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The role of illness perceptions in adherence to surveillance and quality of life in patients with Familial Adenomatous Polyposis

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Title: The role of illness perceptions in adherence to surveillance and quality of life in patients with Familial Adenomatous Polyposis (FAP)

Short title: Illness perceptions, adherence to surveillance and quality of life in FAP

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Abstract

Objective

To examine patients' beliefs about their Familial Adenomatous Polyposis (FAP), and their socio-demographic, genetic and clinical characteristic in relation to adherence to endoscopic surveillance and health-related quality of life (HRQoL).

Methods

Adult patients on the national Swedish polyposis registry diagnosed with FAP who had undergone prophylactic colorectal surgery (N=209, 76%) and agreed to participate completed the Illness Perceptions Questionnaire and SF-36 HRQoL.

Results

Non-adherence (14%) to surveillance was associated with being older, having less recently undergone surgery and no previous history of malignancy. Patients' beliefs about their FAP were able to explain unique variance in non-adherence, in particular those who believed FAP was less distressing and serious (X^2=48.48, P=0.01, R^2=0.381). Men were more likely to view FAP as less distressing (r= -.215′ p<0.01) and serious (r= -.231′ p<0.01). Those with family members with FAP, and more positive perceptions of FAP, viewed FAP as less serious (r = -.218, p<0.01) compared to those without experience of family members with FAP. HRQoL was no worse in those who had attended surveillance, but poorer physical HRQoL was associated with older age, testing positive for genetic mutations, and more negative illness perceptions, in particular, a greater illness identity, serious FAP consequences and poorer treatment control (R^2=0.319, F=6.723, p<0.001). Mental HRQoL was worse in younger patients, without experience of a

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family member with FAP, and more negative, or unrealistic perceptions of FAP (R^2=.319, F=6.723, p<.001).

Conclusions

Despite the greater risk of future malignancies, increased complacency was associated with more positive views about FAP.

Key words: Illness perceptions, FAP (Familial Adenomatous Polyposis), genetic-risk, surveillance, adherence, cancer-registry

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Background

Patients with the hereditary colorectal cancer syndrome Familial adenomatous polyposis (FAP) [1] are confronted with several symptoms associated with constraints in physical and mental health [2, 3]. FAP requires prophylactic removal of the colon, followed by life-long endoscopic surveillance. The removal of the colon (ileorectal anastomosis [IRA]) or the colon and rectum (ileal pouch-anal anastomosis [IPAA] or ileostomy) is recommended for patients between the ages of 18 and 20 years [4, 5]. Without prophylactic surgery and life-long endoscopic surveillance, FAP is associated with a 100% risk of developing colorectal cancer [1]. Consequently, prophylactic colorectal surgery and continued adherence to endoscopic surveillance are vital for survival [2, 6]. Non-adherence to endoscopic surveillance in those with FAP has been reported to range anywhere from 14% [7] to 46% [6]. Traditionally, care for patients with FAP has focused on cancer prevention i.e. endoscopic examination with removal any polyps [4]. Recent research taking patient's experiences into account has shown that living with FAP includes a sense of a constant threat to health [3] and that the disease influences people's quality of life in several ways, independent of age and time since diagnosis [2, 3, 8]. Specific concerns that have been pointed out by patients are changed food and toilet habits and burdensome abdominal symptoms that occur irregularly [3, 8] as well as the burden of commitment to lifelong endoscopic surveillance [3]. However, there are still individual differences in patient's quality of life and unexplained variance in adherence that surgical procedures and symptoms alone cannot fully explain.

Meyer et al.'s [9] model of self-regulation of illness representation provides an explanation for the variation in how an illness may be perceived and responded to by the patient [10]. The model organises illness representation around the following dimensions: identity (symptoms associated with the illness), timeline (beliefs about the duration of the illness), cyclical timeline (beliefs about

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the cyclical nature of the symptoms), consequences (beliefs about the negative impact of the illness on life), control (beliefs about the controllability of the illness), treatment control (beliefs about the effectiveness of treatment), illness coherence (a coherent understanding of the illness), the emotional representations (the extent to which the illness is emotional) and cause (perceived causes of the illness). The model posits how a patient's emotions and cognitions are related to perceived health threats, such as symptoms [9, 11, 12], and guides actions (e.g., adherence or non-adherence to treatment) to minimise these perceived threats [13, 14]. It is well documented that a negative illness perception, such as less understanding of an illness, viewing the illness as serious, and attributing negative consequences to the illness, is related to distress and poorer HRQoL in patients with a wide range of illnesses [10, 15-18].

