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Constipation management in people with intellectual disability: a systematic review

Abstract

Background. Constipation can lead to serious health issues and death. This systematic review summarises international research pertaining to the management of constipation in people with intellectual disability.

Method. Studies published from 1990 to 2017 were identified using Medline, Cinahl, PsycINFO, Web of Science, email requests, and cross-citations. Studies were reviewed narratively in relation to identified themes.

Results. 18 studies were reviewed in relation to three themes: laxative receipt; interventions (dietary fibre, abdominal massage and macrogol); and staff issues (knowledge and training). Laxative polypharmacy was common. Studies report positive results for dietary fibre and abdominal massage although study quality was limited.

Conclusion. The main management response to constipation in people with intellectual disability is laxative use despite limited effectiveness. An improved evidence base is required to support the suggestion that an individualised, integrated bowel management programme may reduce constipation and associated health conditions in people with intellectual disability.

Introduction

Constipation is a syndrome defined by bowel symptoms of difficult or infrequent passage of stool, hardness of stool, or a feeling of incomplete evacuation (Bharucha et al., 2013). Constipation can be classified as primary constipation (also referred to as chronic idiopathic constipation (CIC) or functional constipation) and secondary constipation (attributed to comorbid medical conditions or medications) (Sbahi and Cash, 2015).

The concept of constipation is complicated by disagreement among patients and doctors about its nature (Longstreth et al., 2006). Whilst physicians often regard constipation to be synonymous with infrequent bowel movements (usually less than three times a week), patients may have a broader set of symptoms, as while bowel movement infrequency can be distressing to patients it is the quality of, or difficulty associated with, defecation that is the primary determinant of patient-described constipation (Sbahi and Cash, 2015). As such, the Rome III diagnostic criteria for functional constipation (Longstreth et al., 2006) incorporates symptoms such as 'sensation of incomplete evacuation for at least 25% of defecations', and 'straining during at least 25% of defecations'.

The complications of chronic constipation can be serious and life-threatening, including: faecal incontinence (where overflow incontinence may confuse the diagnosis of chronic constipation); haemorrhoids; anal fissure; pelvic organ prolapse; faecal impaction and bowel obstruction necessitating surgery; and bowel perforation and stercoral peritonitis where extremely impacted faeces can compress the colonic wall, causing an ischemic ulcer and subsequent perforation, culminating in stercoral peritonitis and sometimes death (Leung et al., 2011, Serrano Falcón et al., 2016). Faecal impaction can also lead to megacolon (Serrano Falcón et al., 2016). Further, the impairment in health related quality of life (HRQoL) observed in adults with constipation is comparable with that seen in conditions that might be regarded as more 'serious', such as osteoarthritis, rheumatoid arthritis, chronic

allergies and diabetes (Belsey et al., 2010). In children, the level of impairment seen is greater than with gastro-oesophageal reflux and inflammatory bowel disease (Belsey et al., 2010). Early detection and management are crucial (De Hert et al., 2011).

There are a number of reasons underlying a need to focus on constipation in people with intellectual disability. The usual trigger for doctors to consider constipation is the specific mention of constipation by the patient or the communicated history of abdominal symptoms, but patients with intellectual disability may be unable to communicate these (Coleman and Spurling, 2010).   In people with intellectual disability, pain from constipation may present as distress, sleep disturbance or behavioural changes (Coleman and Spurling, 2010), and may be associated with behavioural problems such as aggression and self-injury (Bosch et al., 1997, Christensen et al., 2009, Carr and Smith, 1995). As a result, constipation may be missed.

Constipation can have serious consequences for people with intellectual disability if it is not identified and managed appropriately. Constipation constitutes an ambulatory care sensitive condition (ACSC) for people with intellectual disability (Balogh et al., 2011). A Canadian study on hospitalisation rates for ACSCs found that the hospitalisation rate for constipation for people with intellectual disability was 7.9 times higher (95% CI 4.4, 14.2) than for people without an intellectual disability (Balogh et al., 2010). In England, constipation was found to be one of the common causes of emergency hospital admissions for ACSCs (Glover and Evison, 2013). Constipation can also lead to death. The Safeguarding Adults Board in Suffolk, England, commissioned two Serious Case Reviews in early 2014 into the deaths of two people with intellectual disability (Flynn and Eley, 2015b, Flynn and Eley, 2015c), both of whom died from complications arising from constipation (Flynn and Eley, 2015a).

Several factors put people with intellectual disability at increased risk of constipation. Many medicines are constipating (NICE, 2015) and people with intellectual disability are more likely to be prescribed some of these. For example, constipation is a common side effect of different antipsychotics (De Hert et al., 2011) and people with intellectual disability are much more likely than others to be prescribed anti-psychotic medications (Glover et al., 2015). Progression from constipation to ileus, intestinal obstruction, bowel ischaemia, megacolon and death is not uncommon, particularly in patients (not necessarily with intellectual disability) prescribed clozapine (Every-Palmer et al., 2017). People with intellectual disability are also more likely to have poor diet (Humphries et al., 2009), physical mobility limitations (Cleaver et al., 2009), and low levels of physical activity (Emerson, 2005, Robertson et al., 2000), all factors associated with constipation (Mugie et al., 2011). People with Down syndrome are more likely to have hypothyroidism (Goday-Arno et al., 2009) which is associated with constipation (NICE, 2015).

This increased risk is reflected in findings of a high prevalence of constipation in people with intellectual disability. A recent systematic review on the prevalence of constipation in people with intellectual disability identified 31 relevant studies, of which 14 reported constipation rates of 50% or more, and 21 reported rates over 33% (Robertson et al., 2017). Constipation was more common in those with cerebral palsy and profound intellectual disability, and associated with immobility but not age, suggesting that constipation is a significant issue for people with intellectual disability across the life course. In a further recent study, of 99 people with severe or profound intellectual and motor disabilities, 94% had constipation (van Timmeren et al., 2016).

In view of the serious potential consequences of constipation and the high prevalence of constipation, there is a clear need to consider how services should respond in order to effectively manage constipation in people with intellectual disability. The aforementioned

review included studies of laxative use as an indicator of constipation and it is clear that rates of laxative use are high and likely to constitute the predominant management response to constipation in this population. Based on the most representative study which included 868 people with intellectual disability and 4,305 controls, over 25% of people with intellectual disability received a repeat prescription for laxatives in one year, compared to 0.1% of people without intellectual disability (Straetmans et al., 2007). Of nearly 3,000 adults and children with Down syndrome, the one year prevalence of laxative prescription was 18.8% compared to 3.4% of 8,910 matched controls (Alexander et al., 2015). Of 254 people with profound intellectual and multiple disabilities, 65.0% had been prescribed laxatives in the previous year (van der Heide, van der Putten, van den Berg, Taxis, & Vlaskamp, 2009). Other figures for laxative use included: 73.1% of 26 females with profound intellectual disability (Giesbers et al., 2012), 65% of 55 institutionalized adults with profound intellectual disability (Kozma and Mason, 2003), 43.3% of 806 people aged 50+ known to intellectual disability services (Hermans and Evenhuis, 2014), and 26.4% of 254 people with moderate to profound intellectual disability living in institutions (Van Winckel et al., 1999).

However, the reliance on laxatives as a management response may be inappropriate. Clinical trials show that most laxatives achieve poor results (Jiang et al., 2015). Many community-based patients (not necessarily with intellectual disability) have poorly controlled constipation despite receiving laxatives regularly, with complex, ineffective and/or inappropriate laxative prescribing linked to sub-optimal bowel care (Addison et al., 2003). Whilst further studies are required, there is also some evidence that long term laxative use may be linked to colorectal cancer (Watanabe et al., 2004), particularly with respect to non-fibre laxatives (Citronberg et al., 2014). There are also potential hazards of mineral oil use for chronic constipation in relation to lipoid pneumonia (Bandla et al., 1999).

