Applying a health care model to Huntington's disease – the key worker approach.

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This paper follows on from an overview of the literature and current policy for Huntington's disease (HD) published by the BJNN (Wilson et al. 2014). The previous paper highlighted a paucity of knowledge in terms of best practice available for those commissioning services to draw upon when planning care of those with HD. This discussion paper draws on this literature base and findings from a recent longitudinal research study from Wilson's (2013) unpublished PhD thesis (available online at http://etheses.nottingham.ac.uk/3487/) to suggest a model of care, which may provide some guidance.

Health care models are often used to illustrate key features that service providers should strive for when planning health services. Health service planning has historically been based on the need to provide rapid responses to acute illness or injury. However, the rise of chronic conditions, both globally and across the UK, has prompted a shift in types of care and the ways in which care is provided. The chronic care model suggests a change in the organisation of care for those with chronic conditions (Wagner et al. 2001). The model shifts focus to a proactive approach that aims to keep a person as healthy as possible for as long as possible. Whilst we would suggest that in principle this model has certain application to HD it is generic to chronic conditions, as such flexibility and caution must be applied. We propose that the central element of any model of care for HD should take a holistic approach and involve an inter-disciplinary and multifaceted team (Veenhuizen and Tibben 2009). In this second paper we argue that encompassed within this premise, a key worker approach should be utilised, and continuity of care maximised, across all aspects of service provision.

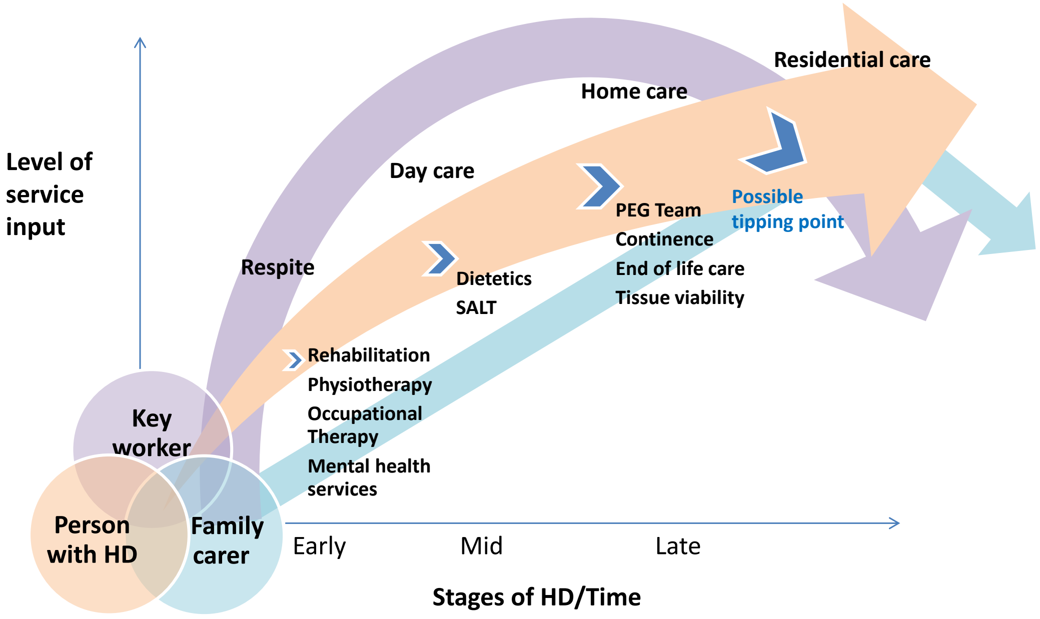
One way of managing equitable care may be through the use of key workers. The key worker role has been in place in the community for some time in various forms with application to mental health, learning difficulties, and older people in the community (Challis and Davies 1985; Dant and Gearing 1990; Payne et al. 2002). The main application of the role has been to facilitate co-ordinated care of chronic illness and disability in children (Greco and Sloper 2004; Rahi et al. 2004). Greco and Sloper (2004) describe many transferable aspects of the key worker role. They highlight the input received by disabled children and their families from a variety of different services such as health care professionals, social work, education, benefits and voluntary agencies and suggest the role of the key worker is to 'represent the single point of contact that families would like' (2004, p13). Further support comes from Payne et al.'s (2002) systematic review who established that the most effective strategy for transferring information between health professionals was the use of key workers to provide a point of contact for professionals from hospital to the community. This transcendence of professional, organisational and sector boundaries is essential to facilitate communication, co-ordination and co-operation between the many services people have to interact with when they are affected by HD.

