NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Centre for Clinical Practice – Surveillance Programme

Surveillance review consultation document

4-year surveillance review of CG105: Motor neurone disease. The use of non-invasive ventilation in the management of motor neurone disease

Background information

Guideline issue date: July 2010
4-year review: June 2014

Surveillance review recommendation

Surveillance review proposal for consultation:

The use of non-invasive ventilation in the management of motor neurone disease guideline should not be considered for an update at this time. It is proposed that CG105: Non-invasive ventilation in the management of MND is amalgamated with the in-development guideline on MND.

Main findings of current 4-year surveillance review

A literature search was conducted for randomised controlled trials and systematic reviews between September 2009 (the end of the search period for the guideline) and June 2014 and relevant abstracts were assessed. Clinical feedback was obtained from members of the guideline development group (GDG) through a questionnaire survey.

New evidence was identified for the current 4-year surveillance review relating to the following clinical areas within the guideline.

Clinical area: Clinical management		
Q: What is the clinical and cost effectiveness of non-invasive ventilation (NIV) for respiratory impairment in people with MND?		
Evidence summary	**GDG/clinical perspective**	**Impact**
<u>4-year surveillance review (2014)</u> A systematic review[1] suggested that NIV significantly improved survival and quality of life in patients with normal to moderate bulbar function when compared to standard care. In those with poor bulbar function, NIV was found not to improve survival and did not improve quality of life in some of the measures used. In another systematic review[2], evaluating the management of respiratory problems in patients with neurodegenerative conditions, weak evidence was found for the use of NIV in amyotrophic lateral sclerosis (ALS).	GDG feedback indicated that diaphragmatic pacing and tracheostomy invasive ventilation should be assessed in relation to NIV. An ongoing trial was identified which compares the effects of diaphragm pacing plus NIV to NIV alone (standard care). The anticipated end date for this trial is 02/02/2015.	The new evidence indicates a benefit of NIV in patients with normal to moderate bulbar function which is supportive of the guideline recommendation which states: offer a trial of NIV if the patient's symptoms and signs and the results of the respiratory function tests indicate that the patient is likely to benefit from the treatment. The new evidence also indicated that for those with poor bulbar function, NIV was not beneficial for survival and did not improve quality of life on some measures. This is unlikely to impact on the current recommendation which states that a trial of NIV for a patient who has severe bulbar impairment or severe cognitive problems that may be related to respiratory impairment should only be considered if they may benefit from an improvement in sleep-related symptoms or correction of hypoventilation. Feedback from the GDG is unlikely to impact on the guideline recommendations at this time as no evidence on diaphragmatic pacing and tracheostomy invasive ventilation in relation to NIV was identified through the surveillance review.
Clinical area: Clinical management		
Q: What are the key elements in the management of the use of NIV for people with MND?		
Evidence summary	**GDG/clinical perspective**	**Impact**

4-year surveillance review (2014) One small trial (n=40) conducted in ALS patients found that the telemonitoring of NIV assessments led to fewer emergency room and office visits and less inhospital admission. Telemonitoring was found to have no impact on compliance and survival only showed a slight trend towards this intervention. The incidence of parameter changes was found to be lower with telemonitoring throughout the survival period but increased during the initial period needed to achieve full compliance.	Feedback from the GDG suggested that there was a lack of consensus about when to inititiate NIV and little guidance about NIV withdrawal.They did suggest the more research on choice of NIV and withdrawal was due out in 2014 but no details of evidence were provided. It was also suggested by the GDG that there was little guidance on the use of transcutaenous CO_2 and overnight O_2. However, no evidence was identified through the review process.	The new evidence is unlikely to impact on current guideline recommendations about NIV assessments in MND patients. Whilst the identified trial did suggest a benefit of telemonitoring NIV assessments (compared to assessment during office visits) for emergency room visits, office visits and inhospital admission, further data is needed on functionality, survival and cost-effectiveness before considering the use of telemonitoring NIV assessments for inclusion in the guideline. No evidence was identified on: when to initiate NIV, the choices of NIV, withdrawal of NIV or on the use of transcutaneous CO_2 or overnight O_2.

For the following areas of the guideline no new evidence was identified:

- The identification and assessment of respiratory impairment in patients with motor neurone disease: clinical symptoms and signs
- The identification and assessment of respiratory impairment in patients with motor neurone disease: respiratory function tests
- Information and support needs of patients with motor neurone disease and their families and carers

Ongoing research

A clinical trial (ISRCTN53817913) is currently recruiting MND patients to compare the effects of diaphragm pacing plus NIV to NIV alone (standard care). The anticipated end date for this trial will be 02/02/2015.

Anti-discrimination and equalities considerations

The GDG indicated that decision making could be affected by fronto-temporal dementia and cognitive change and that this should be made clearer in the guideline. The guideline does include recommendations on decision making for those with a dementia diagnosis but no new evidence in this area was identified through this surveillance review. The GDG also felt that there was a lack of consensus about when to initiate NIV. However, no evidence on NIV initiation in MND patients was identified through the review.

Conclusion

Through the 4-year surveillance review of CG105 no new evidence which may potentially change the direction of guideline recommendations was identified. However, a related in-development guideline on MND was identified. It is proposed that CG105 is amalgamated with the in-development guideline on MND.

References

1. Radunovic A, Annane D, Jewitt K, Mustfa N. Mechanical ventilation for amyotrophic lateral sclerosis/motor neurone disease. Cochrane Database of Systematic Reviews 2009, Issue 4. Art. No.: CD004427. DOI: 10.1002/14651858.CD004427.pub2.

2. Jones U, Enright S, Busse M. Management of respiratory problems in people with neurodegenerative conditions: a narrative review. Physiotherapy, 98[1], 1-12. 2012

3. Pinto A. Almeida JP. Pinto S. Pereira J. Oliveira AG. De Carvalho M. Home telemonitoring of non-invasive ventilation decreases healthcare utilisation in a prospective controlled trial of patients with amyotrophic lateral sclerosis. Journal of Neurology, Neurosurgery & Psychiatry, 81[11], 1238-1242. 2010