The objective of this paper is to present the first systematic review of international research pertaining to the management of constipation in people with intellectual disability. The review aims to summarise research on how constipation is currently managed, the effectiveness of interventions for constipation, and service related issues such as staff knowledge and training.

Method

The review was conducted in accordance with PRISMA guidelines (Moher et al., 2009). Electronic literature database searches were conducted in Medline, Cinahl and PsycINFO (all on EBSCO) and Web of Science (Core Collection) in January 2016 and subsequently updated on March 7th 2017. Searches combined terms for constipation and intellectual disability with the Boolean operator 'and'. An example of database specific search terms (Medline) is given in Appendix One. Searches included broad terms relating to constipation and people with intellectual disability. Specific inclusion and exclusion criteria relating to constipation management were applied as below. The reference lists of studies meeting the inclusion criteria were searched. In addition, in December 2015 a request for information on research relevant to the review was sent to members of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) Health Special Interest Research Group and the Intellectual Disability UK Research mailing list.

<u>Inclusion Criteria</u>

Articles were required to meet all the following criteria:

- Peer reviewed

- English language full text

- Published from 1990 to March 7th 2017

- Quantitative research, evaluation or audit, or qualitative research

- Samples where 50% or more have intellectual disability or mixed samples where results are disaggregated for people with intellectual disability

- Includes data regarding the current management of constipation (including type of laxatives prescribed), intervention effectiveness, or service related issues such as staff training or knowledge of carers regarding constipation

Exclusion Criteria

- Not peer reviewed or peer review status unclear

- Any study employing any research design with a sample size of less than 10

- Reviews, letters, commentaries, editorials, meeting or conference abstracts

- Studies based on neonates (new born infants up to 28 days after birth)

- Studies on conditions where intellectual disability cannot be assumed (e.g. cerebral palsy) where results not disaggregated for people with intellectual disability

- Studies on specific syndromes associated with intellectual disability with the exception of Down syndrome, which is the most common genetic cause of intellectual disability (Sherman et al., 2007).   Less common specific syndromes such as Rett syndrome were excluded although it is evident that some research on such syndromes exists (e.g. Baikie et al., 2014, Schwartzman et al., 2008)

- Studies relating to medication as an intervention where use of the medication is not supported by current knowledge or constipation management guidelines (NICE, 2010, NICE, 2015).

- Studies only presenting information on the percentage of people with intellectual disability who receive laxative medication as this is covered in an existing review (Robertson et al., 2017)

- Studies relating to encopresis (soiling)

- Studies relating to Hirschsprung's disease and Down syndrome, as a meta-analysis of 61 studies relating to incidence, outcomes and mortality already exists (Friedmacher and Puri, 2013).

Initially, titles and abstracts were used to exclude studies which were obviously not within scope (first author). Those retained for further screening were those for which relevance could not be assessed without accessing full text, or those that were chosen as potentially within scope. These studies were screened by the first and last author and discussed until consensus was reached on whether or not they met the inclusion criteria. All relevant studies were included in the review regardless of methodological quality. Study data was extracted from full text articles and entered into an excel database with regard to: authors, year, country, main focus of study, study design, sample source, key sample features, sample size, sample age range (mean, SD and median), sample living situation, percentage of sample male, measures employed, and management related results.

Quality Assessment/Risk of Bias

Study quality was assessed using the Mixed Methods Appraisal Tool (MMAT) which was designed for the appraisal stage of systematic reviews that include qualitative, quantitative and mixed method studies and allows reviewers to concomitantly appraise most common types of study methodology and design (Pluye et al., 2011). In the MMAT, primary studies (or mixed method study components) are rated in relation to four specific methodological quality criteria depending on study type: qualitative; quantitative randomized controlled (trials); quantitative non-randomized; or quantitative descriptive studies. The number of the criteria met is reported in the form of an asterix (*) for each criterion met. For quasi-experimental designs not employing a control group (scored using the criteria for quantitative non-randomized studies) a criterion relating to comparability of groups was not

applicable hence these studies could not attain a score greater than 3* out of 4*. The MMAT is an efficient tool, but reliability needs further improvement, particularly for two items relating to qualitative studies including the sentence 'appropriate consideration' (Souto et al., 2015).

Identification of Themes

An iterative approach was taken in which a list of themes was identified by the first author via reading and re-reading the study summaries in Excel and these themes were allocated to overarching themes (Braun and Clarke, 2006). The themes and overarching themes identified were entered into the Excel database for each study. These were then checked by the last author and discussed until consensus was reached. Results were collated, summarised and reported via a tabulation of key data, descriptive numerical summary of included studies (e.g. number with particular research designs) and a descriptive narrative summary of the identified themes.

All extracted data in Excel was subsequently checked for accuracy and completeness by the last author. MMAT ratings and theme allocation were also checked by the last author. Whilst a third reviewer was available to resolve any disagreements, no instances of disagreement arose.

It was not possible to compare results between studies directly due to variation in the methods used, and therefore a meta-analysis was not conducted.

Results

The process of identifying studies for inclusion is summarised in Figure 1. Searches identified 1,929 articles, with 1,279 remaining following deletion of 650 duplicates. 1,169 articles were excluded based on the title/abstract, leaving a pool of 110 articles for further screening. After examination of full text and the addition of articles cited within these and from other sources, 18 articles met the criteria for inclusion, none of which were based on

data from the same study giving a total of 18 studies. Studies are summarised in Table 1 which lists studies from the oldest to the most recent in order to help elucidate temporal trends.   Studies are reviewed narratively below in relation to three themes (one study contributes to two themes): laxative types; interventions (dietary fibre, abdominal massage and macrogol); and staff issues (knowledge and training). A further two studies on medication were identified but these were excluded as they are not included in current constipation management guidelines. One study looked at Cisapride (Staiano et al., 1996) but this has now been withdrawn from most of the world's health institutes because of its recorded fatalities in addition to serious side effects such as severe arrhythmias (Aboumarzouk et al., 2011). The second study looked at Colchicine (Frame et al., 1998) which has been associated with increased occurrence of abdominal pain, and long-term use may cause granulocytopenia, renal dysfunction, reversible myopathy or neuropathy and hepatitis (Jiang et al., 2015).

Geography

All studies were from high income countries: four from England, three from the Netherlands, two from Belgium, two from the United States, and one each from Australia, France, Hong Kong, Ireland, Italy, Scotland, and Wales.

MMAT Quality Appraisal

Information on MMAT types and scores is given in the first column of Table 1. Only one study met all MMAT criteria, four scored 3*, 10 scored 2*, three scored 1*, and one study did not meet any criteria due to a lack of reported methodological detail. The most common unmet criteria are outlined below.

Qualitative: quality was limited by the lack of reported methodological detail in the two studies resulting in predominantly 'can't tell' ratings.

Quantitative descriptive: only one of the nine studies met criterion two, 'Is the sample representative of the population under study?'.

Quantitative randomized controlled: only one of the four studies met criterion one, 'Is there a clear description of the randomization (or an appropriate sequence generation)?'.

Quantitative non-randomized: No study in this group had a control group making criterion three relating to comparability of groups not applicable. Only one of the four studies met criterion one 'Are participants (organizations) recruited in a way that minimizes selection bias?'.

