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Development and Validation of an Instrument to Measure the Impact of Genetic Testing on Self-Concept in Lynch Syndrome (LS)

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Abstract

Background—A positive genetic test result may impact on a person's self-concept and affect quality of life.

Purpose—The purpose of the study was to develop a self concept scale to measure such impact for individuals carrying mutations for a heritable colorectal cancer- Lynch Syndrome (LS).

Methods—Two distinct phases were involved: Phase 1 generated specific colorectal self-concept candidate scale items from interviews with eight LS carriers and five genetic counselors which were added to a previously developed self-concept scale for BRCA1/2 mutation carriers. Phase II had 115 LS carriers complete the candidate scale and a battery of validating measures.

Results—A 20 item scale was developed with two dimensions identified through factor analysis: stigma/vulnerability and bowel symptom-related anxiety. The scale demonstrated excellent reliability (Cronbach's $\alpha = .93$), good convergent validity by a high correlation with impact of event scale ($r(102) = .55$, $p < .001$) and Rosenberg Self-Esteem Scale ($r(108) = -.59$, $p < .001$), and a low correlation with the Fear questionnaire ($r(108) = .37$ $p < .001$). The scale's performance was stable across participant characteristics.

Conclusions—This new scale for measuring self-concept has potential to be used as a clinical tool and as a measure for future studies.

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Competing Interests
The authors do not have any competing interests.

Keywords

Adjustment; Genetic Testing; Hereditary Nonpolyposis Colon Cancer (HNPCC); Lynch Syndrome (LS); Psychosocial; Self-Concept

INTRODUCTION

Hereditary colorectal cancer accounts for 1 – 3% of all colorectal cancers (CRC) [1]. Lynch Syndrome (LS) or Hereditary Nonpolyposis Colon Cancer (HNPCC) is an autosomal dominant disorder characterized by an early age of onset of CRC and is associated with an increased risk for other cancers [2, 3]. Genetic testing for LS can identify deleterious mutations in four genes that increase the risk of developing various cancers, including mainly colorectal and endometrial, as well some other gastrointestinal, gynecological and genitourinary cancers. LS mutation carriers are estimated to have an up to 60–80% lifetime risk of developing CRC and are advised to follow high-risk screening and surveillance guidelines including colonoscopy every 1–2 years; screening guidelines for other LS associated cancers vary [4].

A number of studies reported on the psychological and behavioral impact of receiving genetic test results for LS [5–9]. The main short-term findings are fairly consistent in that unaffected mutation carriers experience increased distress during the immediate post disclosure period which decreases to baseline or pre-test levels by 6 months [7, 8, 10–14].

Fewer reports described long-term psychosocial impacts of mutation testing in LS mutation positive families [5, 9, 15, 16]. Most elevations in distress at post-result return to baseline by 1 [17, 18] and 3 years [19]. However, studies consistently demonstrate that a subgroup have more adjustment difficulties [8, 18, 20].

Previous studies typically utilize global measures of distress, assessing general anxiety or depression symptoms. These measures may be limited in capturing specific psychological and social issues associated having a gene mutation [20, 21]. In fact, qualitative studies using measures that specifically aim to assess specific distress associated with a cancer diagnosis or heritable risk found impacts on body image and self-perceptions [22–25]. The literature suggests potential impacts on a person's self-concept, in particular, issues associated with a person's identity (e.g. having now a genetic identity), social self, and threat to roles [26–28]. The very language involved with genetic counselling, such as "mutation" and "abnormal gene" suggests meanings of being "defective" or "altered", which may become internalized [26]. In fact, the notion of a genetic self has been described by others [29–31]. Perceived impacts on roles, such as those relating to parenting involving the decision to have children or not, and feelings of guilt associated with passing on a gene mutation have been documented [29, 32, 33]. Impacts on other self-concept domains include an altered sense of attractiveness, the impact of surgical scaring on physical appearance or body functioning, a sense of mistrust of the body or feelings of loss [26, 34].

