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The Experiences of Nurses Caring for Patients with Neurogenic Bowel Dysfunction

in the Acute Setting

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12 Abstract

13 Study design: Qualitative.

14 Objectives: Explore the lived experience of nurses providing bowel care to patients after Spinal
15 Cord Injury (SCI).

16 Setting: UK NHS Acute Care Hospital and Major Trauma Centre.

17 Methods: Semi-structured interviews with 11 registered nurses were undertaken to explore their
18 experiences of providing bowel care.

19 Results: Four major themes emerged: Unpleasantness of task; perceived patient experience;
20 motivation and avoidance; and barriers to care. There was stoic acceptance of the unpleasant
21 nature of bowel care for the nurse but unpleasantness for patient wasn't so readily accepted.
22 Perceived patient experience ranged from the positive aspects of comfort and continence to the
23 negative of embarrassment and discomfort. Nurses were motivated by the medical need for
24 bowel care but often saw it as low priority due to the unpleasant nature displaying avoidance
25 tactics. The barriers concerned inadequate training, the taboo nature of bowel care and potential
26 sexual interpretations of care.

27 Conclusions: Nurses find bowel care unpleasant but accept its medical need and importance. The
28 normalisation of bowel care training and increasing numbers of nurses trained may decrease
29 stigma surrounding provision of care. This study highlights that a male nurses' experience may
30 differ from a female nurses' but this requires further investigation.

31 Sponsorship: No external funding.

32 Key words: #Neurogenic bowel #Spinal Cord Injury #Nursing experience #Bowel care

Introduction: Spinal cord injury (SCI) and resulting lack of coordination with the central nervous system changes gastrointestinal transit. SCI patients frequently lose rectal sensation and ability to defecate normally, termed neurogenic bowel (1). Most SCI patients require bowel care which can include digital rectal stimulation and digital removal of faeces. Patients and specialist nurses have described poor bowel care in SCI patients with devastating impacts on patient dignity and health (2). Nurses reportedly fear bowel care due to a misbelief it is illegal or that they can cause injury to patients (3). Gaps in practice surrounding continence and bowel care in all patient groups has been recognised as a national issue (4). The Royal College of Nursing (3, 5) has recognised an inadequacy of care provision surrounding digital rectal examination (DRE), lower bowel dysfunction, digital removal of faeces (DRF) and digital rectal stimulation (DRS). Despite repeated publishing of guidance and acknowledged gaps in practice no studies have explored the experience of acute nurses who provide bowel care and barriers to quality bowel care provision. Exploring the experience of nurses could help explain gaps in practice will help create a basis to develop an action plan to address issues.

Participants and Methods:

11 registered nurses from 3 ward areas in an UK NHS trauma centre who were deemed competent in provision of spinal bowel care by their current place of work were interviewed. Participants were all experienced in caring for acute stage spinal injury patients with length of experience ranging from 1-10 years with the majority having between 3-5 years (N=7) experience. 2 participants had prior experience caring for SCI patients in other settings and were the only participants who had previously provided SCI bowel care. Most were band 6 nurses (N=7) with the

minority of band 5 participants. The majority were female (N=8, participants F1-8) and worked in a trauma high dependency setting (N=7) with some intensive care nurses (N=4).

The sample was a convenience sample purposive in nature with nurses volunteering to participate. Only indirect means of recruitment were used namely posters and emails sent via a trust-based gatekeeper. Posters were placed in each ward area social space and emails were sent to all employed nurses in each area. The participant then contacted the researcher via email to avoid coercion, if a participant did not attend an interview one email follow up was sent before withdrawal was assumed. Participation was dependent on the nurse being declared as spinal bowel care competent by their current place of work. A list was provided by the research areas of competent nurses prior to the start of the study to ensure participant confidentiality. The numbers of staff nurses deemed bowel care competent was low taking into consideration the frequency of spinal cord injury patients and the acute nature of injuries. At the time the study commenced no staff nurses from the spinal and orthopaedic ward were deemed competent in bowel care. Overall 14% of the permanent nurse workforce in areas that receive SCI patients were deemed able to deliver bowel care.

Table 1 – Percentage of staff per ward deemed competent in providing bowel care to SCI patients

Semi-structured interviews were undertaken based on open ended questions and the audio was digitally recorded. The interviews were transcribed verbatim by the researcher and analysed thematically based on Braun and Clarke's (6) 6 stages. One interview was randomly selected using a computer number generator and the transcript was sent to the participant with codes attached

to ensure validity (member checking). Participants were given a unique identification number to ensure participant confidentiality, female participants we labelled with F whilst male with M and numbered sequentially.

Statement of Ethics: Ethical approval was obtained from the Psychiatry, Nursing and Midwifery Ethics Subcommittee of King’s College London and from the NHS Trust specific Joint Research Compliance Office.

