Patients’ experience of their general practitioner’s follow-up of serious eating disorders

BACKGROUND An eating disorder is an illness that may take a life-threatening course. The health authorities recommend that general practitioners (GPs) should be included in the treatment apparatus. The patients’ feelings of shame, denial of the illness and ambivalence with regard to treatment are disease-specific characteristics that need to be considered.

MATERIAL AND METHOD At two specialised units for eating disorders, patients aged over 18 were handed a questionnaire at the start of their treatment. The questionnaire dealt with GP consultations in which the eating disorder had been discussed. An active GP-patient relationship was defined based on whether the patient had seen the GP at least three times, whether the GP’s office was in proximity to the patient’s place of residence and whether the eating disorder had been discussed during the past year.

RESULTS Altogether 114 patients (90 %) took part in the study. 66 % had an active GP-patient relationship, and 65 % of these had discussed with their GP the impact of the disease on their daily lives. Altogether 75 % were satisfied with the GP’s manner, 47 % found the GP to be an important supporter of their treatment and 44 % visited their GP if their condition worsened. Those patients who were severely underweight and patients with GPs who demonstrated commitment scored highest on satisfaction and support. A total of 39 % of those who had experience of treatment in which their current GP could have been involved in collaboration with the second-line service had found such involvement to be the case.

INTERPRETATION The patients had varying experience of follow-up provided by their GPs. Commitment on the part of the GP appears to result in closer follow-up and greater patient satisfaction.

In 2002, a general practitioner (GP) had an average of ten patients with an eating disorder requiring treatment on his/her list – one with anorexia and nine with bulimia (1). More recent epidemiological studies give no reason to believe that eating disorders have increased, but the number of women with anorexia in the age group 15–19 years is growing – either because they are being detected sooner, or due to earlier onset of the disorder (2).

An eating disorder may have a fatal outcome. The government’s strategic plan recommends that most patients with an eating disorder be treated in general practice, but that those who are most ill must be dealt with by the specialist health service (2, 3). In the strategic plan and the national guidelines, emphasis is placed on collaboration between the treatment levels (3, 4).

A severe eating disorder arises «when the patient’s relationship to food disrupts and prevents normal functioning, socially, at work or at school for beyond a period of six months» (5). In ICPC-2, bulimia and anorexia have the same diagnostic code: P86 anorexia nervosa/bulimia (6). Conscious weight loss denotes anorexia, while repeated episodes of over-eating and vomiting denote bulimia. In ICD-10 a BMI < 17.5 kg/m² is decisive for the diagnosis of anorexia (7). Denial of the illness, feelings of shame and guilt, and ambivalence may prevent the patient from being open about her/his symptoms or from feeling that she/he deserves help (5, 8, 9).

Psychotherapy, which also emphasises symptom reduction, and somatic follow-up/treatment are central elements of the therapy (4). Continuous motivational effort is of crucial importance for recovery (5, 8, 10). A strong alliance with the treatment provider is essential (5, 8–12) and cooperation between the patient and the treatment provider, openness, curiosity, patience, focused and systematic follow-up and an individualised approach are crucial (10). Treatment providers who signal acceptance of the person behind the illness, who are involved and show patience and who communicate with professional authority and certainty, are those who most easily achieve the trust of patients with anorexia (11). Drug therapy, beyond any treatment of comorbid mental conditions such as anxiety, depression and/or compulsive behaviours, has a limited role to play (9).

Persons with eating disorders visit their GPs more frequently than their peers in the...
The purpose of our study was to investigate whether patients with a severe eating disorder had spoken with a local GP about their illness during the year preceding the start of treatment at a specialist unit. We wished to ascertain how close the follow-up was, whether the patients were satisfied with their doctor and whether they would visit their GP if the condition worsened. We were also interested in the patients’ experience with collaboration between the treatment levels.

**Material and method**

The study was conducted at the Outpatient Clinic for Eating Disorders, Department for Personality Psychiatry, Oslo University Hospital, and the Regional Centre for Eating Disorders, Nordland Hospital, Bodø (day unit and outpatient clinic). At both clinics, at least 95% of patients have one of the following four diagnoses (ICD-10): F.50.0 anorexia nervosa, F.50.1 atypical anorexia nervosa, F.50.2 bulimia nervosa or F.50.3 atypical bulimia nervosa. Fewer than 5% have the diagnosis F 50.9 unspecified eating disorder.

Patients over the age of 18 years at the start of their treatment were requested to respond anonymously to a questionnaire on their use and experience of their GP. The duration of the data collection period for Oslo was from 1 August 2009, and for Bodø from 1 January 2010, to 30 June 2011. Five patients who were referred to specialist units by the authors themselves were not included for reasons of habilitation (Fig. 1).

The questionnaire was developed by the authors based on clinical experience from the GP surgery and the specialist unit. It was tested on 45 patients in a pilot study at the Outpatient Clinic for Eating Disorders in Oslo in 2008 and evaluated and edited in line with the experience gained from this. The questionnaire has been published in full as the Halvorsen appendix (in Norwegian) and is described in e-box 1.

