

## Original Research Article

# Health literacy and quality of life following rectal resections for cancer

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## ABSTRACT

**Background:** Health literacy can be a stronger predictor of an individual's health status than income, employment status, education level, and racial or ethnic group. The prevalence and impact of low health literacy in the rectal cancer patient population has received little attention. This study is a cross-sectional population survey to determine if there is a relationship between health literacy and quality of life in rectal cancer patients.

**Methods:** All rectal cancer patients having a clinical encounter with the Colorectal Unit at Westmead Hospital will be invited to participate in the study. Two validated health literacy screens (REALM-SF and NVS) were administered along with the EORTC QLQ-C30 quality of life assessment. The association between health literacy and quality of life will be examined using Spearman regression.

**Results:** 92 patients were recruited between March 2015 and July 2016. A significant proportion of our patients were found to have low health literacy (29.3 percent and 54.5 percent as measured by the REALM-SF and NVS, respectively). The mean QLQ-C30 summary score was 71.5 and the mean global health score was 69.4 (SD 23.3). There appeared to be no statistically significant correlation between health literacy and quality of life in our study. There was a moderately positive correlation between the NVS and REALM-SF ( $\rho = 0.36$ ,  $P < 0.001$ ).

**Conclusions:** A significant proportion of our patients that have had rectal resections for cancer have low health literacy. We have not been able to demonstrate an obvious association between health literacy and quality of life in the present study.

**Keywords:** Health literacy, Quality of life, Rectal cancer

## INTRODUCTION

Health literacy has been defined as, "the degree to which individuals can obtain, process, understand and communicate about health related information needed to make informed health decisions."<sup>1</sup> In studies looking at the issue, health literacy is a stronger predictor of an individual's health status than income, employment status, education level, and racial or ethnic group.<sup>2,3</sup> Indeed, several studies in diverse settings have shown that, even after controlling for a variety of socio-

demographic variables, poor health literacy is associated with a range of adverse health outcomes including decreased use of preventive health services such as cancer screening, increased incidence of chronic conditions such as diabetes and hypertension, and increased risk of hospitalization and mortality, and poorer health related quality of life.<sup>4-6</sup> The prevalence and impact of low health literacy in the surgical patient population has received little attention. Colorectal cancer is the second most common cancer in Australia in both men and women.<sup>7</sup> Rectal cancers account for about half

of these. The management of rectal cancer has improved markedly over the past few decades. These advancements have resulted in more patients receiving sphincter-preserving surgery with a low colorectal or a colo-anal anastomosis to avoid permanent colostomy. Unfortunately, up to 90% of such patients will subsequently have a change in bowel habit, ranging from increased bowel frequency to faecal incontinence or evacuatory dysfunction.<sup>8</sup> This wide spectrum of symptoms after resection and reconstruction of the rectum has been termed 'the anterior resection syndrome and can adversely affect the patient's quality of life.<sup>9</sup> In many ways, living with the bowel dysfunction that may be associated with rectal cancer, and the functional sequelae of its treatment is equivalent to living with a chronic disease that may have adverse effects on health related quality of life in these patients.

The health-related quality of life of patients following rectal resection in Western Sydney is unknown, and to our knowledge, has not previously been studied. The primary objectives of this study are to determine the health literacy of patients who have had rectal resections for cancer in Western Sydney and determine their quality of life. The secondary objectives are to see if there is an association between these two factors.

## METHODS

This study will be a cross-sectional population study of patients who have previously had rectal resections for cancer and have a clinical encounter with Colorectal Unit at Westmead Hospital between the periods March 2015 to July 2016. This can be during an inpatient admission, outpatient clinic, and involves both emergency and elective patients.

Exclusion criteria include non-English speakers and those individuals whose English proficiency requires the aid of an interpreter for an adequate clinical consultation. All eligible patients were given an information sheet about the study and invited to review and sign a consent form. A health literacy screen was then administered by the principal investigator at the time of the clinical encounter.

