence of inability to cope. While we recognise that there is a counselling service available for staff, this tends to be accessed primarily in situations of extreme crisis. Regular formalised support should be made available in the work environment to maintain and improve work-related performance. This is especially important in the current climate where nurses’ roles are becoming progressively extended.

**Acknowledgements**

The author would like to thank all the nurses who have taken time out to complete the evaluation questionnaires and for sharing their personal experiences.

**REFERENCES**


