

January 31, 2017

Dear Dr. Yu,

Thank you for the review of our manuscript, “Chronological Age when Health Care Transition Skills Are Mastered in Adolescents/Young Adults with Inflammatory Bowel Disease”, for publication in the World Journal of Gastroenterology. We have addressed the reviewer’s comments below in italics and have made the requested changes to the manuscript where indicated.

Methods:

1. It would be helpful to frame your 10 years of data collection and 144 patients with the total number of potential patients seen in clinic during this time. What is your capture rate? Was this random sampling? What sampling tool/framework was used? Clarification needed.

Data was collected as routine in our IBD clinic. All patients who came in for a clinic visit were approached on days that a research assistant was available to visit the clinic. We did not systematically collect data on how many patients refused participation and hence cannot describe the capture rate.

2. Throughout the piece there are minor formatting issues, missed words, misspellings. An example of this is in the first paragraph of the methods, “Insurance” I believe was meant to have a bolded I?

Thank you for pointing this out. We have attempted to fix these errors throughout the manuscript. We have also run the manuscript through Grammarly.com to check for any misspellings, missed word, punctuation and style.

3. I struggle to accept your choosing 0.75 as a cutoff. How did you come to accept this value? Additional evidence/support for this number is needed: distribution of scores, previous scorings, scores tied to hard outcomes, etc.

We do not have hard evidence for this cut off. We realize that expecting 100% correct answers is not realistic. In one published study the authors reported on an institutional benchmark of 90% (Gray et al, Inflamm Bow Dis, 2015) but only 5.6% of young adults could reach this benchmark.. In our own – unpublished- data among patient’s parents, only one of the ten TRxANSITION scales had a mean score above 0.9. In a recent study among adults with IBD (mean age 36 years old) significant gaps were found in medication knowledge and self-management skills (Fishman et al J Pediatr Gastroenterol Nutr 2016). For example, full independence was seen in only 57% of adults. The authors suggested that expectations for transition readiness may be set too high in most clinics. Therefore, we thought 90% benchmark as suggested by Gray and Colleagues was too high. Based on our own data showing average mean over all scales among parents of our patients was 0.77, we set our own institutional benchmark at 0.75.

4. Thank you for references 8&9. Very helpful in tool identification, validation, etc.

Thank you for your positive comment.

Results:

1. Re: 85 pts completed x1, 41 x2, 18 3+ times. I feel a discussion of retention rate needs to be addressed. Could this be related to the sampling frame question above?

The retention rates are 48.2% for two times and 21.2% for three times. The low retention rates have several reasons: (1) We included patients who made no more than one visit to our clinics (either because

they moved, or because their visit was within the past year), and (2) patients were not specifically targeted at their follow-up visits. Gaps in data collection may be due to unavailability of research personnel to visit the clinic during the follow-up visit.

2. You note that “On average, females had higher transition scores, when compared to their male counterparts.” Why would this be? Please consider commenting on this apparent inherent disparity. *We cannot know from our current study why females have higher transition scores. However, gender differences in transition readiness have been reported in other studies. Girls are known to achieve developmental milestones of independence earlier than boys (Park et al 2006 J Adolesc Health), which may translate to independence in disease self-management as well. We have added the following in our discussion section, par. 3 on page 9: “We found increased HCT transition skills among female AYA, which is consistent with previous literature¹⁴.”*

3. Likewise, please consider commenting on race disparities. *Thank you for suggesting this. We have added the following section commenting on racial disparities in the discussion section, par.3 on page 10: “Additionally, we found disparities in HCT skill acquisition between Caucasian AYA and AYA of other races. This is consistent with previous literature highlighting racial disparities in the transition to adulthood for youth with special healthcare needs^{13,16–18}. Both low-income and non-white AYA are already at-risk for poorer health outcomes than their Caucasian, middle and high income families¹⁹.”*

4. Also, any comment on the relative size of disparities? Does insurance status/SES explain more variation than does race?

In the multiple regressions we performed in the paper, the coefficients are interpreted as the impact of an independent variable on the dependent variable while keeping other covariates constant. For example, the coefficient of age in column 1 of Table 4 suggests that one unit (i.e., a year) increase of age is associated with 0.42 increase of the total transition score while keeping other variables constant.

Unfortunately, we cannot compare the relative explanatory power of each independent variable in this type of multiple regression because the variables' scales are different. However, we can perform a standardized regression, which transforms each independent variable to z-scores, to compare the relative strength of each independent variable in explaining the dependent variable. The result of the standardized regression is shown below (in the Beta columns). A larger absolute value of beta represents relatively larger explanation power of the independent variable. Regarding the level of total transition score, age has the largest beta and therefore explain more variation than other variables do. For the growth of total transition score, age and insurance explain more variation than other variables do. We have not made changes to the manuscripts based on this comment.

