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Quality of Life in Patients Post Colectomy for Pediatric Onset Ulcerative Colitis

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Abstract

Background—Ulcerative colitis in children can have a negative impact on quality of life (QOL).

Methods—We included 16 of 31 patients who underwent colectomy for ulcerative colitis before 20 years of age between 1980-2005 at UCSF Benioff Children's Hospital. A disease-specific QOL questionnaire (IBDQ-32), validated for adults, was used to determine QOL and an additional questionnaire addressing bowel function and reproductive health in long term follow up of these patients.

Results—Median age at the time of survey was 20.3 years (17.9-25.3) and time post colectomy was 6.9 years (4.8-9.0). Mean total score was 159.7±43.3 (58-210). Two patients (12.5%) had scores of ≥200, 12 (75.0%) had 101-199, and 2 (12.5%) had ≤100. Patients ≤18 years at the time of survey showed higher QOL, particularly in emotional health (p=0.020), social function (p=0.014), and overall QOL (p=0.009). Social function scored highest of all systems (median 7; IQR 4-7). Patients with scores ≤100 had repeated episodes of pouchitis (16-30) compared with the other 14 patients (0-3). Children diagnosed ≤12 years of age tended to have higher QOL (p=0.072). Years post-colectomy did not correlate to QOL. Eleven patients were sexually active. Two males had feelings of impotence and decreased libido, and six females experienced dyspareunia. Three women tried unsuccessfully to conceive after colectomy. One woman became pregnant four times, each leading to miscarriage.

Conclusions—Younger age at time of colectomy, diagnosis, and survey show higher QOL. Highest satisfaction was found in ability to attend school, work, and social engagements. Pouchitis continued to be an issue for a small number of the patients, with two patients having recurring episodes that severely affected QOL. Patients reported decreased sexual activity and fertility at the time of survey due to colectomy, especially for females.

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Keywords

Inflammatory Bowel Disease; Children; Adolescents; Fertility; Sexual Function; Surgery for IBD; Fertility; Complications of IBD; Pouchitis

Introduction

Pediatric patients with chronic ulcerative colitis (UC) experience frequent disease flares, regular doctor visits, long-term care, occasional procedures, hospitalizations, and interruption of life plans that can have a negative impact on their quality of life (QOL).[1,2,3] Surgical resection of the large intestine offers a "cure" for their disease. Surgery is typically performed when a patient remains symptomatic or has complications of the disease despite ongoing, often intensive medical therapy.[4,5] Colectomy is often performed in patients who desire to ultimately eradicate their disease due to poor response to medical management.[6] Colectomy can restore patient health from acute or chronic disease and minimize the risk of cancer of the large bowel in patients with UC.[5]

To date, however, limited and conflicting data to document UC patients who undergo this major procedure when onset is during childhood. Chronic ulcerative colitis in children can have a negative impact on QOL. Evaluation of QOL post-colectomy might help physicians gain insight into the problems that arise after surgery. Health-related QOL improvements were seen as early as 1 month postoperatively.[8] Studies in adults suggest that colectomy leads to improvement in QOL to levels similar to the general population.[1,7,9] In an adult sample of 645 patients, 93% demonstrated a good QOL, mainly improving 1 year after surgery as patients return to a normal lifestyle.[7]

We studied a subset of patients included in a previous retrospective study reporting post-surgery complications in 31 UC patients at the University of California in San Francisco (UCSF).[10] We used a validated, disease specific QOL questionnaire[11] to further describe different age groups at diagnosis and colectomy and associations with quality of life in pediatric patients with ulcerative colitis.

Methods

Pediatric patients under 20 years of age at the time of colectomy with IBD who underwent colectomy between 1980 and 2005 at the UCSF Benioff Children's Hospital were recruited via mailed letters. Patients were identified by retrospective chart review in the UCSF Department of Surgery, Division of Pediatric Gastroenterology, Hepatology and Nutrition, and Health Information Management Systems (medical records).