Two validated screening tools for health literacy were used. The first being the Rapid Estimate of Adult Literacy in Medicine Short Form (REALM-SF).<sup>10</sup> In this brief screen of written document literacy, the patients were asked to read seven words and marked according to the REALM-SF protocol by the principal investigator at the time of the clinical encounter. Patients who scored no correct answers have a reading level of or below the Third grade, and are likely to need repeated oral instructions, or material composed primarily of illustrations, or audio and video tapes. Scores of between one to three indicate a Fourth to Sixth grade reading level. These patients may not be able to read prescription labels. Scores of between four to six indicate reading ability at the Seventh to Eighth grade level. These

patients are likely to struggle with patient education materials. Patients who were able to read all seven words are likely to be able to read all patient education materials and instructions.

The second health literacy assessment used is the Newest Vital Sign (NVS) questionnaire.<sup>11</sup> In this, the participants are presented with a hypothetical nutritional information label and then asked to answer six questions about the information displayed. The probability of limited health literacy is estimated by the number of questions answered correctly. With one or less correct answers, participants are scored as having a high probability (50% or more) of limited health literacy. With two to three correct answer, a person has the possibility of limited health literacy. A higher score of four to six almost always indicates adequate health literacy.

Quality of life was assessed using the recognised and validated European Organization for the Treatment of Cancer (EORTC) health questionnaire QLQ-C30.<sup>12</sup> This consists of thirty questions that combine to make six functional scales (physical, emotional, cognitive, social, role functioning, and global function), three symptom scales, and a number of additional single item scales to measure 15 outcomes in total. Patient responses were combined and converted to a 0-100 scale according to guidelines provided by the EORTC.<sup>13</sup> Higher functional and global health scores represent better functioning and quality of life, whereas higher symptom scores reflect greater symptom distress and lower quality of life. Correlation analysis was done using the aggregate summary score calculated from the QLQ-C30 questionnaire as recommended.<sup>14</sup> This is to reduce the risk of committing a type I error in analysing the multiple outcome measures in the survey.

Information regarding the operative approach (open versus laparoscopic), the type of resection done, and the presence of a stoma was documented. A high anterior resection was defined as being a resection with the anastomosis being at or above the peritoneal reflection; a low resection with an anastomosis within 10 cm of the anal verge; an ultralow resection within 6 cm of the anal verge. The presence of a stoma was also documented. Analysis of the health literacy and quality of life data was done as per publisher instructions. Descriptive statistics were performed to characterize the study population and the results of the health literacy assessment and quality of life assessment. Spearman regression was used to calculate pairwise correlation between the QLQ-C30 summary score and health literacy as determined by the NVS and REALM-SF questionnaires. The use of nonparametric tests were used as recommended to accommodate for the skewed variables which is a common phenomenon in quality of life data.<sup>15,16</sup> All statistics were performed using SPSS 24.0 (IBM Corp. 2016) The sample size required to detect a weak correlation (Spearman rho = 0.3) was calculated to be 85 (2 sided p-value 0.05, 80% power). Local institutional

ethics approval was granted by the Western Sydney Local Health District Human Research Ethics Committee prior to study commencement.

## RESULTS

92 patients were successfully recruited to participate in the study. The patient characteristics are presented in Table 1. Most of our patients were under 70 years of age (n=57, 62%) with the median age being 63 (mean 64.1). There were slightly more male than female participants in the study (52.2%, n=48). The vast majority of operations were performed laparoscopically (n=78, 84.8%) and sphincter preservation was found in 84.8% (n=78) of the participants. Of this group, 31 (39.7%) had defunctioning ileostomies.

## Health literacy

In our study 65 of participants (70.7%) were found to have good reading literacy as assessed by the REALM-SF (Table 2). 52 patients (56.5%) clearly had adequate numerical literacy as assessed by the NVS (Table 3). In both assessments, a significant proportion (29.3% and 43.5% respectively) were found to have low health literacy.

## Quality of life

The mean QLQ-C30 summary score was 71.5 (SD 18.7) and the mean global health score was 69.4 (SD 23.3). The full results of the EORTC QLQ-C30 data is displayed in Table 4.

