



Severe Adhesion Related Disorder (ARD); Pattern Of Bowel Dysfunction And Obstruction, Social And Physician Issues: An Internet Survey

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Disclosure

- Via my company – Synechion - Johnson & Johnson, Genzyme, Confluent Surgical, Florida Hospital, Kytogenics, ARC Pharmaceuticals, various other companies/organisations with a financial interest in adhesions and their prevention and treatment.
- No consulting fees were specifically in support of any work submitted here.
- Shares held in Johnson & Johnson, Genzyme
- Adhesions.org (owned by Synechion), has received monies from patients, companies, organizations, medical professionals with a financial interest in adhesions and their prevention and treatment.
- No monies were specifically in support of any work submitted here.



Background

Previous studies have documented the incidence and cost of adhesions in the overall population.

No studies have documented the profile of patients suffering with Adhesion Related Disorder (ARD).



Method

An internet-based survey was conducted among patients who visit the web site www.adhesions.org, or who have subscribed to its mailing list.

Dec 31 2002 – Nov 17 2005

Patients reporting a diagnosis of adhesions were asked to complete a survey regarding:

Time since diagnosis
GI disturbances
Ability to work
Social support structure

Bowel obstruction
Nutritional status
Ability to receive disability benefits



Adhesions and Bowel Obstruction Survey

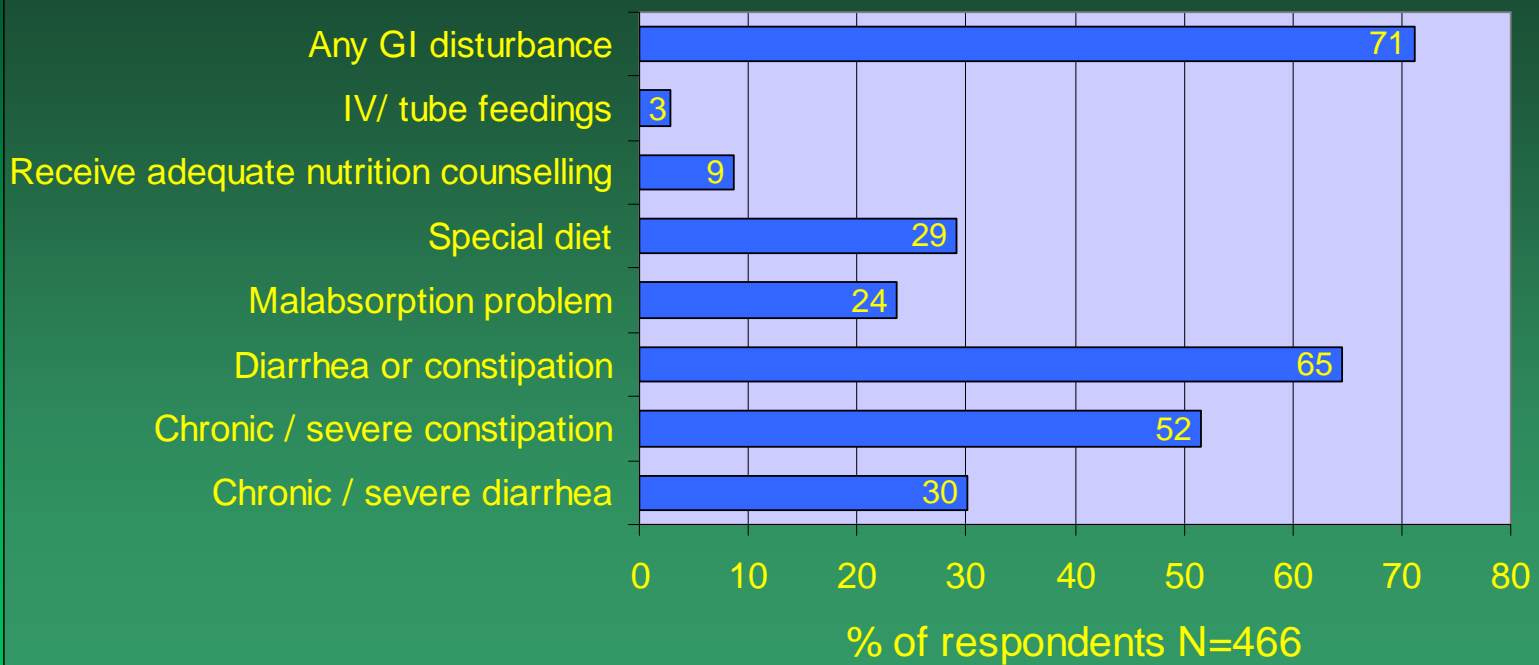
Please complete this survey if you have been diagnosed with pelvic or abdominal adhesions. You consent to the use of these results which will be masked or aggregated with other results. Please check all that apply.

