

EXPLORING PATIENTS' EXPERIENCES OF MRSA TO HELP REDUCE HCAIS

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AUTHOR Pauline MacDonald, MSc, BSc, ARRC, is nurse consultant in communicable disease, public health department, Dudley PCT.

ABSTRACT MacDonald, P. (2008) Exploring patients' experiences of MRSA to help reduce HCAIs. *Nursing Times*; 104: 9, 32–33.

A literature review of research on living with MRSA revealed a dearth of information and produced a narrow picture of the phenomenon. A wider review of patients' experiences with other conditions provided a more holistic perspective. Three important themes – knowledge and understanding, fear and stigma, and camaraderie – are presented. National policies on reducing healthcare-associated infections (HCAIs) fail to acknowledge the importance of patient information. Further qualitative studies are needed to inform on patients' experiences of living with MRSA.

BACKGROUND

MRSA prevalence is increasing. In 1990 only 5% of all *Staphylococcus aureus* bacteraemias (blood infections) were MRSA. Between 2001–2006 the proportion rose to around 40% (Health Protection Agency, 2006). MRSA is now endemic in most UK hospitals. Only six of the 73 acute trusts in England reported no MRSA bacteraemias between October 2005 and March 2006.

Eradication of MRSA is difficult and cannot be guaranteed. MRSA can live harmlessly on patients' skin and in their noses – this is termed colonisation. It also has the capacity to cause infections ranging from boils to bacteraemia. The organism resists eradication and the word 'cured' is rarely applied to affected patients. For many, it has become a long-term state, existing as colonisation, with or without infection.

AIM

Living with MRSA is likely to have a significant impact on patients' daily lives but what are their experiences and how might

IMPLICATIONS FOR PRACTICE

- National initiatives should acknowledge the importance of patient experiences and the contribution patients can make to care planning and policy decisions.
- Local Expert Patients Programmes could be expanded to include people affected by MRSA.
- As part of the Department of Health's commitment to improve patient involvement, every local authority will have involvement networks that could be consulted when planning and implementing initiatives.
- All practice-based commissioning clusters must hold patient forums, to host discussion and consultation of local infection prevention and control issues.

the negative effects be mitigated? A review of the current empirical qualitative literature was carried out to investigate patients' experiences of living with MRSA and to identify implications for practice, policy and further research.

METHOD

It became clear there was minimal research examining the phenomenon of living with MRSA. An extensive search was performed electronically, manually and online.

When the terms 'MRSA', 'lived' and 'experience' were used, no references were obtained. 'MRSA' and 'psychological' produced only seven articles, only three of which fulfilled the inclusion criteria. It was also apparent that there had been no literature reviews previously conducted on the topic.

Only two studies considered patients' perceptions of having MRSA (Criddle and Potter, 2006; Newton et al, 2001). This led to a decision to include studies of patients' experiences of living with other long-term conditions, infections and isolation. It was hoped these might reveal common themes that may be experienced by patients with MRSA, which could be confirmed or discounted with further research.

Some studies of mixed and descriptive quantitative methodology were included, particularly those examining the experiences of patients in isolation.

RESULTS

Nineteen studies were included in the review – for the full reference list see nursingtimes.net. Although different terminology was used, there were similar subject matters in the study findings. In the qualitative studies, topics and subjects were organised into themes. These themes, and the findings of the quantitative studies, were grouped to produce what was termed 'review themes'. These were: knowledge and understanding; fear and stigma; isolation dichotomy; mood disturbance; communication; care facilities; normalcy; body image; camaraderie; faith and fate; and physical effects and pain. This article focuses on three of the main themes.

Knowledge and understanding

This theme was found in every article, regardless of the subject. It looked at the knowledge and understanding of patients, relatives, visitors, acquaintances and staff and included the need to understand the microbiology, aetiology, epidemiology, treatment and disease course.

For many patients consistent information was lacking. Rarely did they feel well informed but when they did, it empowered them to take control of their lives (Kralik, 2002). There was a criticism that healthcare staff do not understand MRSA themselves and so do not transmit accurate information to patients (Criddle and Potter, 2006; Newton et al, 2001). There were strong calls



for more written and verbal information, particularly concerning the rationale and procedures for isolation (Madeo, 2003).

There was evidence that, in the absence of reliable sources of information, patients with MRSA may use the media and internet – sources that, sadly, can be inaccurate and sensationalist (Hamour et al, 2003).

Fear and stigma

This encompassed patients' fears for their own health, of infecting others and of being isolated, stigmatised and rejected. The fear of rejection appeared to be caused by other people's fear of contracting the infection. Fear and stigma were intrinsically linked to the theme of knowledge and understanding. Ignorance of the disease increased patients' fear and that of those around them.

The fear of infecting others, particularly family and friends, led to an avoidance of loved ones and self-imposed isolation (Criddle and Potter, 2006). Feeling stigmatised was reported in accounts of being isolated (Madeo, 2003; Newton et al, 2001), quarantined (Cava et al, 2005) and infected with hepatitis (Temple-Smith et al, 2004). Some participants felt like 'lepers' as they were avoided and shunned by others.

Camaraderie

Patients gained comfort from knowing others had their disease, having access to the support and help of other patients and not feeling alone with their disease.

Participants in the studies of long-term conditions and infection drew comfort from knowing they were not alone in suffering from their condition (Öhman et al, 2003). Many wanted to share their experiences and help educate others (Öhman et al, 2003; Kralik, 2002).

Those who were isolated commented that they missed the contact and comfort that was provided by other patients.

Most people with a long-term condition are served well by self-help and support

groups. Although the theme of camaraderie was not identified in the two MRSA studies, the popularity of the MRSA Discussion Forum (www.robprince.net/mrsa/forum.asp) as a means of support confirmed that this concept is relevant to patients' experiences.

DISCUSSION

National guidance, initiatives and directives were examined to assess the inclusion of information-giving, patient experience or patient involvement in policy and planning. For full details see nursingtimes.net.

The DH has made the reduction of MRSA one of six priorities for the NHS, and there is a national programme and strategy for the control of HCAs, including MRSA. As well as a strategy for reducing HCAs the DH also has one for involving patients and the public in health policy. An examination of DH documents revealed, however, that the ethos of involving patients in health planning does not seem to be embedded in the initiatives to reduce HCAs.

FUTURE RESEARCH

There are many possibilities for research in this much-neglected area. If patients are to be involved in MRSA-reduction initiatives, there must be a better understanding of their experiences. A qualitative study using phenomenological methodology would give a rich, authentic view of what it is like to live with MRSA at home.

Funding from a peer-reviewed body is necessary for wider studies to explore this area. Study designs would have to consider those colonised or infected with MRSA, and address the differing experiences of patients in relation to gender and age. In particular, they would need to investigate patients' everyday experiences in their own homes.

CONCLUSION

MRSA is an important infection for those who contract it and their carers. It can cause high morbidity and mortality, and its control and treatment can have negative impacts on these experiences. Evidence suggests patients' experiences are improved if they can access support groups and accurate information, as well as being involved in helping to educate and support others.

Patients' experiences may be valuable in the planning and implementation of infection prevention and control initiatives but there is minimal evidence that patient experience

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and involvement is at the core of national projects to reduce MRSA. At local level, providers should ensure that opportunities provided by the Expert Patients Programme, and GP and local-authority patient panels are used to make MRSA patients' involvement in healthcare delivery a reality. ■



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