

To whom it may concern ...

Information transfer into the family after 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 more relatives than healthy individuals at-risk for developing cancer.
- Psychological distress, anxiety or depression were not associated with the dissemination of information.

Results

- Second- and third-degree relatives in general were informed less often (Tab. 1).
- Female and male counselling attendants differ in the number of relatives informed. Females informed more relatives.
- Colon cancer patients informed more relatives than healthy at-risk persons (Tab. 1).

Table 1: Degree of dissemination, mean number of relatives (rel.) informed (SD)

	No. of informed relatives		
	All rel.	First degree rel.	Second degree rel.
Total sample	2,95 (2,11)	2,05 (1,58)	0,30 (0,75)
Colon cancer patients	3,02 (2,09)	2,26 (1,69)	0,24 (0,65)
At-risk persons	2,90 (2,14)	1,88 (1,48)	0,34 (0,82)
Female	3,11 (2,10)	2,07 (1,50)	0,36 (0,79)
Male	2,67 (2,19)	2,00 (1,71)	0,19 (0,68)

- Psychological distress, anxiety or depression did not correlate with the number of informed relatives (Tab. 2).

Table 2: Correlations between total No. of informed relatives and psychological distress (BSI), anxiety and depression (HADS)

	Correlations		
	BSI	Anxiety (HADS)	Depression (HADS)
Total sample	-0,01	-0,02	-0,05
Colon cancer patients	-0,01	-0,01	-0,03
At-risk persons	-0,01	-0,02	-0,06
Female	-0,04	-0,06	-0,01
Male	0,02	0,02	-0,09

Background

- About 5 - 10 % of all colon cancers show a genetic predisposition (e.g. HNPCC, FAP). Genetic susceptibility tests for colon cancers are available since several years.
- Utilization of genetic testing depends 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 rests 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 = 501 individuals who attended genetic counselling for hereditary cancer at the universities Dresden, Bochum, Düsseldorf or Heidelberg (Germany) between July 2003 and July 2007
- Mean age: 42,0 years (SD = 12,7)
- N = 314 (62,7 %) female
- N = 220 (43,9 %) colon cancer patients, N = 281 (56,1 %) healthy at-risk persons

Method

- 2 weeks after genetic counselling:
 - Questionnaire on dissemination of information (number and degree of relatives informed)
 - Brief Symptom Inventory (BSI, psychological distress)
 - Hospital Anxiety and Depression Scale (HADS, anxiety and depression)

Conclusions

- Dissemination of genetic information to first-degree relatives seems to be adequate. However, deficits in the degree of the communication of genetic information to second- and third-degree relatives might be suspected.
- 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.
- Healthy at-risk persons should receive high encouragement and advise to disclose genetic information to their next of kin.

References

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