There is increasing evidence of the utility of the self-regulation model in the context of pre-cancerous and increased genetic familial risk of malignancy [16-19]. Women with increased genetic risk of ovarian cancer who have reported more negative illness perceptions of ovarian cancer risk were also found to be at greater risk of suffering with ovarian cancer-specific disease [17] and women with greater familial risk of breast cancer perceived cancer as more serious, worried more and exhibited more maladaptive copying strategies [16]. Illness perceptions and in particular beliefs that treatment is effective, have also proved useful in discriminating women with abnormal cervical screening tests who do not complete recommended treatment (10% of their sample) compared to those that did complete treatment [19]. Moreover, the self-regulation model has proved a useful framework to develop interventions to improve patient outcomes following a brief cognitive intervention [20, 21].

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This study set out to examine patients' beliefs about their FAP and to investigate the extent to which these beliefs are associated with their adherence to surveillance and quality of life, over and above their socio-demographic background, genetic and clinical characteristics.

Method

Sample and Design

The study employed a cross-sectional design. All patients in the national Swedish polyposis registry diagnosed with FAP who had undergone prophylactic colorectal surgery and were aged 18–75 years (*N*=276) were considered eligible and invited to participate; one patient did not speak Swedish and was therefore excluded. Of the remaining 275 patients, 209 (76%) consented to participate.

Instruments

Illness perception was assessed with the Revised Illness Perception Questionnaire (IPQ-R)[22]. The questionnaire includes nine components: *Timeline-chronic* (6 items; e.g., "My condition is likely to be permanent rather than temporary"); *Timeline-cyclical* (4 items; e.g., "My symptoms come and go in cycles"); *Consequences* (6 items; e.g., "My condition has major consequences on my life"); *Personal control* (6 items; e.g., "There is a lot which I can do to control my symptoms"); *Treatment control* (5 items; e.g., "My treatment is effective in curing my illness"); *Emotional representation* (6 items; e.g., "Having this illness makes me feel anxious"); *Illness coherence* (5 items; e.g., "I have a clear picture or understanding of my condition"); *Causes* (18 items; e.g., hereditary, chance or bad luck, overwork), and identity (17 symptoms; e.g., stomach pain, weight loss, fatigue). The respondents are asked to indicate their level of agreement with the posed statements on a 5-point Likert scale ranging from 1 ("strongly disagree") to 5 ("strongly agree"). Higher scores on the timeline-chronic and timeline-cyclical components represent endorsing beliefs that the condition is

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lasting or cyclical rather than acute or stable in nature. Higher scores on the consequences and emotional representation components represent endorsing beliefs that the condition will have a negative impact on life and more negative emotional responses to the illness, whereas higher scores on the personal control, treatment control, and illness coherence components represent a positive belief about personal control, the effectiveness of treatment and a greater perceived understanding of the illness. Finally, the identity component is measured by 17 stated symptoms that the patients endorse as being induced by the disease. On the recommendation of the developers of the IPQ-R, the illness identity component should include illness-specific symptoms, in addition to more general symptoms (e.g., fatigue and sleeping difficulties). Higher scores on the identity component reflect a higher number of symptoms attributed to the illness. The Swedish version of the IPQ-R has shown good internal consistency and test-retest reliability [23]. In the present study, Cronbach's α coefficients for the IPQ-R components were all above 0.70, except treatment control $\alpha = 0.622$, although all item-total correlations were above 0.3. In addition, the item 'My disease is very unpredictable' was dropped from cyclical timeline in order to achieve an $\alpha > 0.7$, as it did not seem to correlate with other items on the cyclical timeline sub-scale.

The SF-36 was used to measure HRQoL [24, 25]. The physical component summary score and mental component summary scores summaries: physical functioning, role physical (role limitations due to physical health), bodily pain, general health, vitality, social functioning, role emotional (role limitations due to mental/emotional health), and mental health [24]. Greater weights are applied to physical functioning, role functioning, bodily pain and general health for the physical component summary score and the remaining domains to the mental component summary score. Higher scores represent better HRQoL.

