

Using the Theoretical Domains Framework to improve access to cervical screening for women with intellectual disabilities

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Summary

Regular attendance for screening can prevent most cervical cancers, but women with learning disabilities are potentially at greater risk of developing and dying from cervical cancer because current screening processes and practices create inequitable barriers, restricting their access to screening. In response, an objective of Public Health England's 2018 'Screening Inequalities Strategy' was to reduce inequalities through 'evidence-based contributions' to policy and best practice (Public Health England, 2018b). Health psychologists could contribute to this objective by facilitating collaborative work with cervical screening practitioners using the Theoretical Domains Framework. This enables health psychology evidence and theory, combined with the perceptions and experiences of screening practitioners, to identify relevant barriers and enablers to access, and this information can inform interventions and policy changes to make cervical screening programmes more open and effective for women with learning disabilities.

Introduction

Females with intellectual disabilities experience poorer health and wellbeing across the lifespan, with life expectancy 20 years below that of the general population (Hatton et al., 2016). Healthcare providers have a legal obligation under the 2012 Health and Social Care Act to reduce health inequalities (National Archives, 2012), but women with learning disabilities continue to suffer 'endemic' healthcare discrimination (Chapman et al., 2018).

Health screening identifies medical conditions in presumed healthy people at risk of developing certain illnesses. Early diagnosis through screening reduces the need for more invasive treatments and has improved health outcomes for bowel, breast and cervical cancers (National Health Service, 2018). In England, the cervical screening programme (CSP) invites all women with a cervix aged 25-65 for screening every 3 to 5 years. The test detects abnormal cell changes in the cervix and the human papillomavirus (HPV). HPV is a common sexually transmitted disease which is responsible for 99.8% of cervical cancers in the UK (Cancer Research, 2019) and is easily transmitted through skin-to-skin contact of the genital area including vaginal, oral or anal sex (National Health Service, 2019).

It is estimated that 375,000 women in England live with a learning disability (Emerson et al., 2011). Undiagnosed disabilities may make this figure much higher, with an estimated 77% of adults with intellectual disabilities absent from GP disability registers and described by Hatton et al. (2016) as the hidden majority. The evidence about rates of cervical cancer among women with learning disabilities is limited to selective, institutionalised populations of women with severe learning disabilities. Studies showed smear test abnormalities in up to 4% of those samples, compared with 7% for women without learning disabilities (Wood & Douglas, 2007). These figures contribute to underestimates of the risk for cervical cancer among this group because they do not represent the larger population of women with moderate or undiagnosed learning disabilities who live in the community and are more likely to be sexually active (Emerson et al., 2012).

The success of population-based screening depends on regular attendance (Waller et al., 2009) and the UK national attendance target for cervical screening is 80% (Public Health England, 2019a). However, the attendance rate for eligible women with learning disabilities is just 31%, compared with 73% for women with no learning disability (Primary Care Domain, 2019), and restricted access to cervical screening services was recognised as a key cause of low attendance for women with learning difficulties (Public Health England, 2019b).

Public Health England's Screening Inequalities Strategy acknowledged their moral and legal obligation to challenge inequities in health screening, but also recognised that there are only limited opportunities for screening programme workers to challenge inequities at an organisational level (Public Health England, 2019b). Health psychologists also have an important role to play in reducing health inequities. They could collaborate with healthcare providers to develop and implement theory-driven interventions, enabling cervical screening programmes to improve access for women with learning difficulties at the point-of-contact stage, within local healthcare practice. They could also be involved in collaborative lobbying and advisory efforts to implement the Screening Inequalities Strategy by providing evidence-based pathways to identify inequities. The objectives of the Inequalities Strategy included providing evidence and tools to "identify screening inequalities ... using research to identify and address barriers that prevent people and communities from engaging with or participating in screening" and "recognising and supporting best practice and making evidence-based contributions to policy debate and to the wider system that support reductions in health inequalities." (Public Health England, 2019b, p. 17). This article outlines a collaborative model for developing such interventions and policy objectives using the Theoretical Domains Framework.

A collaborative approach

Health psychologists can use evidence and theory in discussion workshops to help guide healthcare professionals to identify aspects of best and worst practice. This should be a collaborative alliance between psychologists and healthcare practitioners in interdisciplinary teams, including clinicians and administrators, to build multi-level partnerships between practitioners and management.

This approach increases motivation to change and gives ownership of the initiative to those who deliver the service (Graham et al. 2002). It has the potential to liberate frontline healthcare professionals from the restrictions of everyday roles to discuss openly the facts and issues related to inequitable access to cervical screening for women with intellectual disabilities, sharing best practice and identifying the barriers and enablers to more effective services.

The health psychologist's role is firstly to facilitate the process, secondly to provide evidence and theory to inform the interpretation of practitioners' experiences and

perceptions, and thirdly to guide the translation of those insights into interventions to improve the services. Using evidence and theory in the development of service interventions makes them much more likely to be effective, but only 22.5% of healthcare guidelines and interventions in one review were based on evidence-based theory, and when behaviour change theories were employed, interrelated concepts were often used, which reduced opportunities to identify effective components (Cane et al., 2012).

The Theoretical Domains Framework

The Theoretical Domains Framework (TDF) is a framework to guide behaviour change interventions, with 16 domains including knowledge, skills, role identity, environment, resources, belief in ability and belief in consequence. It provides a structure for discussion workshops on inequities in healthcare that is evidence-based and has contributed to developing complex interventions such as clinical guidelines for multiple clinical and administrative healthcare workers (Atkins et al., 2017).

