

# Patient-rating of distressful symptoms after treatment for early cervical cancer

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**Background.** More refined information on sources of symptom-induced distress in a patient population can improve the quality of pretreatment information, make follow-up visits more efficient and guide research priorities in the efforts to modify treatments.

**Methods.** In a population-based epidemiological study covering all of Sweden, data were collected 1996–97 by means of an anonymous postal questionnaire. We attempted to enroll all 332 patients with stage IB-IIA cervical cancer registered in 1991–92 at the seven departments of gynecological oncology in Sweden.

**Results.** A total of 256 cases (77%) completed the questionnaire. After surgery, alone or in combination with intracavitary radiotherapy, several symptoms related to sexual dysfunction are the primary sources of symptom-induced distress (reduced orgasm frequency: much distress 23% (surgery alone) and 23% (intracavitary radiotherapy and surgery), respectively, overall intercourse dysfunction: much distress 17% and 20%, respectively, followed by lymphedema (much distress 14% and 14%, respectively). Dyspareunia (much distress 24%) and defecation urgency (much distress 22%) are two leading causes of distress after surgery and external radiotherapy. After treatment with radiotherapy alone, loose stool and dyspareunia were the two most distressful symptoms (much distress 19% each). When a symptom occurs, fecal leakage and reduced orgasm frequency are the two most distressful ones (measured as much distress, 38% each).

**Conclusions.** The observed symptoms are distressful and should, if one focuses on patient satisfaction, be given priority.

**Keywords:** cervical cancer; sexual dysfunction, lymphedema; urinary dysfunction; bowel dysfunction

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Knowledge of distressful symptoms after a specific therapy can improve the quality of preoperative information, make follow-up visits more efficient and guide research priorities in the efforts to modify treatments. Long-term side-effects among women treated for early cervical cancer include vaginal changes that compromise sexuality (1), lymphedema (2) and both urinary (3) and bowel dysfunction (4). Little is known, however, of the rela-

tive importance (for emotional and social life) of the different symptoms or to what extent they, when occurring, distress the women (5, 6). To rank the relative importance of different symptoms, one needs to ask the same abstract question on the corresponding distress.

Often used instruments for the follow-up of women having undergone treatment for early cervical cancer include the French-Italian glossary (7), SOMA (developed by the Radiation Therapy Oncology Group, RTOG; 8) and QLQ-C30 (9). While certainly providing important information, none of

**Abbreviations:**

Gy, Gray; HDR, high dose rate; LDR, low dose rate.

these instruments include a standardized question on corresponding distress for each symptom. Thus, for the present study we developed a new questionnaire. Symptom-induced distress can be seen as a way to summarize how a specific symptom influences emotions and social activities; the relevance of a symptom. Lymphedema may, for example, not affect the possibilities to satisfactory shopping; still the symptom may seriously affect the well-being. Thus, just enumerating emotions or social activities that are affected by each symptom may give a compromised picture of the overall relevance of a symptom.

In this study we have, as an abstract question, asked women who have had early cervical cancer to what extent a specific symptom distresses them, with answers on a 'verbal' category scale. Here, we use this information for two purposes. First, in each group we rank symptoms according to the distress it causes. The figures can be seen as a product between symptom occurrence and corresponding distress. A physician can use this information to describe the post-therapy situation and prioritize efforts during follow-up. Second, we examine the proportion of women who are distressed by a specific symptom, when it occurs. This information provides basic knowledge on the influence on emotions and social activities the different symptoms have.

### Materials and methods

The patient population comprised all 332 women aged 27–80 years registered at the seven departments of gynecological oncology in Sweden as having early (FIGO stage IB-IIA) cervical carcinoma in 1991–92 who were alive at the start of the study in November 1996. A questionnaire was distributed between November 1996 and May 1997, approximately five years following treatment.

