

Challenges of colorectal cancer screening in patients with learning disabilities: the way forward

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ABSTRACT

People with learning disabilities (LD) are now living longer; thus, the incidence of cancer within this population is increasing. Available data indicate an excess of digestive tract cancers in people with LD, but colorectal cancer has rarely been specifically studied or extensively reviewed. This is despite risk factors such as being overweight, obesity, and lack of exercise being more frequent in people with LD. Published data showed that the frequency trends slightly higher than that found in the general population. Screening presents a unique opportunity to discover early colorectal cancer, but it is an underused utility in people with LD compared to the general population due to multiple reasons. Furthermore, the clinical presentation is frequently masked, particularly by challenging behaviours, and colorectal cancer is, therefore, often diagnosed late, making treatment difficult due to the advanced stage of these tumours. To improve the colorectal cancer detection rate in people with LD, we recommend that the government may have to review the screening age, provide more resources to support them and their caregivers, educate and increase awareness of the risk factors and signs and symptoms of colorectal cancer.

KEY WORDS: learning disabilities, screening, colorectal cancer.

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INTRODUCTION

Colorectal cancer is the second commonest cancer in women and the third commonest cancer in men, and the UK is one of the top twenty-five countries with the highest rate of colorectal cancer (CRC) [1]. In the UK, the lifetime risk of colorectal cancer is estimated to be about 5% [2]. Early detection and treatment of cancer is the key to success and to achieve this objective screening remains an important tool whereby early cancerous or precancerous lesions are identified before they become advanced or metastatic [3].

Learning disabilities (LD) constitute a group of developmental disorders whereby an individual faces variable degrees of difficulty in understanding new information and learning new skills and is often associated with a variable level of communication problems [4]. People with LD are believed to have a shorter life span as compared to the general population. After cardiovascular causes, cancer is the second most frequent cause of

death in the LD population [4]. Screening of cancer has helped in early diagnosis and management of CRC [5]. Here we present a review article on CRC and LD as CRC is the second commonest cause of death in men and the third commonest cause of death in women and, as mentioned above, cancer as a whole is the second commonest cause of death in the LD population.

METHODOLOGY

We searched different databases such as Cochrane, AMED, Embase, Ovid EMCARE, HMIC, and Ovid MEDLINE with the key words “colorectal cancer, bowel cancer and learning or intellectual disability”. This yielded 217 results. After the initial review, 28 articles were selected. Deduplication of the selected articles yielded 21 articles. However, we used the NHS website, the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) report and the UK Home Office website to gather the required information as well.

UNDERSTANDING LEARNING DISABILITY

The term learning disability represents a wide spectrum of carer-dependent conditions that are characterized by difficulties in understanding new or complex information, learning new skills and, therefore, these people are dependent on carers for their special needs; the level of care required is basically determined by the degree of LD [4, 6-8]. LD are, therefore, classified as mild, moderate, severe and profound depending upon the challenges faced and, therefore, the support the people with LD need. People with the milder form of the disability require a lower level of care as they can communicate to some extent and can perform basic jobs for themselves and, as such, show some degree of independence in their life [6]. According to the NHS, there are about 1.5 million people with learning disability, out of whom around 20% have the severe form of the disability [6].

BURDEN OF COLORECTAL CANCER IN THE GENERAL POPULATION AS COMPARED TO PEOPLE WITH LEARNING DISABILITY: EPIDEMIOLOGY AND TREATMENT

There are very limited data on the incidence of colorectal cancer in the LD population and even those studies have multiple limitations and, therefore, the reported data suggest that the incidence and risk factors for colorectal cancer are similar to those of the general population [4]. There have been case reports suggesting some linkage of LD with CRC syndromes such as APCC and hereditary nonpolyposis colorectal cancer (HNPCC); being case reports they do not represent the general distribution, but they do establish a basis for further research [9]. However, an association between FAP and learning disabilities and low IQ has been described [9]. Although there is not a described syndrome having LD and CRC as components, there have been reports of HNPCC and FAP patients with LD. A Danish data on patients with Turner syndrome showed that patients with mild LD had a higher probability of developing CRC than women in the general population [9]. Studies have shown the prevalence of GI cancers in patients with Down's syndrome but overall the rate of gastrointestinal cancer is lower than in those with LD. The evidence here is mostly case reports which do not tend to represent the trend in the general population; however, these case reports do tend to open up new horizons for further research. So far, given the current data, people with LD are believed to have similar likelihood of developing CRC [9].