Two definitions were introduced as the results were processed, namely «own GP» and «active GP-patient relationship» (Box 2).

The data were analysed using a chi-square test and a one-way ANOVA test with SPSS version 20.

Written consent was obtained from the participants, and the study has been approved by the Regional Ethics Committee.

**Results**

**Response rate**

Altogether 140 patients commenced treatment in the study period (Fig. 1). Eight of these were not given the questionnaire due to an oversight or because they were too ill to participate. Five were referred by the lead author, and one patient declined to participate. Of the 126 who received the questionnaire, 114 responded (90%). There were 76 outpatients in Oslo (67%) and 38 patients (33%) in Bodø (of whom 20 had been admitted).

We found no significant differences between the patients in Oslo and the patients in Bodø with regard to age, living situation, income, length of illness, somatic comorbidity (thyroid disease, diabetes, Crohn’s disease, ulcerative colitis, coeliac disease or lactose intolerance), proportion of those who...
were severely underweight, and experience of treatment.

**Background data**

Three of the patients were men, and 64 patients (56%) were in the age group 18–25 years. Altogether 83 (73%) had been ill for at least five years. In all, 49 (43%) of the patients supported themselves with a salary or student loan (Table 1). Every third patient received a work assessment allowance. Half of those who lived alone received this allowance.

Altogether 24 patients (21%) had never previously undergone treatment for an eating disorder. Forty (35%) were only treated as outpatients, whereas 49 (43%) had had one or more admissions in addition to any outpatient treatment. One patient did not respond to the question regarding whether she had been admitted. Hospital treatment had been provided in the Department for Internal Medicine (n = 26), the Department for General Psychiatry (n = 24) and in the Specialist Unit for Eating Disorders (n = 33).

Average self-reported BMI was 20.2 kg/m² (SD 3.8 kg/m², median 19.8 kg/m²). Altogether 28 patients (26%) were severely underweight (BMI < 17.5 kg/m²), and 70 (61%) had been severely underweight in adulthood. The average change in weight in adulthood was 19.5 kg (SD 10.1 kg, median 17.0 kg).

**Consultations**

In all, 75 patients (66%) had an active GP-patient relationship according to the study’s definition (Box 2, Fig. 1). Of these, 55 (73%) had had more than two consultations in the past year during which the eating disorder was discussed (Table 2). In total 49 (65%) had spoken to their GP about how the illness affected their everyday life (Table 3). Those who were severely underweight and those who had used psychopharmaceuticals/hypnotics visited their GP more frequently than the others (Table 2).

Altogether 32 patients (43%) who had an active GP-patient relationship were allocated a check-up appointment (Table 3). Those who were severely underweight were allocated the greatest number of check-up appointments (71 % versus 33 %, p = 0.007). Those who had discussed the impact of the illness on their daily lives were more likely to be allocated a check-up appointment than others (57 % versus 16 %, p = 0.001). Ten patients (13 %) had experienced that their GP had contacted them outside normal hours. Altogether 21 patients (28 %) had cancelled their appointments or not attended, without booking a new appointment. A total of 33 patients with an active GP-patient relationship (44 %) stated that they were accustomed to contacting their GP if their condition worsened. The severely underweight constituted the greatest proportion of these (72 % versus 35 %, p = 0.006).

<p>| Table 1 | The patients’ source of income and living situation, given as number of persons [%] |
|---------------------------------|-------------------------------------|---------------------------------|-------------------------------------|-------------------------------------|</p>
<table>
<thead>
<tr>
<th>Type of living arrangement</th>
<th>Total</th>
<th>Number [%]</th>
<th>Sickness benefit</th>
<th>Work assessment allowance</th>
<th>Financially provided for by others</th>
</tr>
</thead>
<tbody>
<tr>
<td>With partner and/or children</td>
<td>36</td>
<td>19 [53]</td>
<td>6 [17]</td>
<td>8 [22]</td>
<td>3 [8]</td>
</tr>
</tbody>
</table>

| Table 2 | Number of GP consultations regarding the eating disorder during the past year for those with an active GP-patient relationship, given as number of patients [%] |
|---------------------------------|-------------------------------------|-------------------------------------|-------------------------------------|-------------------------------------|
| Type of living arrangement      | 1–2 consultations in past year | 3–6 consultations in past year | > 6 consultations |
|---------------------------------|---------------------------------|---------------------------------|------------------|---------------------------------|---------------------------------|---------------------------------|---------------------------------|------------------|---------------------------------|---------------------------------|---------------------------------|---------------------------------|
| Number                          | Number [%] | Number [%] | Number [%] | Number [%] | Number [%] | Number [%] | Number [%] |
| Total                           | 75      | 20 [27] | 30 [40] | 25 [33] | 0.032 |
| Current BMI < 17.5 kg/m²        | 18      | 2 [11] | 6 [33] | 10 [56] | 3 [20] | 0.097 |
| Current BMI ≥ 17.5 kg/m²        | 54      | 18 [33] | 23 [43] | 13 [24] |        |
| No previous treatment           | 23      | 7 [47] | 5 [33] | 3 [20] | 0.097 |
| Previously admitted (and possible outpatient treatment) | 49 | 5 [14] | 14 [40] | 16 [46] |        |
| Psychopharmaceuticals¹          | 47      | 8 [17] | 21 [45] | 18 [38] | 0.049 |
| Sickness benefit                | 13      | 2 [15] | 4 [31] | 7 [54] | 0.35 |
| Financially provided for by others | 5      | 1 [20] | 1 [20] | 3 [60] |        |