A questionnaire was constructed. It was initially developed during successive in-depth interviews with patients and clinicians to map the relevant symptoms and symptom-induced distress. A preliminary questionnaire was based on the interviews and previous questionnaires developed in our group (10). It was tested at successive face validity interviews, and was adjusted progressively. Two pilot studies were conducted; each with 30 patients and 30 control women, and the questionnaires and procedures for collecting the data were refined. The questionnaire consisted of questions regarding different aspects of urinary, bowel and sexual function and lymphedema (assessed as perceived swelling and/or heaviness of the legs and lower abdomen). The whole questionnaire consisted of 136 questions (293 variables). The sections assessing lymphedema and urinary, bowel and sexual function consisted of

77 questions. The answers were given in six to seven verbal categories ranging from no symptoms to severe symptoms. Different aspects of a symptom were assessed with separate questions measuring occurrence, duration, quality and/or intensity. To compare the symptom-induced distress between specific symptoms, we choose to ask for it in an abstract (not time and place dependent) way. Thus, the impact of the symptoms or conditions was assessed by 22 different questions evaluating the distress it produced by way of five verbal alternatives: 'Not relevant, I do not have the symptom', 'It does not distress me', 'It distresses me a little', 'It distresses me moderately' or 'It distresses me a lot'. With regard to the relevance of an assessment of the subsequent distress, the women were subcategorized into the categories 'All', denoting all women answering the specific question, and 'Affected', denoting those reporting the symptom or condition (irrespective of the occurrence, intensity or duration). In the presentation of the reported distress, we show three groups: those reporting much distress, those reporting moderate or much distress and all those reporting distress of any degree (a little, moderate or much). First, in each group we rank symptoms according to the distress it causes (reflecting occurrence as well as distress). Secondly, we examine the proportion of women who are distressed by a specific symptom, when it occurs (reflecting symptom severity).

The treatment in Sweden for early stages of cervical cancer is surgery with or without preoperative intracavitary radiation therapy depending on the local tradition. The surgery typically consists of radical hysterectomy and pelvic lymph node adenectomy (Piver type III; 11). Most patients with lymph node metastasis or other poor prognostic signs (close or positive surgical margins) are treated with postoperative external radiotherapy. The standard postoperative external radiotherapy comprises 40–54 Gray (Gy) to a pelvic field (photon energy), with an extended field (40 Gy) covering the para-aortic lymph nodes up to the renal artery level at one center, typically over a period of 4–6 weeks. During this period, four centers used low dose rate (LDR) intracavitary radiotherapy and three centers used high dose rate (HDR) intracavitary radiotherapy. Inoperable patients (advanced age, concomitant diseases) are treated with radiotherapy alone. The study was approved by the Regional Ethics Committee of the Karolinska Institute (Stockholm, Sweden).

### Statistical analyses

The results are calculated as the number of women indicating much distress, or moderate and much

distress, or little, moderate and much distress, divided by the total number of women answering the specific question (Tables II, III, IV and V). In Table VI, only affected women (with the symptom) are in the denominator.

## Results

We received completed questionnaires from 256 (77%) of 332 patients (Table I). The different treatments and population characteristics are listed in the table.

Among women treated with surgery alone, the most distressful symptoms or conditions were sexuality-related (Table II): reduced orgasm frequency distressed 23% of the women much, overall intercourse dysfunction distressed 17% much, as did reduced orgasmic delight. Lymphedema was

associated with much distress in 14% of the women treated with surgery alone. Overall sexual dysfunction was the most distressful condition (45%), when distress of any degree (little, moderate or much), was considered.

Patients treated with intracavitary radiotherapy and surgery (without external radiotherapy) (Table III) also ranked sexuality-related symptoms among the highest: reduced orgasm frequency distressed 23% much, as did reduced intercourse frequency, while overall intercourse dysfunction and vaginal changes distressed 20% much, respectively. Lymphedema distressed 14% much. When distress of any degree was considered, lymphedema ranked the highest (46%).