CURRENT SCREENING TOOLS FOR COLORECTAL CANCER IN THE GENERAL POPULATION

The national bowel cancer screening programme involves faecal occult blood testing (FOBT) and trials have proved that this screening can reduce the mortality by 16-25% [10]. This is based on detecting occult bleeding every two years in otherwise healthy patients aged

60-74 years. A FOBT kit is sent to the patients along with instructions on how to collect the sample which are then sent to designated laboratories which report the results in a fourteen days' time. If the tests are positive the patients are then further investigated endoscopically on a rapid access pathway [5].

CHALLENGES OF ACCESSING HEALTH FACILITIES AMONGST PEOPLE WITH LEARNING DISABILITIES

Although a number of UK policy documents urge that all people with LD should have equal opportunities to access the health facilities, it is very easy to be distracted from the physical health conditions because of the primary diagnosis of LD, and, therefore, underlying serious health conditions such as cancer are easily missed [4, 11, 12]. This is further complicated by the limited communication skills and comprehension abilities. Both these issues lead to diagnostic overshadowing and ultimately inequality in access to services [11]. The Equality Act 2010 urged all the related bodies to make suitable adjustments to their programmes so that people with LD are included as well. This policy is supported by the NHS Cancer Screening Programme in the documents suggesting people to work on the Mental Capacity Act and the Best Interest Decision [13]. Despite all these efforts, people with LD have a lower participation rate in the screening programme as compared to the general population, around 10% lower [13]. Because of all these factors, the diagnosis of CRC tends to be late in people with LD [9].

HOW FEASIBLE ARE THESE TOOLS IN PEOPLE WITH LEARNING DISABILITIES? THE IMPACT OF IMCA AND CONSENT

Cancer was reported as one of the most common underlying causes of death by the CIPOLD for people with LD [4]. Although the frequency of cancer as an underlying cause of death in the general population is 30% as compared to 20% in the LD population, deaths from cancers hit LD people at a younger age [4].

The report also highlighted that people with LD had a variable degree of involvement in the screening programmes; especially the bowel screening was particularly challenging in engaging the LD patients. The report identified a number of causes of this such as inability to understand the significance of the screening, non-availability of support to complete the process, limited understanding of the carers, and inadequate training of the carers to collect the sample from incontinent patients [4, 11-13]. Because of these facts, the diagnosis is difficult and delayed, leading to deaths being assessed as premature. The best way forward in these situations is to seek guidance from the Mental Capacity Act and the Code of Practice. The Mental Capacity Act sets out the law regarding capacity and consent and the Code of Practice

provides guidance through the correct process in cases where there are concerns that an individual may not have the capacity to take an informed decision. It postulates that if a person lacks the capacity to consent, then the decision should be made on behalf of the person in their best interest [12, 13].

RIGHT APPROACH OF DEALING WITH PEOPLE WITH LEARNING DISABILITIES AS RELATES TO BOWEL SCREENING

All screening programmes require participants to give informed consent before testing. People with LD should be assumed to have the capacity to consent to the test unless there are good reasons to think that they lack the ability to make this decision at this time [12]. Where an individual is considered to lack the capacity to consent, the staff involved would have to decide if it is in the individual's best interest to be screened or not [12, 13]. Where the test is non-invasive and painless, such as bowel screening, the decision to proceed would depend on behavioural compliance, as screening is likely to be in the patient's best interests [13].

