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## **Staff perceptions of diagnosis and treatment of Helicobacter Pylori infection in adults living or working in a learning disability service.**

### **Abstract.**

Helicobacter Pylori is a bacterial infection that is prevalent in individuals who live in communal homes and / or have a learning disability. However barriers to assessment and treatment of helicobacter are numerate and include lack of awareness, difficulties with identifying signs and symptoms, lack of national guidance around screening and re-testing following treatment, as well as difficulties with gaining or completion of screening and first line treatments. This paper reviews the experiences, attitudes and beliefs of staff supporting individuals with a learning disability regarding identification, treatment and preventing the spread of Helicobacter Pylori, which were explored during two focus groups with clinical staff working in the National Health Service and independent sector. In conclusion, professionals need greater awareness of Helicobacter Pylori, the need for routine screening in people with a learning disability, knowledge about adverse effects of screening and treatment and preventative measures that can be employed.

### **Background / rationale.**

Helicobacter Pylori is a bacterium that lives in the stomach gastric mucosa layer and is a class 1 carcinogen that increases risk of stomach and duodenum ulcers, gastro-oesophageal reflux disease (GORD) and stomach cancer. Stomach and duodenum ulcers have been found to affect 15% of people with Helicobacter Pylori and a slight increase in the statistics have been reported for stomach cancer (NHS, 2009). Emerging evidence is also linking Helicobacter Pylori with neurodegenerative diseases such as Alzheimer 's disease, multiple sclerosis and glaucoma (Kountouras et al 2017; Doulberis et al, 2018).

Within the general population the prevalence rates for Helicobacter Pylori can be as low as 15% in some areas in England (McNully et al, 2017) and is generally reported to be under 40% (NHS, 2009). In contrast, reported rates of Helicobacter Pylori in populations of people with a learning disability range from 70 to 85% dependent on age, living arrangements and increased levels of maladaptive behaviour or profound learning disability (Clarke et al, 2006; Wallace et al, 2004; Douraghi et al, 2011). Furthermore, prevalence rates appear to correlate with health comorbidities and level of support needs as demonstrated by higher prevalence rates of GORD in individuals with severe and profound learning disability (Hoghton and Hounslow, 2016) and gastric carcinoma (Hardy et al, 2011).

A range of factors may contribute to high prevalence rates. For example, acceptability of the test and treatment for Helicobacter Pylori may have implications for screening of this vulnerable patient group. In addition, difficulty in communicating symptoms and limitations in capacity to make decisions for treatment options as well as an asymptomatic presentation, poor understanding by health professionals and limited staff resources leading to complications accessing primary care centres may further elude people with a learning disability from treatment options (Wallace et al, 2003).

The increased risk of reoccurrence following successful treatment for Helicobacter Pylori has also been highlighted in the literature, with a seven fold increase being found in people with a learning disability compared to reoccurrence in the general population (Wallace et al, 2004). It is reasonable to suggest that this high rate of recontamination is due to the likelihood of other service users and

staff in the individual's home also being found as positive on screening for Helicobacter Pylori. Adjusted odd's ratios of 1.98 (De Schryver et al, 2007) have indeed been found in staff members working with people who have a learning disability compared to controls. De Schryver et. al. (2007) conclude that 49% of the attributable risk, in logistic regression analysis, was faecal contact and caring for individuals who need support with personal care including bowel management. Vyse et al (2002) reported that around 80% of people with Helicobacter Pylori were asymptomatic which explains why Helicobacter Pylori often remains undetected in staff teams supporting people with a learning disability. It is thus important to raise awareness of Helicobacter Pylori in both staff and the service users that they support.

Despite the serious pattern emerging a dearth of literature exists which specifically applies to individuals with a learning disability and their families or carers. Many studies previously cited are conducted prior to or following the closure of the larger institutions, thus the risks and prevalence rates are likely to have changed with the changing socio cultural context in which these individuals reside. Further studies are now needed to consider the current issues with identification, screening and treatment of Helicobacter Pylori and how to best educate the workforce to support individuals with a learning disability to use preventative strategies. An exploratory study was felt appropriate due to the lack of contemporary evidence that is available to investigate helicobacter pylori in people with a learning disability which considers the perceived barriers for staff and service users in identifying, treating and preventing the spread of the bacterium.

Aims.

The overall aim is to explore issues around the diagnosis and treatment of Helicobacter Pylori in people with a learning disability. This is divided into two main objectives.

Objective 1: To gain insight about the current attitudes, beliefs, experiences and behaviours of staff working with people with a learning disability who are undergoing assessment and / or treatment for Helicobacter Pylori.

Objective 2: To understand issues related to barriers encountered when using preventative strategies, completing assessment and treatment of Helicobacter Pylori in people with a learning disability

### **Methodology.**

Design.

