



# Health and lifestyle behaviors in colorectal cancer survivors with and without Lynch syndrome

Kirsten M. Donato<sup>1</sup> · Katelyn Moore<sup>1</sup> · Wendy M. Parker<sup>1</sup> · Susan K. Peterson<sup>2</sup> · Ellen R. Gritz<sup>2</sup> · Christopher I. Amos<sup>3</sup> · Karen H. Lu<sup>4</sup> · Patrick M. Lynch<sup>5</sup> · Miguel A. Rodriguez-Bigas<sup>5</sup> · Y. Nancy You<sup>6</sup> · Allison M. Burton-Chase<sup>1</sup>

Received: 11 September 2018 / Accepted: 8 April 2019 / Published online: 23 April 2019  
© Springer-Verlag GmbH Germany, part of Springer Nature 2019

## Abstract

Lynch syndrome (LS), a hereditary cancer syndrome, accounts for approximately 3% of colorectal cancers (CRC). Positive health behaviors and surveillance are preventive strategies, but research on whether recommended behavioral guidelines are followed by individuals with LS is limited. Additional health education and promotion could be beneficial to the improved survivorship of CRC survivors. Explore health and lifestyle behaviors in CRC survivors with and without LS. We conducted a case-control study of CRC survivors with and without LS using a mailed questionnaire. Recruitment was conducted via patient registries at The University of Texas MD Anderson Cancer Center (cases  $n = 33$ ; controls  $n = 75$ ) and through social media (cases  $n = 42$ ). CRC survivors with and without LS in our study had substantially lower smoking prevalence (5.5% and 2.7%) compared to national prevalence (18.0%). However, they had higher levels of alcohol consumption (36.8% and 10.3% for male and female LS survivors, respectively, and 35.8% and 22.0% for male and female sporadic survivors, respectively) compared to national prevalence of 13.88% for males and 6.02% for females. Both groups of CRC survivors participate in negative health behaviors that impact survivorship. More research is needed to examine the relationship between personal engagement in preventive behaviors and patient–provider relationships to improve health behaviors and explore strategies for intervention. Additionally, better health education and lifestyle change recommendations would promote and reinforce positive health outcomes in the CRC population and especially in LS survivors.

**Keywords** Lynch syndrome · Health behaviors · Colorectal cancer survivors · Health education · Cancer prevention education

✉ Kirsten M. Donato  
kirsten.donato831@gmail.com

<sup>1</sup> Department of Population Health Sciences, Albany College of Pharmacy and Health Sciences, 106 New Scotland Avenue, Albany, New York 12208, USA

<sup>2</sup> Department of Behavioral Science, The University of Texas MD Anderson Cancer Center, Houston, TX, USA

<sup>3</sup> Department of Community and Family Medicine, Dartmouth College, Hanover, NH, USA

<sup>4</sup> Department of Gynecologic Oncology and Reproductive Medicine, The University of Texas MD Anderson Cancer Center, Houston, TX, USA

<sup>5</sup> Department of Gastroenterology, Hepatology, and Nutrition, The University of Texas MD Anderson Cancer Center, Houston, TX, USA

<sup>6</sup> Department of Surgical Oncology, The University of Texas MD Anderson Cancer Center, Houston, TX, USA

## Introduction

Lynch syndrome (LS), or hereditary non-polyposis colorectal cancer, is characterized by mutations in DNA mismatch (MMR) genes (*MLH1*, *MSH2*, *MSH6*, and *PMS2*) or an *EPCAM* deletion (Lindor et al. 2006; Lu and Daniels 2014; Andrejs et al. 2010; Steel et al. 2017). LS is an autosomal dominant condition, which results in an increased susceptibility to multiple cancers, most commonly colorectal cancer (CRC) (Lindor et al. 2006; Lu and Daniels 2014; Andrejs et al. 2010; Steel et al. 2017). The estimated lifetime risk of CRC in individuals with LS is 60%, with studies reporting a mean age of diagnosis of the first cancer in the mid-40s compared to 64 years old for CRC in the general population (Lindor et al. 2006; Andrejs et al. 2010). Additionally, women with LS have a lifetime ovarian cancer risk range of 8–12% and a lifetime endometrial cancer risk range of 35–60% (Lu and Daniels 2014). For comparison, lifetime CRC risk for the

