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Increasing participation of people with learning disabilities in bowel screening

Jonathan Gray

ABSTRACT

Learning disability nurses have a key role in addressing the health inequalities experienced by people with learning disabilities. People with learning disabilities are less likely to participate in bowel screening than other sectors of the population, despite there being evidence of this population being at an increased risk of developing bowel cancer. There are a range of barriers at individual and systemic levels that impact on participation in bowel screening by people with learning disabilities. Actions to address these barriers have been identified in the literature and learning disability nurses are a key agent of change in enabling people with learning disabilities to participate in the national screening programmes.

Key words: Learning disabilities ■ Health inequalities ■ Learning disability nursing ■ Bowel screening ■ Bowel cancer

A key aspect of the learning disability nursing role is to address the health inequalities experienced by people with learning disabilities through supporting access to mainstream services (Scottish Government, 2015). Despite the increasing life expectancy of people with learning disabilities there remain significant disparities between this population group and people without learning disabilities (O'Leary et al, 2017) with life expectancy for people with learning disabilities remaining on average 20 years less than for the population without learning disabilities. Some of the reasons for increased mortality are related to causes that are preventable through access to national screening programmes or amenable to change through the provision of better quality health care (Heslop et al, 2013). Although it is generally accepted that deaths from cancer are less common in people with learning disabilities than in the rest of the population, there is evidence that people with learning disabilities have higher rates of bowel cancer than other sections of the population (Glover et al, 2017). Bowel cancer is associated with obesity, poor diet and lack of exercise, all of which are areas of concern in the health of people with learning disabilities, suggesting that enabling access to bowel screening by this group should be a priority area of focus for learning disability nurses (Read and Latham, 2009).

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Bowel cancer is the fourth most common cancer in the UK (Cancer Research UK, 2016) and the second most common cancer-related cause of death (Read et al, 2016). Across the UK around 41 000 people are diagnosed with bowel cancer each year and it is more common in people over 50, especially men (Cancer Research UK, 2016). All four nations of the UK have bowel screening programmes in place where people are automatically invited to participate every 2 years, although the eligible age range differs in some of the nations. In England, Wales and Northern Ireland the eligible age groups are men and women between 60 and 74, while in Scotland the eligible age groups are men and women between the ages of 50 and 74 (Cancer Research UK, 2015). The aim of the screening programmes are to find bowel cancer at an early stage in people who have no symptoms and to find other changes in the bowel such as pre-cancerous growths called 'polyps'. If bowel cancer is diagnosed early it can be amenable to treatment and there are high survival rates if treatment is started early in the disease process (Read and Latham, 2009). It is estimated that bowel screening reduces the risk of death from bowel cancer by approximately 16% (Hewitson et al, 2007).

Three main methods of bowel screening are in common use. These are the faecal occult blood test (FOBT), colonoscopy and sigmoidoscopy. In the four countries that comprise the UK the FOBT is used, while other nations such as the USA and Canada use colonoscopy and sigmoidoscopy as preferred options for screening. Scotland is due to make a move to using the faecal immunochemical test (FIT) in 2018. This test has a number of advantages over the FOBT as it is easier to complete, requires only one sample from one stool (as opposed to two samples from each of three stools), and measures the level of blood in the stool rather than just providing an indication that blood is present (NHS Health Scotland, 2017).

The literature on the participation in bowel screening by people with learning disabilities is limited in scope. Regardless of model, uptake of bowel screening has consistently been found to be lower for people with learning disabilities than for people without such disabilities (Osborn et al, 2012; Horner-Johnson et al, 2014; Bowler and Nash, 2015; Ouellette-Kuntz et al, 2015; Joel and Marcellino, 2016; Deroche et al, 2017). Uptake of bowel screening in England is consistently lower in people with learning disabilities than the rest of the population (Glover et al, 2014; Bowler and Nash, 2015; Joel and Marcellino, 2016). In the south west of England Joel and Marcellino (2016) found the uptake in bowel screening in people with learning disabilities

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in primary care practices in their area was 8%. In the north east of England Bowler and Nash (2015) found that uptake of bowel screening by people with learning disabilities in their area was 47%, which was lower than the national average at that time. In reviewing data from the Joint Health and Social Care Self-Assessment Framework for the years 2012/2013 Glover et al (2014) found that for England as a whole the median level of uptake was 25.8% in comparison with 39.4% for people without learning disabilities. There are no published papers relating specifically to the participation of people with learning disabilities in the bowel screening programmes in Scotland, Wales or Northern Ireland. For the UK as whole Osborn et al (2012) found that over a 10-year period people with learning disabilities were less likely to have participated in any of the national programmes than the rest of the population. When focusing specifically on bowel screening, the study found that uptake levels for people with learning disabilities were lower throughout the 10-year period. Although increases in uptake of bowel screening were apparent across all population groups, the gap between people with learning disabilities and those without learning disabilities remained fairly constant.

