Implementing an Adaptation of the Carer Support Needs Assessment Tool (CSNAT) Intervention to Provide Tailored Support for Family Carers of People with Motor Neurone Disease

Gail Ewing, Sarah Cooke, Christine Rowland, Alex Hall, Gunn Grande. University of Cambridge, UK; University of Manchester, UK

Background Family carers face substantial demands when supporting people with Motor Neurone Disease (MND) (Aoun et al., 2013). Timely support from healthcare professionals is crucial to enable carers to fulfil their caregiving role and to look after their own wellbeing. The CSNAT intervention is an evidence-based approach for person-centred assessment and support. This project aimed to adapt the CSNAT intervention to the context of MND care, and test its implementation within specialist MND services.

Stage 1 involved interviews and focus groups with carers (n=33) to explore carers’ support needs at key stages of the patient’s illness; stage 2 involved workshops with carers (n=19) and practitioners (n=22) to adapt the content of CSNAT intervention and its delivery within MND care. Stage 3 involved implementation of the adapted CSNAT-MND in three specialist MND services, and interviews with practitioners (n=6) and carers (n=6) exploring their experiences of the intervention.

Content of CSNAT-MND included an additional domain on support with relationships. Intervention implementation adapted to (1) legitimise assessment of carer support needs as part of routine care in MND by practitioners, (2) deliver of a stand-alone introduction stage of the CSNAT-MND intervention and (3) provide a dedicated assessment and planning conversation at a subsequent contact. This basic model was then suited to fit the working practices of three different MND services. This project provides insights into how carers of people with MND want to be assessed and supported, how this process can be delivered, and the feasibility of implementing the CSNAT-MND in routine practice.

The Usefulness and Acceptability of a Personal-Health Record to Young People with a Life-Limiting Condition: A Realist Evaluation

Janet Diffin, Bronagh Byrne, Peter O’Halloran, Hospice UK, Queen’s University Belfast, UK

Background Communication between young people (YP) with life-limiting conditions and healthcare professionals (HCPs) can be challenging, particularly during transition from children to adult services. Personal-health records (PHRs) have the potential to increase YP’s selfadvocacy yet have not been evaluated thoroughly with this population.

Aim Use realist evaluation to test and refine a programme theory on how PHRs are thought to work with YP with a life-limiting condition.

Methods Qualitative study informed by realist evaluation. YP aged 16–24 years old living in Northern Ireland with a life-limiting condition were invited to use a PHR; semi-structured interviews conducted at three, six and nine months to examine acceptability and use. Framework method used for analysis.

Results Eight YP and two parents (on behalf of child) participated. 4/10 used the PHR; reasons included: (i) to help organise their care, (ii) feel more confident with communication, (iii) reduce the need to repeat details about condition(s)/medications, and (iv) manage health care when aspects of their lives were changing. PHR use depended on the level of need, desire for autonomy/self-management, and whether it brought benefits over how they currently managed their condition. Two additional contextual considerations which influenced PHR use were identified (i) YPs previous experiences in communication with HCPs, and (ii) the timing of the introduction of the PHR.

Conclusion PHRs may be useful for YP who wish to become more independent over management of their healthcare but should be targeted towards those who identify a need, and their usage supported by HCPs.

LaB1 identified six topics carers want to learn about breathlessness. LaB2 is co-developing (with carers, patients and clinicians) a prototype web-based educational intervention for carers on breathlessness. Content for five of the six topics was developed, but additional work was needed for the sixth topic, ‘What to expect in the future’, to ensure utility and sensitivity.

Method Two disease-specific focus groups and six interviews with bereaved carers of people with breathlessness due to...