Women treated with surgery and external radiotherapy (with or without intracavitary therapy) reported sexuality-related and bowel symptoms as

Table I. Characteristics of women with cervical cancer after treatment and controls

Characteristics	Cases			
Women identified in registries	332			
Answering the questionnaire	256 (77%)			
Mean (standard error) age at time of study (years)	51 (0.77)			
Treatment		Age, range (median), in years	Menopausal before treatment	Currently on systematic HRT
Surgery alone	93 (36%)	21–80 (47)	15 (16%)	39 (42%)
Surgery and intracavitary radiotherapy	57 (23%)	29–81 (49)	11 (19%)	51 (89%)
Surgery and external radiotherapy ( $\pm$ intracavitary)	79 (31%)	27–80 (49.5)	23 (29%)	55 (79%)
Radiotherapy alone	22 (9%)	33–80 (68.5)	15 (68%)	9 (41%)
Information missing	5 (2%)			

Table II. Symptom-induced distress, patients treated with surgery alone, total, sliding scale; ranking, percent and total proportions

Surgery alone, all ( $n=93$ )	Much	Moderate, much	A little, moderate, much
Reduced orgasm frequency	<b>1</b> 23% (20/88)	<b>2</b> 29% (26/88)	<b>7</b> 38% (33/88)
Overall intercourse dysfunction	<b>2</b> 17% (15/88)	<b>4</b> 28% (25/88)	<b>3</b> 41% (36/88)
Reduced orgasmic delight	<b>2</b> 17% (15/88)	<b>5</b> 26% (23/88)	<b>10</b> 36% (32/88)
Reduced intercourse frequency	<b>4</b> 16% (14/89)	<b>3</b> 29% (26/89)	<b>8</b> 37% (33/89)
Vaginal changes	<b>5</b> 16% (15/90)	<b>10</b> 22% (20/90)	<b>6</b> 39% (35/90)
Reduced lubrication	<b>6</b> 15% (13/88)	<b>1</b> 31% (27/88)	<b>2</b> 44% (39/88)
Lymphedema	<b>7</b> 14% (13/91)	<b>6</b> 25% (23/91)	<b>4</b> 41% (37/91)
Dyspareunia	<b>8</b> 12% (11/89)	<b>12</b> 20% (18/89)	<b>5</b> 40% (36/89)
Overall sexual dysfunction	<b>9</b> 11% (10/88)	<b>9</b> 23% (20/88)	<b>1</b> 45% (40/88)
Reduced sexual interest	<b>10</b> 11% (10/91)	<b>6</b> 25% (23/91)	<b>11</b> 35% (32/91)
Reduced genital swelling	<b>11</b> 11% (9/85)	<b>8</b> 24% (20/85)	<b>12</b> 33% (28/85)
Reduced attractiveness	<b>12</b> 9% (8/90)	<b>10</b> 22% (20/90)	<b>9</b> 37% (33/90)
Abdominal pain	<b>13</b> 9% (8/91)	<b>14</b> 15% (14/91)	<b>16</b> 31% (28/91)
Constipation	<b>14</b> 7% (6/89)	<b>16</b> 12% (11/89)	<b>14</b> 31% (28/89)
Overall bowel dysfunction	<b>15</b> 6% (6/93)	<b>17</b> 12% (11/93)	<b>15</b> 31% (29/93)
Urinary urgency	<b>16</b> 5% (5/92)	<b>15</b> 15% (14/92)	<b>17</b> 27% (25/92)
Overall urinary dysfunction	<b>17</b> 4% (4/89)	<b>13</b> 17% (15/89)	<b>13</b> 33% (29/89)
Recurrent urinary tract infections	<b>18</b> 4% (4/90)	<b>19</b> 9% (8/90)	<b>21</b> 9% (8/90)
Loose stool	<b>19</b> 4% (4/93)	<b>21</b> 6% (6/93)	<b>20</b> 18% (17/93)
Defecation urgency	<b>20</b> 3% (3/89)	<b>18</b> 10% (9/89)	<b>19</b> 19% (17/89)
Fecal leakage	<b>21</b> 2% (2/93)	<b>22</b> 3% (3/93)	<b>22</b> 8% (7/93)
Urinary leakage	<b>22</b> 1% (1/90)	<b>19</b> 9% (8/90)	<b>18</b> 22% (20/90)

the leading distressing conditions (Table IV): dyspareunia distressed 24% much, overall bowel dysfunction distressed 23% much, as did overall intercourse dysfunction. Overall bowel dysfunction was the most important source of distress of any degree (62%).