To address the research questions, a qualitative descriptive research study was undertaken aiming to identify the prevalence of staff supporting individuals through testing for Helicobacter Pylori perceived barriers to identifying signs and symptoms, screening and treatment as well as perceived knowledge regarding preventative strategies.

Focus groups were deemed appropriate to gain insight about staff experiences. A total of 14 services were approached, following information about the study being provided two service managers agreed to facilitate focus groups. Staff were reassured that this was not an evaluation of their knowledge but was interested in finding out about their experiences in supporting service users with a learning disability. Therefore, information regarding Helicobacter Pylori was provided to potential participants in advance of the focus groups. Prior to these groups participants may have completed

further independent searches about the topic and had time to consider how this impacts on their practice .

#### Participants.

Managers of GP practices, NHS staff attending CCG meetings, residential care home managers from the independent sector and NHS management team were contacted by a research assistant to seek their interest in the study. Potential participants were then sent the information sheet including data and facts about Helicobacter Pylori in people with a learning disability and an electronic invitation letter with a contact email address.

The two focus groups included 16 participants, 7 nurses from a range of NHS Services for people with a Learning Disability, including managers and senior staff nurses working across a number of residential services. In addition 7 Child and Adult Nursing practitioners, 1 Mental Health Nurse and 1 Learning Disability Nurse employed in an independent sector organisation participated in the second focus group. All of the participants currently worked in services whose aim is to support people with a learning disability. Prior to commencement of the focus groups informed consent was obtained from all participants.

#### Data collection .

Two semi-structured focus groups were conducted with staff working with people with a learning disability to explore attitudes, beliefs, experiences and behaviours.

The following topics were addressed during the focus group:

- Experience and prevalence of supporting service users to gain a diagnosis of Helicobacter Pylori
- Barriers to Helicobacter Pylori screening
- Acceptability of Helicobacter Pylori screening tests and the need for re-testing
- Symptomatic or asymptomatic presentation of Helicobacter Pylori in people with a learning disability
- Staff and service user knowledge regarding Helicobacter Pylori
- Adherence with Helicobacter Pylori treatment and Helicobacter Pylori prevention methods
- How Helicobacter Pylori reinfection can be reduced or prevented.

The overarching themes emerged from the literature which were developed further through discussion with the research team members. These topics were expanded upon in consultation with an advisory group consisting of people with a learning disability. The topics were presented to them in an easy read / pictorial format following an explanation of Helicobacter Pylori and how this impacts on a person's health.

#### Data analysis.

The focus groups were audio recorded and transcribed. The content of this qualitative data was analysed thematically as depicted by Schreier (2012) and thus focussed on selected aspects of the material to systematically describe and code the data. The data was entered in Nvivo in order to enable emergent themes to be coded and thematically analysed across datum to show similarities. The data analysis was conducted by two members of the research team to increase rigour of the results and any conclusions drawn from the analysis.

The emergent themes and examples of data collected were disseminated to the learning disability advisory group to allow their interpretation of the data to be considered, before being circulated to participants to check for credibility.

Ethical approval was gained from the Faculty Ethics Research Committee prior to the commencement of this research study and from the National Research Ethics Service.

## **Results.**

The data from the two focus groups were thematically analysed and six themes emerged: Prevalence, signs and symptoms, diagnosis, re-testing, treatment and knowledge of Helicobacter Pylori. Barriers were an overarching theme evident in the analysis for each of the domains.

### Prevalence

Accurate prevalence figures could not be ascertained from the focus groups due to the limited number of service users that had recently undergone screening. Participants from one of the services reported to know of one service user whose Helicobacter Pylori test which was found to be positive for the bacteria. The prevalence rates of Helicobacter Pylori reported by staff in a different service following initial screening were reported as 1 in 5; while this data was unknown by staff from other service providers due to only service users displaying clinical signs and symptoms being tested. The service user's consultation group reported that they were not aware of anyone being tested for the bacterium which reflects the findings reported above.

When asked the reasons why their own experiences are different than the current picture, members of the focus group believed that the size of the service had an impact as does the type of service provided. The divergence from the literature where the majority of service users were positive for Helicobacter Pylori was explained by staff as resulting from the size and type of service as well as service user needs, abilities and behavioural presentation. In services where service users smear faeces and in larger services participants considered there to be a greater risk for spread on infection.

Therefore indicating that the picture portrayed within previous research completed decades earlier may no longer be a true reflection with one staff member summing this up nicely as:

*“What we haven't got and as we raised with the guy from the NHS improvements is the picture across the country on people reporting on Helicobacter Pylori and doing any work around it.”*

Barriers to identifying signs, symptoms and diagnosis of Helicobacter Pylori.