Laxative Types

The type of laxatives used by participants is outlined in seven quantitative descriptive studies (Böhmer et al., 2001, Connor et al., 2014, Joos et al., 2016, van der Heide et al., 2009, Van Winckel et al., 1999, Veugelers et al., 2010, Ganesh et al., 1994). The highest quality study found that the most commonly used laxatives in children with severe generalized cerebral palsy mostly living in the family home were disaccharide (24.3% of 152 children) and polyethylene glycol (macrogol) (13.2% of 152 children) (Veugelers et al., 2010). The most recent study found that macrogol combinations were received by 48.1% of 156 institutionalised adults and children with profound intellectual disability using enteral feeding tubes in Belgium, the second most common medication received by this population after the anti-epileptic valproic acid (Joos et al., 2016). Macrogol combinations were also the most frequently prescribed laxative for adults and children with profound intellectual and multiple disabilities (PIMD) living in institutions in the Netherlands (30% of 254 people with PIMD) followed by bisacodyl (29%) and lactulose (14%) (van der Heide et al., 2009). An earlier study in England found only four of 181 people living in community based care homes (2.2%) to be taking macrogol, with the most frequent being lactulose (46 of 181; 25.4%) and senna (27 of 181; 14.9%) (Connor et al., 2014).

A number of people with intellectual disability receive rectal laxatives, enemas or suppositories, with figures reported being 22.4% of 152 children with severe generalized cerebral palsy living mainly in the family home (Veugelers et al., 2010), 5.5% of 181 residents living in a community based care homes in one trust area (Connor et al., 2014), 10% of 215 adults and children with intellectual disability living in institutions (Böhmer et al., 2001), 57.9% of 38 adults with profound intellectual disability in one institution (Ganesh et al., 1994), at least 10% of 254 adults and children with PIMD in institutions (10% received sodium phosphate enemas, 3% docusate sodium but it is not possible to tell if these figures are mutually exclusive) (van der Heide et al., 2009), and 12.4% of 420 adults and children with intellectual disability living in institutions (Van Winckel et al., 1999). One study found that in one institution, despite adult men and women having similar disabilities, most of those receiving suppositories were women and it is suggested that this may reflect different practice on the wards (Ganesh et al., 1994). Manual evacuation was also reported for 6.7% of 215 adults and children living in institutions (Böhmer et al., 2001) and 9.2% of 152 children with severe generalized cerebral palsy mostly living in the family home (Veugelers et al., 2010).

Where reported, use of multiple laxatives was common. Of 149 adults and children with constipation living in institutions, 34.2% used two laxatives and 9.4% used three laxatives (figures include sodium phosphate enemas) (Böhmer et al., 2001). Of 65 community based care home residents taking laxatives in one trust area, 30.8% used two laxatives, 15.4% used three laxatives, and 4.6% used more than three (figures include enemas/suppositories) (Connor et al., 2014).

Laxatives were not necessarily effective, with efficacy being variable in adults and children in institutions (Böhmer et al., 2001). In a randomized crossover studying comparing laxatives to abdominal massage for adults in an institution or associated group homes, 43% of participants showed no improvement in colonic transit time when on their usual laxative

regime compared to the baseline period with no treatment (Emly et al., 1998). One study found that 36% of 83 children mainly living in the family home with severe generalized cerebral palsy taking laxatives nonetheless showed symptoms of constipation (Veugelers et al., 2010). In this latter study, of the total sample of 152 children, water intake was below recommended amounts for 86.5% of children and daily intake of fibre was below recommended amounts in 53.2%, with six tube fed children receiving no fibre at all.

Interventions

Ten studies considered specific interventions for constipation. Five of these evaluated dietary interventions (fibre), three of which were quantitative randomized controlled trials and two of which were non-randomized studies. Four focused on abdominal massage: one was a quantitative randomized controlled trial; one was a non-randomized study; and two were qualitative studies obtaining feedback from those involved in implementing abdominal massage. One non-randomized study looked at the efficacy of polyethylene glycol 3350 plus electrolytes (PEG+E).

Dietary Interventions

All dietary interventions reported in this review considered the effect of dietary fibre. The dietary intervention study with the highest MMAT score looked at the effect of the dietary fibre glucomannan on chronic constipation in neurologically impaired children (Staiano et al., 2000). After 12 weeks of treatment with glucomannan, no side effects were reported and there were significant increases in stool frequency, significant reductions in laxative or suppository use, significant improvements in stool consistency, and significant reductions in episodes of painful defecation. With placebo, none of these improvements were found. However, neither glucomannan nor placebo had a measurable effect on total and segmental transit times.

One study investigated the effect of adding fibre (All-Bran®) to the breakfast of orally fed children living in a large institution (Tse et al., 2000). Baseline fibre intake was found to be very low at around 2 g/day. Increasing fibre intake to 17 g/day (stage 1) led to a significant reduction in laxative use. Increasing fibre intake further to 21 g/day (stage 2) led to a further reduction in the use of laxatives but there was no statistical significance between stage 1 and stage 2 of fibre supplementation.

A further study found that fibre and fluid intake were below recommended amounts in adult training centre residents with bowel dysfunction, and controlled trials of a dietary supplement with approximately 7g additional fibre per day were subsequently undertaken (Capra and Hannan-Jones, 1992). In the treatment group, enemas reduced from seven to five per fortnight and the overall texture of bowel movements improved. Controls had no reduction in enemas (eight per fortnight), and experienced a significant reduction in the number of bowel motions and a worsening of stool texture. It should be noted that the dietary supplement also included the natural laxative dihydroxyphenyl isatin (found in prunes) which stimulates intestinal motility.

One crossover study looked at tolerance of a paediatric adapted enteral formula with added soy fibre in children (mostly in foster care) receiving enteral feeding and using elimination aids (Tolia et al., 1997). The formula with added fibre was well tolerated and there was a slight trend towards decreased use of elimination aids to induce a bowel movement during the fibre supplemented formula phase (i.e. more with spontaneous defecation).

One study looked at the effects of three levels (fibre free, 12 to 20 g/day, 18 to 25 g/day) of purified dietary fibre (soy polysaccharide) over a one year period on stool frequency, size and consistency in non-ambulatory, enterally fed youths with chronic constipation in an institution (after the study commenced five of the 11 participants were

found to experience loose stools as a consequence of chronic antacid medication) (Liebl et al., 1990). Whilst the use of elimination aids was not reduced by either level of fibre, fibre was found to improve bowel function, with increases in daily stool frequency, stool moisture, wet stool weight and dry stool weight.

Abdominal Massage

In relation to abdominal massage, the study with the highest MMAT score used a randomised cross-over design to compare abdominal massage (five times a week for 20 mins) for adults in an institution or associated group homes with the participant's usual laxative regime (Emly et al., 1998). The effects of laxative and massage therapy for this group (48% of whom always required an enema to defecate) were not demonstrably different. However, abdominal massage had no side effects and structured interviews with keyworkers provided anecdotal evidence of increased tolerance to touch and improved behaviour and communication, while the period of one-to-one contact was believed to enhance the therapist/nurse-patient relationship.

In a service development initiative in one area of England, parents of children with physical and learning disabilities or complex needs living in the family home were trained and asked to complete abdominal massage for 20 minutes a day over a 6 week period and record outcomes (Bromley, 2014). Results reported a wide range of quality of life improvements, including relief in symptoms of constipation (87.5%), increase in optimal stool type from 13% to 59%, reduction in laxative medication (58%), improved dietary intake (41%), and improved sleep pattern (37%). Qualitative data indicated positive experiences described by parents which included enhanced parent-child relationships. The estimated annual cost saving from reduced laxative use was £1,322.03 whilst the estimated cost of education/training was £35.20 per family. However, parents were provided with information

to increase their understanding of constipation and it is not clear to what extent positive results can be attributed solely to abdominal massage, for example some parents reported the introduction of toileting plans during the 6 week period.

In an area of England where abdominal massage was implemented as part of a total bowel management programme, a questionnaire consisting of open ended questions was sent to families and carers to gain feedback on the experiences of adults and children with intellectual disability living in the community and their carers with regards to abdominal massage (Connor et al., 2014). All feedback was positive and included ease of learning and implementation; bowel movement changes; improvements in pain, mood or behaviour; reduction of laxatives; and providing opportunities to develop the therapeutic relationship. However, as abdominal massage was part of a total bowel management programme which included attention to diet, fluid intake, mobility, and toilet regimen and positioning, it is again not clear to what extent positive results can be attributed solely to abdominal massage.