The small group of women not operated on at all, but treated with radiotherapy alone, had rank-

ings that differed from those of the other women (Table V): they reported much distress for loose stool: 19%, dyspareunia: 19%, overall bowel dysfunction: 15%, overall urinary dysfunction: 15% and urinary urgency: 15%. Various bowel symptoms were the most common cause of distress of any degree.

When actually having a symptom ('affected pa-

Table III. Symptom-induced distress, patients treated with intracavitary radiotherapy and surgery, total, sliding scale; ranking, percent and total proportions

Intracavitary radiotherapy and surgery, all (n = 57)	Much	Moderate, much	A little, moderate, much
Reduced orgasm frequency	1 23% (13/57)	1 33% (19/57)	4 44% (25/57)
Reduced intercourse frequency	1 23% (13/57)	4 30% (17/57)	7 40% (23/57)
Overall intercourse dysfunction	3 20% (11/56)	5 29% (16/56)	5 43% (24/56)
Vaginal changes	3 20% (11/56)	5 29% (16/56)	3 45% (25/56)
Dyspareunia	5 18% (10/56)	7 27% (15/56)	12 38% (21/56)
Reduced sexual interest	6 18% (10/57)	3 32% (18/57)	6 42% (24/57)
Overall sexual dysfunction	7 15% (9/55)	9 25% (14/55)	15 35% (19/55)
Overall urinary dysfunction	8 16% (9/57)	11 25% (14/57)	10 39% (22/57)
Lymphedema	9 14% (8/56)	10 25% (14/56)	1 46% (26/56)
Reduced lubrication	10 14% (8/57)	1 33% (19/57)	7 40% (23/57)
Urinary leakage	11 12% (7/56)	16 18% (10/56)	17 30% (17/56)
Reduced attractiveness	12 12% (7/57)	13 23% (13/57)	14 35% (20/57)
Reduced orgasmic delight	12 12% (7/57)	8 26% (15/57)	13 37% (21/57)
Reduced genital swelling	14 11% (6/55)	12 24% (13/55)	19 25% (14/55)
Abdominal pain	15 11% (6/57)	17 18% (10/57)	7 40% (23/57)
Defecation urgency	15 11% (6/57)	17 18% (10/57)	16 32% (18/57)
Urinary urgency	15 11% (6/57)	14 21% (12/57)	10 39% (22/57)
Overall bowel dysfunction	18 7% (4/56)	15 20% (11/56)	1 46% (26/56)
Loose stool	19 5% (3/57)	19 16% (9/57)	18 30% (17/57)
Recurrent urinary tract infections	20 4% (2/56)	21 5% (3/56)	21 16% (9/56)
Constipation	21 4% (2/57)	20 7% (4/57)	20 23% (13/57)
Fecal leakage	21 4% (2/57)	22 4% (2/57)	22 12% (7/57)

Table IV. Symptom-induced distress, patients treated with surgery and external radiotherapy (with or without intracavitary treatment), total, sliding scale; ranking, percent and total proportions