All patients who were diagnosed with UC before age 18 and who had a colectomy before their 20th birthday were eligible for enrollment. Twenty-eight patients deemed eligible for the study were mailed a letter describing the study and a consent form. Patients were then contacted by telephone to further explain the study. Updated contact information was not available for 5 patients, 7 patients did not respond to our mailing, and informed consent was obtained from 16. Following consent, the study coordinator completed the IBDQ-32

validated questionnaire for patients with inflammatory bowel disease (IBDQ-32; McMaster University in Ontario, Canada)[11] and a supplemental questionnaire that addressed bowel function and reproductive health, developed by the authors. The same study coordinator administered all questionnaires via telephone. Additional data were collected by retrospective chart review. The project was approved by the UCSF Committee on Human Research.

IBDQ-32 was measured to assess four primary categories: bowel system (frequent stools, loose stools and abdominal pain), emotional health (irritability, anger and depression), systemic system (fatigue, difficulty sleeping and maintaining weight), and social function (attending social engagements, work or school).[12] The IBDQ-32 addressed 10 bowel system, 5 systemic system, 12 emotional function, and 5 social function questions. Each question was rated on a scale of 1 (“all of the time”) to 7 (“none of the time”). Total scores ranged from 32 to 224, higher scores indicating a better QOL. The maximum possible scores in each system were as follows: 70 for bowel systems, 35 for systemic systems, 84 for emotional function, and 35 for social function. We reported patient’s total QOL scores based on classification by Meyer et al (≥200=excellent, 101-199=good or regular, ≤100=bad).[13] Two additional categories, bowel anastomosis function (pouchitis, accidental leakage and urge for defecation) and reproductive health (infertility, conception and sexual function), were included in a supplemental questionnaire (see online-only Appendix, http://links.lww.com/MPG/A108) that included quantitative questions such as number of children and episodes of Pouchitis. Subjects under age 18 at the time of the survey were interviewed the same as other participants except they were not asked questions regarding sexual function. Data were analyzed using Mann Whitney U Rank Sum Test. Results are presented as median and interquartile range (IQR).

Results

Demographics and Patient Characteristics

Sixteen patients (6 male) were enrolled in the study. Thirteen patients (81.3%) were Caucasian and three (18.7%) were African-American. The survey was administered at a median age of 20.3 years (17.9-25.3) and 6.9 (IQR 4.8-9.0) years post-colectomy. Five patients were ≤18 at the time of survey (Table 1).

QOL Findings

Children who underwent colectomy and were diagnosed ≤12 years of age had slightly (non-significantly) higher QOL. QOL scores were not associated with age at the time of colectomy or age at diagnosis. (Table 2, 3) Years post colectomy associated with QOL systems did not yield significant results. Patients ≤18 years at the time of survey showed higher QOL in all categories, significance achieved in emotional health (p=0.020), social function (p=0.014), and overall QOL (p=0.009). (Figure)

Total scores were 173.0 (IQR 154.5 – 186.8, total range 58 – 210). Two patients (12.5%) had overall IBDQ scores of ≥200, twelve (75.0%) had scores of 101-199, and two (12.5%) had scores ≤100. According to Meyer et al classification, 12.5% of patients had excellent

QOL, while 12.5% had bad QOL. The youngest patient in our study, who was 3 years at diagnosis, 6 years at colectomy, and 10 years at survey, had the highest overall QOL score of 210 of the possible 224. No differences were found comparing males and females. Social Function was scored the highest of all systems (median 7; IQR 4-7). Six of the 16 patients had a score of 7 across all social function questions, not found for any other system.

Colectomy

Ileal Pouch-anal Anastomosis (IPAA) total colectomy with a functional J-pouch was performed in 15/16 (93.8%) patients; one had a Hartmann pouch. A majority (13/16, 81.3%) of patients had hand-sewn anastomosis. Nine patients had an elective colectomy, and seven had an urgent colectomy. Ten patients had either a laparoscopic or laparoscopic-assisted colectomy, while 6 had an open colectomy. 8/16 patients had a 1 stage planned operation, 5 had a 2-stage, and 3 had a 3-stage planned operation. None of the operative factors correlated with QOL.