**Table 1: Patient characteristics (n = 92).**

|                    |                              | n  | %    |
|--------------------|------------------------------|----|------|
| Age (median 63)    | Less than 70 years           | 57 | 62.0 |
|                    | More than 70 years           | 35 | 38.0 |
| Gender             | Male                         | 48 | 52.2 |
|                    | Female                       | 44 | 47.8 |
| Type of resection  | Hartmann's procedure         | 4  | 4.3  |
|                    | Abdominoperineal resection   | 10 | 10.9 |
|                    | Ultra-low anterior resection | 18 | 19.6 |
|                    | Low anterior resection       | 28 | 30.4 |
|                    | High anterior resection      | 32 | 34.8 |
| Stoma              | No stoma                     | 47 | 51.1 |
|                    | Permanent colostomy          | 14 | 15.2 |
|                    | Defunctioning ileostomy      | 31 | 33.7 |
| Operative approach | Open                         | 14 | 15.2 |
|                    | Laparoscopic                 | 78 | 84.8 |

**Table 2: Health literacy – Realm SF.**

| Score | Interpretation   | n  | %    |
|-------|--|----|------|
| 0     | Third grade and below; will not be able to read most low-literacy materials; will need repeated oral instructions, materials composed primarily of illustrations, or audio or video tapes. | 0  | -    |
| 1-3   | Fourth to sixth grade; will need low-literacy materials, may not be able to read prescription labels.  | 4  | 4.3  |
| 4-6   | Seventh to eighth grade; will struggle with most patient education materials; will not be offended by low-literacy materials.  | 23 | 25.0 |
| 7     | High school; will be able to read most patient education materials.  | 65 | 70.7 |

**Table 3: Health literacy-newest vital sign.**

| Score | Interpretation                                    | n  | %    |
|-------|---|----|------|
| 0-1   | High likelihood (50% or more) of limited literacy | 24 | 26.1 |
| 2-3   | Possibility of limited literacy                   | 16 | 17.4 |
| 4-6   | Almost always adequate literacy                   | 52 | 56.5 |

**Table 4: Quality of life EORTC QLQ-C30.**

|                             | Mean | Range     | Std. Deviation |
|-----------------------------|------|-----------|----------------|
| <b>Quality of life</b>      |      |           |                |
| Summary score               | 71.5 | 29.2-98.7 | ± 18.7         |
| Global health status        | 69.4 | 8.3-100   | ±23.3          |
| <b>Functional Scales</b>    |      |           |                |
| Physical functioning        | 81.6 | 13.3-100  | ±19.6          |
| Role functioning            | 72.5 | 0-100     | ±41.5          |
| Emotional functioning       | 71.4 | 8.3-100   | ±25.2          |
| Cognitive functioning       | 81.9 | 33.3-100  | ±20.3          |
| Social functioning          | 56.2 | 0-100     | ±35.9          |
| <b>Symptom scales/items</b> |      |           |                |
| Fatigue                     | 44.4 | 0-100     | ±30.0          |
| Nausea and vomiting         | 22.1 | 0-100     | ±26.2          |
| Pain                        | 34.4 | 0-100     | ±34.0          |
| Dyspnoea                    | 16.7 | 0-100     | ±22.9          |
| Insomnia                    | 38.4 | 0-100     | ±36.3          |
| Appetite loss               | 39.1 | 0-100     | ±35.8          |
| Constipation                | 23.9 | 0-100     | ±33.3          |
| Diarrhoea                   | 14.5 | 0-100     | ±23.9          |
| Financial difficulties      | 25.4 | 0-100     | ±32.9          |

**Table 5: Correlation (Spearman rho).**

|                 |                         | QLQ-C30 Summary score | REALMSF | NVS    |
|-----------------|-------------------------|-----------------------|---------|--------|
| QLQ-C30 summary | Correlation coefficient | -                     | .179    | -0.161 |
|                 | Sig. (2-tailed)         | .                     | .087    | .125   |
| REALM-SF        | Correlation coefficient | .179                  | -       | .356** |
|                 | Sig. (2-tailed)         | .087                  | -       | .000   |
| NVS             | Correlation coefficient | -0.161                | .356**  | -      |
|                 | Sig. (2-tailed)         | .125                  | .000    | -      |

### Correlation

There was a moderately positive correlation between health literacy as determined by the NVS and REALM-SF questionnaires (Spearman rho = 0.36, P<0.001). However, there appeared to be no statistically significant correlation between health literacy and quality of life in our study (see Table 5).