Variable	Level Effect			Growth Effect		
	Coefficient	P-value	Beta	Coefficient	P-value	Beta
Age	0.42***	0.00	0.54	0.21***	0.00	0.32
Female	0.41**	0.05	0.13	0.03	0.90	0.01
Race: African American	-0.43**	0.06	-0.11	-0.06	0.87	-0.02

Race: Other	-0.75***	0.01	-0.12	-0.43*	0.09	-0.06
Public insurance	-0.02	0.94	-0.00	-0.96***	0.01	-0.23
No insurance	-0.70*	0.07	-0.18	-0.70*	0.06	-0.11
Age at diagnosis	-0.00	0.99	-0.00	0.05	0.23	0.09
Lag total score				0.42***	0.00	0.45
Constant	0.05	0.95		0.96	0.26	
N	226			82		
R square	0.32			0.52		

5. Table 2 reveals very low N for the 18-19 yo group and >19 yo group. Should we only compare the first 3 groups? Please provide evidence that we can still trust your conclusions about the latter 2 groups.

This is a very good suggestion. If we combine the last two groups, the observation number is 21 (9% observation). The table has been updated in the manuscript. Our result that many knowledge related skills are mastered between age 12-14 and the other half of skills are not mastered until after age 18 still hold. The only difference is that the skill to find a new care provider is not mastered even after age 18 in the updated analysis.

6. Table 3 bolding of first letters is distracting, though I recognize this may be a factor of the submission website.

We have removed the bolding.

7. Figure 1. I am unclear what the numbers by the dots mean (N?). Good figures stand alone. If they are N, very low numbers on the right to base conclusions on.

Yes, the numbers mean N. The updated graph has this information in the legend. Thanks for attending us to this. We agree that the very low numbers of observations on the right cannot be used to base conclusion on. Therefore, we base our conclusion on who are >18 years instead of each year of age.

8. Table 4. Please reference comments 2-4 above.

Discussion:

1. You state in your second sentence that “These findings can be used in clinical care in order to benchmark AYA’s skills in relation to their peers...” I think this statement is true, but only if one assumes that your population is similar enough to ours. A qualifying statement is needed.

Thank you for pointing this out. We have added the qualifying statement to this sentence in the discussion section par. 2 on page 9. The sentence now reads, “These findings can be used in clinical care, in clinical settings with AYA of a similar demographic, in order to benchmark AYA’s skills in relation to their peers, ensure that they are on track in their development, and as a reference point for the development of clinical interventions teaching skill mastery earlier and in a more step-wise fashion.”

2. In the 4th full paragraph, you state “In the United States, it is common for AYA to leave their parental home around the age of 18 to live independently.” Is this true of your population? Are there plans to assess this? There are some data that suggest that the current trend is for >18yos to stay in their parents’ homes longer. I might suggest you support/check this assumption.

Thank you. In the discussion section, par. 4, page 10, we have amended this sentence to include more specific data and have cited this statement. The sentence now reads as follows: “There is evidence that in the United States, approximately 60% of young adults ages 18 to 24 live outside the parental home²⁰.”
Citation: “Manzoni A. Intergenerational Financial Transfers and Young Adults’ Transitions In and Out of the Parental Home. Soc Curr. 2016;3(4):349-366. doi:10.1177/2329496515616822.”

3. Did the authors mean chronological age in the sentence beginning “In some studies, providers have identified psychological...”? Please proofread and consider revising this sentence.

Yes, thank you. We have edited this sentence accordingly in par.4 of the discussion section, on page 10. The sentence now reads: “In some studies, providers have identified psychological and developmental maturity as more important factors in assessing transition readiness than chronological age^{21,22}”

4. With respect to the sentence beginning “Understanding of the US healthcare system...”, this is a bit of a stretch. Do any of us need to understand the US healthcare system to receive adequate clinical care? I agree that everyone needs to be able to navigate their particular health system. Are you suggesting that adolescents are ill-equipped to know their own particular health system? In certain parts of the country, it seems that they find the ED just fine...

Thank you for requesting this clarification. We have edited this sentence to include more specific aspects of the healthcare system in par. 4 of the discussion section on page 10. It now reads: “Navigating some of the complex systems of the US healthcare system, such as health insurance and reimbursement, requires a relatively high level of executive functioning, so it is possible that adolescents are simply not yet cognitively equipped to master these skills before they reach young adulthood.”

5. I wholeheartedly agree with the following sentence, “Conversely, it is possible that AYA do not develop these skills at a younger age because their parents and healthcare team do not have an expectation that adolescents participate in these responsibilities.”

Thanks for your positive feedback

6. Re “Future interventions should focus on assisting AYA in developing mastery of HCT transition skills before living independently.” This suggestion rings true if your assumption about independent living is true. Please check/support the assumption that it is common for AYA to leave their parental homes around age 18.

Thank you again for pointing this out. As discussed in #2 above, we have amended our statement to be more specific and added a citation for this.

7. Consider moving the study’s strengths to the top of the discussion section.

Thank you for this suggestion. We have changed this accordingly

