

Supportive care for patients with Huntington's disease and their carers

This study explored the needs of patients with Huntington's disease and family carers and their views on support services provided by a community-based unit

INTRODUCTION

This study looked at the needs and coping strategies of people with Huntington's disease and their relatives or carers. It also examined support from a specialist community-based unit, which provided a multidisciplinary day service and outreach in patients' homes.

Huntington's disease is a long-term neurodegenerative condition caused by a genetic mutation in the Huntington gene. Those who carry the full gene mutation will develop the condition unless death occurs from another cause before symptoms present. Age of onset is typically 30–50 years.

Huntington's disease may last for up to 30 years and there are far-reaching implications for patients, relatives and carers. Services for families must offer expert psychological and practical support, but be planned and flexible.

THE STUDY

The study had three main aims:

- To identify patients' and family carers' support needs and coping strategies;
- To establish the extent to which they were supported by the unit's specialist service;
- To identify service users' unmet needs.

The researchers used qualitative methods to obtain in-depth data from a range of people. Five focus groups and three individual interviews were used to gather data from people with Huntington's disease, family carers and staff at the unit (n=33).

KEY FINDINGS

The following three main themes emerged:

- Transitions and the Huntington's 'journey';
- Challenges in finding and giving support;
- The unit's role in giving supportive care.

KEY POINTS

- Although this service was considered to be supportive, the need for flexibility was stressed.
- Patients felt it was important to be known as the person they had been, despite the changes caused by the illness.
- Service provision in a dedicated unit is an appropriate way to support patients and carers.
- It is helpful to allow patients control over timing and frequency of contact with health professionals.

Transitions and the journey

Patients and carers described a series of 'decisional tasks' or adjustments to be addressed, including:

- Finding out about the condition;
- Deciding whether to have the genetic test;
- Making decisions about relationships and starting a family;
- Deciding how and when to tell children about the genetic implications;
- Watching a family member change and eventually die with Huntington's disease.

Many patients and carers said receiving the diagnosis and realising its implications was devastating. However, some had found living with uncertainty about their future difficult and, while upsetting, diagnosis offered some relief from this.

Patients referred to needing information on the condition to prepare themselves and expressed frustration with health professionals' lack of knowledge.

Some family members related traumatic experiences, such as seeing a relative become aggressive. Staff and carers said that supporting patients to carry out activities outside the home could be difficult because of patient depression or lack of motivation. Patients' reluctance was often compounded by stigmatising reactions from members of the public.

Challenges related to support

Every patient had some mobility issues and a general loss of their ability to do things. Both staff and some patients noted conflict in ensuring the service provided freedom of choice, while being sufficiently proactive to help patients overcome symptoms. For

REFERENCE

Soltysiak, B. et al (2008) Exploring supportive care for individuals affected by Huntington disease and their family caregivers in a community setting. *Journal of Nursing and Healthcare of Chronic Illness*; 17: 7b, 226–234.

To read this study in full, go to: tinyurl.com/huntington-s-disease

those who wanted to use health and social care services, continuity and access to care were important. Having a flexible service where patients could maintain some control over their own access was seen as essential.

Patients stressed that it was very important to them to be in contact with people who had known them before they became ill. Carers seemed to respond to the 'real' person and showed a true commitment to patients.

The unit's role in giving supportive care

Both services were seen to provide useful support, enabling patients to engage with others in a safe environment. Some patients were uncomfortable having contact with others who were affected, but some appreciated the opportunity for social interaction. Patients who received the community outreach service appreciated having someone visit them at home. Both carers and patients felt the unit provided a service that supported carers, promoted their well-being and provided respite.

CONCLUSION

Service provision in this dedicated unit is much valued by patients, families and carers. Patients with Huntington's disease face several challenges – this unit helps them to address these.

Soltysiak et al (2008) argue that more work needs to be done to improve understanding of the condition in the community. They add that getting to know patients personally and letting them make choices about management can help them and their carers to cope. n