For example, in the development of an intervention to improve triage, transfer and treatment of stroke patients in emergency departments in Australia, the TDF combined evidence-based behaviour change theory with consideration of practical issues such as feasibility and acceptability. Analysing documented cases identified relevant practitioner behaviours, and workshops with practitioners identified further barriers and enablers. These informed an intervention that involved behaviour change techniques including interactive education for clinicians, site support, and use of local clinical opinion leaders (Craig et al., 2017).

Discussion workshops

The emphasis of the workshops should be on core elements of behaviour change, such as: *Who needs to change? What behaviour is being changed? When, where and how often will this take place? What outcome measures are applicable?* (Atkins et al., 2017). Group discussions about equitable access to the cervical screening programme that are based on the TDF can more easily incorporate evidence-based psychological theory, which allows workshop participants to discuss the issues without need for theoretical validation.

Table 1. Sample of workshop prompts for health providers related to the TDF to assess causes of inequitable cervical screening access.

Theoretical domains	Prompts for discussion
Knowledge	Do you understand the meaning of equitable cervical screening access? What, if any, recommendations/guidelines or protocols are you aware of?
Skills	What skills do you think are needed/helpful in giving a woman with a learning disability the opportunity to make her own decisions about attending cervical screening?
Social/professional role identity	To what extent do you see providing equitable access to cervical screening for all women as part of your role?
Beliefs about capability	How confident do you feel providing reasonable adjustments (such as longer appointments or explanations of the procedures) for women with learning disabilities during cervical screening?
Beliefs about consequences	What factors influence your own decision to consider someone ineligible for cervical screening?
Environmental context and resources	What factors support or hinder you in providing equitable access to cervical screening for all women? How do the systems in place support you to provide an equitable screening service?

NOTE: Adapted from Chater et al. (2019)

Some of the avoidable causes of inequities can be located by identifying recurring themes from workshop discussions of the views, opinions and experiences of front-line service providers. Several themes for discussion come from published evidence about inequalities for women with learning disabilities and cervical screening including:

- *Motivation* (healthcare providers believing that low cervical cancer rates in women with learning disabilities mean that screening is not justified) (Hanna et al., 2010);

- *Uncertainty of role description and embedded culture* (system-wide inequitable healthcare for this group) (Ali et al., 2013);
- *Lack of knowledge* (inadequate registers of patients with learning disabilities) (Wood & Douglas, 2007);
- *Leadership* (no coordination between different teams) (Wood & Douglas, 2007);
- *Assumed ineligibility* (due to assumed sexual inactivity in this group) (Parish et al., 2013); and
- *Information* (lack of access and knowledge of user-friendly information about the Cervical Screening Programme that is tailored for this group) (Wood & Douglas, 2007).

A set of prompts for discussion workshops, adapted from a previous application of the TDF (Chater et al., 2019), is given in Table 1.

A worked example

‘Assumed ineligibility due to sexual inactivity’ was identified as a barrier for access to cervical screening in several studies (Cobigo et al., 2013; Osborn, 2012; Waller et al., 2009; Wood & Douglas, 2007). The research evidence suggested this assumption was not true and that women with learning disabilities are more sexually active than is often assumed (Gesualdi, 2006). Women with learning difficulties also encounter barriers to open discussion of their sexual history or activity, such as the presence of a carer during a consultation, which may make discussion difficult or embarrassing. Disabilities affecting communication can also prevent women with learning disabilities from fully explaining their sexual history, and non-consensual sexual activity may be difficult to disclose (Cobigo et al., 2013).

The relevant domain in the TDF for assumed ineligibility would be *beliefs about consequences*, because the practitioner concerned has decided to class someone as ineligible for screening as they believed the person was sexually inactive, so not at risk of cervical cancer. Their beliefs about the consequence are that not inviting the person to screening would have no health implications, whereas inviting them for screening could cause an unnecessary and invasive procedure. A practitioner with those beliefs would probably decide not to invite the person for screening.

After discussion and analysis of the issue of assumed ineligibility, there might follow a recommendation for policy change, for example, for Public Health England to issue guidelines to ensure that no women of eligible age should be assumed to be sexually inactive by cervical screening services. The analysis could also prompt future research into more accessible and effective ways for women with communication difficulties to disclose their sexual history and activity.

Inequities in cervical screening for women with intellectual disabilities need not reflect individual practitioners' prejudices, for some organisational aspects of cervical screening programmes show signs of a standard, 'one size fits all' approach, which disadvantages minorities and people with disabilities. Specialised cervical screening resources for women with learning difficulties do exist (Jo's Cervical Cancer Trust, 2018). However, a discursive study of health workers' attitudes to cervical screening for women with learning disabilities found a preference for generalised screening material, believing this was more equitable for patients and simpler for practice nurses to implement. There was also a consensus among healthcare workers that specialised communication for women presenting with learning disabilities could be insulting or embarrassing (Wood & Douglas, 2007).

Based on existing evidence, cervical screening practitioners' communication with women with learning difficulties could be significantly improved, which should encourage early engagement with this vulnerable group. Organisation-level aspects of screening, as well as national policy for screening, could also be improved in order to enable cervical screening programmes to be adapted to meet the specific needs of women with learning difficulties.

The patterns in this specific example of learning difficulties and cervical screening apply across a wide range of minority groups and health services, for making assumptions about the consequences of denying access to healthcare for vulnerable groups and rejecting person-centred communication risks health inequities across the entire health system.

Conclusions

The Theoretical Domains Framework is an evidence-based method that can help identify and address the causes of discrimination, inequalities and inequities. Tools like the TDF mean health psychologists are well equipped to engage with healthcare practitioners and managers in collaborative efforts to confront the causes of healthcare inequities. This

process can focus on screening practice and behavioural aspects of screening, fulfilling the objectives outlined in documents like the Screening Inequalities Strategy, and addressing system-wide and organisation-level policy issues.

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