Key workers develop disease, patient and family specific knowledge alongside a wider knowledge of local services. This is a single point of contact and co-ordination of care services for families that promotes continuity of service and personnel. Such continuity and built trust is something particularly important to those with HD, especially when they may be cognitively impaired or lack insight into their condition and level of need. Ongoing work by NHS Improvement teams (2012) is currently focusing on providing equitable care seven days a week with an important element being the *accessibility* of this care. However, for those with HD *continuity* of care is increasingly being shown to be important (Aspinal et al. 2012). Equitable access can therefore be a challenge to continuity of care. However, current NHS reforms emphasising the need to integrate health and social care funding to allow services to work more closely together (NHS England 2014) will be of considerable advantage to those with HD. In addition, changes to the configuration of services, such as the introduction of community matrons, are being made to deliver timely interventions to people in the community to reduce unnecessary hospital admissions. These policy initiatives may support better services for people with HD and will need to be considered by providers (for an example see Osborne's 2009 paper on service provision for people with Parkinson's disease).

A model of care for HD should also promote ways for people to manage by themselves for a long as possible and create services that are accessible when needed. Where they are available and willing to provide care, family carers are fundamental to the process. A family carer will often take on the role of coordination of, and liaison with, services. As cognitive function decreases the family carer will take over the majority of organisational tasks alongside the demanding role of physical care.

The model below is based on the current literature, UK policy (see the first paper in this series - Wilson et al. 2014) and findings from 15 longitudinal case studies of patients with HD, their family carers and the health professionals involved in their care. The study took place across three settings; a community-based nurse-led multi-disciplinary service, a hospital-based consultant led outpatient service and three specialist care homes for people with neurological conditions. Data collection was undertaken between 2007-2011 and each case was followed for a period of approximately three years. The study resulted in 68 interviews and 47 periods of observations to allow a clearer understanding of living with HD (Wilson 2013). This model is by no means exhaustive but aims to provide a summary for the potential development of long-term care provision.

Wilson's model of long-term care provision in HD



The model shows how symptoms and the need for service input increase over time. The types of services that might need to be introduced over the phases of HD are included within this model. However, both the type and timing of such services should only be considered as a guide as not all people with HD will require or want these services. As highlighted by Nance (2007) psychiatric services would also ideally be included in any model of care for HD. However, accessing such services and even getting services to recognise HD as partially psychiatric, and not a solely organic, condition is challenging (Kenny and Wilson 2012). It is important to note that this model is necessarily flexible and offers only a guide to service providers as to the types of services they may wish to consider including in HD provision. Provision will vary depending on area of the country and will need to be based on prevalence of the condition in the area as well as existing local services and funding structure.

In addition, this model highlights that consistency in services and personnel are of benefit to those with HD. This is not only because those with the condition find change particularly disruptive, but also because it allows staff to build the disease, person and service specific knowledge necessary for quality care (Liaschenko and Fisher 2004). The model also shows the potential tipping point at which time it may no longer be possible to care for the person with HD at home. Evidence from the longitudinal case study research demonstrated that for those without family carers this might occur earlier in the illness trajectory (Wilson 2013). At this stage, the balance between care provision and need may be tipped and a move to residential care may be necessary. Respite, day care, home care and psychiatric services may also be needed throughout the illness trajectory. Again, what type of service and when it is needed will vary depending on the patient and their family. The key worker should take a role in organising and co-ordinating all care input alongside supporting decision-making processes.

SELF-MANAGEMENT AND THE KEY WORKER ROLE

Despite being part of current policy drivers self-management can mean different things to different people and not all will want, or be able, to participate in self-management techniques or formal programmes. In a report commissioned by the King's Fund, Corben and Rosen suggest that to most people self-management means 'developing an understanding of how their condition affects their lives and how to cope with their symptoms' (2005, vii). Whether or not people want to, and do, engage with self-management will be dependent on a number of aspects including time since diagnosis, severity of the symptoms, age, level of education and their social, psychological and emotional needs (Corben and Rosen 2005).