When examining self-concept in other genetic populations (e.g. *BRCA1/2)* we found significant impacts of a positive genetic test result included feeling of being stigmatized or vulnerable, and a loss of, or sense of hope around future health. Fear-arousing health information can result in a person feeling "stigmatized", "alienated", "different from others" and "vulnerable" [35, 36]. There may also be positive impacts, including a feeling of resilience which may emanate from the familial experience of previous losses or multiple diagnoses facilitating an individual to form a "survivor" sense of self [33, 37].

In colorectal cancer, there are unique areas of potential impacts related to the need for frequent screening of the colon and post surgery bowel functioning. The early-onset of colorectal cancer and faster progression from benign polyp to malignant colorectal tumor calls for more frequent colonoscopy screening in a person with LS. Someone with a known LS mutation who develops colorectal cancer might consider undergoing a sub-total colectomy which may result in post surgery bowel seepage, incontinence and urgency. These issues may intensify a person's feeling of stigma, or result in frequent monitoring, resulting in greater anxious preoccupation with bowel functioning.

Recent reviews recommend psychosocial instruments specific to the field of genetic testing [20, 28, 30, 38]. The purpose of this study was to develop and validate a self concept instrument to capture relevant self perceptions associated with impacts of genetic testing for LS.

Definition of Self – Concept

The Schema model of self-concept [39–41] guided the research. According to this perspective, human responses to social stimuli are mediated through an internal system of knowledge structures, or self-schema, that forms a person's self-concept. Schemas are derived from experience [42], are content-specific and can also be formed through internalized cultural values and norms [43]. For example, Western Society's cultural emphasis on the pursuit of thinness can shape a person's self perception of body image and evaluation of the self [44]. Self-schemas actively integrate, shape and summarize perceptions and experience, much like templates [40] and can be developed about any aspect of a person, including body weight [44], exercise [45], sex roles [40], and academic performance [46]. Individuals who have a positive perception of the self are more apt to endure threat, loss and misfortune, as compared to those with a more negative self- concept [47]. People have conceptions of who they are in the present, who they were in the past, and who they might be in the future. Future "possible selves" relate to the self one expects, fears or wishes to be [39, 48]. For example, a person may strive to "be married and have children" or have a self they "hope to avoid becoming" (e.g. being the victim of cancer). Self-concept can influence motivations to adopt screening or engage in health-protective behaviors [39, 49].

Purpose

This paper reports on the development and initial validation of an instrument measuring self-concept in an adult population who carry LS mutations, and builds on our previous work in BRCA1/2.

METERIALS AND METHODS

The study consisted of two phases: Phase 1: LS-specific self concept item generation and refinement and Phase 2: Further item assessment and scale development and initial validation in adult LS carriers, age 18 years and older.

Phase 1: Supplemental Colorectal Cancer-specific Item Generation

During Phase 1, Ethics approval from the Mount Sinai Hospital Research Ethics Board in Toronto was obtained. We consulted with five certified genetic counselors working in colorectal cancer genetics and invited individuals with mutations associated with LS to participate in a focus group interview. Eight carriers consented to the focus group invitation where they were asked to consider a number of questions (e.g., How does the genetic test results impact on how you view yourself?). Responses from the genetic counselors and focus group participants helped to generate additional bowel-specific self-concept items, to

supplement the 17 generic self-concept items published from a sample of *BRCA1/2* mutation carriers. The *BRCA1/2* scale items demonstrated promising psychometric properties [26] and were deemed relevant to LS genetic testing.

Bowel-specific Items

The following 7 bowel-specific self-concept items were generated by the genetics professionals and patients: “I am worried about bowel symptoms (like bleeding) when I go to the bathroom”, “I worry about changes in my bowels”, “I’m afraid of having bowel pain”, “I feel pressure to live life in healthy ways (like having a low fat diet)”, “I feel cursed because of my test result”, “I am very aware of my body sensations” and “I feel embarrassed when I go for my bowel screening”. These 7 were added to the 17 items from the BRCA1/2 scale, resulting in a total of 24 items to be further refined in phase 2.

