

## Peer Review File

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### Reviewer A

#### Title page:

Comment 1: Please add the word count for the manuscript.

Reply 1: We have added a word count for the manuscript.

Changes in the text: We added the manuscript's word count (See page 1, line 19).

#### Introduction:

Comment 2: The important role of urologists in neurogenic bowel care was recently reported in this article, consider adding this to support your statements in the introduction: Kelly MS, Stout J, Wiener JS. Who is managing the bowels? A survey of clinical practice patterns in spina bifida clinics. *J Pediatr Rehabil Med.* 2021;14(4):675-679. doi: 10.3233/PRM-201512. PMID: 34864702.

Reply 2: We agree that this article offers strong support to our introduction.

Changes in the text: As suggested, we added the findings of this survey to our introduction (See page 3, lines 13-14).

Comment 3: The authors did a nice job simplifying NBD for readers in the second paragraph.

Reply 3: We appreciate your comment and hoped to make this accessible to readers with this simplification.

Changes in the text: N/A

Comment 4: Consider adding the medical issues associated with NBD beyond QOL. Such as hemorrhoids, anal fissures, skin breakdown, increased rates of UTI and urinary incontinence, temporary VP shunt malfunction etc.

Reply 4: We appreciate the addition of issues beyond QOL that are associated with NBD. We had already discussed that proper bowel management reduced the frequency of UTI and incontinence. Sacral pressure ulcers had been discussed further in our section dedicated to bowel diversion.

Changes in the text: Following our discussion of QOL impact, we mentioned the other issues that may result from fecal incontinence or a distended bowel (see page 4, lines

2-6).

Comment 5: The objective is clear and defined to adults with SB.

Reply 5: We appreciate your comment. We had aimed to make this clear, as management SB in adults often differs greatly from that of children and adolescents.

Changes in the text: N/A

### **Transition to adult care:**

Comment 6: The second paragraph could be strengthened with registered available in several studies using the National Spina Bifida Patient Registry (NSBPR) that has looked at associations in fecal continence and variables such as lesion level, sex, etc.

Reply 6: Thank you for the suggestion. Based on Comment 12, we opted to discuss reflexic vs. areflexic NBD in this section to strengthen the discussion of predictors available to clinicians.

Changes in the text: We added a discussion of reflexic and areflexic NBD based on the level of spinal lesion (see page 5, line 7-14).

### **Literature Search**

Comment 7: I don't see any reference to the SBA's recent publication, the Lifespan Bowel Management Protocol, which outlines a protocol for handling adults with NBD secondary to SB. The authors may want to look at that publication and its references for additional information for adults with NBD and SB.

Reply 7: We appreciate the recommendation and will add a specific reference to the SBA's publication.

In fact, this protocol was encountered and used as one of the resources during our search literature search. Many of our references overlap with those used in their protocol.

Changes in the text: We added a specific mention of the Lifespan Bowel Management to the summary of our literature search (See page 6).

Comment 8: It seems that this literature search was a bit selective by the authors regarding what was included. There are many articles on SB NBD that span beyond childhood that don't seem to be referenced. These exclusions should be mentioned, or the rationale for including what you have should be expanded.

Reply 8: We discussed a predicament encountered during our literature search. Notably in the literature, studies of adult NBD management tend to focus on those patient populations with acquired dysfunction such as SCI, while pediatric studies are

more likely to discuss SB or other congenital causes. Because of this, we found that studies using SB adults with NBD to be less represented. Hopefully this clarifies to readers some of our reasoning here.

Changes in the text: We added this insight into our discussion about our literature search (see page 6).

### **Lifestyle adaptations**

Comment 9: Consider providing references to appropriate fiber intake. For many individuals with NBD fiber is not straightforward and studies have shown in those with SB and SCI increased fiber can have a reversed effect.

Reply 9: We have cited the Academy of Nutrition and Dietetics for our 15-30g fiber recommendation. This appears to be the general consensus and has been cited elsewhere including by the SBA. We also discuss the diminishing/adverse effects of excess fiber. Although we used the AND as a reference later in this paragraph, we will specifically cite them after our specific gram fiber recommendation.

Changes in the text: We specified the limit of fiber at 30g as tolerated by patients and cited Academy of Nutrition and Dietetics (see page 7, lines 14&15).

Comment 10: There are several published bowel diaries for individuals with SB; consider citing one for clinicians to use.