1. I am male (do not check if you are female)
2. I have had at least one full bowel obstruction which was due to adhesions
3. I have had at least one partial bowel obstruction which was due to adhesions
4. I have been diagnosed as having adhesions within the last ONE year
5. I have been diagnosed as having adhesions within the last TWO years
6. I have been diagnosed as having adhesions within the last THREE years
7. I have been diagnosed as having adhesions within the last FOUR years
8. I have been diagnosed as having adhesions within the last FIVE years
9. I have been diagnosed as having adhesions within the last SIX years
10. I have been diagnosed as having adhesions within the last SEVEN years
11. I have been diagnosed as having adhesions within the last EIGHT years
12. I have been diagnosed as having adhesions within the last NINE years
13. I have been diagnosed as having adhesions within the last TEN years
14. I have been diagnosed as having adhesions within the last FIFTEEN years
15. I have been diagnosed as having adhesions within the last TWENTY years
16. I was diagnosed as having adhesions more than TWENTY years ago
17. Since being diagnosed with adhesions, I have had a full or partial bowel obstruction on average at least once every 6 months
18. Since being diagnosed with adhesions, I have had a full or partial bowel obstruction on average at least once a year
19. Since being diagnosed with adhesions, I have had a full or partial bowel obstruction on average at least once every three years
20. Since being diagnosed with adhesions, I have had a full or partial bowel obstruction on average at least once every four years
21. Since being diagnosed with adhesions, I have had a full or partial bowel obstruction on average at least once every five years
22. Since being diagnosed with adhesions, I have had a full or partial bowel obstruction on average less than once every five years
23. Due to my adhesions, I suffer from chronic/severe diarrhea
24. Due to my adhesions, I suffer from chronic/severe constipation
25. Due to my adhesions, I have a malabsorption problem
26. Due to my adhesions I have a special diet
27. I receive adequate counseling regarding proper nutrition
28. I require IV/ Tube feedings
29. I suffer from chronic pain
30. I take medication for chronic pain
31. My chronic pain medication makes my bowel problems worse
32. I have tried physical/ massage therapy for my bowel condition
33. The physical/massage therapy has improved my condition
34. Because of my condition I am unable to work
35. I have been unable to obtain disability benefits related to my inability to work
36. Because of my condition my family relationships have suffered
37. My family/ friends are very supportive of me
38. My current doctor is able to help my condition somewhat
39. My current doctor acknowledges my adhesions problem, but is unable to help
40. My current doctor does not acknowledge that adhesions are a problem, and is unwilling to help

Respondents

	<u>Male</u>	<u>Female</u>	<u>Total/ All</u>
Patients	51	415	466
Years since Dx with adhesions	7.2 \pm 1.2	7.0 \pm 0.3	7.0 \pm 0.3
Years between obstructions	0.9 (n=40)	1.0 (n=230)	0.9 (n=270)
Number of obstructions	12.1 \pm 2.3 (n=40)	9.1 \pm 0.7 (n=230)	9.1 \pm 0.7 (n=270)
Pts. w/ obstruction	45	272	317

