

Evaluating the costs and cost-effectiveness of interventions for people with learning disabilities and behaviour that challenges: the need to improve the evidence base

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Abstract

Purpose

The purpose of this paper is to provide a commentary on the challenges associated with evaluating the costs and cost-effectiveness of interventions for people with learning disabilities and behaviour that challenges.

Design/methodology/approach

The paper is a commentary on a range of evidence relating to the findings of "Positive behavioural support for children and adolescents with learning disabilities: an initial exploration of service and costs". Specific attention is paid to gaps in the literature and the evidence base for the cost of care for people with learning disabilities and behaviour that challenges.

Findings

Recommendations for patient centred care and increased use of behavioural and psychological interventions for people with learning disabilities and behaviour that challenges are based on limited evidence. The literature is particularly sparse in relation to the cost implications for service providers or informal carers of implementing these services and if they do indeed reduce costs through preventing residential placements and long term inpatient admissions.

Originality/value

More high quality research is required in the area of behavioural and psychological interventions for people with learning disabilities and behaviour that challenges. Trials in this area should include high quality economic evaluations including budget impact analysis to provide information on the cost implications for different government agencies and cost-effectiveness analysis incorporating impact on quality of life.

Introduction

Over the past few decades in the United Kingdom (UK) and other developed countries there has been an increased emphasis on services to provide person centred care for people with a learning disability. In England this has included the recent Department of Health (DH) guidance framework for people with learning disabilities with the framework strongly recommending the use of psychological and behavioural measures (DH 2014). A programme of work has also been set out by various government agencies detailing how services will be provided to ensure people with learning disabilities receive care in the community close to home (NHS England 2015). The aim of these recommendations is to prevent the use of physical and chemical restraint, out of area placements and long term inpatient stays and provide a mechanism for achieving person centred care. These same recommendations have also been echoed in the National Institute for Health and Care Excellence (NICE) guidance Challenging Behaviour and Learning Disabilities (NICE 2015).

These recommendations have been made with the needs, well-being and dignity of people with learning disabilities and behaviour that challenges in mind. They have been made though in the context of limited high quality evidence available to support them (NICE 2015, Robertson et al. 2006). This is primarily a result of a paucity of high quality randomised control trials (RCTs) assessing the clinical and cost-effectiveness of psychological and behavioural interventions for people with learning disabilities and behaviour that challenges.

A Cochrane review of RCTs of psychological and behavioural interventions for people with learning disabilities and behaviour that challenges, capturing papers published up until April 2014, found six studies for inclusion with a total of 309 participants. There were no studies of behavioural interventions of sufficient quality for inclusion in the review, including no RCTs of Positive Behavioural Support (PBS). Evidence of the cost-effectiveness of psychological and behavioural interventions is also lacking, with only one study included in the review assessing quality of life and cost (Ali et al. 2015). This limited evidence of cost-effectiveness makes evidence based commissioning of services for people with learning disabilities and behaviour that challenges problematic. In an environment of limited research any additional evidence is welcomed, although high quality evidence is preferred.

In this issue of Tizard Learning Disability Review authors xx have provided additional evidence for the costs of PBS support packages for children and adolescents with learning disabilities and behaviour that challenges. The study presents cost data for 10 children with learning disabilities and behaviour that challenges from one Borough in London that currently receive care in the community but were

at risk of residential placements. The assumption is that PBS in the community helped to prevent residential care and utilised a Delphi exercise to assess the potential cost savings. Although the reasoning behind this is potentially sound what is currently missing is any strong and consistent evidence to support this.

Do people with learning disabilities and behaviour that challenges have greater costs?

Knapp et al (2005) is commonly cited as the evidence for the relationship between the cost of care for people with learning disabilities and behaviour that challenges. The observational study of 930 adults with learning disability found a significant, non-linear increase in the cost of care for adults with more severe learning disabilities and higher scores for challenging behaviour. Although the study was published in 2005 the data for this study was collected for the cohort of patients in 1996. Since then there have been a number of additional policy documents published on the importance of person centred care and care in the community (DH 2001, DH 2014). The number of people being admitted to long term inpatient care has also slowly reduced, partially as a result of the review of care provided in Winterbourne and the Transforming Care plan (NHS England 2015). As a result it is likely that services for people with learning disabilities and behaviour that challenges look different now to how they did in 1996 and the results of Knapp et al (2005) may no longer apply.

Indeed, more recent studies have not found the same relationship between behaviour that challenges and costs. A 2013 study of 27 urban adolescents with learning disabilities and challenging behaviour transitioning to adult services in one Borough in London found no relationship between challenging behaviour and costs (Barron et al. 2013). That the relationship between cost and challenging behaviour was not significant may be because of the small sample size and limited scope of the study, only relating to one area in London. What was included in Barron et al, but not in Knapp et al, was the cost of informal care provided by a family member or another close person. The cost of informal care accounted for 66 percent of costs and 96 percent (26 of the 27) of the young people in the sample had a family member or other close person who provided an average of 86 hours of unpaid care per week for the child. This same care if provided by the local authority would have cost £1554 per week.

One of the reasons why people with learning disabilities and behaviour that challenges may cost more is because they are more likely to be placed away from home and outside of their local area. Hassiotis et al. (2008) in a study of 5 North London Boroughs and 97 service users found that out-of-area placements were more likely for adults with learning disabilities and behaviour that challenges with the cost of out-of-area placements likely to cost more than local placements. The reason that these placements cost more though may have been because the patients placed out of area had

more complex needs. When level of need is taken into account other studies have found that out of area placements cost less than in area placements (Perry et al. 2013).