general population is 4.4%, lifetime endometrial cancer risk is 2.8%, and lifetime ovarian cancer risk is 1.3% (American Cancer Society 2018). Individuals with LS are at increased lifetime risk of cancer in additional sites including the stomach, ovary, urinary tract, hepatobiliary tract, brain, small intestine, and skin (sebaceous adenomas or carcinomas and keratoacanthomas) with a trend toward increased risks for pancreatic cancer (Lindor et al. 2006). Consequently, increased cancer screening for individuals with LS is highly recommended with colonoscopies offered as early as 20–25 years of age, every 1–2 years (Lindor et al. 2006; Lu and Daniels 2014; Steel et al. 2017).

Several lifestyle factors have been shown to decrease CRC risk. These lifestyle factors can be categorized under dietary and health behaviors. The dietary behaviors include fat and fiber consumption as well as alcohol intake. The health behaviors include physical activity and smoking. There is a 50% lower risk of CRC with higher intake of dietary fiber and, inversely, a high consumption of red meat (beef, pork, or lamb) in both men and women results in a higher risk of CRC (Gingras and Beliveau 2011). Greater levels of physical activity are associated with an approximately 40% reduction in the risk for CRC (Gingras and Beliveau 2011). Tobacco use has been consistently associated with an increased risk of CRC; smokers are at a 20% increased risk of CRC compared to non-smokers and have a 2.5 times increased risk of overall CRC-specific mortality (Boyle et al. 2013). Tobacco also has been shown to be a cofactor in the development of colorectal adenoma in individuals with Lynch syndrome (Watson et al. 2004). The risk of CRC significantly increases with the amount of years the individual smoked and the number of cigarettes smoked daily (Jinhui et al. 2010). An alcohol consumption of  $\geq 30$  g per day is associated with increased risk of CRC (Boyle et al. 2013; Cho et al. 2004). Progress has been made in identifying lifestyle changes that affect cancer risk, but a limited amount of data is available in identifying the effectiveness of lifestyle changes on LS-associated cancer risks. The limited data available suggest that cigarette smoking cessation should be an integral part of ideal health behaviors for patients with LS, in addition to high fruit and vegetable intake that has established benefits in decreasing the risk of CRC in all individuals (Lindor et al. 2006; Cho et al. 2004).

Increasing awareness of preventative measures such as healthy eating and smoking cessation through direct patient education could be part of the solution toward lower mortality rates for any individual diagnosed with cancer. However, there is insufficient research on the specific lifestyle behaviors of individuals at risk of LS-associated cancers. Therefore, the purpose of this study is to look at health and lifestyle behaviors in CRC survivors with and without LS to help provide insights into their behaviors and to provide recommendations for providers on how to educate this population on healthy lifestyle recommendations.

## Methods

### Participants

This study was approved by the Institutional Review Board at The University of Texas MD Anderson Cancer Center (MD Anderson). This study employed a case-control design with frequency matching through stratification. Matching was completed based on characteristics such as sex, age, cancer stage, geography, ethnicity, and time of diagnosis. The study population included 150 adults who were ages 18 years or older diagnosed with LS-associated or sporadic CRC. Eligible participants were recruited from the MD Anderson tumor registry. LS participants were recruited from MD Anderson ( $n = 33$ ) and through social media ( $n = 42$ ). Sporadic CRC survivors were recruited from the MD Anderson Tumor Registry. All eligible participants had received a CRC diagnosis from 6 months to 5 years prior to enrollment in the study. This allowed us to focus on individuals who were beyond the initial treatment phase but were not yet classified as long-term cancer survivors. Exclusion of sporadic CRC participants was based on personal/family history of LS, familial adenomatous polyposis (FAP), inflammatory bowel disease, and first-degree relatives with CRC.

### Study procedure

Data were collected primarily with an extensive mailed, self-administered questionnaire. Eligible participants were mailed a packet containing an introductory letter, questionnaire, and self-addressed stamped return envelope. Non-respondents received identical follow-up mailings 3 weeks after the original mailing and then a follow-up reminder phone call at 6 weeks with the option to complete the questionnaire over the phone. Participants who completed the questionnaire were compensated with a \$10 gift card.

### Measures

#### Demographics

Demographic variables were obtained from the registry, when available, and for study design (matching) purposes, and confirmed via self-report on the survey. These variables included sex, age, race/ethnicity, marital status/partner status, education, household income, and number of biological children.