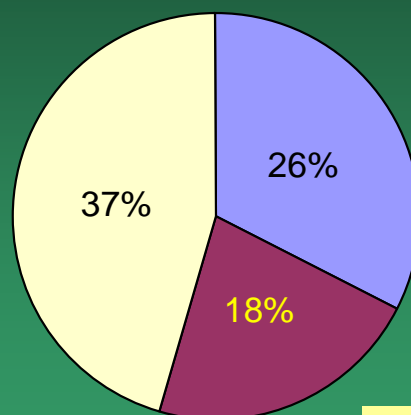
GI Disturbances



**71% report some
GI disturbance**

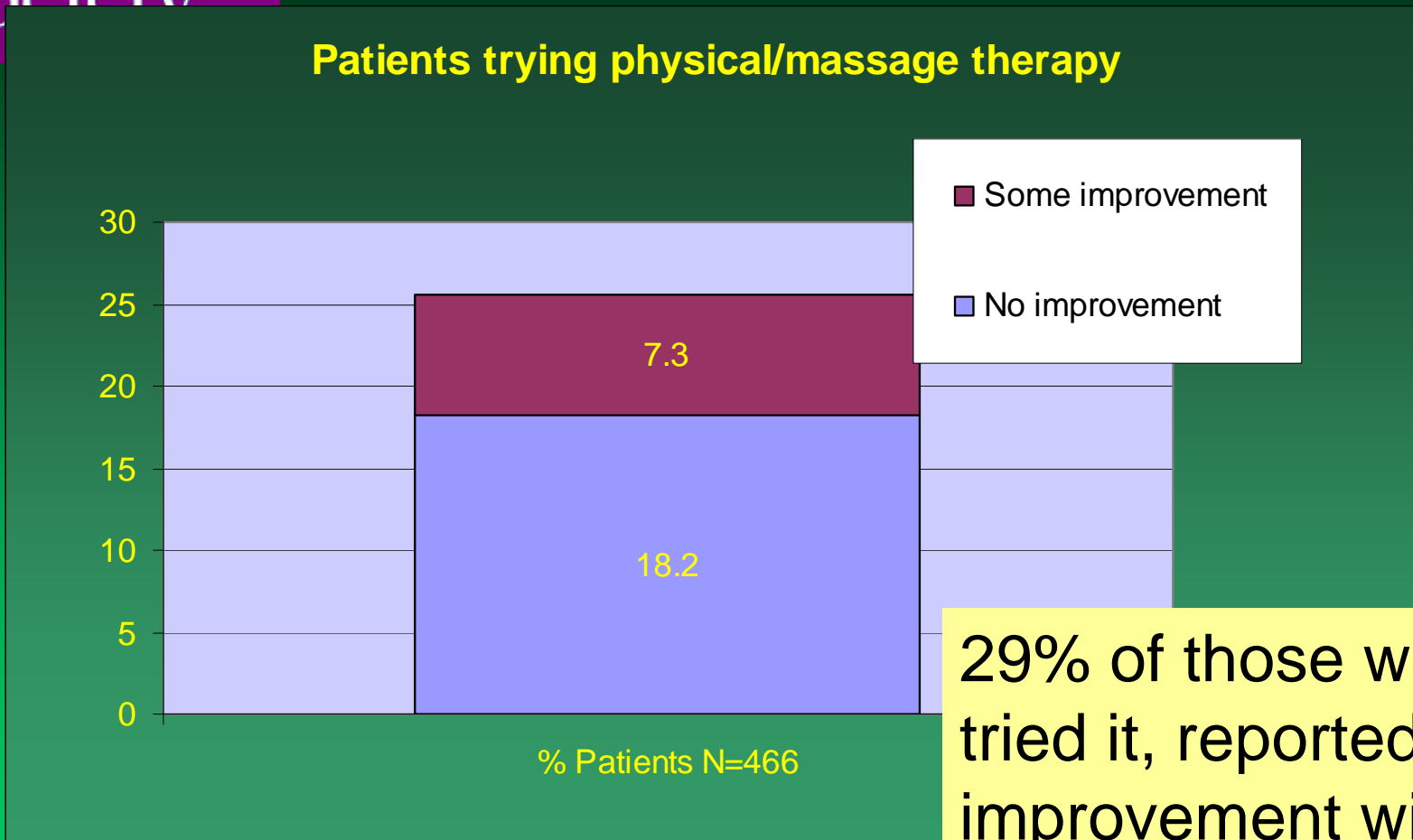
Chronic Pain Medications and Bowel Problems

