Cancer patients’ satisfaction with doctors’ care

Consequences and contributing conditions

CAMILLA FRÖJD
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Abstract

The main aims were to: explore whether there is a relation between doctors’ ability to identify patients’ worry and wish for information and self-efficacy with regard to communicating with patients about difficult matters; describe which cues doctors consider when estimating patients’ worry and wish for information, and investigate whether there is a relation between patients’ satisfaction with doctors’ care and patients’ psychosocial function.

Eleven doctors and 69 patients (of which 36 patients participated in the longitudinal study) with carcinoid tumours participated. Doctors’ self-efficacy, and ability to identify patients’ worry/wish for information were investigated at patients’ first admission. Doctors were interviewed about which cues they considered when estimating patients worry/wish for information. Patients’ satisfaction with care (CASC SF 4.0) and psychosocial function (EORTC QLQ-C30, HADS) were measured longitudinally, during the first year after diagnosis.

Doctors reported higher self-efficacy when showing good ability to identify patients’ wish for information, than when showing less good ability, overestimated patients’ worry and underestimated patients’ wish for information. Doctors considered patients’ verbal behaviour and body language together with knowledge and experience when estimating patients worry and wish for information. Patients who met doctors showing good ability to identify their wish for information, reported a higher cognitive function than patients who met doctors showing less good ability. At all assessments patients expressed high satisfaction with doctor’s care and patients’ satisfaction did not change over time. Patients’ satisfaction with doctors’ care were related to their psychosocial function shortly after the first three admissions to specialist care. Patients with carcinoid tumours in some respects reported a worse HRQoL than the general Swedish population. Fatigue, diarrhoea, limited possibilities to work/pursue daily activities, and worry that the illness will get worse were among the most prevalent, and worst, aspects of disease- and treatment related distress.

Keywords: Carcinoid tumours, Doctor, Worry, Information, Satisfaction with doctors’ care, Psychosocial function, Self-efficacy

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In memory of my mother

I miss you

Even if I knew that tomorrow the world would come to an end
I would still plant my apple tree

Martin Luther King
List of papers

This thesis is based on the following papers, referred to in the text by their Roman numerals.


II Fröjd, C., Lampic, C., Larsson, G., Birgegård, G. & von Essen, L. Patient attitudes, behaviours and other factors considered by doctors when estimating cancer patients’ worry and wish for information. Accepted for publication in *Scandinavian Journal of Caring Sciences*.


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Introduction

This thesis

A cancer diagnosis is likely to affect a person’s life in several ways. Patients may experience psychosocial problems, arising as consequences of the disease and its treatment, and they often have to undergo frequent admissions to hospital for examinations and treatments. The relationship with the doctor, in the literature most often called physician, often becomes significant.

This thesis is a first step towards revealing whether certain conditions related to doctors’ skills and abilities contribute to patients’ satisfaction with doctors’ care and whether patients’ satisfaction with doctors’ care contribute to patients’ psychosocial function. The assumptions were: doctors’ self-efficacy with regard to communicating with patients about difficult matters and doctors’ ability to identify a patient’s worry and wish for information are conditions which can contribute to patients’ satisfaction with doctors’ care whereas patients’ satisfaction with doctors’ care can contribute to patients’ psychosocial function, in this work measured in terms of health-related quality of life (HRQoL), worry, anxiety, and depression.

Doctors’ self-efficacy with regard to communicating about difficult matters

Doctors’ self-efficacy (1) with regard to communicating about difficult matters may contribute to doctors’ ability to communicate. Self-efficacy with regard to a specific task may influence the choices we make, the efforts we put forth, and how long we persist in performing the task (2, 3). It has been shown that people tend to avoid situations they believe exceed their skills (2). The level of self-efficacy may vary within individuals according to the perceived difficulty of a specific task and to the individual’s emotional state. Individuals are more likely to experience high self-efficacy when experiencing low tension or stress, and adversely, low self-efficacy when being tense and stressed (2). Low self-efficacy with regard to communicating with
patients about difficult matters may cause doctors to avoid posing open ques-
tions. Thereby the doctors’ communication with patients could be restricted
(4-6). As an attempt to spare patients from harm doctors may avoid dealing
with patients’ problems, withhold unfavourable information, and use
euphemisms (7, 8). As a result, the patient’s needs and psychosocial function
may remain unidentified.

Doctors’ ability to identify patients’ psychosocial
function and wish for information

In order to provide patients with good care it is necessary for doctors to
identify patients’ physical as well as psychosocial needs. When cancer pa-
tients meet doctors for a consultation, they may experience worry and/or
anxiety, and depression (9-15). It has been shown that at follow-up visits
approximately a fourth of cancer patients worry, just before meeting the
doctor, e.g. about what the tests or examinations may show, the doctor over-
looking signs of cancer, and about having to see a new doctor (9). It has also
been reported that approximately a fifth of patients, newly diagnosed with
cancer, report a clinically relevant level of anxiety (10, 16). In a retrospec-
tive, cross-sectional study of patients recently diagnosed with cancer it was
found that doctors’ attention to psychosocial issues such as the patient’s
emotional reactions about diagnosis and treatment and about how the disease
affects the patient’s family is related to patients’ satisfaction with the consul-
tation (17). It has also been shown, for women with breast cancer, that ex-
periencing doctors as caring, competent, and understanding is related to sat-
isfaction with the consultation as well as less long-term depressive symp-
toms (18, 19). Other findings have shown that cancer patients perceive it as
very important to have an opportunity to pose questions to the doctor about
the diagnosis and treatment and to discuss the impact of the treatment (20).
Furthermore, doctors’ empathy and attentiveness is related to patients’ satis-
faction with the consultation and distress among cancer patients (21).

An individual expresses his needs verbally and non-verbally, e.g. through
body language (22-29). The communication between doctors and patients
has been observed (27, 30-37). However, it has not been reported which
patient attitudes and behaviours doctors, according to self-reports, consider
when estimating patients’ worry and wish for information. This appears im-
portant to investigate as it has been shown that it is difficult for doctors to
estimate how much anxiety/worry a certain patient experiences (16, 38-42).
Over- (39, 41, 43) as well as underestimations (38-40) have been shown.

In order to provide a certain patient with an optimal amount of informa-
tion it is necessary for doctors to be able to identify how much information
the patient wishes. It has been shown that approximately 90% of cancer pa-
Patients want as much information as possible (44-47). This illustrates that although most cancer patients want as much information as possible, all patients do not wish all available information. This is important to consider as it has been shown, among cancer patients, that being provided with an amount of information that matches one’s need is related to psychosocial function and satisfaction with the consultation with the doctor (21, 30, 48-52). Doctors’ attitudes regarding the amount, and content of information cancer patients’ should receive have been investigated (53-56), however studies regarding the agreement between doctors’ and patients’ ratings of patients’ wish for information have not been found.

Is cancer patients’ satisfaction with doctors’ care related to their psychosocial function?

Patients’ ratings of their satisfaction with care may provide important information about the extent to which their needs and expectations about care are met. The ratings may, in addition to personal preferences and expectations, reflect realities of the care received (57, 58). Doctors’ ability to identify patients’ psychosocial function as well as psychosocial and informational needs can be assumed to be important aspects of the patient’s care. Doctors’ self-efficacy with regard to communicating about difficult matters may be related to their ability to show empathy and to encourage patients to express their feelings (59-62) and thereby to provide patients with good care in these respects.

Patients tend to provide high ratings of the care they receive and are reluctant to express dissatisfaction, when they do so they wish to have an opportunity to explain the reason behind the negative expression (63, 64). Loyalty, faith, and gratitude may keep patients from expressing dissatisfaction (65). In addition, patients’ ratings of satisfaction are related to their characteristics such as age (66-68) and health (66, 67, 69, 70).

It has been reported that cancer patients assign greatest importance to doctors’ technical competence (correctness of treatment, cancer specialist competence), interpersonal skills (doctors understanding patients feelings), and communication skills (opportunities to ask questions and receive information) and highest satisfaction with doctors’ technical competence and interpersonal skills (71, 72). Other results have shown that patients assign high satisfaction to doctors’ technical skills whereas lower satisfaction with doctors’ interpersonal skills (73, 74).

Some findings have shown that patients’ satisfaction with doctors’ care is related to their psychosocial function (73, 75-78) whereas findings from one study showed an opposite pattern (79).
Psychosocial function among patients with carcinoid tumours

Carcinoid tumours are slow-growing malignancies belonging to the family of neuroendocrine tumours, with an incidence of 2.5/100,000 per year (80). Common symptoms are flush, diarrhoea, bronchial constriction, and right heart failure. The management usually includes a life-long treatment with biological agents such as somatostatin analogues and interferon-α (80). Both agents control the disease but do not provide a cure. The aims of treatment are to reduce hormone levels, control hormonal symptoms, prevent tumour growth, and possibly also tumour reduction (80). The most common adverse effects of somatostatin analogues are nausea, abdominal cramps, loose stools, mild steatorrhea, and flatulence (80). Chronic fatigue and mild depression may develop in approximately 50% of the patients treated with interferon (81).