Surgery + external RT (with or without IC), all (n = 79)	Much	Moderate, much	A little, moderate, much
Dyspareunia	1 24% (18/75)	7 29% (22/75)	12 40% (30/75)
Overall bowel dysfunction	2 23% (18/78)	4 37% (29/78)	1 62% (48/78)
Overall intercourse dysfunction	3 23% (17/74)	1 39% (29/74)	4 50% (37/74)
Defecation urgency	4 22% (17/77)	3 38% (29/77)	3 52% (40/77)
Loose stool	5 22% (17/78)	2 38% (30/78)	5 49% (38/78)
Lymphedema	6 19% (14/75)	13 25% (19/75)	12 40% (30/75)
Overall sexual dysfunction	6 19% (14/75)	6 33% (25/75)	6 47% (35/75)
Abdominal pain	8 17% (13/77)	5 35% (27/77)	2 53% (41/77)
Vaginal changes	9 16% (12/75)	7 29% (22/75)	7 45% (34/75)
Reduced intercourse frequency	10 16% (12/76)	9 29% (22/76)	14 39% (30/76)
Reduced orgasmic delight	11 15% (11/74)	12 26% (19/74)	18 34% (25/74)
Reduced orgasm frequency	11 15% (11/74)	10 27% (20/74)	15 39% (29/74)
Reduced sexual interest	11 15% (11/74)	15 23% (17/74)	17 36% (27/74)
Fecal leakage	14 14% (11/78)	18 19% (15/78)	20 27% (21/78)
Urinary urgency	14 14% (11/78)	11 27% (21/78)	8 44% (34/78)
Overall urinary dysfunction	16 13% (10/77)	17 22% (17/77)	9 43% (33/77)
Reduced lubrication	17 11% (8/74)	15 23% (17/74)	10 42% (31/74)
Urinary leakage	18 10% (8/78)	20 17% (13/78)	16 38% (30/78)
Recurrent urinary tract infections	19 9% (7/77)	21 12% (9/77)	21 14% (11/77)
Reduced attractiveness	20 8% (6/73)	14 23% (17/73)	11 41% (30/73)
Reduced genital swelling	21 4% (3/74)	19 18% (13/74)	19 28% (21/74)
Constipation	22 4% (3/78)	22 9% (7/78)	22 13% (10/78)

Table V. Symptom-induced distress, patients treated with radical radiotherapy alone, total, sliding scale. Ranking, percent and total proportions

Radical radiotherapy alone, all ( <i>n</i> = 22)	Much	Moderate, much	A little, moderate, much
Loose stool	<b>1</b> 19% (4/21)	<b>2</b> 38% (8/21)	<b>2</b> 52% (11/21)
Dyspareunia	<b>2</b> 19% (3/16)	<b>11</b> 19% (3/16)	<b>13</b> 25% (4/16)
Overall bowel dysfunction	<b>3</b> 15% (3/20)	<b>3</b> 30% (6/20)	<b>1</b> 75% (15/20)
Overall urinary dysfunction	<b>3</b> 15% (3/20)	<b>3</b> 30% (6/20)	<b>5</b> 40% (8/20)
Urinary urgency	<b>3</b> 15% (3/20)	<b>9</b> 20% (4/20)	<b>5</b> 40% (8/20)
Defecation urgency	<b>6</b> 14% (3/21)	<b>1</b> 43% (9/21)	<b>4</b> 48% (10/21)
Urinary leakage	<b>6</b> 14% (3/21)	<b>5</b> 24% (5/21)	<b>7</b> 38% (8/21)
Overall intercourse dysfunction	<b>8</b> 11% (2/19)	<b>8</b> 21% (4/19)	<b>12</b> 26% (5/19)
Reduced orgasm frequency	<b>8</b> 11% (2/19)	<b>13</b> 16% (3/19)	<b>10</b> 32% (6/19)
Reduced orgasmic delight	<b>8</b> 11% (2/19)	<b>13</b> 16% (3/19)	<b>19</b> 21% (4/19)
Fecal leakage	<b>11</b> 10% (2/20)	<b>15</b> 15% (3/20)	<b>13</b> 25% (5/20)
Abdominal pain	<b>12</b> 10% (2/21)	<b>5</b> 24% (5/21)	<b>2</b> 52% (11/21)
Reduced sexual interest	<b>12</b> 10% (2/21)	<b>10</b> 19% (4/21)	<b>8</b> 33% (7/21)
Lymphedema	<b>12</b> 10% (2/21)	<b>17</b> 14% (3/21)	<b>16</b> 24% (5/21)
Vaginal changes	<b>15</b> 6% (1/17)	<b>12</b> 18% (3/17)	<b>17</b> 24% (4/17)
Reduced intercourse frequency	<b>16</b> 6% (1/18)	<b>7</b> 22% (4/18)	<b>18</b> 22% (4/18)
Reduced attractiveness	<b>16</b> 6% (1/18)	<b>18</b> 11% (2/18)	<b>8</b> 33% (6/18)
Overall sexual dysfunction	<b>16</b> 6% (1/18)	<b>18</b> 11% (2/18)	<b>21</b> 17% (3/18)
Reduced genital swelling	<b>19</b> 5% (1/20)	<b>20</b> 10% (2/20)	<b>13</b> 25% (5/20)
Recurrent urinary tract infections	<b>19</b> 5% (1/20)	<b>22</b> 5% (1/20)	<b>22</b> 10% (2/20)
Reduced lubrication	<b>21</b> 0% (0/20)	<b>15</b> 15% (3/20)	<b>11</b> 30% (6/20)
Constipation	<b>21</b> 0% (0/19)	<b>21</b> 5% (1/19)	<b>19</b> 21% (4/19)