Phase 2: Scale Development and Initial Validation

The goal of this phase was to select from the total of 24 items the best scale items as suggested by Briggs and Cheek [50].

Procedure

Ethics approval from the Mount Sinai Hospital Research Ethics Board and the Memorial University Ethics Review boards was obtained. Potential candidates were identified from the Familial Gastrointestinal Cancer Registry (FGICR) at Mount Sinai Hospital in Toronto and the Newfoundland Familial Colorectal Cancer Registry (NFCCR) in St. John’s Newfoundland. Letters of invitation to participate in the study were mailed to men and women who had received a positive genetic test result for one of the LS mutations from the two participating registries and who indicated that they would like to be contacted for new research studies. Respondents were assured that participation was voluntary, that responses were anonymous and that participation in the study (or not) would not impact on their medical follow up. Participants signed and returned informed consent documents with completed study questionnaires.

Participants for Item Selection—A total of 160 adults were approached for the study through a mail survey. One hundred and fifteen consented to the study, representing a response rate of 71.9%. Participants had a mean age of 50 years with a range from 23 – 80 years, 62% were females, 78% were married, and 63% had a previous diagnosis of colorectal cancer. Average time since receipt of their genetic test results was 4.7 years (range 1 to 14 years). (See Table 1)

Materials—The mail survey consisted of: 1) the 24 candidate self-concept items in a Likert scale format. Respondents indicated their agreement with each statement on a 7-point scale ranging from strongly disagree = 1 to strongly agree = 7 and not applicable = 8; 2) the battery of standardized validating measures including the Impact of Event Scale, the Rosenberg Self-Esteem Scale, the Marlowe-Crowne Social Desirability Scale, the Phobic Fear Questionnaire, and the single item linear analogue scale; and 3) demographic information such as age, marital status, and time since receipt of a LS diagnosis and/or genetic test result.

Assessing Psychometric Property of the Scale

Reliability—Using SPSS 17.0 (www.ibm.com), the following statistical analyses were performed for the scale development. As a first step, items were required to have at least an 80% response rate. Second, each item was examined to determine its contribution to the internal consistency of the total 24-item scale. An item was eliminated if the inclusion of

that item resulted in a lowering of Cronbach's alpha to a value of less than .80 [51]. In addition, item-total correlations for each of the candidate items were examined. The minimum criterion for selection was .35. Third, correlations between each of the candidate items and the Marlowe-Crowne Social Desirability Scale were examined to test for evidence of social desirability contamination. Items were only retained if they had correlations of less than .30 with social desirability. Forth, an item was eliminated if its item-total correlation was lower than its correlation with any other of the scales [52].

Validity—A principal components factor analysis with varimax rotation was performed on the candidate scale to examine the factor structure, the loading of the items in the factor analysis and specifically, to determine the number of factors and to ensure that the a priori themes are represented in the final scale. An examination was also conducted on relationship between the final scale and the validating measures to assess convergent, discriminate validity and concurrent validity.

To assess the convergent validity of the candidate scale, the *Impact of Event Scale,(IES)* a 15-item self-report questionnaire was used to assess subjective distress related to the experience of genetic testing [53]. The IES has been used to assess the stress response to many traumatic life events from disease diagnoses to the experience of natural disasters [54]. The Cronbach's alpha ranges from 0.72–0.92 for intrusion and 0.65–0.9 for avoidance subscale [54]. For this study, the IES was anchored to the diagnosis of having a mutation for LS.

