

Family Communication about Genetic Counselling for Hereditary Colorectal Cancer

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KEY MESSAGES

- Individuals who have attended genetic counselling are expected to disseminate information about genetic risks to their relatives.
- The study results show that most individuals who attended genetic counselling informed their first-grade relatives. Second- and third-grade relatives were less frequently informed.
- Cancer patients informed less relatives than individuals at-risk for developing cancer.
- Psychological distress was not associated with the dissemination of information.

Results

- On average, more relatives than expected were informed.
- Female and male counselling attendants did not differ in the number of relatives informed.
- Second- and third-degree relatives were informed less often (Tab. 1).
- Colon cancer patients informed less relatives than healthy at-risk persons (Tab. 1).

Table 1: Degree of dissemination of information (%)

	Degree of dissemination of information g (%)				
	g=0	g<1	g=1	g>1	0/0
All relatives (M=1,39)	2,6	38,3	22,7	36,4	-
First-grade relatives (M=1,39)	2,6	19,8	34,3	43,4	-
Second-grade relatives (M=0,75)	28,8	6,0	7,6	19,7	37,9
Third-grade relatives (M=0,59)	13,6	1,5	0,0	6,0	78,0
Patients (M=0,97)	2,4	47,6	31,0	19,0	-
At-risk persons (M=2,13)	4,2	20,8	8,3	66,7	-

- Pre-counselling psychological distress did not correlate with the degree of dissemination of information, and there were no differences in dissemination between subgroups of distressed individuals either (Tab. 2).

Table 2: Psychological distress (BSI) and degree of dissemination of information (g)

	T	BSI		g	
		N	%	M	SD
BSI low	24-39	11	14,5	1,33	1,30
BSI normal range	40-65	54	71,1	1,32	12,4
BSI high	66-80	11	14,5	1,76	1,71

Background

- About 5 % of all colon cancers show a genetic predisposition (e.g. HNPCC, FAP). Genetic susceptibility tests for colon cancers are available for several years.
- Utilization of genetic testing is dependent on the dissemination of information to individuals at-risk for developing hereditary cancers.
- In Germany, like in many other countries, genetic counsellors are not allowed to disclose genetic information to the patients' at-risk relatives. This duty lies with the individual who has attended genetic counselling.
- So far, only a few studies have looked at the communication of genetic risk information within families. Most of these studies have used a qualitative approach [1, 2, 3].
- The aim of this study was to document the dissemination of genetic information within families and to investigate whether this process would be associated with psychological distress.

Sample

- N = 76 individuals who attended genetic counselling at the Institute for Clinical Genetics, Universitätsklinikum Dresden, between July 2003 and July 2005
- Mean age: 41,8 years; 64,5 % female
- 59,2 % ill patients, 40,8 % at-risk persons

Method

- t0 (2 weeks before genetic counselling): Brief Symptom Inventory (BSI, psychological distress)
- t1 (genetic counselling session): determination of the pedigree (number of relatives to inform)
- t2 (2 weeks after genetic counselling): Questionnaire on dissemination of information (number of relatives informed)
- Index g (number of relatives to inform / number of relatives informed)
- g=0: none informed, g<1: informed less than expected, g=1 informed all relatives expected to, g>1 informed more than expected

Conclusions

- Dissemination of genetic information to first-degree relatives is adequate. However, there are deficits in the degree of the communication of genetic information to second- and third-degree relatives.
- Genetic counsellors should encourage patients/at-risk persons who attend genetic counselling to disclose information about genetic risk to their relatives, especially second- and third-degree relatives.
- Patients suffering from hereditary colon cancer should receive high encouragement and advise to disclose genetic information to their next-of-kin.

References

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