tients') (Table VI), the symptom associated with most distress was fecal leakage (38% much distress), followed by reduced orgasm frequency (38%) and dyspareunia (37%). Fecal leakage was also the most distressful symptom when distress of any degree (89%) was considered.

The results pertaining to sexuality-related distress differed with age. There were no significant differences between the age group 'under 40 years'

and '41–52 years', and '53–65 years', or 'above 65 years'. However, there was a gradient indicating that elder women were less distressed by sexual dysfunction than younger women. For example, the variable 'overall sexual dysfunction' (much distress): women above 65 years: 6% (2/32); the whole group of women below 65 years: 17% (34/204); or when restricted to the group of women below 40 years: 20% (10/51; not in table).

Table VI. Symptom-induced distress, affected patients only in the denominator, sliding scale; ranking, percent and total proportions

Affected patients only	Much	Moderate, much	A little, moderate, much
Fecal leakage	<b>1</b> 38% (18/47)	<b>5</b> 53% (25/47)	<b>1</b> 89% (42/47)
Reduced orgasm frequency	<b>2</b> 38% (46/122)	<b>3</b> 56% (68/122)	<b>11</b> 79% (96/122)
Dyspareunia	<b>3</b> 37% (42/114)	<b>8</b> 50% (58/114)	<b>8</b> 80% (91/114)
Overall intercourse dysfunction	<b>4</b> 35% (46/133)	<b>2</b> 57% (76/133)	<b>14</b> 78% (104/133)
Reduced orgasmic delight	<b>5</b> 34% (36/107)	<b>1</b> 58% (62/107)	<b>12</b> 79% (84/107)
Lymphedema	<b>6</b> 32% (39/123)	<b>11</b> 50% (61/123)	<b>5</b> 82% (101/123)
Recurrent urinary tract infections	<b>7</b> 31% (14/45)	<b>12</b> 49% (22/45)	<b>19</b> 69% (31/45)
Vaginal changes	<b>8</b> 30% (38/127)	<b>13</b> 49% (62/127)	<b>13</b> 78% (100/127)
Reduced intercourse frequency	<b>9</b> 29% (41/140)	<b>9</b> 50% (70/140)	<b>22</b> 65% (91/140)
Defecation urgency	<b>10</b> 27% (30/111)	<b>6</b> 52% (58/111)	<b>9</b> 79% (88/111)
Overall sexual dysfunction	<b>11</b> 26% (35/137)	<b>16</b> 46% (63/137)	<b>18</b> 72% (99/137)
Reduced sexual interest	<b>12</b> 25% (34/134)	<b>15</b> 48% (64/134)	<b>20</b> 69% (92/134)
Urinary urgency	<b>13</b> 25% (26/106)	<b>9</b> 50% (53/106)	<b>2</b> 86% (91/106)
Reduced lubrication	<b>14</b> 23% (29/125)	<b>4</b> 54% (67/125)	<b>6</b> 80% (100/125)
Abdominal pain	<b>15</b> 23% (31/137)	<b>18</b> 43% (59/137)	<b>15</b> 77% (106/137)
Loose stool	<b>16</b> 22% (29/129)	<b>19</b> 43% (55/129)	<b>21</b> 67% (86/129)
Overall urinary dysfunction	<b>17</b> 22% (26/119)	<b>17</b> 45% (53/119)	<b>7</b> 80% (95/119)
Reduced attractiveness	<b>18</b> 21% (23/110)	<b>14</b> 48% (53/110)	<b>4</b> 83% (91/110)
Overall bowel dysfunction	<b>19</b> 21% (32/156)	<b>21</b> 37% (58/156)	<b>16</b> 77% (120/156)
Reduced genital swelling	<b>20</b> 20% (19/94)	<b>7</b> 51% (48/94)	<b>17</b> 73% (69/94)
Urinary leakage	<b>20</b> 20% (19/94)	<b>20</b> 39% (37/94)	<b>3</b> 83% (78/94)
Constipation	<b>22</b> 15% (11/72)	<b>22</b> 33% (24/72)	<b>10</b> 79% (57/72)

