

# Social support during the process of genetic testing for HNPCC

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## Background

Perceived social support is a main resource for the effective coping with (chronic) diseases, especially for cancer (1). This study addresses the levels and stability of social support in persons undergoing a genetic counseling/testing for hereditary non-polyposis colorectal cancer (HNPCC).

Social support is defined as a result of cognitive, emotional coping- and appraisal processes of experienced social interactions in which a person needed the assistance of other persons to achieve their goals and/or to cope with specific demands.

## Methods

The study took part between 2003 und 2010 in three university hospitals in Germany (Bochum, Dresden, Heidelberg). N=825 persons who joined a genetic counseling/testing for HNPCC were initially included. The mean age of the participants was 41.8 years, 60.3 % of the participants were female. 42.6 % of the participants were patients suffering from colon cancer.

The participants completed comprehensive questionnaires at five measurement points: t0: 14 days before the first genetic counseling, t2: 14 days after genetic counseling, t3: six months after genetic counseling, t4: 14 days after test disclosure, t5: one year after genetic test disclosure.

N=347 persons took part over the complete five measure points (62.8 % female, 51.7 % patients suffering from colon cancer, mean age 43.5 years).

Among others perceived social support was administered at the points of time t0, t3 und t5 with the questionnaire F-SOZU (2). This questionnaire consists of 54 items. The questionnaire F-SOZU measures social supports detailed on seven different scales, e.g. emotional support, practical support, satisfaction with social support or social integration. A total score for social support can be calculated. Norm values for the German population and for different subgroups of patients are available.

Different aspects of psychological health were measured among others with the questionnaires Brief Symptom Inventory (BSI), Hospital Anxiety and Depression Scale (HADS), Impact of Event Scale (IES), SF-12 Health Survey (SF-12) and Gießßen Subjective Complaint List (GGB-24).

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## Results

Data showed a high level of perceived social support (see figure 1):  
1) among all the different participants of the study,  
2) in all different areas of social support measured by the F-SOZU-Questionnaire and  
3) over the three measurements points in the process of genetic counseling/testing (14 days before/six months after genetic counseling, one year after test disclosure).

During the process of genetic counseling/testing social support remains stable on a high level (see table 1), no changes over the time could be observed. This can be also found for different subgroups of the patients, e.g. for participants with a positive vs. participants with a negative test result (mutation found or not).

No differences between different groups of participants could be found, e.g. male vs. female, healthy risk persons vs. cancer patients, persons fulfilled/fulfilled not Amsterdam or Bethesda criteria, older vs. younger participants (see figure 2), person with high vs. person with low educational level, participants living alone vs. participants living together with a partner and other socio-demographic characteristics.

A higher level of perceived social support is at all points of time associated with better psychological health (see table 2). Patients who reported more social support have lower levels of psychological distress (BSI), anxiety and depression (HADS), intrusion or avoidance (IES), somatic symptoms (GGB-24) and higher levels of quality of life (SF-12).

## Discussion

For the first time we measured social support detailed with a comprehensive questionnaire in a large sample of patients with or with the risk of HNPCC over a time period beginning 14 days before the first genetic counseling and finishing one year after test disclosure.

For persons searching genetic counseling and/or genetic testing for HNPCC social support is a main source for the effective coping with this disease/risk of developing the disease.

The perceived social support remains stable during the process of genetic counseling/testing for HNPCC. It is in contrast to others studies (3) not influenced by socio-demographic characteristics, characteristics of illness risk status (Amsterdam or Bethesda criteria) or status of the person (healthy persons vs. patients suffering from cancer).

Higher social support is associated with better psychological health. Therefore counselors in genetic fields should address this important resource in order to help their clients to cope with the possible harmful and stress inducing results of a genetic testing procedure.

## References

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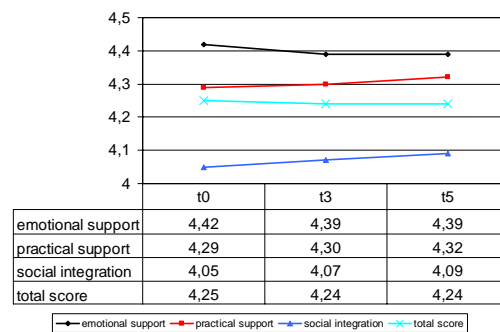
**Table 1:** Changes in social support from t0 to t5 (percentages of participants with total score below/within/above ranges of norm values)

	t0 below norm	t0 within norm	t0 above norm
t5 below norm	6 (2.33 %)	10 (3.88 %)	0 (0.00 %)
t5 within norm	14 (5.42 %)	100 (38.76 %)	22 (8.53 %)
t5 above norm	0 (0.00 %)	38 (14.70 %)	68 (26.40 %)

**Table 2:** Correlations between social support (total score) and different aspects of psychological health at three points of time (\*\*p<0.001)

	t0	t3	t5
BSI-GSI	-.46**	-.49**	-.50**
HADS-Anxiety	-.34**	-.39**	-.45**
HADS-Depression	-.46**	-.48**	-.52**
IES-Intrusion	-.13**	-.26**	-.25**
IES-avoidance	-.23**	-.30**	-.31**
SF-12-K	.03	.20**	-.01
SF-12-P	.40**	.46**	.43**
GGB-24-E	-.24**	-.34	-.27**

**Figure 1:** Perceived social support (emotional support, practical support, social integration and total score) in the process of genetic counseling/testing for HNPCC (means)



**Figure 2:** Perceived social support (total score) in the process of genetic counseling/testing for HNPCC in three different age groups (means)