Person centred planning has commonly been cited as a way to reduce the cost of care for people with learning disabilities and behaviour that challenges, with researchers asserting that person centred planning may prevent people from moving into residential care or help them return to living in the community, as is the assumption made by xx et al in the article published in this issue. There is conflicting evidence though that this is the case for person centred planning and there is no evidence for PBS. Holburn et al. (2004) found that person centred planning increased the speed by which people were moved into community care in a study of 19 people living in the United States (US), but the same effect was not seen in an equivalent study in the UK. Robertson et al. (2006) in a longitudinal study of person centred planning for 65 people with learning disabilities in the UK found that the additional cost of introducing person centred planning was US\$1202 per person, with no significant reduction in costs.

In summary there is limited, conflicting and potentially out of date evidence that people with learning disabilities and behaviour that challenges do cost significantly more than people with learning disabilities that do not have behaviour that challenges. Additionally it is not clear what the cause of the additional cost may be other than people with behaviour that challenges are more likely to have more complex needs such as a diagnosis of a mental health problem. If people with learning disabilities and behaviour that challenges do cost more there is currently limited evidence of what is the most clinically and cost-effective strategy for managing this.

Cost-effectiveness or cost?

When policy makers, service commissioners and providers talk about wanting to implement cost-effective interventions what they commonly mean is that they want interventions to be cost saving.

In most economic evaluations the new intervention being evaluated costs more than current treatment. The aim of an RCT is to test the hypothesis that the new intervention is more clinically effective than current treatment or control. If something is more clinically effective but also costs more the aim of a cost-effectiveness analysis is to provide decision makers with additional information on if the intervention results in sufficient additional health benefit compared to current treatment to be worth the additional cost. This information is summarised as an incremental cost-effectiveness ratio: the average cost of the new intervention compared to the cost of current treatment divided by the additional health benefit of the new intervention compared to current

treatment (Drummond et al. 2005). Economic evaluations of new interventions rarely evaluate the cost impact on service providers, also called budget impact analysis (Sullivan et al. 2014) instead focusing on cost-effectiveness. Budget impact analysis though is important when considering how new interventions will be implemented, particularly in learning disabilities.

The provision and commissioning of learning disabilities services is a complex interaction between health care, local authorities, non-statutory services and informal care. Broadly speaking health care are responsible for specialist learning disabilities, acute care and primary care services and local governments are responsible for residential and social care, and education costs in the instance of children and young adults. The increased push for providing care in the community for people with learning disabilities has resulted in a challenge for commissioning services for people with learning disabilities. Resources currently tied up in residential, inpatient or out of area placements need to be freed up to ensure that there are suitable services available for children and adults in the community close to home (Mansell et al. 2007). Children with learning disabilities present a particular challenge to commissioners. Although there has been a significant push to ensure that adults with learning disabilities have suitable accommodation in the community many children still live in specialist residential schools and have high cost out of area placements far from their family (Hassiotis et al. 2008). What commissioners need is more evidence of the cost impact and service reconfiguration implications of providing behavioural and psychological interventions. Some evidence was provided in a report on the cost impact of deinstitutionalisation by Mansell et al (2007) but economic evaluations should aim to enhance this information by reporting not just the cost-effectiveness of new interventions but also the budget impact on different stakeholders.

Cost-effectiveness though should still be an important consideration in economic evaluations of interventions for people with learning disabilities and behaviour that challenges. The limited evidence for cost-savings associated with interventions such as person centred care and the assertion that services will either prevent residential or inpatient placements or help people move into the community may not be due to interventions being ineffective, but instead may be because of the relative inflexibility of learning disabilities services. An intervention may facilitate the movement of someone from inpatient care or residential care into the community or close to home but only if there are suitable services available to them to do so (Knapp et al. 2005, Mansell et al. 2007, Robertson et al. 2006). Trials also rarely have follow-up durations that are long enough to capture the potential cost impact. In xx et al high need users they were in contact with services for 22 months. Follow-up in trials in learning disabilities and challenging behaviour is longer than 12 months in only one third of trials (Heyvaert et al. 2010), with 10-months considered a long follow-up duration (Ali et al. 2015). As a result the full impact on costs of reductions in challenging behaviour is

potentially not captured. Due to the difficulties in capturing cost-savings some researchers have emphasised the importance of measuring the quality of life improvements of interventions for people with learning disabilities and challenging behaviour (Robertson et al. 2006). If an intervention is cost neutral but results in significant quality of life gain the intervention would be considered cost-effective.

Economic evaluations of learning disabilities services commonly do not include quality of life as their outcome when calculating their incremental cost effectiveness analysis or cost per gain in outcome (Romeo and Molosankwe 2010). Part of the problem is that the questionnaire recommended for cost-effectiveness analyses in the UK to make the results generalizable across programmes or work, EuroQol's EQ-5D, may not be acceptable or reliable measure of quality of life for people with learning disabilities.

Future research

Evidence of the clinical and cost-effectiveness of behavioural interventions such as PBS is increasing. A recent before and after study of 5 adults with learning disabilities and behaviour that challenges found that PBS was effective in decreasing the severity and frequency of behaviour that challenges at a cost of £2,296 per week (Iemmi et al. 2015). An RCT currently in progress, evaluating the clinical and cost effectiveness of training staff in PBS versus usual care will also help to improve the evidence base further. The trial aims to recruit 246 adults to the trial with 12-months follow-up (Hassiotis et al. 2014). In addition to providing information on a mechanism for implementing PBS in services it presents an opportunity to increase the evidence for the cost of challenging behaviour in learning disabilities.

More high quality research though is required in the area of psychological and behavioural interventions for people with learning disabilities and behaviour that challenges. Health economists conducting economic evaluations in learning disabilities should ensure that they include a measure of cost-effectiveness which includes improvements in quality of life as well as budget impact taking into account the role of different government and non-statutory agencies and informal carers.

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