The Rosenberg Self-Esteem Scale was selected as an additional measure of convergent validity. The scale consists of 10 items with answers ranging from strongly agree to strongly disagree on statements like "On the whole, I am satisfied with myself". The higher the total score the higher the self-esteem [55]. The Rosenberg scale has shown high reliability with test retest coefficient of 0.85 [56] and cronbach's alpha from 0.74 to 0.80 [57, 58].

The Marlowe-Crowne Social Desirability Instrument (Short form) was used to test the developed scale for social desirability contamination (i.e. the tendency to respond in a manner likely to present oneself favorably to others). The 13-item short form developed by Reynolds was easy to administer with an acceptable level of reliability ($r_{kr\text{-}20}$=.76) and correlated highly with the original Marlowe-Crowne full scale [59].

The Fear Questionnaire, an instrument designed to measure phobic fear was used as a measure of discriminant validity. Phobic fear involves a specific anxiety or emotional response that is often irrational and excessive. Items, for example, "I would avoid large open spaces" or "I would avoid speaking or acting to an audience", address specific phobic fears. The coefficients of internal consistency were found to be satisfactory from 0.68 to 0.86 [60]. This instrument does not measure global fear or the fear of having a life threatening disease such as cancer [61].

A linear analogue item was used to assess concurrent (i.e. criterion) validity with the candidate scale. Each participant was asked to indicate, "the extent to which the diagnosis of LS has changed how you view yourself" on a single item. The responses, rating from 0 ("not at all") to 10 ("completely"), assessed the concurrent validity of the candidate scale by examining its relationship with the single item.

Criteria Used in the Scale Development

The developed LS self-concept scale assigns a higher score to indicate a greater negative impact of the LS test result on self-concept. The following criteria were established for

expected relationships between the developed LS self-concept scale and the validating measures.

1. A minimal relationship (i.e. correlation coefficient < .30) between the developed self concept scale and the Marlowe-Crowne Social Desirability Scale.
2. A positive relationship between subjective distress (i.e. of a diagnosis of LS) as measured by the Impact of Event Scale and the developed self concept scale.
3. A negative relationship between the Rosenberg self-esteem scale and the developed self-concept scale.
4. A positive correlation between the linear analogue item asking individuals to rate the extent to which their diagnoses changed how they view themselves and the developed self concept scale.
5. A low correlation between the Fear Questionnaire and the developed self-concept scale.
6. The developed self-concept measure would have a Cronbach's reliability of at least 0.80.

RESULTS

Reliability

A reliability analysis was performed on the 24 items and 20 items were selected based on the criteria for item selection described above. A total of 4 items were removed; 3 items were from the original BRCA1/2 self-concept scale because they had less than the cut-off for item-total statistics (i.e. "I am in control of my health", "I am very aware of my body sensations" and "I know my body well" and one of the supplemental items "I feel pressure to live life in healthy ways (like low fat diet)".

The mean inter-item correlation of the remaining items was .40, within the range of .20–.40 that Briggs and Cheek [50] suggest is the optimal level of item homogeneity for a scale. The Cronbach's α reached 0.93. These findings suggest that the scale has a high level of internal consistency.

Factor Analysis

The preliminary 20-item scale was created. The factor analysis resulted in a psychometrically sound 2-factor solution, with two subscales representing the dimensions of stigma/vulnerability and bowel symptom-related anxiety. Each of the two factors met the minimum Eigen value criteria of 1. The first, 15-item factor, (ALPHA = .92) is a *Stigma and Vulnerability* subscale and includes items associated with the impact of having a LS mutation on feelings of stigma, isolation and lack of control. (i.e. "I feel different from others my age", "I feel labeled", "I feel my body has betrayed me" and "I feel cursed because of my test result"). This factor accounted for 32% of variance.