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Procedure

A letter was sent to those patients in the Swedish Polyposis Registry who fulfilled the inclusion criteria. The letter included information about the study and contained a package of questionnaires. The letter emphasised that participation was voluntary and that nonparticipation or withdrawal of consent would not affect a patient's care or treatment. The patients who subsequently agreed to participate were asked to complete the set of questionnaires and to return them in an enclosed prepaid envelope. Patients who did not return the questionnaires were sent a reminder after three weeks. All the returned questionnaires were checked for missing data, and the participants were contacted by phone for completion when necessary. Ethical approval was granted by the Regional Ethical Review Board in Stockholm.

Demographic (e.g. age and gender) and additional clinical characteristics (diagnosis, age at diagnosis, time since surgery, age at surgery, type of surgery, FAP in the family, and adherence to endoscopic surveillance) were obtained from the Swedish Polyposis Registry. Patients were considered non-adherent if they had not undergone endoscopic examinations (lower or upper gastrointestinal tract) within one year after recommended intervals. Participants with a family history of FAP (having FAP within the family) were registered as "FAP in the family".

Data analysis

Statistical analyses were performed with the Statistical Package for Social Sciences (SPSS) for Windows version 22.0 (SPSS Inc. Chicago, IL, USA). Descriptive statistics were computed for scales and standardised questions. Pearson's Correlations were used for continuous level measures and point-biseral correlations were used for nominal level data. Hierarchical logistic and linear regression analyses were computed to regress socio-demographic and clinical factors, and the

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components of the IPQ-R onto adherence and quality of life: (i) socio-demographic factors such as age, sex and educational attainment (ii) FAP in the family and genetic status (iii) the time since diagnosis and the time since last colorectal surgery and (iv) illness perceptions were force entered into the model in sequential steps. Assumption testing was through examining: (i) standardised residuals (required to be <3.00), (ii) leverage (<1.00), (iii) Cook's distance (<1.00), and (iv) variable inflation factors (co-linearity <10). The models were evaluated by a significance level of $p<0.05$), R^2 and in the logistic regression, the percentage of cases correctly classified.

Results

The demographic and clinical characteristics of the sample are presented in Table 1. In total, 209 (76%) participants (116 women) who had undergone prophylactic colorectal surgery, representing 111 of 135 Swedish families with FAP, were enrolled in the study (Table 1). No statistically significant differences in demographic and clinical characteristics were found between the participants and nonparticipants or between participating men and women (data not shown). The removal of the colon or colo-rectum had been performed in all but three participants who had undergone segmental resection of the colon. Sixty-three percent of the participants had undergone one colorectal procedure, 32% two colorectal procedures, and 5% three or more colorectal procedures. At the time of the study, 34% had undergone an IRA, 39% an IPAA, 19% an ileostomy, and 7% a continent ileostomy. Furthermore, FAP-related cancer had been diagnosed in 24% of the participants.

Table 1 about here

Illness perceptions

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The means and SDs of the IPQ-R components, and their inter-relationships are presented in Table 2. Overall, patients perceived FAP to be chronic and that they had a coherent understanding of their condition. A stronger illness identity related to a perception of a more chronic timeline ($r = 0.301$, $p < 0.001$) and a greater understanding of FAP was associated with having family members with FAP ($r = 0.264$, $p < 0.001$), more stable disease ($r = -0.203$, $p = 0.003$) and less serious consequences ($r = -0.343$, $p < 0.001$). Lower mean value was found for the component timeline cyclical (lower scores indicate that the condition is not believed to be cyclical in nature). Cyclical timeline was lowest in men ($r = -0.168$, $p = 0.015$) and those with higher educational attainment ($r = 0.159$, $p = 0.021$), and strongly associated with greater illness identity ($r = 0.560$, $p < 0.001$). There was also a fairly low perception of personal control and this was associated with being more highly educated ($r = 0.179$, $p = 0.009$) and perceiving FAP to have a shorter duration ($r = -0.232$, $p < 0.001$). Overall, patients did not agree or disagree that FAP was a serious condition, but they were less likely to see it as serious if they were male ($r = -0.231$, $p < 0.001$), or had a family member with FAP ($r = -0.281$, $p < 0.001$) and more likely to perceive FAP as with serious consequences if they identified more symptoms as FAP related ($r = 0.553$, $p < 0.001$), thought it was a chronic ($r = 0.283$, $p < 0.001$) and cyclical condition ($r = 0.326$, $p < 0.001$). On average patients did not agree that FAP was controlled by their treatment. Older age ($r = -0.235$, $p < 0.001$), the longer they had been diagnosed with FAP ($r = -0.258$, $p < 0.001$) and lower sense of personal control was associated with having poorer treatment control. Emotional responses to FAP were higher in women ($r = -0.215$, $p < 0.02$), those that perceived it as chronic ($r = 0.190$, $p < 0.06$), less stable ($r = 0.325$, $p < 0.001$), associated with more symptoms ($r = 0.430$, $p < 0.001$) and especially if FAP had more serious consequences ($r = 0.621$, $p < 0.001$). For the component causes, 92% of the patients believed that “heredity” was the reason for their disease. This explains the relatively low levels of psychological, immunity, risk factor and chance causal