Reply 10: Thank you for the suggestion, we agree that referencing an available bowel diary would be beneficial for clinicians.

Changes in the text: We mentioned a template bowel diary available from the SBA (see page 7, line 6-7).

Comment 11: Are there any references you can cite for the alcohol, caffeine, and prune statement?

Reply 11: Thank you for this suggestion. We neglected to cite this statement but will reference the article we had originally intended. With this statement we hoped to provide a few specific dietary triggers but emphasize that the bowel diary may become the main resource for an individual patient basis.

Changes in the text: We added a reference for our statement about specific bowel triggers (see page 7, lines 22-23)

Comment 12: It may be helpful to discuss areflexic vs reflexic NBD regarding the effectiveness of suppositories and digital stim. These are generally better for NBD secondary to thoracic SB or SCI. You can also cite rates from the NSBPR for those

who use these methods regarding continence.

Reply 12: Thank you for the suggestion. Based on the previous comment we chose to introduce the distinction of reflexic vs. areflexic NBD in the previous section concerning transition to adult care, which we felt was an appropriate place for this information. However, this distinction was also helpful to reiterate when discussing digital stimulation and manual evacuation.

Changes in the text: We commented that the effectiveness of these methods may rely on the level of lesion of each patient (see page 5, line 7-14; page 8, lines 7-8).

## **Pharmacologic**

Comment 13: These patients will have NBD for life and the very large majority require long-term bowel management, stating that long-term use of stimulant laxatives should be limited seems conflicting. I think this is listed on the packaging and website for the general population not those with NBD.

Reply 13: We agree that for those with NBD due to SB, long term treatment should be the emphasis. We will still mention the general population recommendation but acknowledge that the guidelines may differ for a neurogenic bowel.

Changes in the text: We altered our discussion of stimulant laxatives, to distinguish the recommendations for the general population from those for NBD patients (see page 9, line 2-5)

Comment 14: Overall NSBPR data shows oral medications alone aren't very effective in most.

Reply 14: We think this is important to mention as a caveat in our paragraph about oral laxatives.

Changes in the text: We added this information as suggested. We referenced a study that uses NSBPR data to report the small percentage of adults with SB relying on oral medications alone (see page 9, lines 5-7).

## **Rectal Meds**

Comment 15: Good use of caution regarding oral treatment only to start this section.

Reply 15: Thank you, we wanted to emphasize that oral medication alone is not always helpful in managing unpredictable bowels.

Changes in the text: N/A

Comment 16: The data on suppositories you provide for reducing bowel program times

is good, but as you mention specific for SCI which is generally a different type of NBD than SB. This distinction is important to mention since suppositories don't work as well with those on SB.

Reply 2: Yes, the literature for suppository use in NBD is predominantly focused on SCI. Although we have mentioned the distinction, we will make this all the clearer to our readers.

Changes in the text: We briefly reintroduced our discussion of areflexic NBD which is more typical of SB patients. Because of this nuance we also stressed caution in applying SCI results. (See page 9, lines 18-21)

## **SNM**

Comment 17: The authors spend a large section of this paper on SNM which is very rarely used in the US and considered by many, including the SBA, to be experimental. I think this should be recommended with caution and the authors should state more regarding the sample size of these few publications on this topic in order to not come across endorsing this too strongly with little evidence.

Reply 17: We had hoped to provide an interesting section on sacral neuromodulation and its niche as a treatment method. We would like to maintain the information on the unique treatment method out of intrigue. However, we understand that the tone of this section may be overstating the effectiveness and prevalence of SNM for the purposes of this review.

Changes in the text: We have changed the tone of this paragraph to emphasize the experimental nature of SNM for NBD and recommend this treatment method with caution. This has been reflected in our discussion as well. We also discussed in more detail the concerning sample size limited evidence specific to SB. (See page 10-11).

## **Reviewer B**

### **1. Figure 1**

Comment 1: Please define PRN in the legend.

Reply 1: As suggested, we have added PRN a definition of in our figure legend.

Changes in the text: Added a definition for PRN, "as needed."

### **2. References/Citations**

Comment 1: References 31 and 64 are the same, please delete one of them and revise both the citation in main text and reference list's order.

Reply 1: As suggested with deleted reference 64 and revised our reference list's order.

In text-citations were also revised in accordance with this change.

Changes in the text: The redundant reference 64 was deleted. The reference list order and in text citations were revised to reflect this change.