The QOL questionnaire showed that 2 patients were concerned about having surgery after colectomy. All but 5 reported having at least one surgery since colectomy, and one patient had 11 surgeries. Six patients reported a small bowel obstruction post colectomy; one had 10 episodes. These did not correlate with QOL.

Pouchitis

Pouchitis was reported by 9 patients (56.3%). The two patients with overall QOL scores ≤100 had repeated episodes of pouchitis compared with the other 14 patients. One patient had 16 episodes of pouchitis (Patient 1), while the other had 30 (Patient 2). (Table 4) Both patients were African-American. Patient 1 was male, 13 at the time of colectomy and 33 at the time of survey. Patient 2 was female, 19 at the age of colectomy and 24 at the time of survey. Patient 1 had a 3-stage total colectomy with ileostomy, while Patient 2 had a 2-stage laparoscopic assisted total colectomy with ileostomy. Both patients reported problems with fatigue, waking up in the middle of the night, and maintaining weight most or all the time (lowest systemic system scores).

Patient 2 was the only patient in our cohort who had a colectomy over 18 years of age (age 19) and the greatest number of complications post colectomy. The subject had 30 pouchitis episodes and 1 small bowel obstruction within 5 years post colectomy. After 2 successful pregnancies before colectomy, the patient was unable to become pregnant post colectomy and felt that colectomy had severely restricted sexual function. This patient had the lowest scores of 1 across all systemic system domains.

Sexual Activity and Childbearing Abilities

Seven females and four males were sexually active at the time of the survey. Of those eleven patients, six females and two males felt that their sexual activity was somewhat to severely affected by their colectomy. The two males had feelings of impotence and decrease libido, while the six females experienced dyspareunia.

One female and two males had at least one child at the time of survey. The two male patients each had one child post colectomy, but the female patient (patient 2) was infertile despite trying consistently and having two children before colectomy. Three females were trying to become pregnant at the time of survey, and none of the males. Of the three women including patient 2 who tried to have children after colectomy, none were able to successfully conceive a child. One woman became pregnant four times, each leading to a miscarriage.

Discussion

Our study of 16 patients who underwent colectomy before 20 years of age showed that QOL was highest among children diagnosed and who underwent colectomy prior to 13 years of age compared with older patients. A younger age (≤18 years) at the time of survey also showed a significantly higher QOL. Highest satisfaction was found in ability to attend school, work, and social engagements. Pouchitis was an issue for most of the patients, two patients suffering from recurring episodes.

Our study, while small, supports prior reports of decreased sexual function, including fertility and rate of conception especially in females following IPAA for UC.[14-18] Cornish et al recently reported an increase from 12 to 26 percent of infertility rate following restorative proctocolectomy among 945 patients,[19] and Waljee et al reported a threefold increased risk for infertility in women with UC following IPAA.[20] Our study showed that women may have difficulty conceiving and are potentially at increased risk for miscarriages. Sexual function was decreased in 2 of 4 sexually active males, but it did not seem to affect ability to conceive children, as reported by the two males who conceived children after colectomy.

Few prior studies have been published that investigate QOL for children who undergo colectomy. In one study, Richards et al (2001) concluded that chronic ulcerative colitis patients who undergo IPAA with a functional pouch have 92% chance of a normal QOL.[6] Hahnloser et al reported a normal QOL for patients 15 years after IPAA. They also observed that 92% of patients stayed in the same employment, and 83% of patients' work was unaffected by the surgery.[21] Other investigators report that although IPAA patients have a QOL similar to general healthy population, one third of the patients with IPAA have bowel dysfunction that negatively affects their daily lives, with 65% having 5 to 10 bowel movements a day.[22] Lichtenstein et al elaborated further by stating that UC surgery does not constitute a cure, restore bowel function or QOL to normal levels, and can introduce additional negative problems with sexual function and fertility.[1]

Data in adults suggest that patients after surgery have improved QOL.[1,6,7,13,21] Our study found that younger age at the time of colectomy, diagnosis, and survey show better QOL than older age. Females have lower sexual function and fertility, while males have decreased sexual function but appear capable of conceiving a child. Pouchitis appears to detract from improved QOL overall.

