

## University of Groningen

### Lotgenotencontact bij kankerpatiënten

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## SUMMARY

The primary aims of the research described in this book are two-fold: 1) to gain insight into the predisposing factors in cancer patients for social comparison with fellow-patients and their actual contacts with fellow patients; and 2) to examine the effects of these contacts on the problems experienced by the patients.

Data were collected at two points in time from samples of patients with Hodgkin's diseases (or non-Hodgkin's lymphoma) and breast cancer in accordances with a quasi-experimental, non-equivalent control group design. Initial data were gathered in January and February of 1982. At that time the 282 breast cancer patients were under treatment in the outpatient department or doing control visits. During a few weeks time period, all breast cancer patients who visited the main treatment centers for consultation were asked by their specialists to participate in the research. Of the 216 Hodgkin patients 38% were approached in the same manner. The other Hodgkin patients were approached by the contact group for Hodgkin patients to which they belonged. In order to be able to approach patients, the cooperation of 22 medical specialists located at 15 major clinics in the Netherlands was obtained.

A review of the research studies centering on the effects of contacts with fellow-patients shows that most of them do not satisfy the methodological conditions necessary to draw firm conclusions. Also, most of these studies are not well-grounded in theory and as a result, this situation leads to the generation of conflicting hypotheses. Also certain problems seem to be neglected. Hardly any attention, for example, is paid to the experiences of uncertainty by patients in these studies. Furthermore, problems such as loss of control and certain negative feelings like loneliness are virtually ignored. Finally, most of these contacts effect studies involve contacts in larger self-help groups, while most contacts between fellow-patients in the Netherlands are dyadic (one-on-one).

In terms of findings in these studies some show positive effects of contacts with fellow-sufferers. It is difficult, however, to compare these findings because they utilize different criteria for judging the impact of contacts on the psychological and physical health of the patients. An other difficulty is that in investigations where fellow-patients' contacts are established in terms of a group, a professional usually participates. Although the professional has an nondirective role or a nondominating educational role, these studies do not permit the unequivocal conclusion that any effects are due to the contacts with fellow-patients. Also, in virtually no study is attention given to the characteristics of the group process that could be responsible for the effects. There are also no studies in which comparisons are made between the different conditions under which contacts with fellow-patients occur (e.g. manipulations of fellow-patients contacts).

The major research question addressed in the book is developed from social comparison theory and attribution theory. Hypotheses are formulated and tested as follows:

- 1) The predisposing factors leading to contacts with fellow-patients are the attempts to reduce negative feelings, uncertainty, and loss of control and to increase self-esteem; and
- 2) These contacts will lead to a reduction of negative feelings, uncertainty, and loss of control and to an increase in self-esteem.

The results indicate that approximately half of the Hodgkin patients and 30% of the breast cancer patients report being (very) much in need of social comparison with fellow patients at the first measurement. Also, more than half of the Hodgkin patients and the breast cancer patients report having had contact with fellow patients one or more times.

Most of the variance in the data is explained by the extent to which patients experience uncertainty (See Chapter 6). Specifically, a high degree of uncertainty is related to a high need for social comparison with fellow-patients. Additional variance is explained by the extent to which patients are lonely and have received written information about the disease. Intense feelings of loneliness are related to a high need for social comparison. The more the patients have read about the illness and its treatment, the greater the need for social comparison with fellow-patients. Also the need for social comparison is higher for Hodgkin patients than for breast cancer patients.

The results show further that certain coping strategies and attributional styles are interrelated with the problems experienced by patients and connected with the need for social comparison. For example, fear appears to be less strongly associated with the need for social comparison for those patients who seek comfort in their religion in comparison to those who do not seek comfort in this way. The need for social comparison appears to be relatively low in patients who do not attribute a strong influence on the course of their illness to themselves and who at the same time experience little feelings of loss of control. It also appears to be low specifically in Hodgkin patients who are inclined to submit to their problems and who at the same time experience little uncertainty. In contrast, the need for social comparison is high in those Hodgkin patients who are very uncertain and interestingly in those who are simultaneously inclined to submit to their problems.

Patients who have had contact with fellow-patients maintain that their main motive for establishing this contact is the reduction of uncertainty (See Chapter 7). Their second motive is the helping of other patients. In third place the motive is the acquisition of support in order to solve emotional problems.

Patients who have never had contact with fellow-patients report on their important reasons: 1) I can handle my own business; 2) I felt no need for such contacts; 3) I did not know anyone; 4) I did not want it; 5) I did not see much point in having such contacts.

Social barriers to contacts with fellow-sufferers as a consequence of

negative attitudes in their social environment hardly ever occurred. If it did occur, it was due to people in the primary groups, e.g., the partner. Besides the exploration of motives for making or not making contacts with fellow-patients and experienced social barriers, hypotheses were tested regarding the background leading up to the initiation of contacts in terms of differences in the characteristics of patients who initiated or did not initiate contacts. It was found that the basic motives are not related to the initiation of actual contacts. However initiators had a greater need for information after the discovery of the disease. They also mentioned that they had received little relevant information from their family doctors and criticized them for not sending them to the hospital soon enough. Although patients who had contacted fellow patients talked readily about their illness, they had fewer contacts with their partner, relatives, and neighbours to discuss these feelings. They also reported receiving less support from their general practitioner and priest or pastor and were less inclined to repress their problems and less inclined to seek support in religion.

A **subjective** evaluation of patients- contacts with fellow-sufferers shows that these contacts were not very important as a vehicle for obtaining information about their illness and its treatment. Finally, with respect to the effects of the contact on the **actual** problems (Chapter 9) this research shows that regular contact was important because it led to a decrease in negative feelings (depression, state-anxiety, and psychological complaints) and an increase in self-esteem. This finding was obtained specifically during the period of treatment or after a recurrence of the illness.