Royal College of Nursing

National Institute for Health and Care Excellence

Rifaximin for maintaining remission from episodes of hepatic encephalopathy [ID496]

Royal College of Nursing

Introduction

The Royal College of Nursing (RCN) was invited to review the Appraisal Consultation Document (ACD) for Rifaximin for maintaining remission from episodes of hepatic encephalopathy.

Nurses caring for people with hepatic encephalopathy reviewed the documents on behalf of the RCN.

Appraisal Consultation Document – RCN Response

The Royal College of Nursing welcomes the opportunity to review this document. The RCN's response to the questions on which comments were requested is set out below:

i) **Has the relevant evidence been taken into account?**

The scope of the document addresses the "hard" evidence surrounding research trials however it fails to capture other aspects.

Research based evidence regarding quality of life in people with hepatic encephalopathy is difficult to ascertain as they suffer a wide variety of cognitive issues and their ability to elucidate fluctuates according to a number

of precipitating factors which was briefly mentioned. This has meant that we do not have a robust evidence base, however we see in our clinical practice that hepatic encephalopathy can have devastating effects on the individual and carer/ family quality of life.

ii) **Are the summaries of clinical and cost effectiveness reasonable interpretations of the evidence?**

Treatment with lactulose has been predicated on preventing constipation and reducing ammonia which can contribute to hepatic encephalopathy. As described people find lactulose a difficult medicine to tolerate; it is a sweet, sickly tasting liquid. It causes diarrhoea, faecal urgency and sometimes faecal incontinence. From the individual's perspective this raises issues of dignity and privacy plus the feeling of embarrassment and can hamper their quality of life as they do not wish to be far from a toilet. Rifaximin on the other hand is a tablet and appears to be well tolerated by those that are prescribed it.

The “cost” of caring for a person with hepatic encephalopathy cannot be capture in monetary terms. These people and their families have to endure day in, day out disruption to their lives on many levels. Individuals with hepatic encephalopathy are unlikely to be able to work, which has financial implications for them and their families. Many are unable to be left alone as it is unsafe. This leads to carers/family members having to make sacrifices in relation to their own employment, education, financial security and wellbeing. Many become isolated and their relationship with their spouse (usually) is altered from partner to carer.

Other costs that are unable to be quantified are the resource requirements both in primary and secondary care to support these people. Many carers report increased contact with GPs, district nurses and require ongoing supportive care in the community. A precipitation of hepatic encephalopathy necessitates admission to hospital; this normally requires an ambulance as they are unable to be brought to hospital by relatives due to the level of their hepatic encephalopathy. The cost of their inpatient stay (sometimes in an ITU environment) plus time to recuperate and review the impact of their treatment

prior to discharge all need to be considered. Specialist nurses within secondary care can spend a large amount of time supporting both the individual and their carers as well as liaising with local services. Again many of these costs cannot be quantified but they are a drain on NHS resources due to the increased interdependency that occurs with increasing hepatic encephalopathy.

iii) **Are the provisional recommendations sound and a suitable basis for guidance to the NHS?**

Anecdotally we know that Rifaximin works, based on comments from our liver nurse colleagues across England and between centre to centre. We are also aware of this as we share care between tertiary and secondary hospitals for many liver patients.

We consider that many of these patients will not benefit from a cost benefit analysis of their UKELD/MELD scores and whether these are improved by the use of Rifaximin. This is because group of patients tend to deteriorate from a liver function perspective unless other treatments are instigated. We consider that Rifaximin management clinically will help to improve quality of life for the patients by reducing hepatic encephalopathy. This can have a positive effect for the patients as they are more likely to improve with their nutrition, their cognitive abilities and also have some opportunity to be able to organise their affairs. The effect on their quality of life needs to be taken into consideration as the effect of the disease can be debilitating and some liver patients may have fractured relationships as a result and may wish to mend this. Also they tend to be younger and may not have recognised up to this point that they need to get their affairs in order. There is also a positive effect for the family/carer as they feel benefit from caring for someone who has improved cognitive function.

iv) **Are there any aspects of the recommendations that need particular consideration to ensure that NICE avoids unlawful discrimination against any group of people on the grounds of race, gender, disability, religion or belief, sexual orientation, age, gender reassignment, pregnancy and maternity?**

We are not aware of any specific issue at this stage. We would ask that any guidance issued should show that an equality impact analysis has been considered and that the guidance demonstrates an understanding of issues relating to all the protected characteristics where appropriate.