Finally, an audit 18 months after the introduction of abdominal massage in one area of England used a questionnaire with open ended questions to look at the views of nurses and healthcare workers involved in its implementation in a community based home for adults with profound physical disability and intellectual disability (Emly et al., 2001). There was a change in clinical practice and staff attitudes to bowel management, and increased confidence and knowledge of bowel care including more awareness of faecal impaction risk. There was greater emphasis on diet, fluid intake, exercise and passive movement. Initial anxieties regarding the withdrawal of laxatives were unfounded.

Medication

As noted previously, two studies relating to medication were excluded (Staiano et al., 1996, Frame et al., 1998) as the medications are not currently recommended. One study based on retrospective analysis of hospital and pharmacy records examined the safety and

efficacy of polyethylene glycol 3350 plus electrolytes (PEG+E) for people with intellectual disability living in an institution who were treated with PEG+E for 24 months (Migeon-Duballet et al., 2006). There were significant increases in the mean number of stools per patient per month and episodes of diarrhoea (which was defined as 'a large number of stools not necessarily watery'). PEG+E was not associated with adverse effects on body weight or blood biochemistry values. The total cost of laxatives per medical ward per year decreased from 3788.17 to 1767.39 Euros. However, whilst PEG+E was received by 54 participants, comparative data prior to the introduction of PEG+E was based on only 16 participants.

Staff Related Issues

Two quantitative descriptive studies provide information on staff related issues. One study using information from records and interviews with staff explored diet and bowel management (not restricted to constipation per se, e.g. includes encopresis) in adults with intellectual disability who had moved from a hospital to community based staffed homes four years previously (Dickson et al., 2002). An increase in bowel medication since moving to the community was associated with support by staff with no training, whilst a decrease was associated with support by staff with training. Eighteen staff (41%) had any training in relation to diet and/or bowel management, 16 of whom had received a half-day course on basic nutrition from a dietician. None of the 44 participants received input from clinical psychology for behavioural management in relation to bowel control. For 41 of the 44 participants, support staff decided on their diet.

A survey of registered nurses supporting people with intellectual disability in one major intellectual disability service provider in Ireland found good overall knowledge regarding the prevention and management of constipation (Marsh and Sweeney, 2008). However, there were some knowledge deficits, for example 33% incorrectly identified the best position for having a bowel movement as on the toilet with feet hanging freely above the

floor. In addition: only 64 (65%) correctly identified anticonvulsants as increasing

constipation; 68 (69%) did not recognise diabetes as being associated with constipation; and

whilst 81 (83%) recognised the need for 5 daily portions of fruit or vegetables, 65 (66%)

correctly identified 2 litres of fluid a day as a minimum recommendation.

Discussion

Despite broad inclusion criteria, only 18 studies have been identified in relation to the

management of constipation in people with intellectual disability. 'Interventions' was the

theme covered in the greatest number of studies, and these were restricted to five intervention

studies involving dietary fibre, two intervention studies involving abdominal massage, two

studies obtaining staff/carer feedback on abdominal massage, and one retrospective study of

PEG+E. 'Laxatives types' was also a common theme. Only two studies considered service

related issues such as staff knowledge and training.

A number of studies including both institutional and family home based settings

report below recommended levels of fluid and/or fibre intake in people with intellectual

disability (Capra and Hannan-Jones, 1992, Tse et al., 2000, Veugelers et al., 2010), with the

implication that improving intake may help with constipation. Indeed, all four studies

looking at the effect of dietary fibre interventions report some positive results relating to

bowel function and/or laxative/enema use. As suggested by Capra and Hannan-Jones (1992),

even when there is chronic constipation, dietary intervention may be warranted. However, as

noted by Tse et al (2000), increasing dietary fibre intake will not solve the problem of

constipation entirely since there are many other related factors, e.g. medication, physical

inactivity, possible underlying defects in gut innervation and musculature (related to

spasticity) and inadequate fluid intake due to oromotor dysfunction. Indeed, in one study

children continued to be chronically constipated, having a prolonged intestinal transit time

despite improvements in outcomes such as stool frequency and painful defecation (Staiano et al., 2000).

Whilst the effectiveness of abdominal massage was found not to be demonstrably different to that of laxatives for adults in one study (Emly et al., 1998), a number of positive outcomes have been attributed to abdominal massage, both in relation to relief in the symptoms of constipation and secondary outcomes such as improved sleep in children (Bromley, 2014), improvements in pain, mood or behaviour (Connor et al., 2014), and enhanced therapeutic relationships between those implementing and receiving the abdominal massage across a range of settings (Emly et al., 1998, Bromley, 2014, Connor et al., 2014). Concomitant reduction in laxative use for children living in the family home was also associated with cost savings (Bromley, 2014). However, it is not clear to what extent positive results can be attributed solely to abdominal massage, with implementation being confounded by, for example, the introduction of toileting plans during the study period (Bromley, 2014) or by additional components of a total bowel management programme (Connor et al., 2014).

A wide range of laxative types were reported to be used by people with intellectual disability (Böhmer et al., 2001, Connor et al., 2014, Joos et al., 2016, van der Heide et al., 2009, Van Winckel et al., 1999, Veugelers et al., 2010), most frequently osmotic variants. Laxative polypharmacy was common (Böhmer et al., 2001, Connor et al., 2014). A number of people with intellectual disability also received rectal laxatives, enemas or suppositories, with figures reported ranging from 5.5% of residents in community based care homes (Connor et al., 2014) to 57.9% of adults with profound intellectual disability in one institution (Ganesh et al., 1994). Manual evacuation was also reported for a small proportion of people with intellectual disability (Böhmer et al., 2001, Veugelers et al., 2010). Laxatives were not effective for all people with intellectual disability (Böhmer et al., 2001, Emly et al., 1998, Veugelers et al., 2010). However, only two studies provides information on laxative use for

those living in community based settings (Connor et al., 2014, Veugelers et al., 2010) and older institutional based studies may report practices that are no longer common.

The one study specifically on laxative effectiveness identified suggests that PEG+E is safe and effective in the clinical management of constipation in people with intellectual disability in an institutional setting (Migeon-Duballet et al., 2006). In relation to the general population, PEG received a 'grade A' recommendation for improving stool frequency and consistency (Zurad and Johanson, 2011). Two recent studies involving institutional settings found that macrogol (polyethylene glycol) combinations were the most commonly prescribed laxative for people with profound intellectual disability (Joos et al., 2016, van der Heide et al., 2009). However, care should be taken when using PEG in people who have dysphagia where liquids are thickened with starch, as a precipitous loss of thickening has been found to occur to liquids when PEG is added, although PEG may be compatible with xanthan gum based thickeners (Carlisle et al., 2016).

Support staff have the potential to play a vital role in the management of constipation in people with intellectual disability, for example they are often in control of the diet people with intellectual disability receive (Dickson et al., 2002). However, only two studies provide any information in relation to this theme. For registered nurses supporting people with intellectual disability in Ireland, some deficits have been found in knowledge regarding the prevention and management of constipation (Marsh and Sweeney, 2008) and it is plausible that knowledge deficits could be greater in non-nursing support staff. Staff training in relation to diet and/or bowel management has been found to be associated with a decrease in bowel medication for adults following a move to the community from a hospital setting, with increases being associated with support by staff with no training (Dickson et al., 2002). Dickson et al note that training may play a role in two ways: making staff alert to the

requirements of a healthy diet in relation to bowel management; and making staff alert to the need to refer clients to GPs for monitoring and adjustment of medication.