Individual women added comments voluntarily in the questionnaires and reported an increased understanding of symptoms and reactions, and asked for more information on side-effects before, during and after treatment.

## Discussion

These data can be used to prioritize efforts to improve the long-term situation for women having had stage IB-IIA cervical cancer. After surgery, alone or in combination with intracavitary radiotherapy, several symptoms related to sexual dysfunction are the primary sources of symptom-induced distress, followed by lymphedema. Dyspareunia and defecation urgency are the two leading causes of distress after surgery and external radiotherapy. When a symptom occurs, fecal leakage and reduced orgasm frequency are the two most distressful ones (measured as much distress).

Undoubtedly, sexual function is the primary source of distress. If patient preferences are the main interest, our efforts to better these women's long-term quality of life should focus on sexual rehabilitation. The highest prevalence of much distress was found concerning reduced orgasm frequency. However, it may be unreasonable to ask about reduced orgasm frequency at a short follow-up visit. At the same time, it is noteworthy to discern that one fifth of all women with a history of cervical cancer are much distressed by this circumstance (compiled number, not in table). To focus on women's needs, special facilities for sexual guidance at departments of gynecological oncology may be fruitful.

It may seem contradictory that, for example, dyspareunia distressed more women than, for example, overall sexual dysfunction. When assessing the latter, it is plausible that sexual life's non-physical manifestations may be incorporated in the evaluation. Psychological, social and interpersonal aspects probably influence the assessments (12, 13).

In the case of lymphedema and urinary and bowel dysfunction the restrictions the symptoms impose on everyday activities possibly contribute to the level of distress. Varying intensity or frequency of the symptoms probably modifies the distress (e.g. urinary leakage: 20% much distress, 83% any degree of distress; urinary urgency: 25% much distress, 86% any degree of distress). Data indicate that for some women the urinary urgency hinders the everyday activities outside home, while for others, the woman just experience more frequent signals than average from the bladder. Fecal leakage had an even greater impact on the level of dis-

tress than urinary leakage when occurring: 38% much distress. This is probably due to potential smell (with its social consequences) and a feeling of uncleanness, fecal leakage may be more emotionally charged than urinary leakage.

There are indeed symptoms that only occur in a minor portion of the population, but when they occur they are highly distressful. One example is recurrent urinary tract infections, which occur in only 4% of all patients (14), but the distress of any degree among those with the problem amounts to 69%, and 31% report much distress. It is therefore also important to inquire about less frequent but distressful side-effects at follow-up as they may have a potentially major influence on the patients' well being if left unattended. Early intervention and prevention of symptoms probably can improve subjective quality of life.