Barriers to participation in bowel screening

Participation in bowel screening is initiated by a letter and accompanying information being sent out to potential participants in the eligible age ranges. Evidence suggests that adults with reduced literacy skills, including people with learning disabilities, often avoid written health information (von Wagner et al, 2009). The lack of accessibility of the invitation letter and accompanying information has proved to be a barrier to participation (Marriott et al, 2014; Bowler and Nash, 2015; Joel and Marcellino, 2016; Read et al, 2016), with some of the language used in these documents being described as being too scientific to be easily understood (Read et al, 2016). The instructions around how to complete the bowel screening test have been identified as being confusing and unclear for people with learning disabilities (Heslop et al, 2013; Bowler and Nash, 2015; Joel and Marcellino, 2016; Read et al, 2016).

Bowler and Nash (2015) found that some people with learning disabilities felt embarrassed about being asked to conduct the screening test. Not having someone available with whom the person is comfortable to talk can exacerbate this issue (Read et al, 2016). People with learning disabilities felt that they were not given the opportunity to talk about bowel screening, with some feeling that there was a need to raise awareness among support staff of the importance of participating in the screening programme (Read et al, 2016). A lack of knowledge among support staff about screening led to them not recognising the importance of facilitating access by people with learning disabilities (Read and Latham, 2009; Heslop et al, 2013; Read et al, 2016). People with learning disabilities may have difficulty with the planning needed to complete the test and, for some, have practical physical difficulties in completing the necessary steps (Joel and Marcellino, 2016). The need for support for people with learning disabilities goes beyond just raising awareness and increasing knowledge of the screening test to providing practical help in some cases (Heslop et al, 2013; Read et al, 2016). In some instances the

lack of reasonable adjustments (e.g. simplifying language) to aid participation has been found to decrease the likelihood of people with learning disabilities undertaking screening (Heslop et al, 2013).

The link between increasing deprivation and increasing levels of health inequalities for people without learning disabilities is well established (Cooper et al, 2015). However, Osborn et al (2012) found that measures of deprivation did not impact on the likelihood of people with learning disabilities participating in bowel screening. Issues around an individual's mental capacity to consent to participate in the programmes has been identified as an additional barrier, with failures to use the legal frameworks available to enable people to participate limiting uptake (Bowler and Nash, 2015).

There are barriers at a systems level that impact on the uptake of bowel screening by people with learning disabilities. These include the absence of links between the centres organising the cancer screening programme and primary care and specialist learning disability services (Bowler and Nash, 2015). This prevents people with learning disabilities being identified on the screening centre databases and means that adjustments cannot be made to the invitations to participate in the programme (Marriott et al, 2014; Bowler and Nash, 2015; Joel and Marcellino, 2016). GPs receive notifications from the screening centres if an individual fails to participate; however, frequently, due to a lack of pathways, this information is not shared with specialist learning disability services who have the necessary skills to assist people to participate (Bowler and Nash, 2015).

The role of the learning disability nurse in increasing participation

Learning disability nurses have a key role in facilitating access to services, including screening programmes, by people with learning disabilities (Atkinson et al, 2010; Mafuba and Gates 2015). Integral to the role of learning disability nurses is the ability to understand the health inequalities experienced by people with learning disabilities and to advise others on the reasonable adjustments that can be put in place to address health inequalities (NHS Education for Scotland, 2013). The literature identifies a number of areas where learning disabilities can contribute.

At an individual level learning disability nurses are ideally placed to deliver education programmes to people with learning disabilities, their families and paid carers. Enabling access to information that is accessible and understandable for people with learning disabilities helps to enable participation. The use of films and audio information (Joel and Marcellino, 2016; Read et al, 2016) has been found to have a positive impact on levels of participation. Training and education programmes helped to increase the likelihood of people participating in the screening programme (Bowler and Nash, 2015; Joel and Marcellino, 2016). The inclusion of screening kits and body system mannequins were found to enhance accessibility of educational interventions and promoted interest in learning about bowel and other cancers more generally (Read et al, 2016). Having people who are knowledgeable about screening and able to offer practical support has been found to enable

KEY POINTS

- People with learning disabilities are at increased risk of developing bowel cancer yet have lower participation rates in bowel screening programmes
- Barriers to participation in bowel screening by people with learning disabilities exist at both an individual and systemic level
- Learning disability nurses have a key role in improving access to mainstream services, including national screening programmes

participation (Read et al, 2016). These include not just formal support from specialist learning disability health services but also from within formal and informal care support networks. Ensuring that paid social care staff have an increased awareness of the benefits of participation in screening programmes can play a part in enabling people with learning disabilities to participate (Joel and Marcellino, 2016; Read et al, 2016). Some people require the physical assistance of a carer to complete the screening test due to physical or cognitive impairment (Joel and Marcellino, 2016) and learning disability nurses can help ensure that staff and family members have the necessary skills to provide this assistance.