- Chronic pain, no medication
- Take pain med without effect on bowel
- Pain med makes bowel problem worse



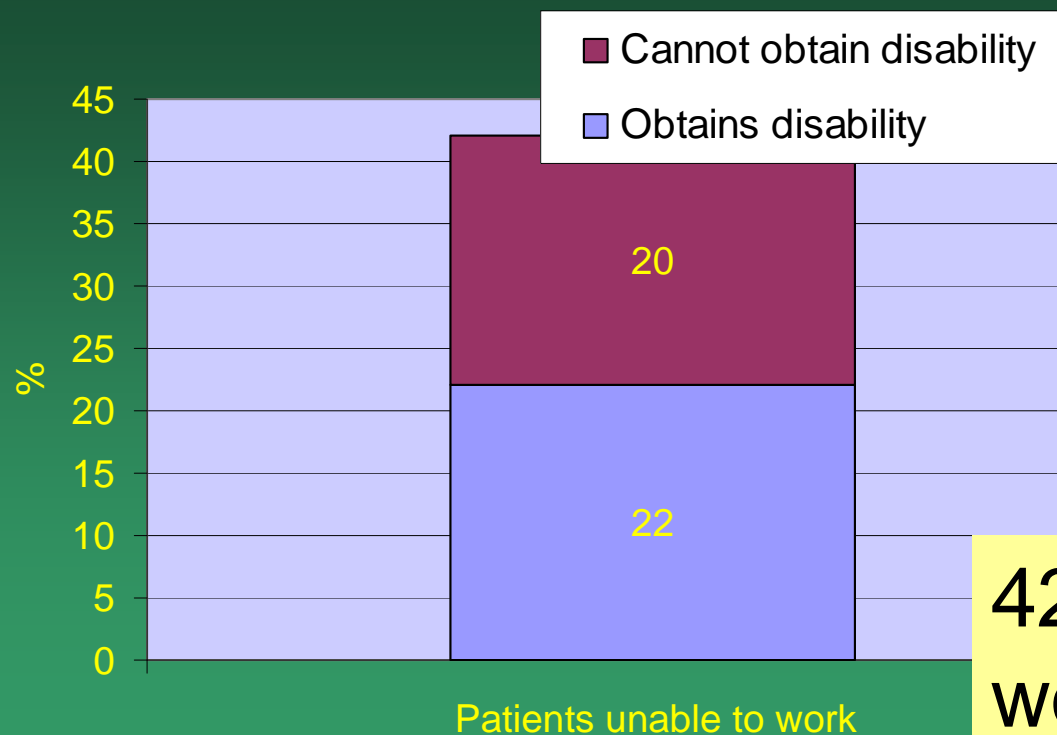
81% suffer from chronic pain

Patients trying physical/massage therapy



29% of those who tried it, reported improvement with PT/massage

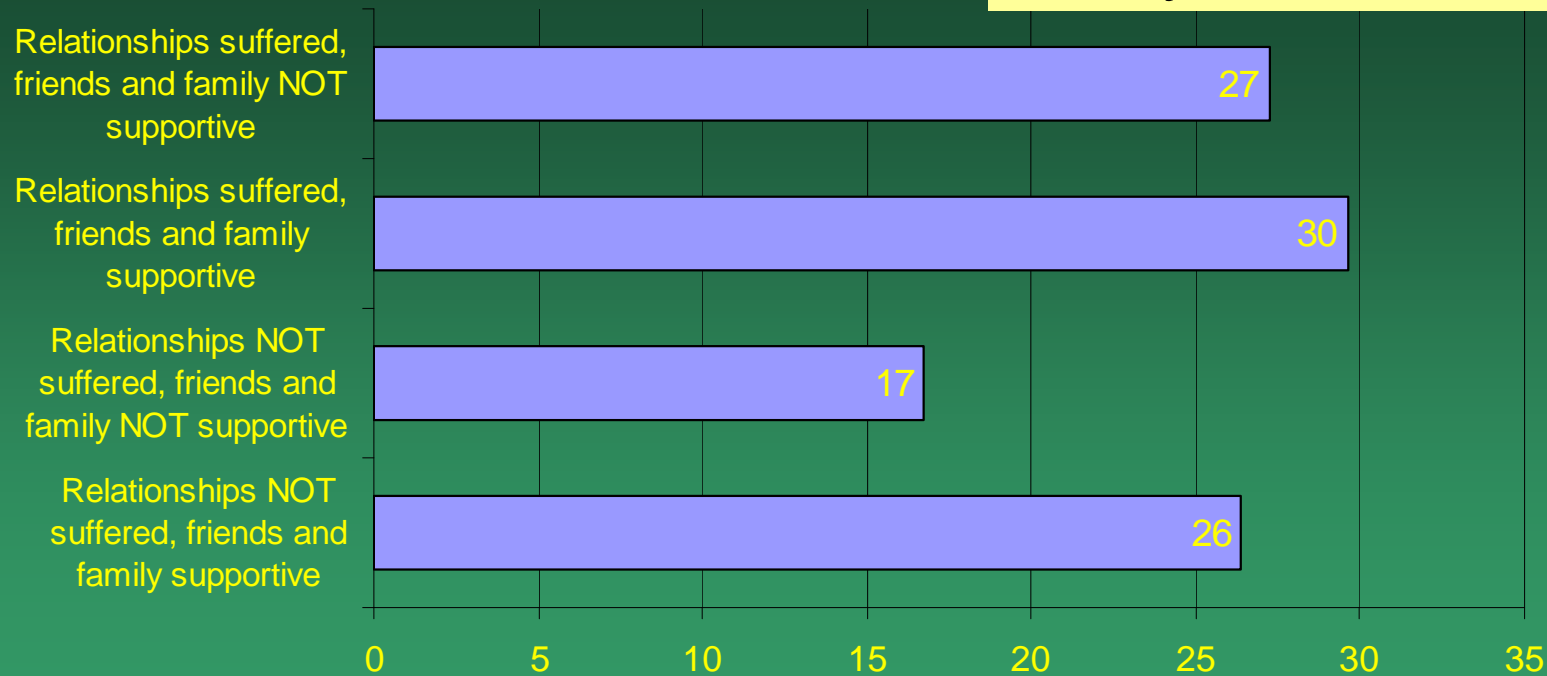
Work and Disability



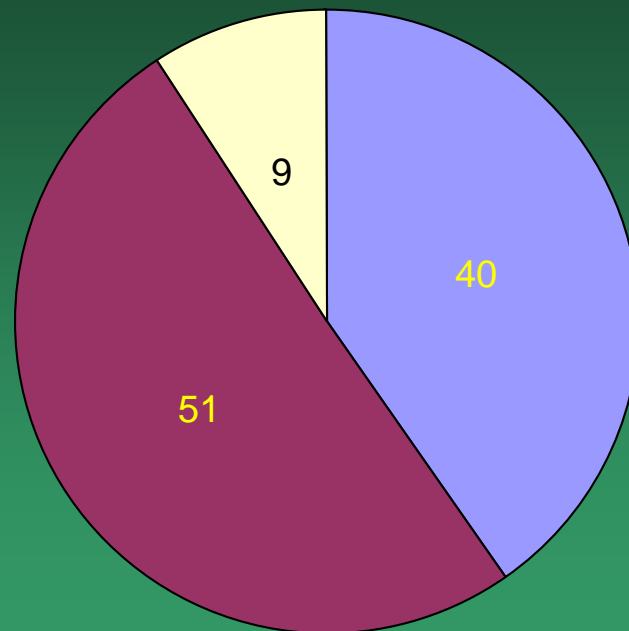
42% could not work due to condition

74% reported had problems with family or friends

Social Support



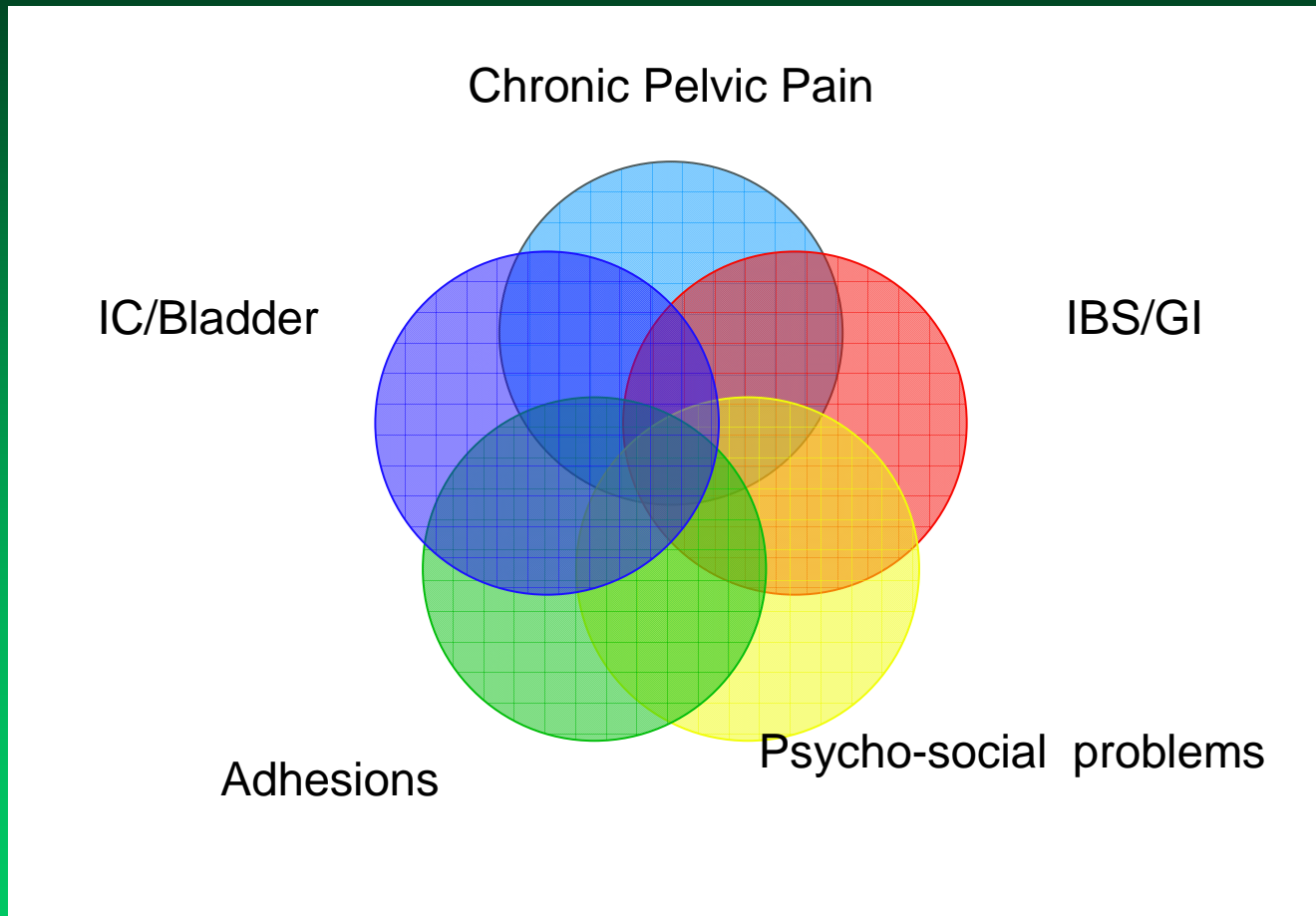
Attitudes about Doctors



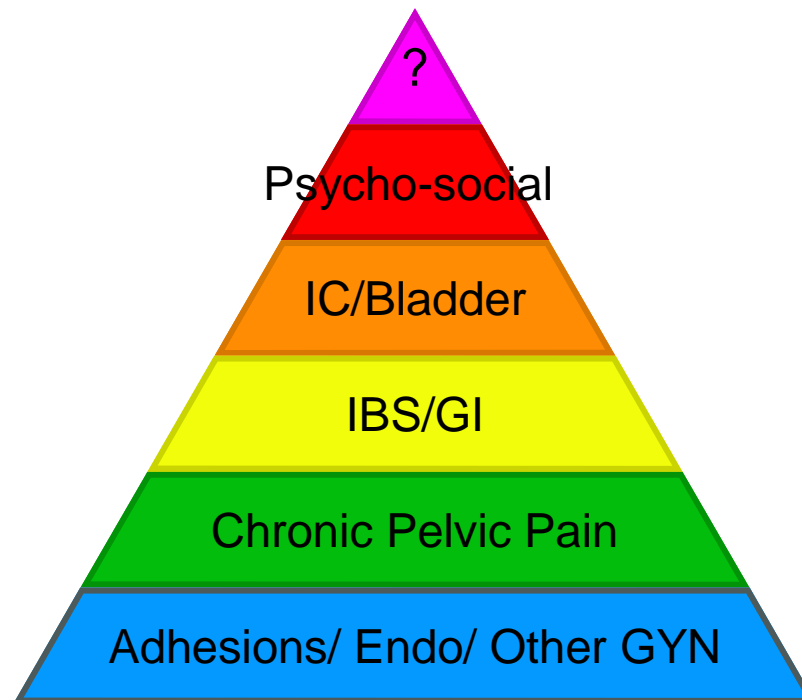
- Doctor able to help somewhat
- Acknowledges problem, unable to help
- Does not acknowledge problem, unwilling to help

Only 9% reported physician unwillingness to help

High coprevalance of other conditions



Disease Progression





Despite shortcomings inherent in a survey of this kind, a description of the severe ARD patient has been provided for the first time.