Findings:

Four major themes emerged: Unpleasantness of task, perceived patient experience, motivation and avoidance and barriers to care. Sub themes emerged in each of the themes:

Table 2 - Themes and Subthemes

Unpleasantness of task

Unpleasantness of task had sub-themes of: for nurse and perceived patient. The majority of nurses discussed the unpleasantness of task (N=9) largely in a stoic fashion. Handling faces was viewed as an integral aspect of nursing and as such the unpleasant nature for the nurse was accepted.

98 *F1: "Its poo...I wouldn't have come into the nursing profession if I didn't have a strong*
99 *stomach"*

100 *F7: "The smell, I hate it because of the smell and the whole process, I don't particularly like*
101 *it, but I have to do it"*

102 The unpleasant experience for patient was exacerbated by the acute nature of the injury and the
103 new physically dependent state of the patient. There was widespread appreciation for the
104 unpleasant nature of the care for the patient especially due to acute nature of injury.

105 *F8: "Obviously they have just had a traumatic spinal cord injury so they tend to be quite*
106 *fragile anyway and then they have someone emptying their bowel for them which is*
107 *obviously not pleasant for them"*

108

109 Perceived Patient Experience

110 Patient experience was very important to the nurses. They were well educated in the reasoning
111 behind provision of bowel care. They understood the need for the bowel care and the comfort a
112 good bowel motion could provide.

113 *M3: "It is a need [bowel care]. The positive thing about it is you are able to relieve a*
114 *patient. Make them feel...patients won't experience autonomic dysreflexia. Patients are*
115 *more comfortable for daily living and also it trains the patients, trains the bowel for a*
116 *certain time and certain bowel aids that they prefer to use."*

117

118 Promotion of continence through good care was seen as an empowering factor for patients that
119 allowed rehabilitation and improved quality of life.

120 *M1: "There is also the possibility that they could become incontinent [without proper*
121 *bowel care] which is obviously very unpleasant for them."*

122 *F5: "I think when it is instigated and it works well and their bowel is trained then it is*
123 *brilliant as you can get them out during the day it doesn't interfere, having their bowel*
124 *open, doesn't interfere with their rehab and things like that."*

125

126 The negative patient experience was equally important. The experience of the patient had a direct
127 impact on the experience the nurse took from it. Patients who were particularly young,
128 embarrassed or had rectal sensation were viewed the most difficult patients for the nurses to
129 provide care to. The invasive and nature of the care made the participants feel embarrassed on
130 the patient's behalf.

131 *F5: "I think that it can be quite embarrassing for the patient, I don't think they really like it,*
132 *because often our patients are awake when we are doing it, and aware."*

133 *M2: "Its somebody's bum. Having to insert my finger somewhere I don't want to insert it.*
134 *Umm Nine times out of ten when we are doing it the patients are awake and they are very*
135 *aware of what we are doing and that makes me feel uncomfortable and it's the actual*
136 *manual evacuation is just the worst thing that I can ever ever do and I have done a lot of*
137 *weird things in nursing but that is the worst thing I have come across."*

138

139 Privacy and dignity was difficulty to maintain during the care due to the acute setting and the time
140 required to complete the procedure.

141 *F8: "If the patient has a side room ideally. It's not nice for them to have to go through the*
142 *indignity, as some may call it, and they are in a bay area or you have someone continually*
143 *opening the door."*

144

145

146 Gender and Sexuality

147 Gender and sexuality were raised as issues surrounding provision of bowel care by the male
148 participants. The male nurses expressed concerns around caring for a patient of the opposite
149 gender or having their actions perceived in a sexual nature. One male participant expressed their
150 extreme hatred of providing the care and directly expressed reluctance in the insertion of a finger
151 into a patient's rectum separating manual evacuation care from other nursing requirements such
152 as suppository insertion.

153 *M3: "On the first few weeks [female patient] would only prefer female staff to do [bowel*
154 *care]. But in time she got used to it as part of her daily living she started to accept."*

155 *M1: "It [bowel care] is essentially an act of penetration, some people do it for fun.... I know*
156 *that there is no sexual thrill what so ever in it for me, but I do worry that my patient might*
157 *think that there is."*

158 *M2: "Every nurse has a weakness. For me it's the manual evacuation. I mean things like*
159 *the enemas and the suppositories and doing the bowel check that's fine. But when it*
160 *comes to that one part I just cave totally, I really struggle with that."*

161

162 Motivation and Avoidance

163 In Self

164 The medical necessity as well as patient comfort provided the self-expressed motivation in the
165 study. Few nurses expressed avoidance in themselves although one stated they have avoided the
166 care in the past related to their confidence and one participant actively avoided the care provision
167 as much as possible.