In this section we emphasised two studies that have focused on formal self-management programmes for HD. Campo et al. (2012) found that an educational intervention programme supported self-management strategies and improved psychological well-being and coping strategies for both patients and family carers. The programme sessions included education and discussion on information seeking, taking a pro-active role in treatment, self-monitoring of body, cognition and mood, relaxation and stress management by focusing on realistic and helpful thoughts, dealing with and preventing depression, social competence and asking for social support (Campo et al. 2012). The findings showed evidence that the programme was less effective for those in the pre-manifest stage of HD. Although those with pre-manifest HD and their family carers increased their seeking of social support after the programme they did not show any improvement in the psychological outcome measures (Campo et al. 2012). However, there was no longer term follow-up or assessment of the economic feasibility of the programme.

In contrast, a randomised controlled trial for people with progressive long-term conditions, including HD, found that an education programme delivered by an occupational therapist to reduce the risk of falls and pressure ulcers had negative effects (Ward et al. 2004). Those randomised to the education programme arm of the study were comparable at baseline with those in the control group. Post programme outcomes for those in the intervention group at 12-month follow-up showed declining functional ability, with no positive effects on well-being, falls or pressure ulcers (Ward et al. 2004). This research by Ward et al. (2004) challenges the assumption that education and self-management interventions are beneficial and supports the need for further empirical evidence of their effectiveness, particularly for those with degenerative conditions.

Self-management may be desirable and appropriate, particularly in the earlier stages of HD. However, this must be seen in conjunction with open referrals and easy access to specialist care when needed. Other than formal and organised programmes there are a number of other ways in which patients and families will self-manage including online support groups, education leaflets, incorporating exercise, commentary therapies and special diets into their lifestyle. Written information and guidance is provided by the Huntington's Disease Association (HDA), as are education and training days for those who wish to attend. Blogs, internet forums and support groups are also facilitated and this range of approaches may allow for patients and families to engage with self-management as they wish. Any form of 'self-management' can only work effectively when patients are given information and support to manage their condition and know when it is appropriate and necessary to seek additional input from health professionals (Chaplin et al. 2012). Formal self-management programmes may not be the most appropriate format for those with HD. Indeed, it may be more appropriate to focus formal programmes on supporting family carers. Those with HD may benefit from more informal, support and information provided by a key worker on an individual basis, tailored to their needs.

THE CENTRALITY OF KEY WORKERS IN QUALITY CARE PROVISION

A significant component highlighted by the longitudinal study carried out by Wilson (2013) has been the importance of the Clinical Nurse Specialist (CNS) and Regional Care Advisor (RCA) (post provide by the HDA) roles as key workers in community care. However, any appropriate person, such as a neuroscience nurse, rehabilitation nurse, or community matron, may undertake this role. By providing a single point of contact for people with HD, their families and other professionals including care homes (Royal College of Physicians 2011), they are able to act as advocates, liaisons and care co-ordinators, working across disciplines, organisation and sector boundaries (Osborne 2009). Although in principle, any health or social care professional could fulfil this role Aspinal et al. (2012) identified the CNS as best placed to be a case manager, navigating across and between services. A single point of contact and open referral system allows easy access for patients and families amidst a confusing array of appointments, different health professionals and supportive services. The Royal College of Physicians (2011) also advocate for a key worker role for the care of those with long-term conditions. The report recommends specialist nurses to be central to delivery of quality care alongside General Practitioners with a Special Interest (GPSI) in specific conditions. However, although these two roles worked as key workers in the areas included in the longitudinal study by Wilson (2013) this may not be the case in other areas. RCA's are charity funded, often carry very large caseloads, cover significant areas of the country and may be on a part-time basis, hence, the extent of their involvement should be reviewed depending on area. A CNS with experience in HD is a rare and expensive commodity and again may not be available or economically justifiable in every area.

CONTINUITY OF CARE AND THE KEY WORKER ROLE

Continuity of care is taking on increasing importance in the fields of dementia and the care of older people (Cornwall et al. 2012) and is already recognised in neuroscience nursing for people with Multiple Sclerosis and Parkinson's disease (Osborne 2009; While et al. 2009). Freeman and Hughes (2010) suggest that continuity can be broader than the expectation of dealing with the same health professional over time. They differentiate relationship continuity and management continuity. Relationship continuity is defined as 'a continuous caring relationship with a clinician' and management continuity as 'continuity of clinical management, including providing and sharing information and care planning, and co-ordination of care' (p13). A systematic review of the literature suggests that these elements of continuity focus on care which provides: one or more named individuals (i.e. key workers) with whom the person affected by HD can establish and maintain a therapeutic relationship, uninterrupted care for as long as is required, a smooth transition between care providers, adjustment to the person's needs over time, transfer of information, ways to sustain the person's social and personal relationships in the community and enhance quality of life, scope for people to retain control over their own lives and to manage their own health and well-being (Aspinal et al. 2012).