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attributions. Patients agreeing with these aforementioned causal attributions had poorer understanding of their FAP and were less likely to have the experience of having a family member with FAP. They also exhibited more serious consequences, emotional responses and unstable disease, moreover they were more likely to view FAP as a more acute condition (all other relationships were not significant at $p<0.05$, see table 2).

Table 2 about here

Factors associated with non-adherence to surveillance

In Table 3 are the results of the logistic regression. Although older age approached significance in the first step, socio-demographic factors were not able to explain adherence to surveillance (X^2 = 8.33, p = 0.80). Genetic factors were also non-significant (X^2 = 9.77, p = 0.135). Although by step 3, a positive diagnosis for malignancy and a greater duration of time since diagnosis and last surgery were showing collectively a greater tendency to attend recommended surveillance (X^2 = 31.58, p = 0.05, Nagelkerke R^2 = 0.258, 86.5% were classified correctly). However, after controlling for all these factors perceptions that FAP is a serious condition (Exp(β) =2.226, p=0.039, 95% CI 1.040-4.762) and those with more emotional distress (Exp(β) -0.424, p = 0.024, 95% CI 0.202- 0.893) about FAP were significantly more adherent to surveillance. Quality of life was not associated with adherence (X^2 = 0.398, p = 0.310, Nagelkerke R^2 = 0.381, 86.5% correctly classified), although quality of life was marginally lower in those who were attending endoscopic surveillance.

Table 3 here

Factors associated with poorer physical quality of life were older age (β = -0.273, p< 0.001), and testing positive for the APC or MYH on a genetic test (β = -0.154, p< 0.001). Receiving specialist

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care, duration of FAP, recovery time from last surgery and malignancy were not associated with physical health status, when controlling for socio-demographic and genetic factors. Illness perceptions however, significantly improved the model (R^2=0.398, R^2 change = 0.310, F=8.719, p<0.001), specifically having a greater number of FAP symptoms identified as being part of their FAP (β = -0.335, p< 0.001), more serious consequences (β = -0.375, p< 0.001) and poorer treatment control (β =- 0.145, p< 0.028) were most associated with reduced physical health status (R^2=0.398, R^2 change = 0.310, F=8.719, p<0.001).

Poorer mental wellbeing was associated with younger age (β = 0.253, p< 0.001), not having a family member with FAP (β = 0.204, p< 0.03), Clinical factors were not associated. However, illness perceptions were also associated with patients' wellbeing (R^2=0.319, R^2 change = 0.271, F=6.723, p<0.001). Poorer mental wellbeing was associated with more symptoms associated with FAP (β = -0.315, p< 0.001), more serious consequences (β = -0.180, p< 0.049), emotion associated with FAP (β = -0.169, p< 0.035), thinking of FAP as more of an acute problem (β = 163, p< 0.026) and attributing the cause of FAP to psychological factors rather than genetic (β = -0.218, p< 0.033).

Table 4 here

Discussion

The prevalence of non –adherence to endoscopic surveillance was 14% in 76% of the Swedish population who have previously undergone prophylactic surgery. It is a very important issue as non-adherent patients have a substantially increased risk of developing future malignancies. The results

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suggest that cancer prevention from an adherence to surveillance perspective is related to patients' beliefs about their FAP. It is possible that those who perceive FAP to be less serious and less emotional were at greater risk of not attending surveillance. Those who held beliefs that FAP was less serious and emotional were male and who had a family member with FAP, this could be due to lower symptom perception in men, or increased complacency due to increased exposure to FAP. Alternatively, it is possible that that those who had recently undergone endoscopic surveillance (i.e. those adherent) suffered with greater distress associated with FAP and been more recently reminded about the seriousness of FAP. Those who avoided the surveillance may have more positive perceptions and avoided an unpleasant endoscopic procedure in the short term, but with the cost of being at greater risk of future morbidity and mortality (Vasen 2008). A tentative explanation of the result could be that non-adherent patients lack knowledge about the risk of the disease's progress and that the treatment guidelines recommend surveillance throughout life in patients with FAP.[12.]