Patients considering colectomy as treatment for UC lack knowledge of QOL on a long postoperative period (5 years, 6-10 years, 11-15 years, and 16 or more years after surgery). Our analysis was limited due to the small sample size and lack of longitudinal data and

psychometric testing. We were also limited due to a varied patient population (age at survey, age at surgery) and that data were retrospectively collected with the possibility of recall bias. Certainly a larger longitudinal study to assess each patient's QOL before and after colectomy in childhood could improve the ability of patients and families to make the decision to undergo colectomy.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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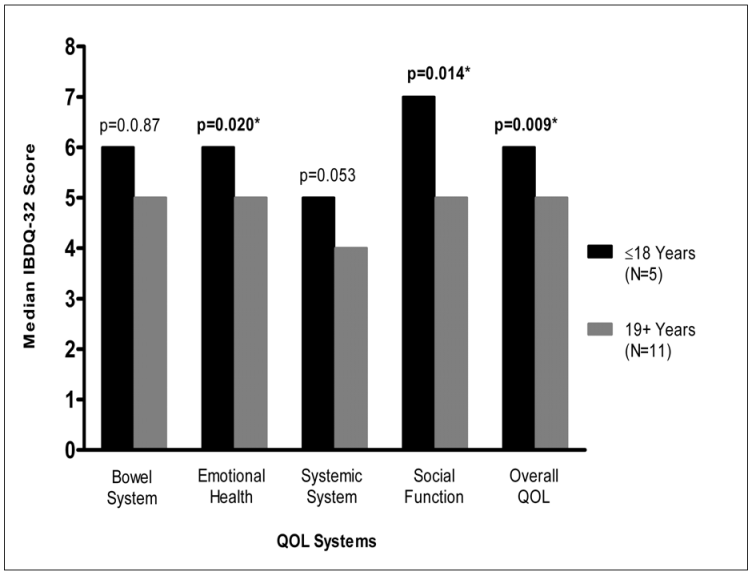

Quality of Life at Age of Survey. Younger age was associated with higher QOL in social function, emotional health, and overall QOL.

Table 1

Patient Characteristics

	Median (IQR)
Age at Diagnosis (yrs)	**11.2 (9.5-14.3)**
≤12 (N=9)	9.8 (8.2-10.9)
13+ (N=7)	14.7 (13.7-15.5)
Age at Colectomy (yrs)	**13.9 (11.3-16.8)**
≤12 (N=6)	9.1 (9.0-11.3)
13+ (N=10)	16.7 (14.4-17.1)
Age at Survey (yrs)	**20.3 (17.9-25.3)**
≤18 (N=5)	16.3 (16.1-17.2)
19+ (N=11)	24.8 (20.3-25.7)
Time Post-Colectomy (yrs)	**6.9 (4.8-9.0)**
≤18 (N=14)	6.0 (4.5-8.0)
19+ (N=2)	22.1 (20.9-23.4)

Table 2

Age at Colectomy by QOL Systems

	≤12 Years	13+ Years	
	Median Score (IQR)	**Median Score (IQR)**	**p**
Bowel System	6 (5-7)	5 (3-7)	0.113
Emotional Health	6 (5-7)	5 (3-7)	0.303
Systemic System	5 (4-6)	4 (1-5)	0.587
Social Function	7 (6-7)	7 (4-7)	0.403
Overall QOL	6 (4-7)	5 (3-7)	0.193

Table 3

Age at Diagnosis by QOL Systems

	≤12 Years	13+ Years	
	Median Score (IQR)	**Median Score (IQR)**	**p**
Bowel System	6 (5-7)	5 (3-7)	0.079
Emotional Health	6 (5-7)	5 (2-6)	0.081
Systemic System	5 (4-6)	4 (1-5)	0.185
Social Function	7 (6-7)	6 (3-7)	0.276
Overall QOL	6 (5-7)	5 (2-6)	0.072

Table 4

Recurrence of Pouchitis by QOL Scores

QOL Total Scores	Pouchitis (N=9)	Number of Episodes (Range)
≤100	2	16-30
101-199	2	0-2
≥200	5	0-3