The application of mental capacity legislation to authorise the participation of people with learning disabilities who lack capacity to consent is a necessary component to enable increased uptake in the screening programme (Bowler and Nash, 2015; Joel and Marcellino 2016). In England and Wales, the Mental Capacity Act 2005 provides the legal framework for the provision of care and treatment for people who lack capacity to consent themselves. Under the Mental Capacity Act 2005 capacity can be assessed by a range of professionals, including learning disability nurses (Department for Constitutional Affairs, 2007). As part of their broader role in addressing health inequalities, learning disability nurses would be ideally placed to assess the capacity of people with learning disabilities who have been invited to participate in the bowel screening programme. Similarly, in Northern Ireland the Mental Capacity (Northern Ireland) Act 2016 provides a tiered approach to addressing issues of lack of capacity to consent to medical treatment, with routine procedures being able to proceed provided there is a reasonable belief that the person lacks capacity and the intervention is in their best interests (Davidson, 2014). In the case of bowel screening, the learning disability nurse would be able to use their expertise to assess understanding and work with others to decide whether or not the screening should proceed.

In Scotland issues of capacity in relation to healthcare are governed by the Adults with Incapacity (Scotland) Act 2000. The legislative framework for capacity in Scotland is structured in a way that would require a medical practitioner to assess and certify incapacity to consent to participate in screening programmes; however, the Code of Practice (Scottish Government, 2010) is clear that medical practitioners should draw on the experience of others to inform their assessments. Learning disability nurses are in a prime position to consider issues relating to the capacity of the individual to participate in the screening programme and to ensure that legal frameworks around capacity to consent to treatment are adhered to throughout the process (NHS

Education for Scotland, 2013). They have the underpinning knowledge around how impairment can impact on the individual's ability to understand information and have the skills and knowledge to advise on how information is presented to maximise the individual's ability to understand and give consent. Through sharing these skills, learning disability nurses can act as a resource for the wider multidisciplinary health and social care teams that are involved in supporting people with learning disabilities.

Engagement by mainstream services with learning disability nurses is one route that could enhance knowledge and skills in working with people with learning disabilities and others who may experience similar types of impairments (Atkinson et al, 2010). Part of this engagement would allow learning disability nurses to lead work to address some of the systemic issues that act as barriers to the participation of people with learning disabilities in bowel screening. This could include ensuring that there are effective information-sharing processes between primary and specialist care services so that when someone who is known to have a learning disability fails to complete the bowel screening test this can be followed up by specialist services to see if the person would like additional help to complete the test.

Ensuring that there are connections between primary care and specialist services increases participation in bowel screening (Marriott et al, 2014; Bowler and Nash, 2015; Joel and Marcellino, 2016). Bowler and Nash (2015) developed a local pathway that enabled referral to be made to specialist learning disability services following notification of non-participation being made to the person's GP. Joel and Marcellino (2016) took the approach of specialist learning disability nurses proactively sending information to primary and secondary care services in their area about the project and attending meetings in these services. Through this they were able to raise awareness of the additional support available to people with learning disabilities to access screening. In the model developed by Tucker et al (2016) learning disability teams were informed by the cancer screening hub that an individual with a learning disability was invited for screening and were then requested to carry out an assessment to see if additional support was required. In the south west of England a learning disability screening liaison nurse followed up people with learning disabilities who had not participated in screening and offered support to the person and carers on how to take part in the screening programme (Turner et al, 2013).

Conclusions

There is clear evidence that people with learning disabilities are less likely to participate in bowel screening than other sections of the population, yet this is one of the key preventive programmes that impacts on the health of this population. There are a range of barriers that inhibit participation at individual, support and system levels, but there is evidence to suggest that these barriers can be addressed. Learning disability nurses are key to addressing these barriers and, through working across organisational boundaries, can begin to address the inequalities that people with learning disabilities face. The available evidence suggests ways in which the barriers at all levels can be addressed

to improve levels of participation in bowel cancer screening by people with learning disabilities. **BJN**

Declaration of interest: none

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CPD reflective questions

- People with learning disabilities face a range of barriers to accessing effective health care. Can you think of any potential barriers to people with learning disabilities accessing care in your area of practice?
- How does your workplace ensure that reasonable adjustments are made to enable people with learning disabilities to access your services?
- Can you think of one thing that you could do that would make it easier for a person with a learning disability to access care in the setting in which you work?

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