#### Risk behaviors

Diet was assessed through a 17-item screening tool development by the National Cancer Institute (NCI). It estimates dietary intake of fruits and vegetables and the percent energy from fat and fiber during the past 20 days (National Cancer

Institute 2007). Physical activity was measured by the Leisure Score Index (LSI) of the Godin Leisure-Time Exercise Questionnaire (GLTEQ). This measure assesses the average frequency of mild, moderate, and strenuous exercise during a typical week (Godin et al. 1986). Smoking history and alcohol use were both adapted from the Centers for Disease Control (CDC) Behavioral Risk Factor Surveillance System (BRFSS) (Centers for Disease Control 2009). Participants were asked whether they had smoked in the last 7 days, smoked at least 100 cigarettes in their lifetime, average number of cigarettes/day, and the number of years as a daily smoker. Alcohol use and consumption were assessed through several questions including consumption of 12 or more alcoholic beverages such as beer, wine, or liquor in your lifetime, how often alcohol is consumed, and about how many drinks of beer, wine, liquor are had in an average week (Nelson et al. 2001).

### Statistical analysis

Health and lifestyle risk behaviors among LS and sporadic CRC survivors were examined to identify the association between these behaviors and demographics. Statistical significance was defined as  $p < 0.05$ . Analyses were performed using Statistical Analysis Software (SAS) 9.4 (SAS Institute Inc. 2011). Descriptive analyses were undertaken to better understand the differences between LS and sporadic CRC patients along these varied metrics.

## Results

### Demographic profile

Table 1 shows participant demographics. As expected given the study design, there were no significant differences

between the demographics of those with LS and sporadic CRC except in terms of treatment location.

### Screenings: health and lifestyle behaviors

Table 2 depicts health behaviors and their significance by gender and participant type which were compared to nationally established metrics for the same year. Self-reported current smoking rates were 5.5% among all LS CRC survivors and 2.7% for sporadic CRC survivors, as compared to 18.0% national prevalence. Sporadic females are more likely to consume alcohol (> 3 alcoholic beverages/day) compared to the national alcohol consumption and LS females (22.0%, 6.02%, and 10.3%, respectively). Looking at dietary behaviors, for fat consumption, all participant groups were higher (LS males 93.8%, LS females 74.4%, sporadic males 81.8%, and sporadic females 78.0%) than national averages (males 70.6% and females 36.8%), having a daily dietary intake of greater than 30% of calories from fat. The same pattern is consistent with regard to the percent of inadequate fiber intake with all four of our groups being higher than the national averages. For physical activity, all groups except for female sporadic survivors (34.1%), report lower percentages with no moderate or vigorous activity than national averages (30.8%). When comparing all groups, across the five risk behaviors, there were no significant differences between LS and sporadic survivors.

## Discussion

In this study, we examined health and lifestyle behaviors between a matched sample of CRC survivors with and without LS. Because of the demographically matched case design, there are no significant demographic differences in the two populations except location of treatment, with all LS patients being treated at a comprehensive cancer center. For the five

**Table 1** Demographics by CRC survivorship group

Characteristic % (n)	LS (n = 71)	Sporadic (n = 74)	p value
Mean age (SD), years	52.3 (12.0)	54.9 (11.6)	0.76
Gender			0.95
Male	45.1 (32)	44.6 (33)	
Female	54.9 (39)	55.4 (41)	
Treatment: comprehensive cancer center	43.7 (31)	100.0 (74)	< 0.001***
Married/committed relationship	85.9 (61)	75.7 (56)	0.12
Have at least 1 child	81.7 (58)	90.5 (67)	0.13
White	91.6 (65)	94.6 (70)	0.48
College education or higher	62.0 (44)	52.7 (39)	0.26
Employed full-time or part-time	64.8 (46)	58.1 (43)	0.41
Difficulty paying bills	18.3 (13)	14.9 (11)	0.58