Previous findings have shown that patients with carcinoid tumours report at least a relatively good psychosocial function measured in terms of HRQoL, anxiety, and depression (82-84). However, in comparison with the general Swedish population the patients report lower emotional- and role function, lower global health status/QoL and more fatigue, nausea/vomiting, appetite loss, and diarrhoea (85). The findings from these studies (82-85) were based on data collected from patients at different times during the disease trajectory which makes it difficult to draw conclusions about the patients’ psychosocial function at certain time points. Impressions from clinical care indicate that the patients experience aspects of psychosocial as well as physical disease- and treatment-related distress not included in the instruments used to assess their psychosocial function in the referred studies (82-85). In order to gain a broader understanding of the psychosocial and physical situation of patients with carcinoid tumours semi-structured interviews about their experiences of disease- and treatment related distress were performed with patients and staff (86). The findings from these interviews illustrate that the patients experience several psychosocial problems not included in the instruments previously used to assess their psychosocial function (82-85). Among these should be mentioned, physical problems such as flush, abdominal pain, and dry skin/mucous membranes and psychosocial problems such as irritation, worry before check-ups, worry that the illness will get worse, worry that the family can not cope with the disease, limited possibilities to work or pursue daily activities and to associate with friends (86-88).
What this thesis plans to add to the literature

Little, if anything, has been reported in the literature on: whether doctors’ self-efficacy with regard to communicating about difficult matters is related to their ability to identify patients’ worry and wish for information; whether doctors’ ability to identify patients’ worry and wish for information is related to patients’ satisfaction with doctors’ care; which patient cues doctors consider when assessing patients’ worry and wish for information; whether patients’ satisfaction with doctors’ care change with time during the disease trajectory, and whether patients’ satisfaction with doctors’ care is related to patients’ psychosocial function at different times during the disease trajectory. The intention of the work presented in this thesis is to add some knowledge in these respects and thereby take a step towards understanding whether good care has an impact on patients’ psychosocial function.
Aims

The main aims were to: explore whether there is a relation between doctors’ ability to identify patients’ worry and wish for information and self-efficacy with regard to communicating with patients about difficult matters; describe which cues doctors consider when estimating patients’ worry and wish for information, and investigate whether there is a relation between patients’ satisfaction with doctors’ care and patients’ psychosocial function.

Specific aims

Study I

To: a) explore whether doctors’ self-efficacy with regard to communicating about difficult matters differ between those who show good versus less good ability to identify how much worry about prognosis/information about disease and treatment a certain patient experiences/wishes during an initial consultation and b) investigate whether doctors and patients agree on how much worry about prognosis a certain patient experiences and on how much information about disease and treatment a certain patient wishes during an initial consultation.

Study II

To describe which patient attitudes, behaviours, and other factors doctors consider when estimating patients’ worry about how the disease may develop and wish for information about the disease and its treatment.

Study III

To investigate whether: a) doctors’ ability to identify patients’ worry and wish for information during an initial consultation, the duration of the initial consultation, and patients’ satisfaction with the initial consultation is related to patients’ psychosocial function; b) patients’ satisfaction with doctors’ care change during the disease trajectory, and c) doctors’ care is related to patients’ psychosocial function.
Study IV

To, among patients with carcinoid tumours: a) investigate psychosocial function at different times during the disease trajectory; b) compare health-related quality of life to that of the general population, and c) investigate prevalence of and worst aspects of disease- and treatment related distress.
Methods

Setting

Study I, III, and IV

Study I, III, and IV took place at the Department of Endocrine Oncology (DepEO), Uppsala University Hospital, Uppsala, Sweden.

Study II

Study II took place at the DepEO and at the Department of Haematology (DepHAE), Uppsala University Hospital, Uppsala, Sweden.

Design

For an overview of the times for assessments in Study I-IV, see Figure 1.

Study I had a cross-sectional, comparative design. Data was gathered in connection to the initial consultation (IC) with a doctor during the patient’s first admission to the DepEO.

Study II had a cross-sectional, descriptive design. The interviews were undertaken right after the IC during the patient’s first admission to the DepEO or DepHAE.

Study III had a longitudinal, cross-sectional, comparative design with regard to specific aim a, and a longitudinal, comparative design with regard to specific aims b and c. Data regarding specific aim a was gathered in connection with the IC at the DepEO, and data with regard to specific aims b and c was gathered within 1-4 weeks after each of the patients’ first 4 admissions to the DepEO.

Study IV had a longitudinal, comparative design. Data was gathered within 1-4 weeks after each of the patients’ first 4 admissions to the DepEO. The longitudinal design includes 4 assessments; each of these took place within 1-4 weeks after the patients’ first 4 admissions to the DepEO (T1-T4). The mean time between the first and the second admission was 3 months.
(SD=1.3), 4 months (SD=1.4) between the second and third admission, and 5 months (SD=1.7) between the third and fourth admission. The mean duration of each admission was 6 days (SD=2) at the first, 4 days (SD=1) at the second and 3 days (SD=1) at the third and the fourth admission.

Figure 1. Overview of the assessments in Study I-IV.

Sample

Doctors

**Study I and III**

During the inclusion period (April 2001-August 2003), all doctors (7 men and 4 women) conducting ICs with patients referred to the DepEO for a suspected diagnosis of carcinoid tumour, were asked about participation and none declined. Their mean age was 39 years (SD=3.8), the mean time working as a doctor was 11 years (SD=5.6), and the mean time working at the DepEO was 4 years (SD=4.3). In Study I, 11 doctors answered for 69 patients, with a range of 1-16 patients per doctor.

**Study II**

During the inclusion period (January 2003-August 2004) all doctors (n=29) conducting ICs with patients referred to the DepEO for a suspected diagnosis of carcinoid tumours, or to the DepHAE for bone marrow transplantation were eligible. Three doctors were not asked about participation.
due to administrative reasons. Seven of the 26 remaining doctors declined participation due to lack of time. Nineteen doctors, 7 women and 12 men, chose to participate. Each participating doctor was to be interviewed concerning a maximum of 3 patients. Three doctors were interviewed about 3 patients, 4 doctors about 2 patients, and 12 doctors about 1 patient. In total the doctors were interviewed about 29 patients, of whom 10 doctors were interviewed about 15 patients at the DepEO and 9 doctors were interviewed about 14 patients at the DepHAE. The mean age of the doctors was 37 years (SD=5.0), the mean time working as a doctor was 9 years (SD=6.0), and the mean time working at the DepEO/DepHAE was 0.5 years (SD=1.0).

Patients

Study I, III, and IV

Patients referred to the DepEO for the first time, ≥ 18 years of age, able to manage the Swedish language in writing, and not cognitively impaired were eligible. During the inclusion period (April 2001-August 2003) 103 patients were referred to the DepEO for a suspected diagnosis of carcinoid tumour. Of those, 5 patients were not approached due to administrative reasons. Ninety-eight patients were asked to participate and 21 patients declined, resulting in 77 participants. Of these, 4 patients were seen by a medical student and 4 patients were missed for inclusion in Study I, they were later asked to participate in Study III and IV. They were thereby unavailable for Study I, which leaves 69 patients to be included in Study I. These, together with the 4 patients who were not asked for participation at the IC due to administrative reasons and the 4 patients who were seen by medical students were eligible for participation in Study III and IV. Of these, 17 were excluded at T1 for the following reasons: 7 were not diagnosed with a carcinoid tumour, 6 would not be further referred to the DepEO, and 4 were too ill to participate. One patient declined participation at T1. Thus, 59 patients were included at T1, of which 36 patients also participated at T2-T4.

For the purpose of examining aim a in Study III, 53 of the 59 patients were included (4 patients were missed due to administrative reasons and 2 patients were seen by medical students). See Figure 2 for a presentation of the sample of patients in Study I, III, and IV.
103 patients referred to the DepEO for verification of the carcinoid tumour → 5 patients were missed due to administrative reasons

98 patients → 21 patients declined

77 patients

4 patients were missed due to administrative reasons
4 patients were seen by a medical student

7 were not diagnosed with carcinoid tumour
6 patients would not be further referred to the DepEO
4 patients were too ill to participate
1 patient declined at the time of the data collection at T1

69 patients participated in Study I

59 patients available at T1

4 patients were missed at the time of the initial consultation and 2 patients were seen by medical students

4 patients were seen by a medical student

53 patients participated in Study III, specific aim a

Attrition at T2-T4
9 patients chose to withdraw
8 patients would not be further referred to the department
4 patients died
2 patients were too ill to participate

36 patients participated in Study III and IV

Figure 2. An overview of patient sample in Study I, III, and IV, and attrition at T2-T4 in Study III and IV.
See Table 1 for a presentation of background and medical data for the patients participating at IC (n=69) and at T1-T4 (n=36) and Table 2 for a presentation of reasons for attrition at T2-T4.

Table 1. A presentation of background and medical data for patients participating at IC (n=69) and at T1-T4 (n=36).

<table>
<thead>
<tr>
<th></th>
<th>Patients at IC (n=69)</th>
<th>Patients at T1-T4 (n=36)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean age, yrs (SD)</td>
<td>62 (12)</td>
<td>60 (10)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>34</td>
<td>19</td>
</tr>
<tr>
<td>Female</td>
<td>35</td>
<td>17</td>
</tr>
<tr>
<td>Social status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/cohabiting</td>
<td>50</td>
<td>25</td>
</tr>
<tr>
<td>Working part or full time</td>
<td>9</td>
<td>7</td>
</tr>
<tr>
<td>Unemployed</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>On sick leave</td>
<td>24</td>
<td>14</td>
</tr>
<tr>
<td>Old age pensioner</td>
<td>35</td>
<td>15</td>
</tr>
<tr>
<td>Metastases and tumour markers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metastatic</td>
<td>25</td>
<td></td>
</tr>
<tr>
<td>Mean levels of Chromogranin A</td>
<td>37</td>
<td></td>
</tr>
<tr>
<td>(ref &lt; 4nmol/liter)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean levels of 5-hydroxy indole</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>acetic acid (ref &lt; 2.1 μmol/h)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interferon</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Octreotid</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Interferon and Octreotid</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Other (Chemotherapy)</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>No treatment</td>
<td>16</td>
<td></td>
</tr>
</tbody>
</table>

\[ \text{\textsuperscript{a}} \text{ Data for medical variables not available at IC.} \text{ \textsuperscript{b}} \text{ Data for medical variables at T1.} \]
Table 2. A presentation of reasons for attrition at T2-T4.