Identifying signs and symptoms that would indicate that testing is appropriate seems difficult. Different challenges were described by the participants. For example, many service users have minor symptoms or are asymptomatic. Symptoms such as bloating, weight loss, acidic smell to reflux, faecal incontinence, and reduction in appetite are reported as observed indicative symptoms. Communication barriers are also reported as a barrier identifying other symptoms that are typically reported in the literature and behavioural presentation was often attributed to pain or as longstanding behavioural issues around toileting which are more prevalent in people who are on the autistic spectrum and have a learning disability with staff often not considering *Helicobacter Pylori*. These challenges are even more significant due to the fact that many people with a learning disability are already prescribed medications to treat the symptoms or prescribed medications that have side-effects which are attributed to such treatments rather than to *Helicobacter Pylori*. It was thus felt that long-term remedies may indicate the need for testing. This is summed up in the two statements below:

*“It is very difficult.... For instance one gentleman is on Omeprazole and two of them are on laxatives to help them so we may not be able to ... detect exactly what is happening in terms of if they have Helicobacter Pylori. We may not be able to use constipation to think about (identification) and some of them they don't have the regular bowel movement like the others.”*

*“Where people have been on long term remedies like that to see if this could be an indicator that that person should be tested to see if this is an indicator that something like this is going on in them. ...there may be the people that are needing your Gaviscons etc. . that may be experiencing some sort of changes that may be down to Helicobacter Pylori but we don't know”.*

Another challenge related to identifying symptoms is the complexity of the tests. Staff felt that testing should be dependent upon the person's preferences and abilities regarding completing breath tests, giving blood samples and faecal samples. Many people refuse to have blood tests taken, thus a stool sample becomes a viable alternative.

In order for the *Helicobacter Pylori* testing to be valid, the patient or service user needs to interrupt their prescribed medication. This is reported as another challenge for staff, as summed up in one person's statement:

*“We had 1 person that prior to having testing stopping his lansoprazole became really unwell through vomiting;he ended up in hospital .”*

Rates of people being tested within organisations varied dependent on staff knowledge and experiences with no clear guidance on how often to test people who live in different settings or with different behavioural phenotypes.

Annual health checks being completed are not always thorough enough to indicate the presence of *Helicobacter Pylori* requiring staff to request testing as many General Practitioners were noted not to have done this even when service users were symptomatic. Staff in the focus group felt that this may be a result of GPs not wanting to add to the cocktail of medications or increase antibiotic prescribing.

Barriers to treatment, testing and re-testing.

From analysis of the discourse in the focus groups it was evident that despite it sometimes being difficult to ascertain a change in the individual's health it was still felt appropriate to treat

Helicobacter Pylori given the increased risks of ulcers, Barrett's oesophagus and oesophageal and stomach cancers. Alleviation of symptoms was also discussed with one person acknowledging that:

*"We have a service user who we noticed was losing weight at an alarming rate and we eventually discovered that it was Helicobacter Pylori, treated it (Has she been alright since?) She has been, it has taken her a while to build her weight back up again. But I think that because she had such an upset tummy she was not eating and because she is on the autistic spectrum she got out of the habit of eating."*

However, many staff felt that treatment should be closely monitored due to possible reactions to antibiotics and poor compliance if service users find it hard to tolerate the side-effects of antibiotic therapy. Treatment should also be monitored for efficacy with some service users requiring a second course of treatment.

The conjunction with the discourses on testing the topic of re-testing was explored. The focus groups revealed that staff felt that there was no clear guidance on re-testing and that this made it difficult to incorporate it into care planning. Adding a section into the annual health check would act as a reminder in order to ensure that staff were considering an appropriate time for re-testing according to the individuals' presentation as well as the type of services that they use e.g. communal living. This was summed up by one participants comment that:

*"How often are they going to keep doing it (re-testing) every month and how often are you going to keep them on antibiotics? So you have all these issues which is still a question mark for us because we are not able to put that properly down on the care plan as well. Like monitoring symptoms, what symptoms are you going to monitor if you do not see a difference even when before and now there is no difference? What are you going to put down?"*

Preventative strategies.

Many of the nurses taking part in the focus groups were able to recollect learning about Helicobacter Pylori decades earlier and recalled that it was thought of as a problem with institutional living that has been forgotten about with the move to community homes, resulting in a lack of awareness by many staff until someone is diagnosed within the service. Therefore training, easy read literature, flash cards and poster displays were felt to be of benefit to raise awareness of preventative steps that could be taken as well as regarding signs and symptoms to monitor for. This is summed up in the quote below, when participants were asked if there was anything else that they felt could help them in their roles

*"Easy read flashcards saying these are the symptoms to look out for, like you said about poor oral hygiene I didn't know that and it would be useful to have on a card. So if someone was unwell you could have a quick flick through with symptoms or whatever. That might prompt you to think about dental appointment, dental hygiene etc. as a preventative measure."*

Some of the barriers to using preventative strategies were also elucidated on including issues with hygiene including doors, walls, hard and soft furnishings all being a potential source of transferring bodily substances if one person has not decontaminated their hands appropriately following personal care. Secondly the need for staff and families to get checked and the difficulties that this may raise with broaching the subject of hand washing with families. Further preventative strategies around oral hygiene regarded service users with spastic jaws or who are hypersensitive to touch and thus find teeth brushing particularly challenging for them.