HRQoL was not associated with attendance at surveillance, instead emotion specific to FAP was associated with adherence. However, there were individual differences in living with FAP and those participants at greater risk have different socio-demographic backgrounds, genetic risk factors, and clinical histories, but out of all these factors, illness perceptions were able to explain unique variance in patient physical and mental quality of life.

Previous research has also indicated that non-adherence to surveillance is a significant problem in patient with FAP [6]. Kinney and colleagues found that 46% of their participants were non-adherence to recommended surveillance protocols. Their higher rates of non-adherence compared to the present study may partly be due to lack of health insurance for CRC surveillance in the US. However, consistently with the Swedish sample, patients' beliefs about the condition were important

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in their decisions about whether to attend surveillance or not. Whereas previous studies have found that non- adherence to surveillance is associated with patients who believe there is no increase in relative risk associated with developing cancer [6] and beliefs that the treatment will not be effective at curing or controlling the condition [19], the present study found that FAP distress and consequences of FAP were worse in those who attend surveillance. One explanation is that during the course of lifelong surveillance patients get more complacent. The longer they have lived with the condition without malignancy and the longer they have lived with FAP without further surgical interventions, their perception of the seriousness of FAP and living with FAP becomes less distressing over time. This more positive perception may have been created out of a false sense of security over a number of years without malignancy or surgical intervention and then an absence of perceived risk results in patients not attending surveillance. Alternatively, it is possible that attending surveillance causes patients to become more distressed and to view FAP as a more serious condition. However, given the frequency of surveillance and the relationships that negative illness perceptions have with HRQoL it is possible that surveillance induced distress may lead to reduced HRQoL indirectly via negative illness perceptions.

Consistently with the Self-Regulation Model, the findings indicated that negative illness perceptions were related to reduced HRQoL [10], in particular stronger illness identity, more serious consequences, and poorer treatment control were directly associated with poorer HRQoL. In addition, greater FAP distress, thinking about FAP as an acute problem instead of a chronic lifelong condition, and attributing the cause of FAP to psychological factors rather than genetic was associated with poorer mental HRQoL. This suggest that participants endorsing unrealistic perceptions of the duration and cause of FAP might be at greater risk of poorer psychological wellbeing. The present study adds to a body of research indicating that illness perceptions are an

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important consideration in precancerous and increased risk populations [18], and in particular with FAP, because of the continued lifelong surveillance, these findings point to the importance of realistic and healthy beliefs for improved adherence and HRQoL with repeated surveillance.

The advantage to identifying modifiable beliefs associated with adherence, is that they may have clinical implication. Beliefs about FAP are amendable to change in a cognitive behavioral intervention, in order to increase uptake of endoscopic surveillance, or improve quality of life. A previous study showed that including illness perception assessments in communication with patients during outpatient visits has a positive effect on their involvement in discussions about treatment and care.[24] In addition, providing disease-specific information has been reported to be associated with greater personal and treatment control and a better understanding of the illness in cancer survivors.[25] Therefore, interventions aiming to improve illness perceptions may also be beneficial for this group of patients, since FAP is a life-long illness, and a commitment to a lifelong endoscopic surveillance program after prophylactic surgery is necessary to prevent cancer.

The study has several strengths. First, the patients were recruited from a national cohort of patients with FAP, including all known FAP cases in Sweden who had undergone surgery. Second, the high response rate resulted in a large, representative sample allowing analysis at a multivariate level. Finally, we used standardised and robust self-report measures. A limitation of the study is the cross-sectional design, which precludes the assessment of causal relationships. However, given the significant findings future research should look at the causal pathways between genetic, clinical and psychological factors in relation to adherence to surveillance.

Conclusion

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Despite the importance of endoscopic surveillance in reducing the risk of future malignancy in FAP, some patients are non-adherent. Patients may be at greater risk of non-adherence to endoscopic surveillance as they get older, if they have not yet developed a malignancy, and a longer time since they had prophylactic surgery. Despite the greater increased risk to these patients, they viewed FAP to be less emotionally distressing and have fewer grave consequences. Men were also more inclined to view FAP as less serious and emotional compared to women. Having other family members with FAP seemed to increase the compliancy of the severity of FAP. Attending surveillance was not associated with significantly poorer quality of life, rather it was patients' socio-demographic background, genetic risk and illness perceptions that were important in explaining differences in attendance. Unhelpful representations for mental wellbeing, were viewing FAP as a more acute and psychologically caused problem, instead of a chronic, genetic condition. These findings have implications for supporting patients living with FAP, so that they do not put themselves at unnecessary risk of malignancy while trying to support patients living with the condition.