<table>
<thead>
<tr>
<th>Reasons for attrition</th>
<th>T2</th>
<th>T3</th>
<th>T4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Withdrawal</td>
<td>5</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Patient would not be referred to the DepEO</td>
<td>4</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Death</td>
<td>-</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Too ill to participate</td>
<td>1</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>10</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

For an overview of the instruments used in Study I-IV, see Table 3.

Table 3. An overview of the instruments used in Study I-IV.

<table>
<thead>
<tr>
<th>Instruments</th>
<th>Study I</th>
<th>Study II</th>
<th>Study III</th>
<th>Study IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Structured questionnaire about doctors’ self-efficacy with regard to communicating about difficult matters</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doctors’/patients’ ratings of patients’ worry</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doctors’/patients’ ratings of patients’ wish for information</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A structured question about patients’ satisfaction with the IC</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Semi-structured interview questions about which cues doctors consider when assessing patients’ worry and wish for information</td>
<td></td>
<td></td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>CASC SF 4.0</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>EORTC QLQC-30</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>HADS</td>
<td></td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Structured questionnaire about patients’ experiences of disease- and treatment related aspects of distress</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

Doctors’ self-efficacy with regard to communicating about difficult matters (Study I)

Doctors’ self-efficacy with regard to communicating about difficult matters was measured with an instrument initially developed to measure the effect of communication skills training on doctors’ self-efficacy with regard to communicating about difficult matters (1). Doctors were asked how confident they felt with regard to performing the following 9 skills/tasks: Initiate a discussion with the patient about his/her concerns; Encourage a patient to talk about emotional concerns; Explore a patient’s intense feelings like an-
ger; Conclude a patient interview with an agreed problem list and plan of action; Assess symptoms of anxiety and depression; Break bad news to a patient; Challenge a patient who denies his/her situation; Manage collusion, and Help a patient deal with the uncertainty of his/her situation. Originally, the responses were provided on scales ranging from 0 to 100 (1). In this work responses were provided on scales ranging from 0 (Not at all confident) to 10 (Totally confident). Thus, the total score for the instrument ranges from 0 to 90, a higher score representing higher self-efficacy. The internal dropout rate was low; answers were missing for a total of ten questions. Missing values were substituted by the group’s mean for the specific question. There are no psychometric data available for the instrument. In this study the Cronbach’s alpha value for the instrument was 0.91.

Doctors’ ability to identify patients’ worry and wish for information (Study I and III)

Doctors’ ability to identify how much worry about prognosis/information about disease and treatment a certain patient experienced/wished was estimated by posing the same two questions to the doctor and the patient separately, just after the IC. The questions concerned a) how much worry the patient felt about the prognosis during the IC and b) how much information the patient wished about the disease and treatment during the IC. Doctors and patients were asked to provide an answer from 0 (No worry/No information) to 10 (Worst imaginable worry/As much information as possible) on Visual Analogue Scales (VAS) with a 100 mm range. When doctors estimated a certain patient’s worry/wish for information within the same third (16.7 mm from the patient’s report in either direction) of the VAS as the patient’s estimation, this was considered as good ability to estimate the aspect, for the specific patient. Thus, the same doctor could show good ability to identify one patient’s worry and/or wish for information whereas less good ability to identify another patient’s worry and/or wish for information.

Patients’ satisfaction with the initial consultation (Study I)

Patients’ satisfaction with the IC was measured, just after the IC, by the question: “How satisfying was the consultation with the doctor?” with the response alternatives: Absolutely not satisfying (1), Not satisfying, Quite satisfying, Satisfying, and Very satisfying (5).
Patient attitudes, behaviours, and other factors considered by doctors when estimating patients’ worry and wish for information (Study II)

In order to focus the doctors’ attention on the scope of Study II, i.e. which factors they considered when estimating a certain patient’s worry and wish for information, they were first asked to estimate the patient’s worry and wish for information from 0 to 10 on Visual Analogue Scales, (0 being No worry/No information and 10 being Worst imaginable worry/As much information as possible). Thereafter the doctors were asked to answer the following questions in the mentioned order: “Which patient attitudes and behaviours did you consider when estimating the patient’s worry about how the disease may develop?; “Did you consider other factors than patient attitudes and behaviours when estimating the patient’s worry about how the disease may develop”?. “Which patient attitudes and behaviours did you consider when estimating the patient’s wish for information about the disease and treatment?, and “Did you consider other factors than patient attitudes and behaviours when estimating the patient’s wish for information about the disease and treatment”? Follow-up questions were asked to help the doctors elucidate and develop their answers. The interviews lasted between ten and twenty-five minutes and were audio-taped and transcribed verbatim.

Patients’ satisfaction with doctors’ care (Study III)

Patients’ satisfaction with doctors’ care was measured by the short version of the Comprehensive Assessment of Satisfaction with Care (CASC SF 4.0) developed by the EORTC quality of life group (89-92). The instrument consists of 32 questions organised in three areas evaluating: a) the doctors, b) the nursing team, and c) the organisation of care and services.

Data concerning patients’ satisfaction with the doctors’ technical skills (DTS), interpersonal skills (DIPS), information provision (DIP), and availability (DAV) is reported in this thesis. Responses were provided on Likert scales with the response alternatives (from 1 to 5): Poor, Fair, Good, Very good, and Excellent. Patients were asked to answer the questions according to their last stay at the DepEO. The scores were transformed to 0-100 scores according to the scoring instructions provided by the EORTC quality of life group (93). A higher score represents a higher level of satisfaction. Missing values were replaced according to the manual for the EORTC IN-PAT SAT32 (93). After replacing missing values complete data sets were available for T2 and T3. At T1 the internal dropout was less than 4% and at T4 the internal dropout was less than 2%. The Cronbach’s alpha values for the subscales were at T1-T4: doctors’ interpersonal skill .84-.93, technical skills .76-.90, information provision .76-.90, and availability .66-.77.
Patients’ HRQoL (Study III and IV)

Patients’ HRQoL was measured at T1-T4 by the EORTC QLQ-C30 version 3.0 (94). The instrument includes 30 questions and incorporates five functional scales: physical (PF), role (RF), cognitive (CF), emotional (EF), and social (SF) function, three symptom scales: fatigue (FA), pain (PA), and nausea and vomiting (NV), and a global health status/QoL (QL) item. Also included are single items assessing: dyspnoea (DY), appetite loss (AP), sleep disturbance (SL), constipation (CO), diarrhoea (DI), and financial difficulties (FI). Responses were provided on Likert scales with the response alternatives (from 1 to 4) Not at all, A little, Quite a bit, and Very much. Responses for global health status/QoL are provided on scales with the end-points 1 (Very poor) and 7 (Excellent). Patients were asked to answer the questions according to the last week. The scores were linearly transformed to 0-100 scores (93). A higher score on functional scales represents a higher level of function, while a higher score on symptom scales represents a higher level of symptoms. Good reliability has been shown for the instrument (94). Missing values for multi-item scales were replaced by the average of the items provided for the scale, if at least half of the items of the scale had been answered, according to the manual for the EORTC QLQ-C30 (93). After replacing missing values complete data sets were available for all assessments except for T2, where an internal dropout of <2% remained. The Cronbach’s alpha values for the subscales were >.70 at T1-T4, with the exception of RF (.60 at T2), CF (.35, .46 and .67 at T2, T3 and T4 respectively), NV (.43, .65 at T1 and T3, impossible to compute at T4).

Patients’ anxiety and depression (Study III and IV)

Patients’ anxiety and depression was measured at T1-T4 with the Hospital Anxiety and Depression Scale (HADS) (95). The instrument consists of two subscales (7 items in each scale), one measuring anxiety (A) and one depression (D). Responses are provided on verbal scales, coded 0-3. Patients were asked to answer the questions according to the last week. The subscale scores range from 0 to 21. A higher score represents a higher level of problems. Missing values were replaced by the mean values of the patient’s answers to the remaining items of the respective subscale, provided that at least four of the items in the subscale had been answered. After replacing missing values complete data sets were available for all assessments. The HADS has proved to be a useful clinical indicator of anxiety and depression (96-98) among patients with somatic illnesses. The Cronbach’s alpha values were high at T1-T4 for the anxiety (.80-.90) and the depression (.82-.92) subscales.
Disease- and treatment related distress (Study IV)

A questionnaire developed specifically for the study consisting of structured questions was used to investigate the prevalence and worst aspects of disease- and treatment-related distress. The aspects were identified in a previous study by means of semi-structured interviews with patients with carcinoid tumours and their staff about distress related to diagnosis, treatment, and being admitted to the ward, and about an especially distressing event (86). Through a content analysis of the interview data, 24 aspects of distress were identified. These were categorized in the following dimensions: physical (10 items), social (5 items), and emotional (9 items). For each aspect of distress patients were first asked whether they had experienced it, and were thereafter, if so, asked to rate how much distress it had caused on a Likert scale ranging from 0 (no distress) to 5 (very much distress). Patients were thereafter asked to, within each dimension, identify the aspect that had caused the worst distress, i.e. had been the worst. The patients were encouraged to identify one aspect only within each dimension. Some patients identified more than one aspect as the worst within each dimension. Finally patients were asked to identify which aspects of physical distress that had caused social distress. Patients were asked to answer the questions according to the last 4 weeks.

Procedure

All studies were approved by the local Ethical Committee at the Faculty of Medicine, Uppsala University. Doctors were provided oral and written information by Camilla Fröjd (CaF) about the overall aim and procedure of the studies and their participation at staff meetings. They were informed that participation was voluntary and that confidentiality was guaranteed. Patients received oral and written information by CaF about the overall aim and procedure of the studies and their participation at their first admission to the DepEO. They were informed that participation was voluntary, that confidentiality was guaranteed, and that neither participation nor non-participation or withdrawal would affect their treatment and care.