Given how common constipation is in people with intellectual disability and the impact it can have on health and quality of life, the lack of research on the management of constipation is surprising. There is a particular lack of research in relation to managing constipation in community based settings. The lack of research and lack of comparison of interventions against each other mirrors the findings of a systematic review of management for those with central neurological disease (Coggrave et al., 2014). Many topics remain to be the subject of research for people with intellectual disability and constipation including: the role of toileting and the toileting environment; the impact of educating staff, carers and people with intellectual disability about constipation; the impact of diet, exercise, fluid intake, or other service related initiatives to try to reduce constipation; and whether learning disability nurses could take a role in education regarding constipation. In addition, no research has been done with people with intellectual disability in relation to approaches to managing constipation including probiotics (Dimidi et al., 2014); transcutaneous electrical stimulation (TES) (Hutson et al., 2015); and physiotherapeutic methods of connective tissue manipulation and Kinesio Taping (Orhan et al., 2016).

Behavioural approaches also warrant further research. It has been suggested that classical and operant treatment methods appear to be the best supported interventions for encopresis, soiling and constipation in children and adults with developmental disability (Matson and Lovullo, 2009). One study (which did not meet the inclusion criteria for this review) used a behavioural approach involving prompted toilet-sitting after meals, rewards for appropriate evacuation and increased fibre in four people with intellectual disability who suffered from chronic constipation, faecal impaction, soiling and were long term users of elimination aids (Smith et al., 1994). Training resulted in near normal bowel function,

although training time was long and it was unclear which elements of the programme were essential to success. The authors note that the work is costly due to the intensive and prolonged nature of the programme and the field is vastly under resourced. One study in this review found that no people with intellectual disability received clinical psychology input for behavioural management in relation to bowel control (Dickson et al., 2002).

Numerous clinical guidelines for managing constipation exist, with one international study identifying 22 clinical practice guidelines for constipation (Tian et al., 2016). Some specifically exclude those with developmental delay (Tabbers et al., 2014). In England and Wales, NICE clinical guidelines for managing constipation in children exist (NICE, 2010) and these specifically state that assessment and management for those with physical disabilities (such as cerebral palsy), Down syndrome or autism should happen in the same way as is recommended for all children and young people (NICE, 2010, p 4-5). Clinical knowledge regarding constipation in adults has also been summarised by NICE (NICE, 2015). However, no clinical guidelines appear to be available specifically for people with intellectual disability.

It has been suggested that national clinical guidelines on constipation in adults with intellectual disability could be formulated so that healthcare workers would have an evidence-based framework to consult (Cockburn-Wells, 2014). In one area of England, failure of current practice to effectively manage constipation led a multi-professional group of health care practitioners to review evidence and develop a clinical guideline for the management of chronic constipation of adults within the community including people with intellectual disability (Emly and Rochester, 2006) and this guideline has recently been updated (Emly and Marriott, 2017). The guideline recommends a multi-faceted treatment strategy involving several health care professionals in the holistic management process, with an individualized programme rather than relying solely on prescription of laxatives. Early

indications on use of the guideline with people with intellectual disability suggest that holistic, individualised bowel management programmes can reduce laxative use and nursing interventions and lead to improved quality of life (Emly and Rochester, 2006).

Raising awareness of the issue of constipation in people with intellectual disability may lead to further efforts within services to address the management of constipation. For example, following an event on constipation by the Public Health England Learning Disabilities Observatory, a group was formed in Central Midlands which aims to improve awareness and treatment of constipation in people with intellectual disability (Whait, 2016).

Böhmer et al (2001) note that until research provides clear answers as to how to manage constipation in people with intellectual disability, the principles for treatment are the same for individuals with intellectual disability as for the general population. As a basic principle, it has been suggested that bowel management should begin with the "eight keys to bowel success" prior to developing an individualised bowel programme: physical exercise, high fibre intake, high fluid intake, consistent habit time, an upright position on toilet or commode, privacy, medication management, and patient and family education (Weeks, Hubbartt, & Michaels, 2000). Whilst early studies on constipation management for people with intellectual disability focused on specific elements of constipation management (e.g. dietary fibre), a recent study considers the management of constipation using abdominal massage in the context of a total bowel management programme (Connor et al., 2014). As noted by Emly et al (1998), maximum benefit of both laxative and abdominal massage interventions will be obtained only within a more general individualised programme of bowel management that addresses additional factors such as diet, exercise and toileting. Further research is required to support early indications that an integrated bowel management programme may be appropriate for managing constipation in people with intellectual disability (Emly and Rochester, 2006).

Limitations

A limitation of this review is the potential loss of information from two main sources. First, the review has not considered how studies regarding approaches to managing constipation in other populations may be applicable to people with intellectual disability. For example, a study involving children and adults with quadriplegic cerebral palsy looked at a nursing intervention using non-pharmacological conservative therapy (intestinal massage; abdominal press; increase in water intake; increase in the use of vegetable oils in main meals; increase in the consumption of laxative fruits, leafy vegetables, and high fibre foods; and decrease in the consumption of constipating foods) (Faleiros and de Paula, 2013). Complete or partial improvement of constipation was observed in 90% of the patients, laxative use was reduced and there were improvements in sleep patterns, appetite, and mood (Faleiros and de Paula, 2013). Second, the review does not consider research relating to specific syndromes associated with intellectual disability such Rett syndrome. In addition, whilst studies were identified from a range of countries, the review is restricted to English language publications. No studies were identified from low and middle income (LAMI) countries. Finally, all data was extracted by one reviewer and checked for accuracy and completeness by a second reviewer. Whilst this is an accepted minimum (Centre for Reviews and Dissemination, 2009), extraction of data by two reviewers independently would have reduced the possibility of errors.

Conclusion

It is clear that the main management response to constipation in people with intellectual disability is laxative use but this is not effective for all people with intellectual disability. Awareness of the issue of constipation management in people with intellectual disability needs to be raised. An improved evidence base with robust high quality studies is required to better understand what works well in managing constipation in people with intellectual

disability.   This should include research to test the suggestion that the best way to manage constipation for people with intellectual disability is an individualised, integrated bowel management programme. In the meantime, services should consider adopting the guidelines for the management of chronic constipation of adults within the community (Emly and Marriott, 2017) which are available online at

https://www.ndti.org.uk/uploads/files/ConstipationGuideline2016.pdf. In addition, a recent report provides information on reasonable adjustments that can be made for managing constipation in people with intellectual disability (Marriott and Emly, 2016). The ideas, information and examples of good practice in relation to managing constipation provided within these resources should help services improve provision for this highly prevalent condition and potentially reduce ill health and deaths associated with constipation in people with intellectual disability.

Appendix One

Example of Database Specific Search Terms (Medline)

Limiters: Jan 1990 – 2017; English language.

((((MH "Constipation") OR (MH "laxatives") OR (MH "fecal impaction") OR (TI constipat* OR TI fecal OR TI faecal OR TI laxative* OR TI defecat* OR TI defaecat* OR TI bowel OR TI colon* OR AB constipat* OR AB fecal OR AB faecal OR AB laxative* OR AB defecat* OR AB defaecat* OR AB bowel OR AB colon*))) AND (((TI (learning N1 (disab* or difficult* or handicap*)) OR TI (mental* N1 (retard* or disab* or deficien* or handicap* or disorder*)) OR TI (intellectual* N1 (disab* or impair* or handicap*)) OR TI development* N1 disab* OR TI (multipl* N1 (handicap* or disab*)) OR TI "Down* syndrome" OR (MH "Developmental Disabilities") OR (MH "Intellectual Disability") OR (MH "mentally disabled persons")) OR (AB (learning N1 (disab* or difficult* or handicap*)) OR AB (mental* N1 (retard* or disab* or deficien* or handicap* or disorder*)) OR AB (intellectual* N1 (disab* or impair* or handicap*)) OR AB development* N1 disab* OR AB (multipl* N1 (handicap* or disab*)) OR AB"Down* syndrome")))