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Conflict of interest

None of the authors declare any competing interest

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Table 1: Clinical characteristics of the Participating Patients with FAP (N = 209)

		mean (SD; range)	n	%
Sex				
	Men		93	44
	Women		116	56
Age (years)				
	All	49 (14; 18-75)		
	Men	48 (15; 18-75)		
	Women	49 (13; 23-74)		
Living situation				
	Partnered		139	67
	Single		61	29
	Living with parents or other		9	4
Education level				
	Elementary school		56	27
	High school		79	38
	University		70	34
Family members with FAP			169	81
Tested Positive for APC/MYH			166	79
Age at diagnosis (years)		26 (12; 3-57)		
Time since first colorectal surgery to study (years)		21 (12; 1-50)		
Times since last colorectal surgery to study (years)		14 (10; 1-50)		
Received a cancer diagnosis			50	24
Specialist Care			57	27

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Table 2: Perceptions of FAP and their association with socio-demographic, genetic and clinical factors.

	Identity	Timeline	Cyclical Timeline	Consequences	Personal Control	Treatment Control	Coherence	Emotional Reps	Psychological attribution	Risk factor attribution	Immune attribution	Chance attribution
Mean (SD)	6.49 (4.16)	4.51 (0.60)	2.55 (1.00)	2.79 (0.94)	2.75 (0.73)	3.00 (0.77)	4.01 (0.85)	2.62 (0.96)	1.47 (0.64)	1.95 (0.52)	1.71 (0.72)	1.88 (0.80)
Age	-.115	-.083	-.073	-.022	-.014	-.235**	-.018	-.110	.097	.133	.069	-.037
Male	-.268**	-.053	-.168*	-.231**	-.006	-.019	-.052	-.215**	-.019	-.025	.027	.056
Higher Education	.163*	.129	.159*	.096	.179**	.083	.105	.091	-.075	-.039	-.019	.036
FAP in Family	.064	.103	-.025	-.218**	-.015	-.008	.264**	-.128	-.258**	-.068	-.286**	-.126
Tested Positive for APC/MYH	-.057	.103	-.025	-.218**	-.015	-.008	.264**	-.128	-.258**	-.068	-.286**	-.126
Years since diagnosis	.108	.035	-.090	-.094	.028	-.258**	.076	-.067	.016	.072	-.034	-.064
Years since the last surgery	-.070	.026	-.031	-.083	-.053	-.126	.002	-.026	.011	.038	-.044	-.094
Cancer diagnosis	-.085	.112	.035	-.116	.014	.067	.032	-.008	-.071	-.006	-.075	.049
Specialist Care	.025	.040	.044	.014	.009	.056	.051	.042	-.038	-.002	.028	.004
Identity		.301**	.560**	.553**	.057	-.067	-.109	.430**	.094	.112	.162*	.039
Timeline			.074	.283**	-.232**	-.260**	.046	.190**	-.233**	-.167*	-.226**	-.168*
Cyclical Timeline				.326**	.150*	.039	-.203**	.325**	.256**	.161*	.206**	.135
Consequences					.000	-.115	-.343**	.621**	.249**	.174*	.283**	.171*
Personal Control						.311**	.028	-.053	.190**	.149*	.167*	.056
Treatment Control							.116	-.064	-.022	-.039	-.082	-.069
Coherence								-.320**	-.357**	-.206**	-.233**	-.228**
Emotional Reps									.184**	.119	.142*	.030
Psychological attribution										.721**	.671**	.365**
Risk factor attribution											.628**	.346**
Immune attribution												.386**
Accident/chance attribution												

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Table 3: Factors associated with non-adherence to recommended surveillance