Study I

Doctors and patients were asked about participation by CaF 5-180 minutes prior to the IC (the patients were also asked for participation in Study I and Study III and IV). The doctors met the patients according to usual routines. Immediately before the IC the doctors answered the questions about self-efficacy with regard to communicating about difficult matters. The mean duration of the ICs was 35 minutes (SD=11.0). Most of the ICs took
place in an examination room. Seven ICs were interrupted shortly. Immediately after the IC the doctor answered questions about the patient’s worry about prognosis/wish for information about disease and treatment, and the patient answered corresponding questions as well as a question concerning his/her satisfaction with the IC.

Study II

The doctors were asked about participation by CaF, right before each IC. The consultations took place according to standard routines. Directly after the consultation the doctors were first asked to estimate the patients’ worry and wish for information, and were thereafter interviewed about which patient attitudes, behaviours, and other factors they considered when estimating the patient’s worry and wish for information.

Study III and IV

The patients were asked for participation at T1-T4, by CaF, during each of the patients’ first 4 admissions at DepEO. After having agreed to participate the patient received the instruments: EORTC QLQ-C30, HADS, the study-specific questionnaire concerning disease- and treatment related distress, and the CASC SF 4.0, by CaF. The patients were asked to complete these at home after the respective hospital-stay and a time when they would be asked to provide their responses via telephone was agreed upon. The data was collected within 1-4 weeks (T1-T4) after the patient’s first four admissions to DepEO. Some patients found it impossible to schedule a telephone interview (one patient at T1, 6 patients at T2, and 5 patients at T3 and T4) and were therefore requested to complete the instruments at home and thereafter return these by mail.

Data analysis

Statistical methods (Study I, III, IV)

The statistical analyses (see Table 4) were performed using the Statview statistical package version 10.0 (Study I) and the Statistical package for the social sciences (SPSS) version 14.0 for Windows (Study III and IV). See Table 4 for an overview of the statistical methods used in Study I, III, and IV.

Unpaired t-tests were applied to investigate differences in doctors’ self-efficacy, patients’ satisfaction with the IC and HRQoL when doctors’ showed good vs less good ability to identify patients’ worry/wish for infor-
information. Paired t-tests were used to investigate differences between doctors’ and patients’ rating of patients’ worry/wish for information. Pearson product moment coefficients was used to analyze agreement between doctors’ and patients’ ratings of patients’ worry/wish for information, and between patients’ ratings of satisfaction with the IC and psychosocial function. Repeated measures were used to investigate patients’ ratings of satisfaction with doctors’ care, HRQoL, anxiety, and depression during the first year after being diagnosed with carcinoid tumours (T1-T4). One-sample t-tests were used to compare patients’ HRQoL to that of the Swedish population norms. Cochran’s Q was employed to investigate differences over time regarding the prevalence of disease- and treatment related aspects of distress.

Table 4. An overview of statistical methods used in Study I, III, and IV.

<table>
<thead>
<tr>
<th>Test</th>
<th>Study I</th>
<th>Study III</th>
<th>Study IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unpaired t-test</td>
<td>aim a</td>
<td>aim a</td>
<td></td>
</tr>
<tr>
<td>Paired t-test</td>
<td>aim b</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pearson product moment coefficient</td>
<td>aim b</td>
<td>aim a, c</td>
<td></td>
</tr>
<tr>
<td>Repeated measures ANOVA</td>
<td>aim b</td>
<td></td>
<td>aim a</td>
</tr>
<tr>
<td>One-sample t-test</td>
<td></td>
<td>aim b</td>
<td></td>
</tr>
<tr>
<td>Cochran’s Q</td>
<td></td>
<td></td>
<td>aim c</td>
</tr>
</tbody>
</table>

Sensitivity and specificity (Study I)

Sensitivity and specificity was calculated to explore agreement between doctors’ and patients’ ratings of patients’ worry/wish for information. For calculations with regard to worry, patients were categorised into worried versus less worried according to patients’ mean value (M=2.8) for worry. Patients (n=28) giving a rating at or above this value were categorised as more worried whereas the remaining patients (n=41) were categorised as less worried. Sensitivity was defined as a doctor’s ability to identify presence of worry (giving a rating ≥ 2.8) for a certain patient. Specificity was defined as doctor’s ability to identify absence of worry (giving a rating < 2.8) for a certain patient. The same procedure was used to calculate sensitivity and specificity with regard to doctors’ estimations of patients’ wish for information. The mean value for patient ratings of wish for information (M=8.8) was used as the reference point for these calculations. Patients (n=48) giving a rating at or above the patients’ mean value were categorised as wanting more information whereas the remaining patients (n=21) were categorised as wanting less information.
Comparisons to Swedish population norms (Study IV)

Comparisons between patient mean values on the EORTC QLQ-C30 scales and single items and corresponding Swedish population norms (99) were made after correction for age and gender (100).

Clinical significance (Study IV)

As suggested by others (101-103) a difference of more than 10 points between two values for the same scale or single item in the EORTC QLQ-C30, was considered as indicating a clinically significant difference between the values.

Content analysis (Study II)

The answers to the semi-structured interview questions posed in Study II were analysed using content analysis (104-106), which can be used to draw valid conclusions about a manifest message in a communication by objective and systematic identification of specified communication characteristics. Answers to semi-structured open-ended questions are suitable for this technique. The analysis was performed in the following steps: 1) The transcribed text was read and re-read and words and sentences (recording units) which contained information relevant to the interview questions were identified; 2) Recording units were grouped into mutually exclusive categories reflecting central text messages in the interviews. Recording units classified in the same category were presumed to have a similar meaning, either based on the precise meaning of words or on words sharing similar connotations, and 3) Boundaries of each category were defined and descriptions of the central characteristics of each category were developed. No matter how many times a certain recording unit was mentioned by a respondent it was calculated as being mentioned once by that person per interview in the presentation of the results. In order to establish the inter-rater agreement with regard to the categorisation of recording units, an additional assessor independently assigned all recording units to the categories. The Kappa method (107) was used for a comparison between the two categorisations. The Kappa value for the categorisation of all recording units mentioned in response to the questions about worry was 0.94 whereas the Kappa value for the categorisation of all recording units in response to the questions about information was 0.92.

Prevalence of aspects of disease- and treatment related distress (Study IV)

Aspects of disease- and treatment related distress given a rating from 1-5 on the Likert scale were considered prevalent.
Results

Study I

When doctors demonstrated good ability (n=27) to identify how much information a certain patient wished they reported a higher self-efficacy with regard to communicating about difficult matters (M=65.4, SD=1.6) than when they showed less good ability (n=42) (M=57.7, SD=1.4) (t=3.5, df=67, p<.001) to do so. There were no differences with regard to doctors’ self-efficacy when demonstrating good versus less good ability to identify patients’ worry. And, there was no difference with regard to patients’ satisfaction with the IC between those patients who met doctors who showed good versus less good ability to identify patient’s worry and/or wish for information.

Doctors reported that patients experienced more worry about prognosis (M=5.7, SD=2.2) compared to patients’ reports (M=2.8, SD=2.5) (t=10.8, df=68, p<.0001) and that patients wished less information about disease and treatment (M=6.9, SD=2.0) compared to patients’ reports (M=8.8, SD=1.8) (t=6.0, df=68, p<.0001). At the same time patients’ and doctors’ ratings of how much worry a certain patient experienced were associated (r=.55, df=67, p<.001). However, doctors’ and patients’ ratings of patients’ wish for information were not. Doctors estimated patients’ worry with a sensitivity of 100% and a specificity of 24% and patients’ wish for information with a sensitivity of 19% and a specificity of 81%.

Study II

The findings revealed that doctors consider ten categories of factors when estimating patients’ worry about how the disease may develop and nine categories of factors when estimating patients’ wish for information. The categories, with category content, examples, and number of recording units are presented in Tables 5 and 6. In approximately two thirds of the interviews doctors mentioned that they estimate patients’ worry on the basis of patients’ verbal expressions, verbal behaviors, questions, body language, and their own professional knowledge and experience. Patients’ facial expres-
sions were mentioned in half of the interviews. In some interviews patients’
demographic- and medical situation, as well as contextual factors were men-
tioned as considered. In one interview one doctor mentioned trying to put
himself/herself in the patient’s situation when judging a patient’s worry.