The second 5-item factor (ALPHA = .83), accounted for additional 19% of the total variance, and reflected a sense of a person experiencing bowel symptom-related anxiety. The Bowel Symptom-Related Anxiety *Worry* subscale includes items such as "I worry about changes in my bowels", and "I'm afraid of having bowel pain". A higher score indicates greater focus or concern on bowel-related symptoms. See Table 2 for the factor structure and factor loadings of the final 20-item, 2-factor scale. The item "I feel guilty that I might pass on a cancer risk on to my children" loaded relatively low (<0.40) on both factors. Further

examination on the contribution of this item and the external validation of the scale are being carried out with clinical samples in two other countries (70).

Two of the 20 items were positive statements that were recoded so that a higher total score on the scale indicates a more negative impact of having a LS test result on the individual's self-concept. Potential total scale scores range from 20 to 140. The total is calculated by the sum of the raw scores for each of the negative statements and the recoded scores for the positive items. The mean score for our LS sample was (52 ± 20) with a range from 20 – 108. There were no sex differences in the total mean scores for men (49 ± 20) compared to women (54 ± 21). Mean scores were not significantly correlated with current age (p=0.6) or the amount of time since LS carrier notification (p=0.54).

Subscale Correlations

To determine the relationships between the two dimensions of Stigma and Vulnerability, and bowel symptom anxiety, correlations were computed between each set of subscales. The analyses demonstrated that the two subscales had significant moderate correlations with each other ($r(108) = .60$, $p < .001$). These results support the multidimensional character of the LS Self-Concept scale.

Test retest reliability

Test-retest reliability of the scale was assessed using intra class coefficient (ICC) for single measures. This scale was repeated twice over 3 weeks with a sample of 45 individuals in a separate study in Denmark where the scale was examined for its external validity (personal communication) (Petersen HV, 2011). A high degree of reliability of the LS *Self-Concept* scale was demonstrated by an ICC of 0.92. Detail of the Denmark study was reported elsewhere [62].

Preliminary Validation

The convergent validity was demonstrated by the correlation between the developed self concept scale and following measures: a positive correlation with the Impact of Event Scale at $r(102) = .55$, $p < .001$, a negative correlation with the Rosenberg Self-Esteem Scale $r(108) = -.59$, $p < .001$, both in the expected direction. For the concurrent validity, the correlation with the one item linear analogue item on the extent to which their diagnoses changed how they view themselves was at $r(102)=0.50$, $p<0.01$. The discriminant validity was supported by the relatively low correlation with the Fear questionnaire at $r(108)=.37$ $p < .001$) in the expected direction. The developed self concept scale demonstrated a low correlation with the Marlowe-Crowe at $r(108)=0.22$, $p<0.05$, indicating that there was minimal social desirability contamination. See Table 3 for the correlation matrix of validating measures with factor and total scores.

DISCUSSION

The preliminary LS Self-concept scale demonstrates promising psychometric properties in the assessment of the impact of being a carrier of a mutation for LS (See Appendix 1 for the 20-item LS Self-Concept Scale). The scale was developed based on a published 17-item *BRCA1/2* Self-Concept Scale with additional items deemed relevant to LS. High reliability was demonstrated by the alpha coefficient and inter-item correlation of the whole scale and the very good to satisfactory alphas and the inter-correlations of the subscales. The construct validity was supported by 1) moderately high correlations between the LS Self-Concept Scale and other validating measures with which it was expected to have specific relationships, 2) a positive correlation between the scale and the single item analogue rating on self perception, and 3) discriminant validity that was evidenced in the relatively low

correlation with the Fear questionnaire and low correlation with Marlowe-Crowne Social Desirability Questionnaire. The scale can be used for adult men and women who are carry mutations for LS since there were no significant sex differences in scale responses.

To further support external validity, this scale was administered to LS mutation carriers from Denmark and Sweden and results were compared with that from Canada. Principal component analysis identified two sets of linked statements-the first related to feeling different, isolated and labeled, and the second to concern and worry about bowel changes. The scale performed consistently among participants in all three countries [62], supporting its basic structure, and demonstrating its applicability in different Western populations.

