



A quality review of a specialist multidisciplinary service caring for people with long-term neurological conditions/spasticity

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Project background

The project was undertaken by a specialist multidisciplinary spasticity service at the National Hospital for Neurology and Neurosurgery in London. This team provides local and national care for patients with chronic long-term conditions and specialist care for people with spasticity. There are many elements to the management of severe spasticity, and an intrathecal baclofen pump is one option that can be life changing. The project was driven by a desire to understand the experiences of those living with such a pump and to use these insights to improve the quality and care offered by the specialist multidisciplinary spasticity service.

Aims and objectives

The aim of the project was to evaluate the impact of an intrathecal baclofen pump on quality of life for people who have spasticity and their carers. To achieve this, the objectives identified were to:

- Engage key stakeholders in the project
- Capture patient stories
- Undertake a workshop with the ward nursing staff to capture their involvement in the patient pathway
- Understand how a practice development framework will help implement changes in practice for patients and carers
- Plan how patient and staff experiences will help co-design a more user-friendly service

Implications for practice

- Picture cards may be useful as prompts for patients or staff to tell their own stories, offering a reminder of past feelings or giving permission to express a variety of emotions
- Using the adapted emotional touchpoints method provides a valuable narrative for people to share their experiences. It provides an opportunity for sharing positive and negative experiences and helps create the space to discuss possible improvements
- Moving from directive to facilitative leadership involves the development of new skills and knowledge to use in practice

This project was supported by the FoNS Patients First Programme in partnership with the Burdett Trust for Nursing

Online

Further information about the project can be accessed from: fons.org/library/report-details?nstd=71328

Key activities and outcomes

• A multidisciplinary stakeholder group

The project team invited neurologists, clinical nurse specialists, physiotherapists, ward nursing staff and service users to create a multidisciplinary stakeholder group. The group met monthly to plan approaches and evaluate feedback from the project. Some designated time was also set aside for the project during the clinical governance day at the hospital.

• Values clarification exercise

A values clarification exercise was undertaken with the stakeholder group to create a shared vision of what the group wanted to achieve during the project. It was agreed that the focus should be to evaluate the impact of an intrathecal baclofen pump on the quality of life of patients who have spasticity and their carers.

• Staff development workshop

Two workshops for nursing staff from the neuro-rehabilitation unit were held to explore their views and perspectives about caring for people with spasticity. A values clarification exercise revealed a shared purpose of helping to improve their quality of life. Further discussion was facilitated using a claims, concerns and issues exercise, from which three key themes emerged: education and adjustment; improving quality of life; and support of the patient once discharged. All the information discussed was recorded and fed back to the steering group to inform the project further. The nurses highly valued their time together to reflect on the needs of the people they care for.

• Collection of patient stories

The project leader interviewed seven people, who had used an intrathecal baclofen pump for more than six months, using emotional touchpoints. The stories were reviewed and the findings presented in a poster that was displayed at the multidisciplinary meeting. A key theme was that people wanted the opportunity to meet with other people using the pump to share their stories and discuss experiences.

Quality of life carer questionnaire

This questionnaire was distributed via the online SurveyMonkey tool (surveymonkey.co.uk) and proved to be useful as it gave insights into carers' experiences of health and social care. Carers reported that their sleep was disturbed, that they experienced emotional strain, worried about needing to adjust future plans and were unable to complete all their daily tasks. On reflection, the project team thought the questionnaire may have proved even more valuable if it had allowed the carer group to give open, free-text comments.

• Celebration event

Following reviews of the patient, carer and staff feedback it was decided to hold a celebration event to allow an opportunity for everyone to come together to share their stories, to pull all the strands of the project together. In total, 65 staff, patients and carers attended. It was agreed at this event to create a cascade email system for any future sharing of information. Three service users volunteered to undertake the task of getting this system up and running.