In almost every interview doctors mentioned that they consider patients’
questions when estimating patients’ wish for information. Doctors’ profes-
sional knowledge and experience and patients’ verbal expressions were men-
tioned in half of the interviews. In approximately one third of the interviews
doctors mentioned that they take patients’ body language and facial expres-
sions into account. In some interviews, contextual factors, patients’ verbal
behaviours, and demographic variables were mentioned. In one interview the
doctor mentioned considering the patient’s medical situation when estimat-
ing his wish for information.
<table>
<thead>
<tr>
<th>Category</th>
<th>Category content</th>
<th>Examples of recording units</th>
<th>Number of recording units^a</th>
</tr>
</thead>
</table>
| Patients’ verbal expressions     | Content of a patient’s verbal expressions, i.e. the words he/she used or the fact that he/she said nothing at all | “It is what he himself says, expresses directly.”  
“I was what he said or rather what he did not say…he was a very silent patient.”                                                                                                                                         | 22                          |
| Patients’ verbal behaviours      | The way patients express themselves verbally other than the actual words they use | “It was his, the way he was talking.”                                                                                                                                                                                                                                           | 19                          |
| Patients’ questions              | Content of patients’ questions                                                    | “It was, at first how she, what questions she posed and if she posed any questions at all.”                                                                                                                                                                     | 19                          |
| Patients’ body language          | The way patients sit, stand or move their body/parts of their body                | “He hardly moved. He was sitting very still and very stiff.”                                                                                                                                                                                                                      | 19                          |
| Doctors’ professional knowledge  | Doctors’ knowledge, previous experience, and information acquired from medical     | “Eh, well to start with, I know that he has got a very serious illness.”                                                                                                                                                                                                              | 19                          |
| and experience                   | records                                                                                                                                     | “I always look through the medical records before meeting a patient and there one might find indications that a patient is worried. In this case there were no indications.”                                                                 |                             |
| Patients’ facial expressions     | Facial expression, eye contact, crying                                            | “I believe it is possible to tell from facial expressions if one is worried, the eyes, that she almost had tears in her eyes.”                                                                                                                                         | 15                          |
| Patients’ demographic variables  | Patients’ age or social situation                                                 | “I think he has a good social network to support him, wife and children.”                                                                                                                                                                                                          |                             |
| Patients’ medical situation      | Medical, physical parameters, e.g. blood pressure, pulse, trembling, general condition                                               | “Yes, she is an old woman.”                                                                                                                                                                                                                                                                                       | 10                          |
| Contextual factors               | Presence of relatives or close friends                                           | “The pulse rate was not very high; the rate is usually high if a person is nervous.”                                                                                                                                                                                                     | 7                           |
| Doctors’ intuitive understanding | Doctors put themselves in a patient’s situation                                  | “His wife, or his cohabitant, was with him, so then I realised that…yes…there was a great deal of worry there.”                                                                                                                                                                                                 | 5                           |
| of a patient’s situation         |                                                                                   | “Yes, but of course one tries to imagine how it would be if one had…well, one tries to put oneself in the patient’s position.”                                                                                                                                                                                                 | 1                           |
aNo matter how many times a certain recording unit was mentioned by a respondent, it was calculated as mentioned once by that person per interview in the presentation of the results.
Table 6. Categories, category content, examples, and number of recording units with regard to factors considered by doctors when assessing patients' wish for information.

<table>
<thead>
<tr>
<th>Category</th>
<th>Category content</th>
<th>Examples of recording units</th>
<th>Number of recording units</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients’ questions</td>
<td>Content of patients’ questions</td>
<td>“Then he asked a lot of questions, so he wanted as much information as possible.”</td>
<td>25</td>
</tr>
<tr>
<td>Doctors’ professional knowledge and experiences</td>
<td>Doctors’ knowledge, previous experiences, and information acquired from medical records</td>
<td>“His anamnesis and medical background, I mean, that is what I had to base my estimation upon.”</td>
<td>15</td>
</tr>
<tr>
<td>Patients’ verbal expressions</td>
<td>Content of patients’ verbal expressions, i.e. the words he/she used or the fact that he/she said nothing at all</td>
<td>“It is what she says.”</td>
<td>14</td>
</tr>
<tr>
<td>Patients’ body language</td>
<td>The way patients sit, stand or move their body/parts of their body</td>
<td>“He sat still, and looked at me and was paying attention.”</td>
<td>10</td>
</tr>
<tr>
<td>Patients’ facial expressions</td>
<td>Facial expression, eye contact, crying</td>
<td>“I had eye contact with him and he nodded his head, he seemed to understand what I was telling him and so on.”</td>
<td>9</td>
</tr>
<tr>
<td>Contextual factors</td>
<td>Presence of relatives or close friends and/or doctors’ condition</td>
<td>“His wife was with him, so of course she had an influence on the conversation.”</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“How stressed out I am, here and now, it means a great deal.”</td>
<td></td>
</tr>
<tr>
<td>Patients’ verbal behaviours</td>
<td>The way patients express themselves verbally other than the actual words they use</td>
<td>“Like I said he was talking calmly about his situation, so then one could tell that he wanted a lot of information.”</td>
<td>4</td>
</tr>
<tr>
<td>Patients’ demographic variables</td>
<td>Patients’ age or social situation</td>
<td>“This is a lot of information for someone who has no medical knowledge.”</td>
<td>3</td>
</tr>
<tr>
<td>Patients’ medical situation</td>
<td>Medical, physical parameters, e.g. blood pressure, pulse, trembling, general condition</td>
<td>“How awake and orientated he seems to be. I believe that the patient’s general condition decides how the doctor should provide information.”</td>
<td>1</td>
</tr>
</tbody>
</table>

aNo matter how many times a certain recording unit was mentioned by a respondent it was calculated as mentioned once by that person per interview in the presentation of the results.
Study III

Patients who met doctors showing good ability to identify their wish for information reported a higher cognitive function (M=92, SD=17) (n=20) compared to patients (M=73, SD=27) (n=33) who met doctors showing less good ability (t=2.74, df=51, p<.01) to do so.

See Table 7 for a presentation of mean values for patients’ ratings of satisfaction with doctors’ care. There were no significant changes with regard to patients’ satisfaction with doctors’ care over time.

Table 7. A presentation of mean values (M) and standard deviations (SD) for the CASC SF 4.0 subscales concerning patients’ satisfaction with doctors’ care at T1-T4 (n=36).

<table>
<thead>
<tr>
<th>Scales</th>
<th>T1</th>
<th>T2</th>
<th>T3</th>
<th>T4</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M (SD)</td>
<td>M (SD)</td>
<td>M (SD)</td>
<td>M (SD)</td>
</tr>
<tr>
<td>interpersonal skills</td>
<td>74 (22)</td>
<td>73 (21)</td>
<td>69 (24)</td>
<td>72 (22)</td>
</tr>
<tr>
<td>technical skills</td>
<td>82 (18)</td>
<td>80 (17)</td>
<td>80 (19)</td>
<td>81 (17)</td>
</tr>
<tr>
<td>information provision</td>
<td>72 (23)</td>
<td>76 (19)</td>
<td>72 (23)</td>
<td>72 (22)</td>
</tr>
<tr>
<td>availability</td>
<td>72 (22)</td>
<td>73 (21)</td>
<td>69 (24)</td>
<td>72 (22)</td>
</tr>
</tbody>
</table>

*Scores range from 0 to 100, a higher score represents a higher level of satisfaction.

See Table 8 for a presentation of significant correlations between on one hand patients’ ratings of satisfaction with doctors’ care and on the other hand patients’ ratings of HRQoL, anxiety, and depression. Some significant correlations were found at T1-T3, while only one correlation was significant at T4 (Table 8). Higher satisfaction with doctors’ care was related to higher scores for functional scales and global health status/QoL and to lower ratings for symptom scales, anxiety, and depression. Satisfaction with doctors’ information provision was positively related to emotional function, global health status/QoL, and negatively related to anxiety and depression at T1-T3. Higher satisfaction with doctors’ interpersonal skills was related to lower anxiety at T1-T3. Higher satisfaction with all four aspects of doctors’ care was related to lower levels of problems with diarrhoea at T1, less financial difficulties at T2, and lower levels of depression at T3.
Table 8. A presentation of significant correlations between patients’ ratings of satisfaction with doctors’ care and patients’ ratings of HRQoL, anxiety, and depression at T1-T4 (n=36).

<table>
<thead>
<tr>
<th></th>
<th>T1</th>
<th>T2</th>
<th>T3</th>
<th>T4</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>DIPS d</td>
<td>DTS d</td>
<td>DIP d</td>
<td>DAV d</td>
</tr>
<tr>
<td>PF a</td>
<td></td>
<td></td>
<td></td>
<td>.55**</td>
</tr>
<tr>
<td>RF a</td>
<td>.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CF a</td>
<td>.</td>
<td></td>
<td></td>
<td>.55**</td>
</tr>
<tr>
<td>EF a</td>
<td>.44*</td>
<td></td>
<td></td>
<td>.46*</td>
</tr>
<tr>
<td>SF a</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>QL a</td>
<td>.48*</td>
<td></td>
<td>.45*</td>
<td>.52**</td>
</tr>
<tr>
<td>FA b</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NV b</td>
<td>-.54**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PA b</td>
<td></td>
<td>-.54**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DY b</td>
<td></td>
<td></td>
<td>-.50*</td>
<td></td>
</tr>
<tr>
<td>SL b</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>AP b</td>
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<tr>
<td>CO b</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DI b</td>
<td>-.47*</td>
<td>-.54**</td>
<td>-.44*</td>
<td>-.62**</td>
</tr>
<tr>
<td>FI b</td>
<td>-.52**</td>
<td>-.46*</td>
<td>-.60**</td>
<td>-.55**</td>
</tr>
<tr>
<td>A c</td>
<td>-.45*</td>
<td>-.47*</td>
<td>-.44*</td>
<td>-.50**</td>
</tr>
<tr>
<td>D c</td>
<td>-.50*</td>
<td>-.60**</td>
<td>-.55**</td>
<td>-.54**</td>
</tr>
</tbody>
</table>
a–d An explanation of the abbreviations is available in the methods section. a Scores range from 0 to 100, a higher score represents a higher level of function. b Scores range from 0 to 100, a higher score represents a higher level of symptoms. c Scores range from 0 to 21, a higher score represents a higher level of problems. d Scores range from 0 to 100, a higher score represents a higher level of satisfaction with doctors’ care. * p<.01, ** p<.001
Study IV

See Table 9 for a presentation of the mean values for patients’ ratings of HRQoL, anxiety, and depression at T1-T4. At all assessments the patients reported a score ranging from 53 to 69 for role function and from 58 to 61 for global health status/QoL. Patients’ scores on the remaining functional scales exceeded 75 at all assessments. Patients reported most problems with fatigue (34-38), followed by pain (20-27), dyspnoea (22-30), and diarrhoea (21-30). The patients reported low levels of anxiety and depression at all assessments.

Patients reported lower emotional function at T3 compared to at T4 [F(3, 102)=3.50; p<.01]. And, the mean value for role function increased more than 10 points, i.e. of clinical interest, from T1 to T2, T3, and T4 respectively.

Table 9. A presentation of mean values (M) and standard deviations (SD) for the EORTC QLQ-C30 scales and single items and the HADS subscales at T1-T4 (n=36).