168 *F2: "We have got to get it [bowel care] done because if we don't then they go dysreflexic*
169 *and then you have a medical emergency on your hands"*

170 *M2: "I absolutely hate it [bowel care] I would rather poke my eyes out. It's the only time I*
171 *pull rank."*

172

173 Perceived in Colleagues

174 Avoidance in others was described largely related to avoiding training and therefore being unable
175 to provide the care. The participants felt this was a purposeful avoidance, the nurses felt that their
176 colleagues did not receive the training as they did not wish to provide bowel care. Work load on
177 the participants was viewed as strained due to the avoidance of training by their colleagues.

178 *F4: "I mean we get a lot of spinal cord injuries and saying that you don't have the training,*
179 *isn't really good enough."*

180

181 Barriers to Care

182 Staffing/Skill Mix

183 Bowel care in the acute setting rarely requires only one healthcare professional, it can often
184 requires at least one other to aid rolling the patient or even five, so the patient can be log rolled
185 under spinal precautions. This represents a vast proportion of the nurses/healthcare professionals
186 on ward. The first six months following injury are paramount to establishing an acceptable bowel
187 regime (7), during the initial stages, the process can take extended periods of time to complete
188 further straining the participants time to provide care. The lack of nurses trained as also
189 highlighted as an issue. Often one nurse was providing bowel care for multiple individuals leaving
190 nurses feeling stretched for time to care for other patients.

191 *F5: "Staff constraints... getting people to help you roll."*

192 *M2: "Time. As with everything we do as nurses time. Very much depends on the skill mix
193 and the work load on the unit."*

194 *F7: "At the moment not all nurses are able to do it. You are always getting dragged away,
195 even if it's not your patient".*

196

197 *Training*

198 Training was variable as no national or trust standard exists, variation was reported between
199 participants trained in the same ward. Training varied from study days and presentations to
200 informal discussions, all staff had competency assessments conducted on patients in their clinical
201 areas. Sporadic admission of SCI patients and training teamed with a reported reluctance of staff
202 to undertake this voluntary training was reported to lead to low numbers of trained nurses. The

203 training was not provided routinely was viewed as optional and specialised, this was perceived as
204 a problem.

205 *C1: "Maybe if they did it [training] more routinely as a band 5 like when you come onto the*
206 *ward... you do like IV competencies, maybe in bowel care there was a competency linked to*
207 *it."*

208 *F6: "More formal training probably would be better. A course would be better than*
209 *someone coming in from the spinal unit to train you and then that's that."*

210 *M2: "So our patient's come through in groups so we can go a long period without having*
211 *the spinal injuries and then suddenly we get a rush of spinal injuries so there's no real*
212 *pattern to it."*

213

214 Taboo

215 Bowel care was described as a taboo subject with participants who provide the care unwilling to
216 openly discuss it. This left healthcare professionals unwilling to discuss the care even between
217 themselves and are therefore unable to develop through professional discourse. A separation of
218 the care from the normal tasks of nursing within departments was described. The perceived
219 specialised nature of bowel care added to the taboo nature of the care as well as making care
220 provision more difficult.

221 *M1: "I guess probably the best start is to break down some of the barriers so that people*
222 *are actually able to talk about it. And then we can learn from each other."*

223 *F4: "if more people are trained on it, then it's easier to find people and it will probably take*
224 *the stigma away.. then it's not like a taboo subject."*

225

226 Confidence and Competence

227 Variable training experiences resulted in differing views of competence verses confidence. A lack
228 of formal competency assessments affected the nurses' confidence to provide the care.
229 Assessment of competence was often undertaken on patients and a fear of damaging the patient
230 or upsetting them at a delicate time of their acute injury was present. Assessments of competence
231 varied from one supervised episode of bowel care to three. Some nurses felt this was insufficient
232 and they expressed a feeling abandonment once assessed as they were left without another
233 competent member of staff to guide them in the care provision. A lack of confidence resulted in
234 avoidance of care provision.

235 *F3: "I used to kind of shy away from it, but that was because I didn't feel really confident in*
236 *doing it."*

237 *F7: "I had about 15 minutes theory and then she performed the procedure on the patient*
238 *and then, that was it I was deemed competent."*

239

240 Discussion

241 Bowel disturbances have a major impact on SCI patients and their emotional wellbeing as well as
242 physical health (8). Bowel care in all patient populations is (9)under researched and although
243 research has shown the importance of adequate bowel care to patients the experience of the
244 healthcare professional is largely unknown (10, 11). The first six months of injury are crucial to
245 develop good bowel routines and use of physical techniques are relied upon but are a challenging
246 time of newly injured patients (12). Burns et al (9) interviewed support workers and spouses who

provide bowel care to SCI individuals around their views and experiences. These interviews showed similar findings to research in the nursing population, training remained a prevalent issue with support workers in fear of causing damage and feeling unprepared. The intimate nature of care was also highlighted with spouses and support workers alike finding the care provision uncomfortably intimate. The research by Burns differs from current research as there was no acceptance of the nature of working with faeces. Another crucial difference are there was no concerns regarding gender or sexual interpretations are care described. Differences in the reactions of patients who are in the acute rather than chronic phases of their injury may have influencing factors. Other influences may be due to the time the person providing the care has known the person they are caring for. Acute nurses often only know their patients for short periods of time whilst carers may be with their patients for many years. The support workers interestingly did discuss the difficulty in maintaining professional distance, which may again be a result of the time spent with the SCI individual.