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Figure 1

Flowchart of Study Identification
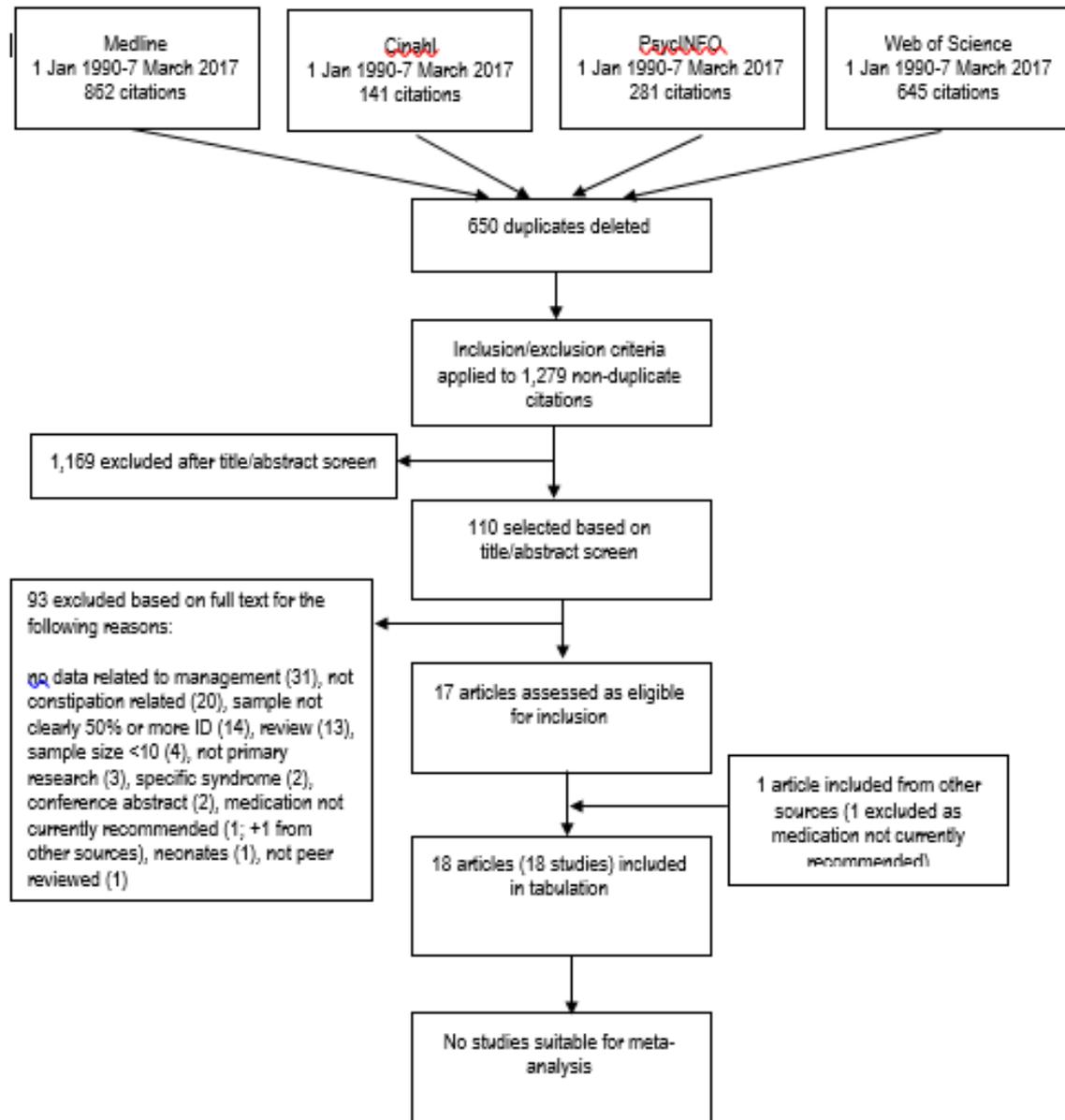
Table One: Summary of studies relating to the management of constipation in people with intellectual disability

MMAT Type & Rating	1st Author & Year	Country	Management Related Focus	Design	Key sample features (age group; setting)	Sample size	Age range (mean (SD); median)	% male	Outcome measures	Management Related Results
QNR **	Liebl 1990	US	Dietary fibre	Within subjects repeated measures with 3 levels of purified dietary fibre source. i 1-60 days fibre free liquid feeding, ii days 61-120 & 121-300 added 5g/240ml purified soy polysaccharide, iii days 301-360 Soy polysaccharide concentration increased by 50%.	Non-ambulatory severely developmentally disabled youths resident at a centre for the developmentally disabled, all enterally fed & chronically constipated (child; institution)	11	7-17 (ns)	46	Stool frequency; size and consistency; wet and dry weight from total stool collections (last 10 days of each period, and 2 x 10 days period 4)	Suppositories were given every 3 days if no BM. Use of elimination aids not reduced by either level of fibre. The second fiber addition significantly increased mean (SD) daily stool frequency from 0.6 (SD 0.2) during the fiber-free diet to 1.1 (SD 0.5). The first addition of fiber compared to the fiber-free diet significantly increased stool moisture from 70% (SD 7%) to 76% (SD 8%) and wet stool weight from 30 (SD 13) g/day to 53 (SD 21); mean stool weight during days 351 to 360 was 87 (SD 45) g/day. Daily dry stool weight significantly increased with the second fiber addition. Soy polysaccharide fiber improved bowel function in this nonambulatory profoundly disabled population
QRC **	Capra 1992	Australia	Fibre & fluid intake; effect of modifying dietary fibre on bowel function	3 x controlled trials: 2 week baseline, 2 week intervention, 2 week post-intervention. Intervention a dietary supplement with approx 7g additional fibre per day as a mixture of soluble and insoluble fibres plus natural laxative dihydroxyphenyl isatin which stimulates intestinal motility	Adult training centre residents with bowel dysfunction; 62.2% immobile; meals from central kitchen (adult; institution)	37	19-72 (ns)	51	Number BM, texture, number of suppositories or enemas used	Estimates of fibre and fluid intakes yielded mean intakes of 18.6g fibre per day (range 14–23g) (current recommendations at the time were 25-30g per day) and 2.2 litres of fluid (range 1.8–2.4 litres) - this included approx 1 litre fluid in food (recommendation at the centre was to give 2-2.5 litres fluid a day above that found in food). Improving fibre and fluid intake may help with constipation management and prevention. Controls had no reduction in enemas (8 per fortnight), treatment group reduced from 7 to 5 per fortnight. For treatment group overall texture of BM improved. Those not receiving the supplement experienced a significant reduction in the number of BMs and a worsening of stool texture, while those receiving the supplement did not. Results suggest that, even when there is chronic constipation, dietary intervention may be warranted
QD **	Ganesh 1994	Wales	Suppository use	Audit	Adults with profound ID living in one institution (adult; institution)	38	24-54 (mean 36.8 for males, 33.7 for females)	50	% receiving suppositories regularly	22/38 (57.9%) were regularly taking suppositories for constipation. 18 of the 22 were women despite men and women having similar disabilities. Suggested that difference in use of suppositories between men and women may be because they are on different wards and reflect different practice on the wards.
QRC **	Tolia 1997	US	Gastrointestinal tolerance of a pediatric enteral formula containing soy fibre & effect on defecation	Double blinded, randomized, 2-month crossover study. During two phases of each 4-week period of the crossover study, subjects were fed Pediasure® either with (PS10) or without (PS)	Children receiving enteral nutrition supplements for >80% of energy requirements. All had difficulty with defecation requiring elimination aids for over 6 months duration. Most in foster care	20	1-17 (4.6 (4.2); 3.3)	50	Gastrointestinal tolerance (incidence of emesis and/or spit up, gas, irritability or fussiness, distention, bloating), stool	No differences in tolerance, stooling, growth, or biochemical measurements between the feeding regimens, in 11 children completing this phase of the study. Slight trend towards using less elimination aids to induce a BM during fiber supplemented formula phase (i.e. more with spontaneous defecation): 2 of 11 (18%) participants needed no elimination aids when using PS compared to 3 of 11 (27%) using PS10. Pediasure with fiber well tolerated in children with developmental disabilities and possibly decreased use of elimination aids.