<table>
<thead>
<tr>
<th>Scales/single items</th>
<th>T1</th>
<th>T2</th>
<th>T3</th>
<th>T4</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M, SD</td>
<td>M, SD</td>
<td>M, SD</td>
<td>M, SD</td>
</tr>
<tr>
<td>PF b</td>
<td>80 (22)</td>
<td>80 (20)</td>
<td>81 (22)</td>
<td>79 (22)</td>
</tr>
<tr>
<td>RF b</td>
<td>53 (39)</td>
<td>64 (31)</td>
<td>69 (28)</td>
<td>69 (35)</td>
</tr>
<tr>
<td>EF b</td>
<td>77 (20)</td>
<td>75 (23)</td>
<td>75 (21)</td>
<td>82 (19)</td>
</tr>
<tr>
<td>CF b</td>
<td>85 (21)</td>
<td>85 (17)</td>
<td>83 (18)</td>
<td>84 (18)</td>
</tr>
<tr>
<td>SF b</td>
<td>77 (26)</td>
<td>80 (28)</td>
<td>80 (26)</td>
<td>79 (27)</td>
</tr>
<tr>
<td>QL b</td>
<td>58 (19)</td>
<td>61 (23)</td>
<td>58 (24)</td>
<td>58 (25)</td>
</tr>
<tr>
<td>FA c</td>
<td>35 (26)</td>
<td>38 (27)</td>
<td>35 (24)</td>
<td>34 (24)</td>
</tr>
<tr>
<td>NV c</td>
<td>3 (8)</td>
<td>10 (20)</td>
<td>6 (12)</td>
<td>7 (12)</td>
</tr>
<tr>
<td>PA c</td>
<td>20 (28)</td>
<td>23 (31)</td>
<td>27 (33)</td>
<td>21 (27)</td>
</tr>
<tr>
<td>DY c</td>
<td>27 (31)</td>
<td>22 (24)</td>
<td>30 (36)</td>
<td>29 (34)</td>
</tr>
<tr>
<td>SL c</td>
<td>18 (24)</td>
<td>11 (18)</td>
<td>13 (18)</td>
<td>18 (26)</td>
</tr>
<tr>
<td>AP c</td>
<td>10 (19)</td>
<td>18 (28)</td>
<td>8 (17)</td>
<td>13 (24)</td>
</tr>
<tr>
<td>CO c</td>
<td>9 (22)</td>
<td>13 (22)</td>
<td>10 (21)</td>
<td>9 (23)</td>
</tr>
<tr>
<td>DI c</td>
<td>25 (35)</td>
<td>21 (29)</td>
<td>23 (31)</td>
<td>30 (27)</td>
</tr>
</tbody>
</table>
See Table 10 for a presentation of the patients’ reported mean values and population norms for HRQoL at T1-T4. The patients reported significantly lower role function at T1-T3 ($t=3.26-4.99$, df=34-35, $p<.01-.001$), social function at T1 ($t=3.17$, df=35, $p<.01$), and global health status/QoL at T1-T4 ($t=3.74-5.75$, df=34-35, $p<.01-.001$), compared to population norms.

The patients’ mean values were more than 10 points below the population norms for role- and social function, and global health status/QoL, and more than 10 points above the population norms for fatigue and diarrhoea at all assessments. All these differences were larger than expected by chance ($t=3.16-5.71$, df=34-35, $p<.01-.001$). At T2 the patients’ mean values were more than 10 points higher than the population norms for appetite loss ($t=2.93$, df=34, $p<.01$), and at T3 and T4 the patient’ mean values were more than 10 points higher than the population norms for dyspnoea.
Table 10. A presentation of mean values (M), population norms (P), and differences (D) between the patients’ mean values and population norms for the EORTC QLQ-C30 scales and single items at T1-T4 (n=36).

<table>
<thead>
<tr>
<th>Scales/ single items</th>
<th>T1</th>
<th>P</th>
<th>D</th>
<th>T2</th>
<th>P</th>
<th>D</th>
<th>T3</th>
<th>P</th>
<th>D</th>
<th>T4</th>
<th>P</th>
<th>D</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>P</td>
<td>D</td>
<td>M</td>
<td>P</td>
<td>D</td>
<td>M</td>
<td>P</td>
<td>D</td>
<td>M</td>
<td>P</td>
<td>D</td>
</tr>
<tr>
<td>PF b</td>
<td>80</td>
<td>87</td>
<td>-7</td>
<td>80</td>
<td>87</td>
<td>-7</td>
<td>81</td>
<td>87</td>
<td>-6</td>
<td>79</td>
<td>87</td>
<td>-8</td>
</tr>
<tr>
<td>RF b</td>
<td>53</td>
<td>85</td>
<td>-32**</td>
<td>64</td>
<td>85</td>
<td>-21**</td>
<td>69</td>
<td>85</td>
<td>-16*</td>
<td>69</td>
<td>85</td>
<td>-16</td>
</tr>
<tr>
<td>EF b</td>
<td>77</td>
<td>83</td>
<td>-6</td>
<td>75</td>
<td>83</td>
<td>-8</td>
<td>75</td>
<td>83</td>
<td>-8</td>
<td>82</td>
<td>83</td>
<td>-1</td>
</tr>
<tr>
<td>CF b</td>
<td>85</td>
<td>88</td>
<td>-3</td>
<td>85</td>
<td>88</td>
<td>-3</td>
<td>83</td>
<td>88</td>
<td>-5</td>
<td>84</td>
<td>88</td>
<td>-4</td>
</tr>
<tr>
<td>SF b</td>
<td>77</td>
<td>91</td>
<td>-14*</td>
<td>80</td>
<td>91</td>
<td>-11</td>
<td>80</td>
<td>91</td>
<td>-11</td>
<td>79</td>
<td>91</td>
<td>-12</td>
</tr>
<tr>
<td>QL b</td>
<td>58</td>
<td>76</td>
<td>-18**</td>
<td>61</td>
<td>76</td>
<td>-15**</td>
<td>58</td>
<td>76</td>
<td>-18**</td>
<td>58</td>
<td>76</td>
<td>-18**</td>
</tr>
<tr>
<td>FA c</td>
<td>35</td>
<td>21</td>
<td>14*</td>
<td>38</td>
<td>21</td>
<td>17**</td>
<td>35</td>
<td>21</td>
<td>14**</td>
<td>34</td>
<td>21</td>
<td>13*</td>
</tr>
<tr>
<td>NV c</td>
<td>3</td>
<td>3</td>
<td>0</td>
<td>10</td>
<td>3</td>
<td>7</td>
<td>6</td>
<td>3</td>
<td>3</td>
<td>7</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>PA c</td>
<td>20</td>
<td>20</td>
<td>0</td>
<td>23</td>
<td>20</td>
<td>3</td>
<td>27</td>
<td>20</td>
<td>7</td>
<td>21</td>
<td>20</td>
<td>1</td>
</tr>
<tr>
<td>DY c</td>
<td>27</td>
<td>17</td>
<td>10</td>
<td>22</td>
<td>17</td>
<td>5</td>
<td>30</td>
<td>17</td>
<td>13</td>
<td>29</td>
<td>17</td>
<td>12</td>
</tr>
<tr>
<td>SL c</td>
<td>18</td>
<td>19</td>
<td>-1</td>
<td>11</td>
<td>19</td>
<td>-8</td>
<td>13</td>
<td>19</td>
<td>-6</td>
<td>18</td>
<td>19</td>
<td>-1</td>
</tr>
<tr>
<td>AP c</td>
<td>10</td>
<td>4</td>
<td>6</td>
<td>18</td>
<td>4</td>
<td>14*</td>
<td>8</td>
<td>4</td>
<td>4</td>
<td>13</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>CO c</td>
<td>9</td>
<td>6</td>
<td>3</td>
<td>13</td>
<td>6</td>
<td>7</td>
<td>10</td>
<td>6</td>
<td>4</td>
<td>9</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>DI c</td>
<td>25</td>
<td>5</td>
<td>20*</td>
<td>21</td>
<td>5</td>
<td>16*</td>
<td>23</td>
<td>5</td>
<td>18*</td>
<td>30</td>
<td>5</td>
<td>25**</td>
</tr>
<tr>
<td>FI c</td>
<td>14</td>
<td>8</td>
<td>6</td>
<td>15</td>
<td>8</td>
<td>7</td>
<td>12</td>
<td>8</td>
<td>4</td>
<td>14</td>
<td>8</td>
<td>6</td>
</tr>
</tbody>
</table>
An explanation of the abbreviations is available in methods section.
Scores range from 0 to 100, a higher score represents a higher level of function.
Scores range from 0 to 100, a higher score represents a higher level of symptoms.
* p< .01, ** p< .001
See Table 11 for a presentation of the prevalence of and worst aspects of physical, social, and emotional distress at T1-T4.

Fatigue was the most prevalent aspect of physical distress at all assessments whereas flush, pain-stomach, dyspnoea, diarrhoea, dry skin/mucous membranes, and appetite loss were among the most prevalent aspects of physical distress at all assessments. A difference over time with regard to the prevalence of flush ($Q(3) 13.2, p<.01$), with a lower prevalence at T4 than at T1-T3 and dry skin/mucous membranes ($Q(3) 12.7, p<.01$), with a higher prevalence at T4 than at T1 was demonstrated. At all assessments fatigue and diarrhoea were reported as being considered as the worst aspects of physical distress by most patients.

Limited possibilities to work/pursue daily activities and to perform physical activities were the most prevalent aspects of social distress at all assessments. At T1-T4 limited possibilities to work/pursue daily activities was reported as being considered as the worst aspect of social distress by most patients. At all assessments fatigue followed by diarrhoea and dyspnoea were reported as causing social distress by most patients.