Step		Wald	Sig	Exp(B)	95% CI		Adherent (N = 180) Mean/N*	Not Adherent (N = 29) Mean/N*
1	Age	4.034	.045	1.031	1.001	1.063	47.64	54.34
	Male	.156	.693	.845	.368	1.944	78 (80)	15 (13)
	Higher Education	1.803	.179	2.068	.716	5.972	65 (60)	5(10)
	Living with Partner	.092	.762	1.141	.485	2.685	121(120)	18(19)
Model summary		X^2 = 8.33, P = 0.80, Nagelkerke R^2 = .072, 86.5% classified						
2	FAP in the Family	.517	.472	1.427	.541	3.761	147 (146)	22(23)
	Tested Positive for APC/MYH	.926	.336	1.568	.627	3.921	146(143)	20(23)
Model summary		X^2 = 9.77, P = 0.135, Nagelkerke R^2 = .084, 86.5% classified						
3	Years Since Diagnosis	1.907	.167	.961	.909	1.017	22.54	23.14
	Years Since Last Surgery	2.377	.123	1.045	.988	1.105	14.00	17.24
	Diagnosed with Cancer	.835	.361	1.619	.576	4.550	142(137)	17(22)
Model summary		X^2 = 31.58, P = 0.05, Nagelkerke R^2 = .258, 86.5% classified						
	Identity	.962	.327	.914	.762	1.095	6.79	4.62
	Timeline	.894	.344	.672	.295	1.531	4.55	4.25
	Cyclical Timeline	.628	.428	.760	.386	1.498	2.61	2.15
	Consequences	4.253	.039	2.226	1.040	4.762	2.81	2.69
	Personal Control	.075	.784	1.124	.487	2.594	2.75	2.78
	Treatment Control	.009	.925	1.033	.530	2.011	2.99	3.06
	Coherence	.516	.472	1.306	.630	2.708	3.99	4.10
	Emotional Representations	5.099	.024	.424	.202	.893	2.69	2.15
	Psychological attribution	.139	.709	.792	.232	2.699	1.47	1.50
	Risk factor attribution	1.385	.239	2.341	.568	9.651	1.94	2.00
	Immunity attribution	.149	.700	.823	.306	2.212	1.70	1.75
	Chance attribution	.628	.428	.741	.353	1.556	1.88	1.90
Model summary		X^2 = 48.48, P = 0.01, Nagelkerke R^2 = .381, 86.5% classified						
	Physical health status	1.885	.170	.967	.923	1.014	47.201	45.567
	Mental health status	.028	.866	1.004	.958	1.053	48.556	49.753
Model summary		X^2 = .398, P = 0.310, Nagelkerke R^2 = .381, 86.5% classified						

*In parenthesis are the frequencies expected by chance. Specialist care was dropped from the model because all were adherent.

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Table 4: Factors associated with quality of life in survivors of FAP

Step		PCS β	PCS Sig.	MCS β	MCS Sig
1	Age	-.273	.000	.253	.000
	Male	.172	.014	.097	.173
	Higher education	.053	.456	-.011	.881
	Living with Partner	.039	.556	.024	.721
	Model summary	R^2=.094, R chg=.112, F=6.283, p<.001		R^2=.056, R chg = .074, F=3.989, p=.004	
2	FAP in Family	.109	.102	.204	.003
	Tested Positive for APC/MYH	-.154	.023	.035	.609
	Model summary	R^2=.121, R chg = .035, F=4.055, p=.019		R^2=.089, R chg = .042, F=4.695, p=.010	
3	Years since diagnosis	-.083	.411	.039	.703
	Number of years since the last lower surgery	.047	.551	-.001	.985
	Diagnosis with Cancer	-.003	.973	.004	.958
	Specialist Care	.058	.405	-.071	.314
	Model summary	R^2=.109, R chg = .006, F=.332, p=.856		R^2=.076, R chg = .005, F=.296, p=.880	
4	Identity	-.335	.000	-.315	.000
	Timeline	.127	.064	.163	.026
	Cyclical Timeline	.017	.812	.020	.797
	Consequences	-.375	.000	-.180	.049
	Personal Control	-.019	.766	.064	.333
	Treatment Control	.145	.028	.073	.295
	Coherence	.084	.199	-.004	.954
	Emotional Representations	.117	.118	-.169	.035
	Psychological attribution	-.070	.466	-.218	.033
	Risk factor attribution	.122	.163	-.020	.828
	Immune attribution	-.044	.594	.135	.129
	Accident/chance attribution	-.020	.755	.048	.480
	Model summary	R^2=.398, R chg = .310, F=8.719, p<.001		R^2=.319, R chg = .271, F=6.723, p<.001	

-chg= change, β standardised regression coefficient

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