



Psychosocial Impact of Familial Adenomatous Polyposis on Young Adults

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Aims of study

- Explore the psychosocial impact of FAP and its treatment amongst young adults (aged 18-35)
- To identify unmet information and support needs
- To develop and validate a FAP-specific multiple domain quality of life measure

Study Design

- **Stage One – qualitative phase**

10 individuals aged 18-35 with a diagnosis of, or at risk of, FAP interviewed to document their experiences, and to explore their support and information needs

- **Stage Two – quantitative phase**

A cross-sectional and retrospective study design, using mailed, self-administered questionnaires

Stage One – qualitative phase

At Risk Individuals

- Being at risk did not seem to have a major impact apart from the inconvenience of screening
- Individuals counselled as young adolescents had a poor understanding of FAP

New mutation carriers

- described significant distress regarding the lack of counselling at the time of diagnosis

Affected Individuals

- Surgery significantly impacted work and social activities
- Majority reported a significant effect on their body image, with some avoidance of intimacy

Support & Information

- Many reported a shortage of available information and a lack of knowledge of, or utilisation of, existing support services

Stage Two – quantitative phase

- Aim to survey 200 young adults through FAP registries in 5 Australian states:
 - a) Aged 18 to 35
 - b) Clinical or genetic diagnosis for FAP, or at 1 in 2 risk of FAP
- 100 participants will be randomly selected to complete a test-retest questionnaire, in addition to the main study questionnaire

Preliminary Results (N=20)

	Affected (N=16)	Unaffected (N=4)
Age M= 27 yrs, Range=19-35 yrs		
Sex		
Male (N=9)	6	3
Female (N=11)	10	1
Genetic Status		
Carrier		2
At-risk		2
Surgery Status		
No surgery	3	
Total colectomy & IRA	8	
Restorative proctocolectomy	4	
Both	1	

Surgery-associated symptoms

- 75% felt troubled by more frequent bowel movements, 17% has loss of bowel control, and 42% has staining of underwear, during the past four weeks
- 58% had abdominal pain, and abdominal bloating, with 75% having excessive wind in the past four weeks

Impact on body image & sexual functioning

- 38% felt less physically attractive, less feminine/masculine
- 85% felt dissatisfied with their body
- 38% reported FAP impacted their sexual desire, 54% on sexual enjoyment
- 38% of post-surgery female participants reported pain during intercourse, and 10% reported difficulty reaching orgasm

Emotional Impact

- Emotional impact of having FAP or being at risk of developing FAP:
 - 35% felt worried/anxious
 - 65% felt sad/depressed
 - 40% felt angry

Emotional Impact

- 5% elevated levels of intrusive thoughts
- 30% had elevated levels of avoidant ideation about FAP
- 10% had scores suggestive of a significant stress response warranting clinical intervention

Psychosocial impact

FAP was reported to have a negative impact on:

- Friendships and social activities: 29%
- Employment or choice of employment: 20%
- Intimate relationships: 20%
- Attitudes towards long-term relationships and marriage: 10%
- Attitudes towards having children: 10% (5% not at all willing to have children as a result of FAP)

Attitudes towards genetic testing

- 55% would not consider pre-implantation genetic diagnosis (PGD)
- 65% would consider prenatal testing
- 85% would not consider terminating a pregnancy if the unborn baby has been found to carry the mutation
- Early childhood or 10-14 years, as the appropriate age to introduce their children to the concept of FAP
- Testing at birth or in early childhood were the most preferred age for genetic testing for FAP

Information needs

- Majority (95%) felt satisfied with the information they have so far received
- Top three sources of information:
 - 1) Family members
 - 2) Consultation with a surgeon/specialist
 - 3) Consultation with a genetic counsellor / geneticist
- The top three most preferred methods of being provided resources for FAP:
 - 1) The internet, including an internet chat room
 - 2) Consultation with a genetic expert
 - 3) Information booklet/pamphlet

Support needs

The major areas where support was needed:

- 1) Dealing with uncertainty about the impact of FAP
- 2) Dealing with fears about developing cancer
- 3) Dealing with the impact of FAP on the family
- 4) Dealing with worry/anxiety about their children developing FAP

Conclusion

- Preliminary data suggests **significant** psychosocial impact on young adults with a diagnosis of FAP, or at risk of developing FAP extends across multiple domains
- This age group has a strong preference for web based resources



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