The initial decision should be specific to providing the faecal smears for the bowel screening test. As this is not invasive, carers can make this decision. However, a positive test will usually lead to further investigation. If the person lacks the capacity to consent to this, a formal best interest decision will be required, for which it will be necessary to discuss with the friends and family of the patient as well as a range of other professionals and carers. This will be arranged by the specialist screening practitioners at the first hospital appointment. This possibility should not affect the decision to complete the initial screening test; it is appropriate to ensure that relatives are aware that the process is happening in case a subsequent decision is required [13]. This is the point where most of the patients with LD miss out on bowel scope, which has higher diagnostic yield and accuracy as compared with FIT or FOBT. The process needs appropriate education and training of the care providers as it is important to inform the care provider that having a negative FIT does not completely exclude CRC because of the low sensitivity (25%) of this test [12-14].

ARE PEOPLE WITH LEARNING DISABILITIES DISADVANTAGED IN TERMS OF SCREENING? THE CIPOLD REPORT

People with LD, given their health and social care requirements, have varied needs when it comes to screening for CRC. Two thirds of the patients have problems with independent mobility, half of them have visual disability, and a quarter have hearing challenges, with one fifth having problems with both hearing and vision. Dementia affects 14% of people with LD, further adding to the challenges of counselling and consent of LD people for screening. Moreover, the hindrance in communi-

cation also poses a challenge to the provision of health care. A survey showed that 12% of people with LD never had an annual check-up. According to the CIPOLD report, 64% of people with LD were living in care homes at the time of their deaths and, therefore, required 24-hour care. This social dependency is a strong factor in determining the response to the national screening programme. Given the above health and social factors, it is obvious that people with LD are at a disadvantage as regard screening for bowel cancers.

DO PATIENTS WITH LEARNING DISABILITIES HAVE POORER OUTCOME FROM COLORECTAL CANCER AS A RESULT OF LATE PRESENTATION?

The commonest cause of death in England and Wales in 2011 was cancer (30%), slightly more common among men than women and with a median age of death between 75 and 79 years for both gender groups. Deaths from cancer in those with LD were less prevalent (20%), again slightly more common among men, but occurred at a much younger age than in the general population, especially among women (median age of death was 55-59 years) [4]. One reason for the late presentation is their inability to communicate effectively. People with LD have different degrees of dependency defined by their communication needs and, therefore, require different skills on the part of the carers to perceive their feelings [15-19]. The carers need to know how to perceive different facial and behavioural expressions of the patient with LD to make an appropriate inference and act accordingly [15, 20, 21].

DO WE NEED TO REVIEW THE SCREENING AGE FOR PEOPLE WITH LEARNING DISABILITIES?

We have to understand that CRC can be associated with cognitive problems but this should not be confused with LD [22]. At the moment, we lack the data to suggest that CRC is more common in people with LD except for a few behavioural risk factors that are common in people with LD, and these risk factors are modifiable. However, the CIPOLD report reflected the challenges associated with the conventional bowel screening tool in people with LD which should be addressed and the programme should be made more suitable to the needs of patients with LD [4].

WHAT SHOULD THE WAY FORWARD BE? CONCLUSION

People with LD have variable requirements in terms of their health and social care needs. Almost all people with LD have at least one long-term illness. They have a variable ability to perceive and understand information as well as a highly varied way of expressing their emotions and understanding which might not be understood by all the people involved in their care [23]. Keeping this understanding in view, a multi-disciplinary approach should be adopted whereby the Learning Disability Nurses, the

carers and the bowel cancer screening team should make collaborative efforts in including these patients in the screening programme [24]. The carers should be trained in communication skills and the collection of samples. A separate database should be made for people with LD for bowel screening, and for early detection of bowel cancers, as they usually will not communicate any change in bowel habit that they experience. Only the more obvious symptoms such as bleeding, weight loss or obstruction will be picked up by the carers [12].

DISCLOSURE

The authors report no conflict of interest.

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AUTHORS' CONTRIBUTIONS

AA prepared the concept of the paper. ZSA, AE, JP collected and interpreted data. ZSA wrote the article. All authors have given their final approval to the final version of the paper.