Worry that the illness will get worse was the most prevalent, and depression, irritation, worry that the family cannot cope with the illness, and worry before check-up were among the most prevalent aspects of emotional distress, at all assessments. A difference over time with regard to the prevalence of bother by changed appearance ($Q(3) 12.0, p<.01$) with a higher prevalence at later assessments than at T1 was demonstrated. At all assessments worry that the illness will get worse was reported as being considered the worst aspect of emotional distress by the majority of the patients.

When taking together all aspects from all 3 dimensions, worry that the illness will get worse, limited possibilities to work/pursue daily activities, fatigue, and diarrhoea were the aspects that most patients considered as the overall worst.
<table>
<thead>
<tr>
<th>Physical distress</th>
<th>Prevalence</th>
<th>Worst&lt;sup&gt;1&lt;/sup&gt;</th>
<th>Prevalence</th>
<th>Worst&lt;sup&gt;1&lt;/sup&gt;</th>
<th>Prevalence</th>
<th>Worst&lt;sup&gt;1&lt;/sup&gt;</th>
<th>Prevalence</th>
<th>Worst&lt;sup&gt;1&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>25 (69%)</td>
<td>11</td>
<td>31 (86%)</td>
<td>15</td>
<td>32 (89%)</td>
<td>12</td>
<td>30 (83%)</td>
<td>17</td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>18 (50%)</td>
<td>10</td>
<td>20 (56%)</td>
<td>10</td>
<td>22 (61%)</td>
<td>11</td>
<td>25 (69%)</td>
<td>13</td>
</tr>
<tr>
<td>Dry skin/mucous membranes</td>
<td>14 (39%)</td>
<td>2</td>
<td>22 (61%)</td>
<td>5</td>
<td>22 (61%)</td>
<td>3</td>
<td>25 (69%)</td>
<td>6</td>
</tr>
<tr>
<td>Pain-stomach</td>
<td>18 (50%)</td>
<td>4</td>
<td>20 (56%)</td>
<td>3</td>
<td>20 (56%)</td>
<td>8</td>
<td>23 (64%)</td>
<td>4</td>
</tr>
<tr>
<td>Dyspnoea</td>
<td>18 (50%)</td>
<td>3</td>
<td>21 (58%)</td>
<td>5</td>
<td>20 (56%)</td>
<td>8</td>
<td>21 (58%)</td>
<td>10</td>
</tr>
<tr>
<td>Flush</td>
<td>19 (53%)</td>
<td>8</td>
<td>21 (58%)</td>
<td>1</td>
<td>21 (58%)</td>
<td>5</td>
<td>11 (30%)</td>
<td>1</td>
</tr>
<tr>
<td>Appetite loss</td>
<td>14 (39%)</td>
<td>1</td>
<td>17 (47%)</td>
<td>5</td>
<td>21 (58%)</td>
<td>4</td>
<td>15 (42%)</td>
<td>4</td>
</tr>
<tr>
<td>Pain-muscles</td>
<td>15 (42%)</td>
<td>1</td>
<td>17 (47%)</td>
<td>6</td>
<td>15 (42%)</td>
<td>5</td>
<td>18 (50%)</td>
<td>6</td>
</tr>
<tr>
<td>Nausea</td>
<td>14 (39%)</td>
<td>1</td>
<td>15 (42%)</td>
<td>3</td>
<td>19 (53%)</td>
<td>5</td>
<td>17 (47%)</td>
<td>6</td>
</tr>
<tr>
<td>Insomnia</td>
<td>13 (36%)</td>
<td>4</td>
<td>15 (42%)</td>
<td>3</td>
<td>17 (47%)</td>
<td>1</td>
<td>18 (50%)</td>
<td>5</td>
</tr>
<tr>
<td><strong>Social distress</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work/pursue daily activities</td>
<td>23 (64%)</td>
<td>15</td>
<td>24 (67%)</td>
<td>15</td>
<td>24 (67%)</td>
<td>13</td>
<td>26 (72%)</td>
<td>13</td>
</tr>
<tr>
<td>Perform physical activities</td>
<td>23 (64%)</td>
<td>7</td>
<td>23 (64%)</td>
<td>3</td>
<td>25 (69%)</td>
<td>10</td>
<td>27 (75%)</td>
<td>6</td>
</tr>
<tr>
<td>To travel</td>
<td>20 (56%)</td>
<td>2</td>
<td>17 (47%)</td>
<td>5</td>
<td>23 (64%)</td>
<td>8</td>
<td>21 (58%)</td>
<td>6</td>
</tr>
<tr>
<td>Dine out/go to theatre etc</td>
<td>17 (47%)</td>
<td>-</td>
<td>18 (50%)</td>
<td>3</td>
<td>19 (53%)</td>
<td>6</td>
<td>19 (53%)</td>
<td>2</td>
</tr>
<tr>
<td>Associate with friends</td>
<td>17 (47%)</td>
<td>3</td>
<td>17 (47%)</td>
<td>3</td>
<td>20 (56%)</td>
<td>6</td>
<td>18 (50%)</td>
<td>6</td>
</tr>
<tr>
<td><strong>Emotional distress</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 11. A presentation of the prevalence of and worst aspects of disease- and treatment related distress at T1-T4 (n=36).
| Dimension | Patients | | | | | | | |
|-----------|----------|---|---|---|---|---|---|
| Worry that the illness will get worse | 33 (92%) | 20 | 32 (89%) | 10 | 30 (83%) | 16 | 31 (86%) | 16 |
| Depression | 32 (89%) | 1 | 27 (75%) | 5 | 29 (80%) | 9 | 26 (72%) | 10 |
| Irritation | 27 (75%) | 5 | 26 (72%) | 5 | 29 (80%) | 6 | 27 (75%) | 6 |
| Worry that the family can not cope with the illness | 29 (80%) | 6 | 29 (80%) | 4 | 25 (69%) | 5 | 23 (64%) | 7 |
| Worry before check-up | 27 (75%) | 4 | 25 (69%) | 3 | 24 (67%) | 7 | 26 (72%) | 7 |
| Worry that the illness will interfere with ability to care for the family | 25 (69%) | 5 | 21 (58%) | 3 | 24 (67%) | 5 | 22 (61%) | 1 |
| Troublesome tests/examinations | 25 (69%) | 4 | 17 (47%) | 4 | 20 (56%) | 1 | 24 (67%) | 2 |
| Bother by changed appearance | 7 (19%) | - | 14 (39%) | 1 | 18 (50%) | 2 | 17 (47%) | 3 |
| Bother by changed sexual activity | 13 (36%) | - | 14 (39%) | - | 16 (44%) | 1 | 19 (53%) | 2 |

1 Within each dimension, patients could report more than one aspect of distress as the worst.
Discussion

General discussion

Doctors reported higher self-efficacy when showing good ability to identify patients’ wish for information, than when they showed less good ability to do so, overestimated patients’ worry and underestimated patients’ wish for information. Patient attitudes and behaviours such as verbal behaviour and body language, together with doctors’ knowledge and experiences and patients’ demographic factors, were considered when doctors estimated how much worry a certain patient experienced and how much information a certain patient wished. Patients who met doctors showing good ability to identify their wish for information, reported a higher cognitive function than patients who met doctors showing less good ability to do so. At all assessments patients expressed high satisfaction with the doctor’s care, and patients’ ratings of satisfaction with doctors’ care did not change over time. Shortly after the patients’ first three admissions to specialist care there were some relations between their ratings of satisfaction with doctors’ care and of psychosocial function. Patients with carcinoid tumours in some respects report a worse HRQoL than the general Swedish population. Fatigue, diarrhoea, limited possibilities to work/pursue daily activities, and worry that the illness will get worse were the aspects of disease- and treatment related distress that most patients experienced. These aspects were also considered as the overall worst aspects by most patients.

The findings revealed a relation between doctors’ self-efficacy with regard to communicating about difficult matters and ability to identify a certain patients’ wish for information. This result indicates that self-efficacy with regard to the ability to communicate about difficult matters may facilitate doctors’ communication with patients and thereby a correct assessment of how much information a certain patient wishes could be facilitated. It is however difficult to explain the result as the findings do not reveal a relation between doctors’ self-efficacy with regard to communicating about difficult matters and their ability to identify how much worry a certain patient experiences. In accordance with previous findings (38, 39, 43), the results revealed that the doctors overestimated patients’ worry. The results did also demonstrate that doctors underestimated patients’ wish for information, and failed
to correctly identify those patients who reported less worry and wished more information than the average patient. In order to understand these results, it was considered important to investigate which cues doctors consider when assessing how much worry a certain patient experiences and how much information a certain patient wishes. Findings from Study II revealed, not surprisingly, that doctors consider patients’ verbal expressions and behaviours, questions, body language and facial expressions when estimating patients’ worry. These results support previous findings (27, 30-34, 108). Interestingly, the findings revealed that doctors considered the same attitudes and behaviours when estimating patients’ wish for information as patients’ worry. In addition to the mentioned cues doctors considered their own professional knowledge and experiences, patients’ demographic variables, and contextual factors when assessing patients’ worry and wish for information. Paying attention to a patient’s attitudes and behaviours is probably often the first step towards an understanding of the patient’s needs, the next step in this process is to understand the meaning of these attitudes and behaviours. In case the doctor’s interpretation of the meaning of the patient’s behaviours and attitudes does not correspond with the patient’s needs it will be difficult for the doctor to provide the patient with a care, e.g. an amount of information and/or psychosocial support that matches the individual patient’s needs. For instance, a doctor may judge a patient who asks many questions to be worried, however the patient may not be worried, just eager to receive information. In addition, patients’ needs may be assessed on the basis of the doctor’s own emotional state.

