

testing subsequent to their PHE, do so in absence of any mention of prostate cancer or PSA screening during the visit.

Keywords: Prostate Cancer; PSA Testing; Cancer

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PS1-08:

Lynch Syndrome Screening Patterns in Colorectal Cancer Patients in a Large Multi-institutional Cohort

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Background/Aims: Up to 5% of colorectal cancer (CRC) patients have a hereditary predisposition to CRC called Lynch Syndrome (LS). Here we use the CERGEN population to investigate how frequently institutions document family history of cancer in a meaningful manner for LS identification. We characterize the individuals who receive LS testing, and determine the pattern of usage among the institutions with regard to the multiple recommended testing schemes. **Methods:** The study population includes 1220 patients with stage III or stage IV CRC, from one of the seven participating Cancer Research Network (CRN) study sites. Eligible patients were initially diagnosed with stage IV CRC between January 1, 2006 and December 31, 2009 or stage III CRC between January 1, 2004 and December 31, 2006. We compute descriptive statistics, such as proportions, counts, means, and variances, to summarize the derived information. Data analyses were conducted using SAS Release 9 (SAS Institute, Cary, NC). **Results:** Family history documentation in the EMR varied, with 3 sites clustering below 70% (279/436, 70/103, 137/199) and 4 sites with over 85% (111/127, 61/63, 119/136, 147/156). Of those with family history documentation 61% (591/971) have a relative with cancer and 20% of these (120/591) report CRC in at least one first degree relative. Less than 5% of the population received LS testing. These individuals tended to be younger (53 versus 67), and have a documented CRC family history. The decision to test for Lynch syndrome tended to be made soon after diagnosis (median 59 days). Microsatellite instability testing and immunohistochemistry testing were both used for initial LS testing, with some individuals receiving both, while a small number of individuals proceeded directly to germline sequencing. Of the individuals who received germline testing, 2 were diagnosed with LS. **Discussion:** Family history of colon cancer is documented for the majority of individuals although this varies by site. Very few individuals are tested for LS at any site, representing a potential under diagnosis of this hereditary condition in patients and their families. When testing is performed, there does not seem to be a preference for immunohistochemistry or microsatellite instability testing for any site.

Keywords: Lynch Syndrome; Colorectal Cancer; Cancer

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PS1-09:

Comparing the Greatest Challenges of Long-Term Rectal Cancer Survivors with Anastomosis Versus Ostomy

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Background: Patients surgically treated for rectal cancer receive either an intestinal ostomy (externalization of the bowel to the abdominal wall) or, more frequently, an anastomosis (reconnection) of the rectum. While the challenges of intestinal ostomies have been previously described by this research team, much less is known about the long-term challenges of living with an anastomosis. Understanding the challenges of long-term rectal cancer survivors with both types of surgeries is important for informing and improving current practice. **Methods:** We mailed our survey to 1000 long-term (at least 5 years post-diagnosis) rectal cancer survivors in KP Northern

California and KP Northwest during 2010-2011. Our overall response rate was 57.7% (577/1000). The survey contained an open-ended question that asked respondents to write about the greatest challenge they experienced after their cancer surgery. Seventy-three percent of respondents provided a response to this "greatest challenge" question. Responses were analyzed qualitatively to compare the challenges reported by patients with anastomosis vs. ostomy. **Results:** Challenges related to managing bowel function and output were found in both groups. Ostomy patients reported challenges to managing ostomy equipment that were unique to their condition—ostomy appliance failures, skin breakdown around the ostomy, and finding suitable places to empty, clean, and reconnect their appliance. Other notable differences in the greatest challenges among ostomy and anastomosis patients included: 1) patients with an ostomy reported a range of psychosocial challenges relating to depression, shame, stigma, and post-operative psychological trauma about having an ostomy and such psychosocial impacts were notably absent among anastomosis patients; 2) patients with ostomies reported regret about having an ostomy, but patients with anastomosis did not report regret about the surgery they received; and, 3) anastomosis patients mentioned more challenges from radiation after effects, including pain, fistulae, and strictures. **Discussion:** Our findings about rectal cancer survivors with ostomies mirror previously published reports. Even in the face of impaired bowel function, rectal cancer survivors with anastomoses express little psychological distress or regret about treatment choice. The lasting effects of radiation therapy, however, are of special concern to this group.

Keywords: Cancer; Ostomy

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PS1-10:

Spiritual Well-being and the Challenges of Living With an Ostomy: Resilience, Adaptation and Loss Among Colorectal Cancer Survivors

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Background: Spiritual well-being (SpWB), defined as hopefulness, inner peace, and sensing a reason to be alive, is integral to health related quality of life (HRQOL). It is only partially related to spirituality and religiosity. The challenges of colorectal cancer (CRC) and subsequent bodily changes can affect SpWB. We explored expressions of SpWB reported by CRC survivors with ostomies. **Methods:** We recruited all adult CRC survivors (>=5 years) with permanent ostomies who were members of Kaiser Permanente Northwest, Northern California, or Hawai'i during 2000-2006 to complete a mailed survey (n=283). We asked participants to respond to an open-ended question about the greatest challenge they encountered in having an ostomy. Responses from the 62% (176 of 283) of patients who answered this question were analyzed based on the City of Hope HRQOL model for 1) content related to SpWB, and 2) to identify and categorize the SpWB themes found. **Results:** The responses of 51% (90 of 176) of participants contained SpWB content. Seventeen SpWB themes were identified, reflecting positive, negative, and ambivalent dimensions. Some responses contained multiple themes but each theme was coded only once for each person. Fifty-three of 90 people (59%) expressed positive themes which included "positive attitude" "appreciate life more" "helping others helps me" "strength through religious faith" "leading an active life" and "I am fortunate." Negative themes included "struggling to cope" "not feeling 'normal'" and "loss" and were least common, expressed by only 28 of 90 people (31%). Ambivalent themes were most common (67%; 60 of 90 individuals) and included "learning acceptance" "ostomy is the price for survival" "reason to be around despite suffering" and "continuing to cope and function despite challenges." **Discussion:** These CRC survivors with ostomies infrequently cited negative SpWB as a major challenge, though the greatest number of SpWB responses were ambivalent. More commonly, SpWB themes were mentioned as a source of resilience or part of the struggle to adapt to their altered body after cancer surgery. SpWB interventions should be broadly constructed to include the many types of SpWB, as opposed to narrowly defining SpWB only in terms of spirituality or religiosity.

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