Elder women (above 65 years) reported less often distress related to sexual dysfunction as compared to younger women (under 40 years), but no upper age limit was found above which no woman is sexually active, or not distressed by sexual dysfunction.

The small number of women treated with radiotherapy alone compromise the generalization of the results in this group, as each individual has a great impact on the ranking, but the results give a notion of the general order of essential problems. These women often reported distress from various irritative or frequency problems from the bladder and bowel, while sexuality-related problems had a relatively less significant ranking.

We chose to let the women do the subjective evaluation of the importance of the symptoms by asking, for each specific symptom, about the distress it induces. An alternative way would have been to construct aggregate measures, or summary scores. The traditional scorings of acute side-effects [RTOG's scoring SOMA (8) and WHO (15)] may compromise assessment of the women's values of long-term outcome. There may be central differences in enduring acute disruptive symptoms, with a possible limited duration, and life-long symptoms, or symptoms conditioned by the situation (sexual relations), even if they are of a lesser degree. For example, in SOMA (8), small intestine/colon dysfunction (nota bene: an aggregate organ assessment) grade 1 has (for example) the criteria 'stool frequency 2–4 per day, occasional non-narcotic pain medication, superficial ulcer <1 cm<sup>2</sup>, iron therapy for bleeding', grade 2 has (for example) the criteria 'stool frequency 5–8 per day, regular non-narcotic pain medication, superficial ulcer >1 cm<sup>2</sup>, occasional transfusion for bleeding', grade 3 has (for example) the criteria 'stool frequency >8 per day, regular narcotic pain medi-

cation, deep ulcer, frequent transfusions for bleeding' and grade 4 has (for example) the criteria 'refractory diarrhea, weight loss >30%, perforation or fistulae, surgical intervention.' The 'S' in SOMA stands for 'subjective', i.e. the patient's report, but they are only asked to indicate the frequency of the symptom, not the intensity, the quality nor the impact on their life. In our material, very few women had more than grade 1 small intestine/colon dysfunction: 1/256 reported stool frequency 5 or more per day, none reported transfusion therapy for bleeding. According to these criteria, the majority had scarcely even grade 1, but rather something between grade 0 and grade 1. Nevertheless, they were highly distressed by various symptoms. The patients' reported distress show the need to have also less than grade 1 symptoms recognized and to get adequate information about how to prevent or relieve the impact. Although the objective dimension is important in defining side-effects of treatment, the patient's subjective perceptions translate that objective assessment into the actual experience. Discussing side-effects with the patients should logically include meaningful end-points from the patient's point of view.

We included more questions pertaining to subsequent distress from sexuality-related conditions than analogous questions concerning urinary or bowel conditions in the questionnaire. We found sexual morbidity to be a major concern among the women we interviewed in our preparatory studies. Unfortunately, we did not include questions concerning distress from problems of emptying the bladder, or summarizing variables pertaining to irritative urinary or bowel symptoms. This would possibly have resulted in additional information on aspects of urinary and bowel dysfunction. Our questions focused on physical symptoms. But psychological and psychosocial conditions can also manifest themselves as physical symptoms, and vice versa. Certainly we may have overlooked important symptoms in our preparatory studies.

Maguire and colleagues (16) found that only 40% of the concerns of women with cervical cancer had been disclosed during the year after the diagnosis. Patients who are allowed to express ideas and concerns in the consultation are more likely to be satisfied and to comply with treatment (16). The information from our survey could form the basis for routine self-report screening questionnaires before follow-up visits to guide the patient-clinician interaction. They could also be used to plan and prioritize post-therapy rehabilitation to prevent the development of chronic conditions. Focusing on important

sources of symptom-induced distress would possibly improve the patient-satisfaction and decrease the level of symptom-induced distress after definitive therapy for early cervical cancer.

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