One of the key issues for HD services is how to achieve continuity of care without creating dependence on one specialist member of staff. Such dependence can be problematic if staff change jobs, take time out or are unwell themselves. HD services are often substantially supported by charity-funded posts, such as RCAs provided by the HDA. This reliance on the third sector to provide care is set to increase as the government brings about changes to widen the role of the voluntary sector and charities in health care provision (Department of Health 2011). Indeed a report by The Centre for Social Justice recommends that the third sector take on roles of care co-ordinators or key workers for those with mental health issues (2011). The report suggests embracing the Department of Health's 'Any Qualified Provider' scheme by using voluntary services and charities to fulfil this role of care co-ordinator. The report argues that as NHS Trusts and Social Services provide the majority of services, this creates a conflict of interests when giving information to, and advocating for, patients and their families. However, as indicated above, we would advocate the benefits of health and social care professionals coordinating care for patients and families and supporting decisions about their wishes and needs (Wilson 2013). Increasing demands on third sector workers raises a number of issues in term of their skills, funding, support and the amount of access they would require to successfully co-ordinate services within the NHS as part of an effective key worker role.

SPECIALIST KNOWLEDGE AND THE KEY WORKER ROLE

Liaschenko and Fisher (2004) suggest that nursing knowledge is made up of case knowledge, patient knowledge and person knowledge. They suggest that the work of nurses goes far beyond that biomedical knowledge and that there is little recognition of the co-ordination of care that routinely takes place and is informed by this range of knowledge types (Liaschenko and Fisher 2004). We would argue that alongside nursing expertise in HD service provision, it is the HD specific knowledge that has been shown to be of paramount importance (Smith 1998; Swarztrauber et al. 2002; Bourke et al. 2012; Wilson 2013). According to Liaschenko and Fisher (2004) 'case knowledge' is the disembodied disease specific biomedical knowledge that is often not found outside specialist services for HD (Wilson 2013). It is this case knowledge that gives staff cues as to what can be expected and is therefore essential for quality care planning. 'Patient knowledge' is seen as how a person becomes created as a patient by gathering certain information about them, and how to get things done for them, across and within organisations, as well as knowledge of the significant others who might be involved in that patient's care. Key workers are often involved in this type of organisation and cross sector co-ordination of care. A third type of knowledge, 'person knowledge', engages with the person's history, spatial and social situations and may only happen during several encounters or an extended period of time. Bjorkland refers to the gathering of this information as 'invisible triage' (2004, p111). Wilson et al. (2011) also found evidence of this practice where staff at residential care homes gathered person knowledge and considered 'getting to know the resident' vital to providing tailored, personalised, and quality care.

Work by Rasin and Kautz (2007) has shown how these different types of knowledge become essential in dementia care in order to manage behaviours yet keep in mind the needs of the person exhibiting that behaviour. We would argue that any key worker for HD requires all of these types of knowledge to provide effective care and effectively case manage those affected by HD.

CONCLUSION:

Huntington's is a complex and multifaceted disease requiring planned and responsive care from a multidisciplinary team. This paper has presented a model of care based on current literature, policy and findings from longitudinal case study research. It aims to provide guidance to those planning services for those with HD by illustrating the types of inter-disciplinary services that may be needed throughout the disease trajectory. The model also highlights the potential for a tipping point at which time the needs of the patient outweigh the level of services provided, potentially resulting in a move to residential care. The model shows a key worker role situated alongside the patient and family. This key worker is central to providing disease, service and person specific knowledge and a continuity of care. In addition, they are able to build relationships with both the person with HD and their family carer, and support self-management as appropriate. We have suggested a CNS may be best place to take on this key worker role but this may vary depending on prevalence of HD and the existing local services and funding. The key challenge for services is to provide such vital continuity within a viable service.

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