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				10g/l dietary soy fiber (soy polysaccharide). Following completion of the crossover study, subjects were fed Pediasure® with fiber for an additional 2 months.	(child; most foster care)				characteristics, elimination aid use	
QRC **	Emly 1998	England	Comparison of abdominal massage & laxative therapy	Randomised cross-over design comparing abdominal massage (x5 a week for 20 mins) and usual laxative regime. Group i massage first, group ii laxatives first. 16 days baseline with no treatment, and two 7 week treatment phases separated by one week washout. Also structured interviews with key worker	Adult residents of an institution or 2 associated group homes; profound or severe ID, with CP or genetic conditions associated with abnormal muscle tone, regular use of laxative/enemas for 12+ months before trial. 90% on laxative/enemas 5+ years; 48% always required enema to defecate (adult; institution & 2 group homes)	32	i. 24-74 (42.3 (ns); ns) ii. 27-61 (43.5 (ns); ns)	44	Gastro-intestinal and segmental transit times; secondary measures included stool frequency, size and consistency, the requirement for enemas and an assessment of patient well-being	Median total colonic transit time was 183 hours for baseline phase and 159 hours for all treatment phases. No evidence of any statistically significant treatment differences between laxative and massage therapy for right, left or rectosigmoid segments either separately or in total. Analysis of secondary outcome measures also failed to find any treatment preferences. The effects of laxative and massage therapy within this environment were not demonstrably different. 43% of subjects showed no improvement in colonic transit time over baseline while on their previous laxative regimen adding weight to clinical concern about long-term laxative dependency. Results reveal grossly abnormal colonic transit times of the study population at all times. Anecdotally, evidence from structured interviews included reports of increased tolerance to touch and improved behaviour and communication, while the period of one-to-one contact was believed to enhance the therapist/nurse-patient relationship.
QD ***	Van Winckel 1999	Belgium	Laxative use as an indirect indicator of constipation	Cross-sectional descriptive study using structured interviews	Patients with moderate to profound ID living in institutions (adult 73%, child 27%; institutions)	420	2-72 (ns ns); 29)	63	Laxative use	Enemas used chronically by 12.4% (52/420) of the residents, of whom 23% (12/52) needed an enema before each defecation. Seventy-nine percent (41/52) used enemas in combination with oral laxatives. Fifty-eight percent (28/52) used phosphate enemas (O), 27% (14/52) sodium lauryl sulfate (O) or sodium docusate (S), 13.5% (7/52) glycerine (O) and 5.5% (3/52) isotonic saline (O). In 70% (40/52), enemas were given after a predetermined number of days without defecation varying from 2 to 12 days (median 4 days).
QRC ***	Staiano 2000	Italy	Dietary fibre	Randomly assigned to double-blind treatment with either glucomannan (n = 10) or placebo (n = 10) for 12 weeks following a 2 wk baseline period. Before patients entered the treatment period, impacted feces were removed with	Children with severe neurological damage (brain damage due to perinatal or prenatal hypoxia) and chronic constipation (at least one year duration) & most evacuation not possible without enema. All fed semi-liquid diet by mouth	20	ns (5.7 (4.2); ns)	74	Symptoms, stool habits, gastrointestinal transit times, anorectal motility, laxative & suppository use.	1 child withdrew leaving 10 placebo, 9 glucomannan. No side effects reported, and treatment well-tolerated in both groups. After 12 weeks of treatment, glucomannan significantly increased stool frequency from 1.8 ± 0.2 stools/wk to 3.8 ± 0.9 stools/wk (p < .01). Stool frequency did not increase with placebo (from 2.3 ± 0.7 stools/wk to 2.0 ± 0.6 stools/wk). Laxative or suppository use significantly (p < .01) reduced by glucomannan (from 1.9 ± 1.3 doses/wk to 0.3 ± 0.5 doses/wk) but not by placebo (from 2.5 ± 0.5 doses/wk to 2.1 ± 0.4 doses/wk). Clinical scores of stool consistency were significantly improved and episodes of painful defecation per week were

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				repeated enemas for 2 or 3 days.	(child; ns)					significantly reduced by glucomannan (p < .01) but not by placebo. However, neither glucomannan nor placebo had a measurable effect on total and segmental transit times. Glucomannan improves stool frequency but had no effect on colonic motility.
QNR **	Tse 2000	Hong Kong	Fibre intake & effect of increasing fibre intake on laxative use	Pilot study. Dietary intake assessed over 3 days. Within subjects repeated measures to look at effect of adding fibre to diet. All-Bran® added in breakfast: stage 1 = 20 days 17g fibre; (followed by 10 day normal diet); stage 2 = 6 weeks 21g fibre	Children with severe developmental disabilities in large residential institution, orally fed, medically stable (child; institution)	20	3-17 (ns (ns); ns)	ns	BMs and the number of laxatives used recorded throughout study (however results do not mention BM just laxatives)	Baseline fibre intake very low at around 2 g/day. Mean number of laxatives required per week per child decreased significantly from a baseline value of 1.22 (about 5 laxatives/month) (SD 0.36) to 0.90 (about 3. 5 laxatives/month) (SD 0.75) in the first stage, and 0.71 (about 3 laxatives/month) (SD 0.40) in the second stage. No significant difference between the two stages of fibre supplementation (17 g versus 21 g).
QD ***	Böhmer 2001	Nether-lands	Frequency and type of laxatives; manual evacuation of faeces	Prospective collection of daily data by nursing staff	People with ID with IQ < 50 (moderate to profound ID) from 4 institutions (adult & child (% ns); institutions)	215	6-80. Constipation group 31.8 (15.8); ns. Not constipated group 34.1 (18.6); ns	60	Frequency & type of laxative; use of manual evacuation	Of 149 (69.3%) with constipation, 57.6% used bisacodyl (S) or magnesium oxide (O), 38.6% used lactulose (O), 13.4% used sodium lauryl sulphoacetate/sodium citrate/sorbitol (O) and 9.6% used sodium phosphate enemas (O). 51 (34.2%) used two of the above in combination, and 14 (9.4%) used 3 of the above in combination. Manual evacuation of faeces by nurses in 10 patients (6.7%). There was a high frequency and variety in laxative treatment with variable efficacy.
Q *	Emly 2001	England	Nursing team perspective of abdominal massage	Audit took place 18 months after introduction of abdominal massage for clients unsuccessfully managed on laxatives. Questionnaire with 10 open-ended questions	4 RNMHs, 6 healthcare workers involved in implementation of abdominal massage programme in NHS group home (staff supporting adults; community home)	10	ns	ns	Responses to 10 open ended questions	There was a change in clinical practice and staff attitudes to bowel management, increasing commitment to the change in practice, increased confidence & knowledge of bowel care. More aware of faecal impaction risk. Initial anxieties on the withdrawal of laxatives unfounded. Greater emphasis on diet, fluid intake, exercise and passive movement.
QD **	Dickson 2002	Scotland	Diet & bowel management 4 years after move from hospital to community; staff training	Retrospective analysis of records & cross-sectional semi-structured interview with staff on duty at time of data collection	People with ID who had moved from a hospital to staffed homes 4 years previously, 45.5% non-ambulant (adult; community homes)	44	ns (49.5 (10.9); ns)	61	Previous & current medication for bowel management	12/44 received no bowel medication. Since moving to community, 14 (32%) had some decrease in bowel medication, 9 (20%) an increase. Age, gender, ambulancy, input from dietician, receiving special diet or deciding own diet not associated with changes in bowel medication. Increase in medication associated with support by staff with no training. Decrease in medication associated with support by staff with training. 41/44 support staff decided on diet. 0/44 received input from clinical psychology for behavioural management in relation to bowel control. 18 (41%) of staff had any training in relation to diet and/or bowel management, 16 of whom received a half-day course on basic