### DISCUSSION

This is the first study to examine the relationship between health literacy and quality of life in rectal cancer patients.

#### Health literacy

Our survey indicates that low health literacy both in reading and numeracy affect a significant proportion of our patients. This is in line with previous estimates of health literacy in the general Australian population.<sup>17</sup>

Health literacy can be difficult to assess and there is no

universally agreed tool for its assessment.<sup>18,19</sup> The REALM-SF focuses on word recognition and pronunciation and is derived from the Rapid Estimate of Adult Literacy in Medicine (REALM), one of the most commonly used measures in health literacy research.<sup>5</sup> It does not assess comprehension or numerical quantitative skill. Past studies have demonstrated that low numeracy skills is not uncommon even amongst patients with adequate reading skill.<sup>20</sup> In consideration of this, we used two separate assessments to look at both domains of health literacy. Our study results demonstrate a positive correlation between these the NVS and REALM-SF (Spearman rho=0.356, p<0.001), and corroborate previous findings.<sup>21</sup>

#### Quality of life

Our EORTC QLQ-C30 survey results indicate that our patients have similar global and functional scores to the published reference ranges for colorectal cancer of all stages.<sup>22</sup> This suggests a comparable health related quality of life. Patients in our cohort did however report

higher scores in the symptom scales (nausea and vomiting, pain, insomnia, appetite lost and constipation). This is in keeping with previous studies that found rectal cancer patients tend to report more symptoms than when compared to all comers of colorectal cancers.<sup>23</sup> Furthermore, it is also possible that this is a reflection of the timing of the quality of life assessment in our patient cohort. A significant proportion of patients were recruited and assessed during the early post-operative and/or during an acute non-elective hospital admission, where higher levels of symptoms are to be expected.

### **Correlation between health literacy and quality of life**

Our results demonstrate an absence of a significant relationship between health literacy and quality of life. Previous studies evaluating this relationship have been mixed. In one study by Wallace of 249 patients in the primary care setting, 28.5 percent of patients had limited health literacy which had a correlation with their self-reported general well-being.<sup>24</sup> In another larger multicenter study of 605 heart failure patients, low literacy was associated with poorer quality of life.<sup>25</sup> Similarly, an analysis of a population based study of 1581 patients newly diagnosed with localized prostate cancer found that patients with low health literacy levels were more vulnerable to mental distress. They did however not find an association with physical well-being.<sup>26</sup> In contrast to this, and more in keeping with our findings, a recent cohort study did not find any association between health literacy and the physical and mental components of quality of life among frequent users of health care services.<sup>27</sup>

All of the cited studies above have been diverse in the population group studied, the health literacy tools used, and the measure of quality of life. Ours is the only study to use two separate health literacy assessments, use the EORTC QLQ-C30 Summary score, and look specifically at a post-surgical patient cohort.

Present study was limited by a number of possible confounders. Many patients were seen in the acute or in the early post-operative setting. This is reflected in the higher symptom score in our quality of life assessment as discussed above. However, this is unlikely to have any impact on their health literacy screen and should not influence its validity. Additionally, we did not account for patient comorbidities, tumour covariates such as staging, history of recurrence or presence of metastasis, or receipt of adjuvant treatment which may potentially have an influence on the quality of life assessment. Other sources of possible selection bias include the significant proportion of non-English speaking patients in our practice which were excluded from our study. Moreover, our study was underpowered to detect a very weak association (Spearman rho <0.3) between health literacy and quality of life which has previously been reported.<sup>24</sup> A larger study would be required to exclude a smaller association between these two variables.

## **CONCLUSION**

A significant proportion of our patients that have had rectal resections for cancer have low health literacy. However, we have not been able to demonstrate an obvious association between health literacy and quality of life in the present study.

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