The Self-Concept Scale for adults with LS mutations is developed with the intention to be useful in guiding clinical follow up. The factor of Stigma and Vulnerability is consistent with findings that medical or genetic diagnoses can impact quality of life, for example a person feeling more vulnerable and isolated [63]. Our team found feelings of stigma and vulnerability to be common domains of self concept impacts among BRCA 1/2, FAP and LS populations [26, 27].

The bowel symptom-related anxiety factor reflects the hereditary nature of LS. Individuals having been diagnosed with LS or who with a number of close family members with the disease, naturally have increased awareness of the potential meaning of bowel functioning changes and may feel anxious [9, 39, 63, 64]. Anxiety around symptoms may impact quality of life if high. However, further research is needed to examine to what degree bowel-symptom related anxiety is helpful in health monitoring, as previous studies found that there is an inverted U relationship between anxiety and screening behavior [65, 66].

The LS Self-Concept scale can assist in identifying individuals who endorse greater negative impacts of a LS test result on specific self domains. Individuals who feel greater stigma or who have high levels of bowel symptom-related anxiety may require increased support in follow up. If an individual feels labeled or different from peers, interventions may be employed that target feelings of stigma or isolation, to enhance self esteem and positive self regard. Among those having negative feelings around bowel functioning or body image, psychosocial interventions geared towards addressing negative cognitive appraisals while fostering a greater sense of control and self image could be developed and tested.

It remains to be seen how changes in specific domains of self-concept affect treatment choice. For example, how do individuals with a greater sense of feeling stigmatized or vulnerable differ from those feeling less vulnerable in medical decision-making? Self-concept has been found to play a variety of roles in health research, as dependent or independent variables, moderators or as mediators [67].

The observed commonality in the stigma/vulnerability dimension in self concept across FAP, LS, HBOC in our work [26, 27] is interesting, and requires additional research. If supported it would suggest that a consistent psychosocial approach can be developed when counselling individuals with different conditions.

Our scale complements recently developed measures [24, 30, 38] for cancer risk and genetic populations. These measures were unfortunately not yet developed when we initiated our study, and therefore were unavailable as validating measures. The Multidimensional Impact of Cancer Risk Assessment (MICRA) has three subscales that measure distress, uncertainty and positive experiences related to the impact of genetic disclosure [38]. The Psychological Adaptation to Genetic Information Scale (PAGIS) [30], which has five factors, measures self-worth and self-efficacy. We would expect our scale to be correlated with these other scales, yet distinct and complementary for measuring specific impacts of genetic testing.

Future studies could investigate hypothesized relationships between these factors and provide additional evidence for their validation.

CONCLUSIONS

This is the first study to develop a scale specifically to measure the impact of having LS mutations on self-concept, resulting in a new 20-item total scale consisting of 2 factors with promising psychometric properties. The scale has several potential uses in the field, including as a clinical assessment tool and as a validated measure for future studies.

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Appendix 1: LS Self-Concept Scale

The following statements focus on the range of reactions that individuals have experienced following notification of their hereditary colorectal cancer gene test results. We are interested in learning to what degree you agree or disagree with these statements or if they do not apply to you. Please indicate your responses by circling the appropriate number for each statement.

1	2	3	4	5	6	7	8
strongly disagree	disagree	somewhat disagree	neither agree nor disagree	somewhat agree	agree	strongly agree	N/A

1.	I am hopeful about my self in the future **(R)**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
2.	I am able to deal with my test result **(R)**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
3.	I am worried about bowel symptoms (like bleeding) when I go to the bathroom	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
4.	I feel my body has betrayed me	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
5.	I feel like a walking time bomb	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
6.	I feel different from others my age	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
7.	I feel cursed because of my test result	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
8.	I feel guilty that I might pass on a cancer risk on to my children	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**