It has been reported that when patients perceive doctors as attentive to their psychosocial and informational needs they report higher satisfaction with care and better psychosocial adjustment (17, 18, 21, 59, 109-111). Based of these findings it was expected that doctors’ ability to identify patients’ worry and wish for information would be related to patients’ satisfaction with the initial consultation as well as to their psychosocial function. However, the findings did not support this expectation. Only one significant relation was found between these variables. It was shown that patients who met doctors who showed good ability to identify their wish for information at the initial consultation reported a higher cognitive function at T1 than those patients who met a doctor who showed a less good ability to do so. This finding needs to be considered with great carefulness. It could however be speculated that, as cognitive function was measured in terms of memory function and ability to remain concentrated, it was easier for doctors to identify a certain patient’s wish for information if the patient was able to remain concentrated and remember important facts during the conversation with the doctor.

At all assessments patients reported high satisfaction with all aspects of doctors’ care and their ratings of satisfaction with doctors’ care did not change over time. High levels of satisfaction were expected at the first as-
The reason for this is that carcinoid tumours may go undetected for some time before patients are referred to specialist care. And, once at specialist care the patients meet doctors who can provide them with information about their disease, its treatment, and prognosis. As it is known that patients may use previous care as a baseline when rating satisfaction with present care (65) it was expected that the patients should express relief and gratefulness via high ratings of satisfaction with doctors’ care at the first assessment. The expectation was to some extent confirmed by stories told by the patients. In parallel to this reasoning it was expected that patients’ ratings of satisfaction would decline over time, as the novelty effect of being admitted to specialist care would wear off. However, the findings did not support this expectation. Instead they illustrate that the patients expressed high satisfaction with doctors’ care at all assessments. When considering this finding it should be taken into consideration that the patients may have felt dependent in relation to the specialist care, and thereby felt reluctant to express dissatisfaction (112), or even less than high satisfaction. It is also possible that the attrition may have contributed to the lack of changes over time (113). However, as data was collected by a person (CaF) not engaged in the care and treatment of the patients, as the patients were guarantied confidentiality and answered the questions about satisfaction at home it is assumed that the patients’ ratings of satisfaction are valid indicators of high satisfaction.

Overall, patients’ ratings of satisfaction with doctors’ care was related to their ratings of problems such as diarrhoea, perceived financial impact, anxiety, and depression rather than to their ratings of functions. The findings demonstrated some relations between these ratings at T1-T3. As patients’ satisfaction with doctors’ care and psychosocial function were measured at the same time it is hard to draw any conclusions about potentially causal directions between these variables. On one hand it could be argued that satisfaction with doctors’ care may have an impact on psychosocial function. On the other hand it could be argued that psychosocial function may have an impact on satisfaction with care. Neither patients’ ratings of satisfaction with doctors’ care nor of psychosocial function were significantly different at T4 compared to at T1-T3 and it is difficult to explain why there were some significant associations between these variables at T1-T3, however not at T4. The findings may however suggest that, in case physical function does not decline, satisfaction with doctors’ care may become less important for patients’ psychosocial function with time from diagnosis.

The patients reported relatively high levels of physical-, emotional-, cognitive-, and social function and low levels of anxiety and depression and most problems with fatigue, dyspnoea, diarrhoea, and pain. Patients’ role- and emotional function increased over time. Aside from these changes, patients’ psychosocial function did not change during the study period. On one hand it could be expected that once the treatment aiming at reducing the hormone-related symptoms is initiated, the problems related to overproduc-
tion in hormones would decrease, and global quality of life would increase. On the other hand it could be expected that patients’ global quality of life, as a consequence of the illness itself and disruption of the previous so-called normal life, would decrease over time. The results did not support any of these expectations and may indicate that both expectations, to some extent, were supported. When considering that the patients reported a low level of depression it should also be considered that many patients reported experiencing depression when answering the questions about the prevalence of a number of disease- and treatment related aspects of distress. And, in spite of reporting a low level of anxiety, the patients reported that they worried about the illness, their families and before check-ups. It cannot be concluded which picture that best illustrates the life situation of these patients, the findings do however illustrate that in order to explore the psychosocial function of patients with carcinoid tumours it seems appropriate to investigate the phenomena from different perspectives.

It is always difficult to interpret the meaning of scores of psychosocial function. For example, which score indicates a good and which score indicates a poor quality of life? One way to interpret the scores is to compare them to those of the general population (103, 114). Such a comparison revealed that patients with carcinoid tumours, in some respects, i.e. fatigue, diarrhoea, global quality of life, and role function, reported a worse quality of life than the general population. These findings correspond to previous results (85). Clinical significance in most cases coincided with statistical significance underscoring that the identified differences in quality of life between patients with carcinoid tumours and the general Swedish population are clinically relevant. This conclusion is also supported by the fact that most patients identified fatigue and diarrhoea as the worst aspects of distress. The fact that the patients considered diarrhoea and fatigue to be the main reasons why they were limited to work and pursue daily activities, indicates that reducing these problems could have important implications for the patients’ quality of life.

Methodological considerations

The conditions to detect potential changes in patients’ satisfaction with doctors’ care were in some regards optimal. The sample of doctors that the patients were in contact with during their admissions to the DepEO, and thereby asked to express their satisfaction with, remained the same at all assessments. In addition, the organisation of medical care and the setting remained unaltered during the study-period.

The patient sample is not large from a statistical point of view, however, when considering the size it should be taken into account that it consists of patients with carcinoid tumours, a very rare disease, and that all patients
were included at approximately the same time in relation to the diagnosis. However, it can still be argued that the number of patients was too small to detect all true differences over time with regard to the investigated variables. The longitudinal design permits conclusions about patients’ satisfaction with doctors’ care and psychosocial function at certain time points during the disease trajectory. Along with a longitudinal design attrition usually follows, as is the case in this thesis. As it could be argued that drop-outs are likely to be different in some respect, than patients who participate throughout a study (115) additional analyses investigating whether there were any differences in HRQoL, anxiety, and depression at T1 between those who did (n=36) versus did not participate at all assessments (n=23) were performed. The results did not show any differences with regard to the investigated variables.

The way doctors’ ability to identify patients’ worry and wish for information was explored may be discussed. Using VAS when measuring psychosocial phenomena has been proven useful and VAS possesses at least acceptable interrater reliability when used for proxy ratings (116-118). The patients’ ratings of worry and wish for information were chosen as the “gold standard” and doctors’ ability was assessed against the patients’ mean values. In case a broader or narrower limit for ability had been chosen different results may have emerged. However, since the results were congruent with previous results this indicates that the chosen definition of good vs less good ability on the VAS may be appropriate.

The findings revealed that doctors, almost without exception, consider the same patient attitudes and behaviors, and other factors, when estimating patients’ worry and wish for information. This may be a reasonable finding as it can be assumed that the processes of estimating worry and wish for information interact. However, it is worth to consider that all doctors first were asked about which factors they consider when estimating worry and thereafter were asked which factors they considered when estimating wish for information. This circumstance may have had an effect on the results. It can be speculated whether the findings would have been different in case half of the interviews would have started with the questions about worry whereas the other half had started with the questions about information.

The procedure to interview doctors right after they had met a patient was chosen in order to make sure that the doctors would “keep a certain patient fresh in mind” and not describe what they in general consider when estimating patients’ worry and wish for information. However, this procedure in some cases interfered with the doctors’ clinical work and thereby may have restrained them from developing their answers. The same circumstance may have been a reason for doctors to decline participation. Another fact to consider is that the mean time the doctors who were interviewed had been working at the respective department was short, approximately 6 months. This is due to the organization of the doctors’ work; usually the new doctors in the clinic attend to new patients, and perform the initial consultation with them.
It is possible that doctors with longer experience would have added information to the investigated phenomena. However, doctors were interviewed until the interviews revealed no new information.

A large number of analyses were performed in Study III and IV why the risk of mass-significance should be considered when interpreting the findings from these studies. However, in order to reduce the number of false significances a p-level of <.01 was chosen. This may of course have increased the risk of type II errors. However, the pattern of correlations between patients’ satisfaction with care and psychosocial function at T1-T4 was consistent when choosing a p-level of <.05.

Conclusions and implications

The work presented in this thesis was a first step towards understanding whether good care has an impact on patients’ psychosocial function.

The assumption that doctors’ self-efficacy with regard to communicating difficult matters to patients is related to their ability to identify patients’ worry and wish for information was partly confirmed. However, the topic needs to be further explored in larger samples. Should the finding be confirmed, the next step could be to investigate whether education and training in communication skills has any effect on self-efficacy with regard to communicating about difficult matters and on the ability to identify patients’ psychosocial and informational needs.

In comparison to patient reports doctors overestimated patients’ worry and underestimated patients’ wish for information. Why this is so cannot be explained on the basis of findings from this study. Whether the factors identified in this work as considered by doctors when estimating patients’ worry and wish for information are related to appropriate estimations of patients’ psychosocial and informational needs should be explored.

As assumed patients’ ratings of satisfaction with doctors’ care were related to their ratings of psychosocial function. However, significant relations were only demonstrated at the first three assessments. This implies that the relation between patients’ satisfaction with doctors’ care and psychosocial function may change during a disease trajectory. It appears interesting to further explore why this is so. As a first step towards this goal it appears important to understand whether patients’ satisfaction with doctors’ care has an impact on patients’ psychosocial function or whether patients’ psychosocial function has an impact on their ratings of satisfaction with doctors’ care.

In some respects, especially role function, global quality of life, fatigue, and diarrhoea, the patients reported a worse HRQoL compared to the general Swedish population. And, most patients considered fatigue, diarrhoea, limited possibilities to work/pursue daily activities, and worry that the illness will get worse as the worst aspects of disease- and treatment related distress.
Increased efforts aiming at further helping patients with carcinoid tumours with the identified distress should be taken in clinical care. In particular, patients’ emotional and social needs should be attended to.
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