Reviewer’s report

Title: Recommended care and care adherence following a diagnosis of Lynch syndrome: A mixed-methods study

Version: 0 Date: 25 Jun 2019

Reviewer: Cathryn Koptiuch

Reviewer's report:

It may seem like I made a ton of comments below, but I really love that you're publishing this great work! My questions and comments are mainly with regard to where the content can be expanded upon and a few places where reorganization and/or clarification is warranted. I do hope that you can address most of these comments. Thanks for your work! This is a thorough study that does fill a gap in the literature regarding adherence to provider recommendations to patients with Lynch syndrome and patient and provider ideas of how to remedy this problem, at least within one specific large medical system. It is a useful analysis that points to areas where providers can improve hospital systems to optimize adherence and therefore health outcomes for these high risk patients.

Overall Comments:

* Since KPNW previously published in HCCP in 2018 on some of the same 22 Lynch syndrome patients that were identified through an EMR query, it would be interesting to compare the responses of patients to the actual EMR data.

* Aim 1 seeks to assess the change of time to LS diagnosis after cancer diagnosis over time, but the paper doesn't mention in the methods the exclusion of LS patients who were diagnosed prior to having cancer. However in results, the authors are more specific and describe that 36% underwent testing due to family history. Please discuss this process in methods.

* Methods section needs to be refined/focused and more concise.

* Since using the initiation of UTS as a data point in patient cohorts, KPNW's start date of UTS for CRC and EC needs to be included in background.

* Results from Aim 4 are quite brief. Did anything else come out of these interviews of interest regarding improving adherence?

Specific Comments on Content:
* Pg4 Lines 107-110: Focus methods section as it is not the place to state aims. "The aim…
gaps in this population" should be replaced with statements about the actual design used
(e.g. EMR queries and chart reviews) used for obtaining data for aims 1-3 stated in the
previous section.

* Pg4 Lines 110: Delete "In order… care gaps" for same reason as above.

* Pg5 Line 124-126: Delete "Because these… diagnosis of LS" and perhaps just add to
next sentence "Under guidance of a genetics professional"

* Pg5 Line 131: Were only patients with genetic test results in the EMR stating likely
pathogenic and pathogenic MMR variants included as "confirmed LS diagnosis" or were
these clinically-described diagnoses as well? Later I see how this is presented in the
results section, but seems appropriate for methods as it defined the cohort.

* Pg 5 Line 131: "Adherence data… 2016" does not fit under the sub-heading "Study
Population"

* Pg6 Line 140: Was information on partial colectomies also collected? Was treatment
information collected?

* Table 1: Delete "(Endometrial surveillance)"

* Table 1: Delete "(TVUS)"

* Table 1: Did you try to look at dermatology screening codes too?

* Pg6 Line 151: Delete "To gain… care delivery", focus on methods.

* Pg6 Line 152: This sentence makes it sound like patients that were already enrolled in
something else were recruited. Is that the case?

* Pg7 Line 163-164: Delete "To determine… over time"

* Pg7, Line 166: Delete "after discovery of LS genes"

* Pg7, Line 167-169: "These dates… and Prevent" can be moved into background. Also, a
comment on whether KPNW initiated a UTS across their entire system the year that
EGAPP came out is important. If adopted later, the date ranges chosen for analysis would
be inappropriate. Also, it should be noted whether KPNW initiated screening of both
endometrial and colorectal tumors or just CRC tumors as was the recommendation of
EGAPP in 2009. If just CRC tumors, when did KPNW start to include endometrial tumor
screening into their UTS?
Were patients who received a diagnosis of CRC who did not receive a total colectomy put were receiving chemotherapy during what would have been the screening interval also excluded from this?

Were the qualitative themes from interviews used to abstract advice for care coordination specifically, or only for data reported elsewhere? Reference to findings from data reported elsewhere can be in background or discussion, not methods. However, this paper can be references for this methods section instead of describing it a second time since it's the exact same cohort. After referencing, specific note on which specific subset of this data from the interviews can be briefly mentioned.

What were the mean and ranges for age of diagnoses for these cohorts being compared?

Variability of these recommendations makes sense due to how the guidelines are laid out for non-CRC screening in LS. If you're going to draw conclusions from this variability, perhaps the variability in the guidelines themselves (and recommendation to tailor management based on family history and ethnicity) should be incorporated into the background section better. Adherence to what was recommended seems like the better item to be analyzing given the wording of LS guidelines. Conversely, this could also be mentioned in the discussion when the authors discuss that variability could be do to modifications of NCCN guidelines over time, when in fact the nature of the extracolonic guidelines not being strict recommendations seems like a more likely correlation.

This statement is difficult to understand. How could patients that are 100% adherent be 0% adherent to certain recommendations? Please make more clear.

Were any of these women getting RR surgeries diagnosed with EC or OC when pathology looked at the resected tissue?

Since a chart review was performed, are the authors able to comment on how many of the cases in the pre-2008 and post-2008 LS cohorts were diagnosed through their UTS? This would help show the relationship between UTS and decreased time and ability to diagnosis LS in patients with CRC and EC.

Might this adherence also be due to the particular mutation that a women carried? Suggest including this.

"an" should be either "a" or "any" when referring to "an LS-related cancer" in multiple sentences.
* Pg3 Line 85: May consider alternate WC for "affected individuals" - perhaps "carriers of pathogenic variants", "LS individuals", or "at-risk individuals"?

* Pg3 Line 89 and Pg4 Line 94: The abbreviation "EMR" is used on page 3 but defined on page 4.

* Pg4 Line 97": delete "and" prior to item 3 as this is not the last item in the list, move prior to last list item in live 98

* Pg 5 Line 122: WC modification - change "who had ever received a possible diagnosis of LS" to "with a high likelihood of having LS"

* Pg7 Line 168: authors should use their previously-defined abbreviation "UTS"

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