9.	I feel isolated because of my test result	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
10.	I feel I have lost my sense of privacy	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
11.	I think about my test result a lot	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
12.	I'm afraid of having bowel pain	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
13.	I am worried that cancer will be found when I go for screening	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
14.	I feel labeled	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
15.	I worry about changes in my bowels	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
16.	I feel burdened with this information	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
17.	I distrust my body	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
18.	My test result gets in the way of who I really am	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
19.	I have become more secretive	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
20.	I feel embarrassed when I go for my bowel screening	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**

Note: **(R)** indicates item to be reverse coded

Table 1

Characteristics of the Study Population (N=115)

All LS mutation carriers	**Mean**	**(SD) Range**
Age (years)	50.0	(13.7) 23 – 80
Time since notification of LS mutation (years)	4.7	(3.7) 1 – 14
	N	**(%)**
Gender:		
Male	53	(46%)
Female	62	(54%)
Marital Status:		
Currently Married/Common law	90	(78%)
Other	25	(22%)
Diagnosed with colon cancer?		
Yes	73	(63%)
No	42	(37%)
Registry Site:		
Ontario	81	(70%)
Newfoundland	34	(30%)

Table 2

LS 2 Factor Solution and Factor Loadings

		Factor loadings	Communalities	Item Total Correlation	Item Mean
17.	I feel labeled	0.77	0.69	.76	2.36
12.	I feel isolated because of my test results	0.75	0.64	.72	1.99
9.	I feel cursed because of my test result.	0.74	0.61	.74	2.38
13.	I feel I have lost my sense of privacy.	0.74	0.62	.73	2.31
19.	I feel burdened with this information.	0.74	0.60	.66	2.56
20.	I distrust my body.	0.71	0.61	.72	2.36
22.	My test result gets in the way of who I really am.	0.70	0.54	.66	2.07
7.	I feel different from others my age.	0.64	0.45	.59	2.88
5.	I feel like a walking time bomb.	0.64	0.52	.63	2.34
1.	I am hopeful about myself in the future.	0.57	0.33	.45	1.86
2.	I am able to deal with my test result.	0.56	0.32	.37	1.69
4.	I feel my body has betrayed me.	0.56	0.48	.65	2.33
14.	I think about my test result a lot.	0.51	0.53	.66	3.00
24.	I feel embarrassment when I go for my bowel screening.	0.48	0.24	.46	2.47
23.	I have become more secretive.	0.48	0.36	.57	2.09
Factor 1 Stigma and Vulnerability: 15 items, Cronbach's α = .92, inter – item correlation = .43, variance explained = 32%					
3.	I am worried about bowel symptoms (like bleeding) when I go to the bathroom.	0.81	0.68	.59	2.73
18.	I worry about changes in my bowels.	0.84	0.74	.68	3.97
15.	I am afraid of having bowel pain.	0.80	0.67	.62	3.26
16.	I am worried that cancer will be found when I go for screening.	0.69	0.51	.53	4.49
11.	I feel guilty that I might pass on a cancer risk on to my children.	0.39	0.28	.46	4.61
Factor 2 Bowel-symptom- related anxiety: 5 items, Cronbach's α = .83, inter – item correlation = .37, variance explained = 19%					

LS final 20 items scale, Cronbach's α = .93, inter – item correlation = .40, Total variance explained = 52%

Total Score: Mean=54.77, SD=20.23, range 20–140

Table 3

Correlations between the LS self concept scale, two subscales and the Validating Instruments

	Impact of Event	Rosenberg	Linear Analogue	Phobic Fear	Marlowe-Crowne
LS Self–Concept	.545** (105)	−.594** (108)	..497** (102)	.367** (108)	.218* (108)
Stigma and Vulnerability Subscale	.521** (108)	−.606** (111)	.481** (104)	.273** (108)	.252** (111)
Bowel Symptom Related Anxiety Subscale	.416** (105)	−.351** (108)	.441** (102)	.409** (108)	.115 (108)

** Correlation is significant at the 0.01 level (two-tailed).

* Correlation is significant at the 0.05 level (two-tailed).