In contradiction to previous research showing that individuals with a profound and severe learning disability were at increased susceptibility, in a service that only one out of 5 residents had a positive result for *Helicobacter Pylori* the low incidence was explained by the increased infection control procedures. One staff member highlights this in the following statement:

“we support people who use wheelchairs so they don’t use door handles, don’t touch surfaces and don’t touch each other really ... I think if you do a lot of personal care anyway that people tend to wash their hands a lot. We support a lot of people with eating and drinking, it is amazing how much you can get on your hands when someone is eating. So you are then going to wash your hands again, so there is a lot of hand washing that goes on”

The service user consultation group who reviewed the findings from the study suggested that online materials should be prepared for service users and staff regarding *Helicobacter Pylori* as they felt that it was necessary to raise awareness. Further suggestions involved encouraging service providers to have antibacterial sprays / gels on walls for example by entrances to buildings, dining rooms and bathrooms.

### **Discussion.**

The dearth of contemporary literature available regarding *Helicobacter Pylori* in people with a learning disability means that current prevalence rates are unknown. The reports from staff during the focus group signify that prevalence rates may have drastically reduced or are not being diagnosed since closure of the larger long stay institutions, it was also speculated that the increased use of personal protective equipment, infection control training and staff considerations of hygienic working environments may have helped to reduce possible cross-contamination. However further larger scale studies are required to verify current prevalence rates.

Barriers to testing, treatment and re-testing were evident in the discourse of the staff attending the focus groups. Staff expressed a lack of appropriate guidance regarding when to test, knowledge of *Helicobacter Pylori* and potential signs and symptoms which may be divergent in presentation than that found in literature regarding the general population. Additionally signs and symptoms are often oligosymptomatic and thus only have minimal minor symptoms or asymptomatic which is supported by previous studies such as that conducted by Vyse et al (2002). In line with previous conclusions drawn within existing literature (Wallace et al, 2003), differences in presentation may be a result of communication barriers meaning that people with a learning disability are not able to express discomfort, diagnostic over-shadowing or medications currently prescribed masking symptomology. Thus it is plausible to argue that service users displaying minor symptoms or those taking medications to control gastro-intestinal conditions should be tested for *Helicobacter Pylori* until further guidance is formulated. In addition consideration of *Helicobacter Pylori* at annual health checks offers a conceivable means in which to gain diagnosis within an appropriate time scale, given that blood and faecal samples may already be requested at health checks no additional burden to service users or their carers is likely to be encountered.

Limitations of this research include the lack of service user specific data in order to ascertain the prevalence rates, type of symptoms displayed, length of time the person has these symptoms before screening and barriers to gaining a formal diagnosis. The lack of response attained from G.Ps, Clinical Commissioning Groups and Independent providers increases the risk of bias. Linked to this it is unsure if saturation was reached due to the limited response from healthcare services that agreed to facilitate the focus groups. Therefore further research is needed that covers a larger catchment area



in order to ensure transferability of findings. Different views and experiences may be found in staff who did not attend the focus groups. The low response rate also meant that the sample size from which the data was collected was small and further research is required that considers the prevalence and treatment of Helicobacter Pylori from different services and geographical areas due to differences in prevalence rates reported across different locations (Harvey et al, 2002). Future research should also consider the medications that service users are currently prescribed which may mask some of the signs and symptoms of Helicobacter Pylori and thus suggests the need for screening.

In addition to additional research being warranted the authors also substantiate the voice of participants that further informative resources are required which aim to raise awareness in people with a learning disability, their families and carers regarding Helicobacter Pylori and how to identify, support reasonable adjustments to gain screening and adopt preventative strategies within the workplace.

In conclusion, little consideration has been given to Helicobacter Pylori in people with a learning disability over the last decade. However this remains a critical health concern which can be identified and treated with support. Staff, carers and individuals with a learning disability should discuss with their G.P. having a blood, stool or breath test to check for Helicobacter Pylori. Having assessment of Helicobacter Pylori added to the annual health check will ensure screening is 'routine' and may reduce further complications or symptoms such as reflux and bloating. Monitoring of side-effects to antibiotic treatment if required as well as to withholding medication during testing is advised. Preventative strategies such as good oral and hand hygiene should be used to reduce the spread of this and other bacteria.

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