\* $p < 0.05$ ; \*\* $p \leq 0.01$ ; \*\*\* $p \leq 0.001$

**Table 2** Health behaviors by CRC survivorship group and gender

Characteristic % (n)	LS (n = 71)	Sporadic (n = 74)	p values
Smoking prevalence (current smoker)			
	5.5 (4)	2.7 (2)	0.40
2012 CDC BRFSS: total percentage of smoking prevalence			
All adults 18.0%			
Alcohol consumption ( $\geq 3$ alcoholic beverages/day)			
Males	36.8 (8)	35.8 (8)	0.98
Females	10.3 (4)	22.0 (9)	0.15
2012 CDC BRFSS: total percentage of alcohol consumption			
Males 13.88%		Females 6.02%	
Fat consumption (% total fat intake $\geq 30\%$ of calories)			
Males	93.8 (30)	81.8 (27)	0.87
Females	74.4 (29)	78.0 (32)	0.95
USDA CSFII: total percentage of fat consumption			
Males 70.6%		Females 63.2%	
Fiber consumption (% inadequate fiber intake)			
Males	56.3 (18)	54.5 (18)	0.89
Females	66.6 (26)	68.3 (28)	0.87
USDA CSFII: total percentage of fiber consumption			
Males 38.3%		Females 40.6%	
Physical activity (no vigorous or moderate activity)			
Males	21.9 (7)	18.2 (6)	0.58
Females	23.1 (9)	34.1 (14)	0.14
2012 National Health Interview Survey (NHIS), CDC/NCHS			
Males 28.3%		Females 30.8%	

health behaviors that were assessed in this study, we saw no significant differences between the two CRC survivor groups; however, we did find differences from national averages. For positive health behaviors, both CRC survivor groups report current smoking rates that are lower than national averages, and all of our groups, except for female sporadic survivors, report being more physically active than national averages. For negative health behaviors, all four of our groups had higher alcohol, fiber, and fat consumption than national comparison data. These findings suggest that alcohol and diet, in particular, are risk factors that should be addressed in the CRC survivor population.

Interestingly, our findings suggest that CRC survivors with and without LS are far more similar than they are different. Dietary and health behaviors have an impact on CRC risk among all CRC survivors, including individuals with LS (Cho et al. 2004; Burton et al. 2010). Given the ongoing elevated cancer risks for individuals with LS, the familial nature of this diagnosis, and the continued interaction with the healthcare system, these findings need to be explored in future research. A recent study points out that among a group of lung cancer and CRC survivors, 24% of people reported no discussion about strategies to improve their health, exercise, or diet habits (Kenzik et al. 2016). Further, cancer survivors are

motivated to improve their health following their diagnosis, which means healthy behaviors and lifestyle change recommendations from their oncology provider may facilitate a better conversation and promote more effective behavior change in this population (Vijayvergia and Denlinger 2015). Research has shown that, through effective communication, healthcare providers have been able to positively impact health-related attitudes and behaviors regarding cancer screening adherence (Fox et al. 2009). One important avenue for future research is to examine whether this finding extends to health behaviors. It is likely that CRC survivors would benefit from their providers educating them about lifestyle changes to promote cancer survivorship and improve health outcomes; however, information about how to best facilitate this conversation is still needed. It also is likely that sharing this information during one clinical visit is not sufficient and that providers will need to use additional resources such as patient portals, patient navigators, or referrals for additional services (such as a consultation with a nutritionist) to effect change in cancer survivors.

Limitations of this study include the following: a relatively small sample, which can limit generalizability and the possibility of recruitment bias because LS patients came from two different sources. The hereditary cancer population is difficult to identify and hard-to-reach, and with the use of case-control matching, these data were gathered for the highest quality possible. As with many studies in this population, research participants are more likely to be White and of higher socioeconomic status than the overall patient population, which limits generalizability. These findings have implications for clinicians, health educators, genetic counselors, and social workers. Specifically, our findings show a potential intervention area in regard to education on health and lifestyle behaviors, particularly in the area of alcohol consumption and diet, for all CRC survivors. The need for comprehensive care and education around a healthy lifestyle and positive behavior choices is crucial for the LS population and improving long-term health outcomes for all CRC survivors. In the future, larger studies need to be conducted in this population, specifically when looking at health behaviors in the LS population and health risk factors. In conclusion, this study contributes to the limited data on health and lifestyle behaviors and also points to the growing need for more direct patient education about health behaviors and lifestyle choices among CRC survivors.