¹ The patients have responded yes to the following question: «Have you taken medication for anxiety, mood swings, psychosis or sleep problems during your period of illness?»
Patients with previous experience of treatment had a greater tendency to contact their GP if their condition worsened (admissions 57 %, outpatient treatment 40 %, no experience of treatment 20 %, \( p = 0.047 \)). Those who were allocated a check-up appointment were most likely to make contact if their condition worsened (59 % versus 33 %, \( p = 0.03 \)). Altogether 53 % of those who had spoken about the impact of the illness on their daily lives made contact if their condition worsened, compared to 27 % of the others (\( p = 0.03 \)).

**Patient satisfaction**

Fifty-six patients with an active GP-patient relationship (75 %) were moderately/very satisfied with how they were met by their GP (Table 3). Thirty-five (47 %) felt that their GP was an important supporter to a moderate/great degree. Patients who had check-up appointments allocated, and patients who had spoken to their GP about the effect of the illness on their everyday lives, were most satisfied with their GP and were also most likely to experience their GP as a mainstay. The GP's gender made no significant difference with regard to satisfaction or the support experienced.

The greater the number of consultations, the more patients were satisfied and thought that they had more support from their GP than those who stated that they did not contact their GP when their condition worsened.

**Collaboration between treatment levels**

Altogether 63 (85 %) of the patients with an active GP-patient relationship wanted collaboration between the GP and their treatment providers. Of the 54 patients with previous experience of treatment for which cooperation with their current GP may have been relevant, 21 (39 %) had found that there had been written or spoken communication between the GP and previous treatment provider(s). In total 17 had not experienced this type of communication, and 16 (30 %) did not know whether any collaboration had taken place.

**Lack of an active GP-patient relationship**

Altogether 38 (34 %) of the patients did not have an active GP-patient relationship. This included 15 patients who did not have their own GP according to the study's definition, eight who had not spoken to their GP about their eating disorder in the past year (all the GPs were aware of the eating disorder), and 15 who had GPs located in another part of the country. One patient did not state whether the GP surgery was close to their place of residence.

Factors such as age, severe underweight or somatic comorbidity were not decisive in whether the patient had an active GP-patient relationship. Those who were financially provided for were least likely to have an active GP-patient relationship (39 %), whereas those on sick leave most frequently had such a relationship (87 %) (\( p = 0.045 \)). Altogether 45 % of the patients who lived alone or in shared housing lacked an active GP-patient relationship (\( p = 0.035 \)).

**Discussion**

Two out of three patients had an active GP-patient relationship, according to our definition (Box 2). Three out of four of these had spoken to their GP about their illness more than twice in the past year. Overall this means that half of the patients in the study had spoken about their illness to a GP in geographical proximity to them more than twice in the past year (geographical proximity defined as the patient living sufficiently close to the GP surgery that the GP can be consulted in case of acute problems connected to the eating disorder).

Two out of three with an active GP-patient relationship had spoken about how the illness affected their everyday lives. Fewer than half were allocated a check-up appointment and fewer than half were accustomed to contacting their GP if their condition worsened. According to our findings in this study, the GP was therefore not necessarily a part of the treatment apparatus, as the national guidelines indicate (4).

Most of the patients who had used psychopharmaceuticals or were on sick leave had been to see their doctor more than twice in the past year. This may indicate that conversations over several consultations have revealed a need for medication or a medical certificate, or that a wish for a prescription and a medical certificate can function as an entry ticket for contact with the GP.

Two out of four patients with an active GP-patient relationship were satisfied with how the doctor dealt with their illness. Fewer than half thought that the GP was an important supporter. Those who were follo-
This finding supports previous research, in Tidsskr Nor Lægeforen nr. 21, 2014; 134–2051 disorder is discussed. The study's strength is the relatively large number of patients, which includes both users and non-users of GP services. The fin-

The choice of design limits, for example, the possibility of understanding and describing the patient’s overall behavioural pattern. It is a weakness of the study that the GPs’ experiences are not presented, and that the questionnaire has not been validated or used in other studies. The fact that the following groups are not represented also constitutes a weakness: patients with a serious eating dis-

Long illness trajectories and several treat-

Strengths and weaknesses of the study

The study’s strength is the relatively large number of patients, which includes both users and non-users of GP services. The find-

We would like to thank Åse Minde, art psycho-

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