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										nutrition from dietician. 1 had training relating to gastrostomy tube feeding, 1 eating, drinking, swallowing difficulty. No association between staff training & whether clients on bowel medication.
QNR *	Migeon-Duballet 2006	France	Long-term efficacy, safety and cost-effectiveness of PEG 3350 plus electrolytes (PEG+E)	Retrospective analysis of records & hospital pharmacy records. Participants treated with with PEG+E (1-3 sachets a day) for 24 months. Data compared with that of 21 months preceding PEG introduction	Residents at specialist unit with severe intellectual & physical disability; less than one stool per 48 h and/or evacuation problems; receiving laxatives (adults (ns – assumed); institution)	54 (pre-PEG+E control data for 16/54)	ns (36.1 (11.9); ns)	56	Number of stools per month, episodes of diarrhoea, weight, haematology and blood biochemistry, monthly use & costs of laxatives, enemas & suppositories	Mean number of stools per patient per month increased significantly from 12.4 (SD 3.4) to 24.9 (SD 6.3), episodes of diarrhoea increased significantly from 0.1 (SD 0.1) to 6.3 (SD 2.9), not associated with adverse effects on body weight or blood biochemistry values, total cost of laxatives per medical ward per year decreased from 3788.17 to 1767.39 Euros after PEG+E
QD **	Marsh 2008	Ireland	Registered nurses' (RNs) knowledge of constipation in people with ID	Survey using self completion questionnaire	RNs supporting people with ID. 166 RNs identified, 59% (n=98) response rate (nurses in one ID health service provider supporting ns age; ns settings)	98	ns	ns	Number of correct responses to 28 factual questions (true/false/ unsure)	Overall accuracy of 64% suggests good overall knowledge in prevention and management of constipation. Knowledge deficits included: only 64 (65%) correctly identified anticonvulsants as increasing constipation; 68 (69%) did not recognise diabetes as being associated with constipation; and whilst 81 (83%) recognised the need for 5 daily portions of fruit or vegetables, 65 (66%) correctly identified 2 litres of fluid a day as a minimum recommendation. 33% incorrectly identified the best position for having a BM as on the toilet with feet hanging freely above the floor.
QD **	van der Heide 2009	Nether-lands	Laxative prescription	Retrospective analysis of medical & pharmacy records	People with profound intellectual and multiple disabilities (PIMD) living in 8 facilities for people with ID (adult 93%, child 7%; institutions)	254	6-82 (ns (ns); 49)	46	Laxatives prescribed in prior 12 months	226 (89%) prescribed medication in prior 12 months. Most frequently prescribed were laxatives (165/254, 65%). Constipation was a registered health problem in 68% (n = 112/165; 95% CI 61–75%) of cases where laxative prescribed. Laxatives prescribed: macrogol PEG) combinations (O) 76/254 (30%); bisacodyl (S) 73/254 (29%); lactulose (O) 36/254 (14%); lactitol (O) 31/254 (12%); sodium phosphate (enema) (O) 25/254 (10%); Isphagula (B) 9/254 (4%); docusate sodium (enema) (S) 7/254 (3%); All medications prescribed for five or less participants 15/254 (6%)
QD ****	Vuegelers 2010	Nether-lands	Prevalence & clinical presentation of constipation	Cross-sectional observational study with diary completion over two weeks	Children with severe generalized CP & ID, most living at home (child; family home 80% (remainder ns))	152	2-18 (9.6 (4.6); ns)	51	Laxative use, fibre and fluid intake	Prevalence of constipation 57% (95% CI 45%, 69%). Of the 152 children, 54.6% used any laxative, 13.2% polyethylene glycol (O), 24.3% disaccharide (O), 7.9% other. Rectal laxative use 22.4%. Manual disimpaction 9.2%. Of 83 children using laxatives, 36% nonetheless showed symptoms of constipation. Dietary intakes below the recommended amounts for water in 86.5% and in 48% of children was more than 500mL below the recommended daily minimum. Daily

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										intake of fibre was below recommended amounts in 53.2%, more than 6g below the recommended minimum in 41%, and 6 children (all tube fed) received no fibre at all. However, no significant relation between fibre or water intake and constipation was found.
QNR *	Bromley 2014	England	Abdominal massage	Service development initiative with pre/post data collection. Parents trained & asked to complete abdominal massage for 20 mins a day and recorded outcomes over 6 week period	All had physical disability and learning disabilities or complex needs and chronic constipation (> 8 weeks) (child; family home)	25	ns (inclusion criteria age 3 mths to 19 yrs)	ns	Bristol stool chart (consistency), frequency BM, perceived improvement in service use & quality of life, laxative use	Results report a wide range of quality of life improvements including relief in symptoms of constipation (87.5%), reduction in laxative medication (58%), improved dietary intake (41%), improved sleep pattern 37%. Qualitative data indicate positive experiences described by parents which include enhanced parent-child relationships. Optimal stool type 4 increased from 13 to 59%. Annual cost saving for 10 who had reduced laxative use estimated to be £1,322.03. Cost of education/training estimated to be £35.20 per family
QD **	Connor 2014 (part I)	England	Audit of bowel care	Audit	People with ID living in care homes in one trust area (age ns; community care homes)	181	ns	ns	Number & type of laxatives	The audit included 181 residents, of whom 65 (36%) taking laxatives every day. 32 took one laxative (none of whom had enemas and/or suppositories), 20 took 2 (3 of whom had enemas and/or suppositories), 10 took 3 (4 of whom had enemas and/or suppositories) and 3 took more than 3 laxatives (for all of whom this included enemas and/or suppositories). Laxatives taken (and type) were: lactulose (O) n=46; senna (S) 27; fybogel (B) 13; bisocodyl suppositories (S) 8; movicol (macrogol/PEG) (O) 4; husk (B) 2; glycerin suppositories (O) 2; bisocodyl (oral) (S) 1; microlax enema (O) 1; unspecified enema 1.
Q -	Connor 2014 (part II)	England	Parent/carer feedback on abdominal massage	Questionnaire sent to families and carers to identify positive and negative aspects of abdominal massage implemented as part of a total bowel management programme	Parents/carers involved in abdominal massage (carers of adults & children (% ns); community based)	ns	ns	ns	Open ended comments on use of abdominal massage	All feedback on the introduction of abdominal massage was positive, including comments regarding: ease of learning & implementation; bowel movement changes; improvements in pain, mood or behaviour; reduction of laxatives. No negative responses received. Some reported that adopting abdominal massage provided further opportunity to develop the therapeutic relationship. Positive case studies (n=4) also given of introduction of massage.
QD ***	Joos 2016	Belgium	Medication used by people with ID with enteral feeding tube (EFT)	Cross-sectional observational study using medication records	92.3% profound ID, all with EFT & receiving chronic medication through EFT, living in residential care facilities (adult & child (% ns); institution)	156	2-80 (ns (ns); 20)	41	Medication administered through EFT	75% used drugs for constipation (2nd most frequent after antiepileptics at 78.2%). 2nd most common chronic drug used was macrogol (PEG) combinations (O) (48.1% of 156 participants). Other laxatives noted were lactulose (O) (n = 24), sorbitol (O) (n = 21).

Abbreviations: BM bowel movement; CP cerebral palsy; EFT enteral feeding tube; ID intellectual disability; PEG polyethylene glycol; PEG+E polyethylene glycol 3350 plus electrolytes; ns not stated; NHS national health service; RNMH registered nurse (mental handicap). Laxative types: B bulk forming; O osmotic; S stimulant. MMAT types: Q qualitative; QRC quantitative randomized controlled (trial); QNR quantitative non-randomized; QD quantitative descriptive.