The nurses accepted the unpleasant nature of bowel care however they separated it from other unpleasant nursing practices. Although the nurses interviewed understood the importance of bowel care the research suggests it was not always a care priority due to the invasive nature causing embarrassment to patient (perceived) and nurse alike. Continence is an integral aspect of adulthood in our culture, however failures in continence care were never as starkly evident as in the Francis report into the care failing in Mid Staffordshire hospital (13). If continence has a low priority it follows naturally that advanced continence measures would also be of a low priority. It however seems greater than a simple extension of the socially unacceptable nature of continence care. It extends into a taboo area for nurses and as such is met with resistance.

270 The fact that training in bowel care was specialist rather than a pre-requisite to working in an area
271 that receives SCI patients is a factor in separating this care from standard nursing practice. Many
272 of the nurses interviewed discussed the low numbers of nurses trained putting a burden of care
273 on the nurses who are. They also thought that if all the nurses could give then care it may remove
274 some of the stigma as it would become 'normal'. The perceived patient experience was very
275 important to all the nurses interviewed. The unpleasant nature of the care for patients was a large
276 determining factor for the nurses interviewed with avoidance of care when the patient was
277 embarrassed. If the handling of faeces which is socially unacceptable can become normal within
278 the profession, the normalisation of bowel care is theoretically feasible but it must be embraced
279 as part of nursing.

280 Gender and sexuality due to the invasive nature of care was expressed by the male participants.
281 This study is limited as only 3 male participants volunteered in the study so the data saturation is
282 unlikely to have been reached. Nursing is traditionally a female dominated profession and
283 stereotypes surrounding men within this workforce remain. Male nurses often feel vulnerable to
284 accusations and misinterpretations of professional intimate touch (14). Male nurses being
285 concerned about sexual interpretations of care has been described in other intimate aspects of
286 care and when caring for female patients (15) directed training to better prepare male nurses
287 could be beneficial (16).

288 Education of both nurses and patients will be important to the future provision of SCI neurogenic
289 bowel care. The development of a national training framework may help reduce the variations in
290 the training experiences described. There has been much debate surrounding the competency
291 based training matrix specifically that it does not take into account the holistic nature of nursing
292 (17). Training in bowel care needs to be more than an assessment of ability to complete the task
293 and should include the emotional impact the care may produce. Addressing the potential negative
294 experiences of patients during this care will be an integral aspect. Further research into the

295 experiences of nurses nationally will add to the body of knowledge and add to the transferability
296 of the research.

297 **Conclusion:**

298 In conclusion nurses find bowel care unpleasant but accept faeces management as an integral
299 aspect of the nursing profession. Manual evacuation and digital stimulation are separated in the
300 nurses' view from other aspects of bowel care and are segregated from nursing care.
301 Embarrassment on behalf of the patient due to the invasive and intimate nature of care are of
302 concern. Inconsistent and often brief training that is specialist rather than an accepted norm of a
303 spinal ward creates both a taboo aspect and increases the patient burden on the few trained staff.
304 Further research into the impact of this intimate care on the male nursing population is required.
305 Standardisation of training programmes should be investigated to see if greater confidence in
306 bowel care provision can be instilled rather than simple competence assessment.

307

308 **Limitations**

309 The research was undertaken in the workplace of the principle researcher, who also conducted
310 the interviews. This could lead to a limitation in the topics the participants were willing to discuss.
311 Some participants may have been drawn to giving the perceived correct answer rather than
312 expressing their own thoughts on the subject. The research was undertaken in an acute trauma
313 centre and transferability of findings may be limited to similar institutions. The sample size was
314 the expected size and is similar to comparable research, however there was a low number of male
315 participants. The exact gender breakdown of the workforce was not known, however the areas
316 were higher in percentage of male nurses than general ward areas. Further research into the male
317 perspective is required as a difference in experience was described.

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321 **Conflict of Interest**

322 No conflict of interest to disclose.

323

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361

362

363 Tables

364 Table 1 – Percentage of staff per ward deemed competent in providing bowel care to SCI patients

365 Table 2 – Themes and Subthemes

366