**Funding information** This research was supported by a cancer prevention fellowship awarded to Allison M. Burton-Chase, PhD, supported by the National Cancer Institute grant R25T CA57730 (Shine Chang, MD Anderson Cancer Center, PI). Support was also provided, in part, by the Patient-Reported Outcomes, Survey, and Population Research (PROSPR) Shared Resource through a Cancer Center Support Grant (CA16672, PI: R. DePinho, MD Anderson Cancer Center), from the National Cancer Institute, National Institutes of Health.

**Compliance with ethical standards** The authors declare no conflicts of interest.

All ethical rules were followed in the data collection for this project, which was approved by the Institutional Review Board at The University of Texas MD Anderson Cancer Center. Informed consent was obtained by all study participants. No animals were included in this study.

The findings reported in this manuscript have not been previously published and the manuscript is not simultaneously submitted and under review at another journal. Some of the data in this manuscript have been presented at a conference by the corresponding author, but the abstracts were not published. The authors have full control of all the primary data used for reporting and agree to allow the journal to review the data if requested.

## References

- American Cancer Society (2018) Cancer facts & figures 2018. American Cancer Society, Atlanta
- Andrejs V, Strumfa I, Arbolins A et al (2010) The concept, diagnostics, surgical prevention and treatment of hereditary colorectal cancer in nowadays medicine. *Acta Chirurgica Latviensis* 10(2):80–85
- Boyle T, Fritschi L, Platell C, Heyworth J (2013) Lifestyle factors associated with survival after colorectal cancer diagnosis. *Br J Cancer* 109(3):814–822
- Burton AM, Peterson SK, Marani SK, Vernon SW, Amos CI, Frazier ML, Lynch PM, Gritz ER (2010) Health and lifestyle behaviors among persons at risk of Lynch syndrome. *Cancer Causes Control* 21(4):513–521
- Center for Disease Control (2009) Behavioral risk factor surveillance system
- Cho E, Smith-Warner SA, Ritz J et al (2004) Alcohol intake and colorectal cancer: a pooled analysis of 8 cohort studies. *Ann Intern Med* 140(8):603–613
- Fox SA, Heritage J, Stockdale SE, Asch SM, Duan N, Reise SP (2009) Cancer screening adherence: does physician-patient communication matter? *Patient Educ Couns* 75(2):178–184
- Gingras D, Beliveau R (2011) Colorectal cancer prevention through dietary and lifestyle modifications. *Cancer Microenviron* 4(2):133–139
- Godin G, Jobin J, Bouillon J (1986) Assessment of leisure time exercise behaviors by self-report: a concurrent validity study. *Can J Public Health* 77:359–362
- Jinhui Z, Halfyard B, Roebathan B et al (2010) Tobacco smoking and colorectal cancer: a population-based case-control study in Newfoundland and Labrador. *Can J Public Health* 281–289
- Kenzik K, Fouad M, Pisu M et al (2016) Are long-term cancer survivors and physicians discussing health promotion and healthy behaviors? *J Cancer Surviv* 10(2):271–279
- Lindor N, Peterson G, Hadley D et al (2006) Recommendations for the care of individuals with an inherited predisposition to Lynch syndrome: a systemic review. *J Am Med Assoc* 296(12):1507–1517
- Lu KH, Daniels M (2014) Endometrial and ovarian cancer in women with Lynch syndrome: update in screening and prevention. *Familial Cancer* 12(2):1–7
- National Cancer Institute. Diet history questionnaire, version 1.0. 2007
- Nelson DE, Holtzman D, Bolen J et al (2001) Reliability and validity of measures taken from the Behavioral Risk Factor Surveillance System (BRFSS). *Social and Preventive Medicine* 46(Supplement 1):S3–S42
- SAS Institute Inc (2011) Base SAS® 9.4 procedures guide. SAS Institute Inc, Cary
- Steel E, Robbins A, Jenkins M, Flander L, Gaff C, Keogh L (2017) How does genetic risk information for Lynch syndrome translate to risk management behaviors? *Hered Cancer Clin Pract* 15(1):1–9
- Vijayvergia N, Denlinger C (2015) Lifestyle factors in cancer survivorship: where we are and where we are headed. *J Pers Med* 5:243–263
- Watson P, Ashwathnarayan R, Lynch H et al (2004) Tobacco use and increased colorectal cancer risk in patients with hereditary nonpolyposis colorectal cancer (Lynch syndrome). *J Am Med Assoc* 164:2429–2431

**Publisher's note** Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.