These data will be useful in devising strategies for the medical, surgical, nutritional, social and financial support of the ARD patient.



Now that we are beginning
understand this condition, we can
start to figure how to prevent and
treat it.



It's not just...

Adhesions

Chronic Pain

Endometriosis

Irritable bowel syndrome

Interstitial cystitis

Fibromyalgia.....

It's.....

C.A.P.P.S.

Complex Abdomino-Pelvic & Pain Syndrome



Multi-factorial disorder
requires

An integrated, multidisciplinary approach



INTERNATIONAL
Adhesions
Society

INTERNATIONAL
Adhesions
Society

www.adhesions.org

www.iscapps.org

Profile

- 7 years since diagnosis
- ~ 9 obstructions
- ~ 1 year between obstructions
- Cannot work – 42%
- Relationships and support structure suffers – 74%
- Physical/ massage therapy may be helpful – 29%
- Chronic pain – 81%
- GI disturbances – 71%
- Chronic diarrhea / constipation – 65%
- Pain medication worsens bowel problems – 67%
- Physician unwillingness to help – 9%
- High coprevalance of other conditions

Action Items

- Define type of physical/ massage therapy and effectiveness
- Explore analgesic methods that avoid GI problems
- Communicate tools to physicians
- Establish integrated care algorithms for ARD patients: adhesions, pain relief, psychosocial issues, nutrition

Results

466 patients (51 male, 415 female) completed the survey with the time since diagnosis of 7.04 ± 0.33 years. 68% of patients reported having had either a full or partial obstruction, with 9.51 ± 0.69 obstructions and mean (geometric) time between obstructions of 0.95 years. 81% of respondents report suffering from chronic pain for which 68% take medication. 68% of whom report that the medication worsens their bowel symptoms. 71% of patients report chronic GI disturbances, including 24% with a malabsorption problem. 42% of patients report that they are unable to work due to the problems caused by adhesions, and 47% of these report being unable to obtain disability benefits. 26% of patients reported having received physical/massage therapy and 29% of these reported receiving a benefit. 26% of patients reported that their family relationships had not suffered and that their friends and family were supportive of their condition. 44% of patients reported that their friends and family were not very supportive. 40% of patients reported that their physician was able to help them somewhat, with another 51% reporting that the physician acknowledged the problem but was unable to provide any help. Only 9% of patients reported that their physician did not acknowledge the problem and was unwilling to help. **Conclusion:** Despite shortcomings inherent in a survey of this kind, a description of the severe ARD patient has been provided for the first time. These data will be useful in devising strategies for the medical, surgical, nutritional, social and financial support of the ARD patient.