Results of the ECPC Nutrition and Cancer patient survey

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WHY A FOCUS ON NUTRITION IN ONCOLOGY?

- Nutrition is a fundamental aspect of the therapeutic course of cancer patients

- Adequate nutrition can:
  - Prevent the development of serious conditions such as cachexia during treatment
  - Prevent weight loss and promote weight gain;
  - Prevent muscle mass depletion;
  - Improve adherence to therapy and reduce adverse events;
  - Improve the efficacy of anticancer therapy;
  - Improve physical status, strength and quality of life;

OBJECTIVES OF THE SURVEY

• Measuring the awareness rate of cancer patients about the importance of nutrition during therapy

• Discovering from the patients’ answers, if and how much nutritional problems during and after oncologic therapy are perceived to be important by the physician

• Obtaining from the patient relevant information to draw up a practical guidance on how to eat better on a daily basis, especially during therapy
THE SURVEY WAS MADE POSSIBLE THANKS TO THE COLLABORATION BETWEEN:

- European Cancer Patient Coalition (ECPC)
- Department of Clinical Medicine, Sapienza University of Rome, Italy
- Healthware International, Italy
A structured, specific questionnaire was designed
All cancer patients and survivors were eligible to answer the questionnaire, except for people diagnosed with brain and breast cancer.
ECPC ensured the dissemination of questionnaire to its Members in 10 countries, who translated and disseminated the questionnaire
PATIENTS’ INFORMATION

• Gender
• Age
• Disease status (Patient or Survivor)
• Type of cancer (Blood, Bone, Chest / Thoracic, Skin, Lung, Liver/Kidney/Pancreas, Gastric, Head and neck, Genital-urinary, Other)
• Illness duration from the first diagnosis
• Treatment duration from the first diagnosis
• Country of origin
DOMAINS OF THE SURVEY

• A. Eating habits during disease and therapy (5 questions)
• B. Appetite and body weight (5 questions)
• C. Loss of muscle mass and physical activity (3 questions)
• D. Nutritional interventions (3 questions)
• E. Cachexia ( 3 questions)
• F. Impact of food on social and psychological aspects (4 questions)
10 European countries

907 patients and survivors
QUESTION 1
WHAT IS YOUR GENDER?

Female 69%
Male 31%

69% of responders were women
31% were men

Answered question 846
Skipped question 61
Age distribution was equilibrated, with the obvious exception of younger patients (18-29 yrs).

Answered question 907
Skipped question 0
QUESTION 3
DISEASE STATUS

Distribution between Patients and Survivors was equilibrated

Survivor 48%
Patient 52%

Answered question 907
Skipped question 0
QUESTION 4
TYPE OF CANCER

- Blood: 22%
- Bone: 4%
- Chest / Thoracic: 22%
- Skin: 3%
- Lung: 4%
- Liver/Kidney/Pancreas: 4%
- Gastric: 15%
- Head and neck: 5%
- Genital-urinary: 19%
- Other: 2%

Answered question: 907
Skipped question: 0
QUESTION 5
ILLNESS DURATION FROM THE FIRST DIAGNOSIS

59% was affected by the illness by <3 years

Answered question  907
Skipped question    0
QUESTION 6
TREATMENT DURATION FROM THE FIRST DIAGNOSIS

46.2% was treated from less than 1 year

Answered question 907
Skipped question 0
QUESTION 7
HAVE YOU ENCOUNTERED ANY FEEDING PROBLEMS DURING THE ILLNESS AND/OR THERAPY?

- No: 27%
- Just a bit: 33%
- Quite a bit: 27%
- Very much: 13%

72.5% encountered feeding problems during illness and/or therapy.

Answered question: 867
Skipped question: 40
QUESTION 8
IS IT IMPORTANT TO HAVE AN ADEQUATE NUTRITION DURING THERAPIES?

97% felt it is important to have an adequate nutrition regimen during therapies.

Answered question: 867
Skipped question: 40
QUESTION 9

DID YOU KNOW THAT, IF YOU ARE NOT FOLLOWING A SUFFICIENT NUTRITION REGIMEN, IT IS POSSIBLE TO USE FOOD SUPPLEMENTS OR ARTIFICIAL NUTRITION, AS FOR EXAMPLE ENTERAL OR PARENTERAL NUTRITION?

37.3% was not informed about the different nutrition options during illness or therapy.

Answered question: 867
Skipped question: 40
QUESTION 10
DID YOUR PHYSICIAN ASK YOU WHETHER YOU HAD ANY FEEDING PROBLEMS DURING THERAPIES?

More than 50% of the physicians didn’t ask the patients whether they had any feeding problems during illness or therapy.

Answered question 867
Skipped question 40

Yes 46%
No 54%
QUESTION 11
IF YOUR PREVIOUS ANSWER WAS YES, DID THE PHYSICIAN/ONCOLOGIST REFER YOU TO EITHER A NUTRITIONIST OR A DIETICIAN?

more than 2/3 of the physicians didn’t refer the patient to a nutritionist

Answered question 602
Skipped question 305
QUESTION 12
DO YOU THINK THAT LOSS OR REDUCTION OF APPETITE ARE A CONSEQUENCE OF YOUR ILLNESS AND/OR A COLLATERAL EFFECT OF THERAPY?

82 % of patients strongly believed that their loss of appetite was a consequence of the illness or therapy.

Answered question 885
Skipped question 71
QUESTION 13
DO YOU THINK IT IS IMPORTANT NOT TO LOSE WEIGHT DURING THERAPY?

86% was convinced that avoiding weight loss during therapy was important.

Answered question 842
Skipped question 65
QUESTION 14

DOES YOUR PHYSICIAN/ONCOLOGIST CHECK YOUR WEIGHT DURING YOUR VISITS?

Only 35% of physicians regularly checked patients’ weight during visits, while a vast majority (65%) did seldom or never.

Answered question 842
Skipped question 65
QUESTION 15
DOES YOUR PHYSICIAN GIVE IMPORTANCE TO CANCER-RELATED WEIGHT LOSS?

46 % of physicians did not give importance to cancer-related weight loss

Answered question 842
Skipped question 65
QUESTION 16
DID YOU LOSE WEIGHT DURING THE ILLNESS?

70 % of the patients declared to have lost weight during therapies, and in more than 1/3 (36.7%) of the case the loss was moderate to severe.

No 30%
Just a bit 33%
Quite a bit 25%
Very much 12%

Answered question 842
Skipped question 65
QUESTION 17
DID YOU KNOW THAT LOSING WEIGHT CAN WORSEN THE ADVERSE EFFECTS OF THERAPY?

53% of the patients believed that weight loss could worsen the adverse effects of therapy.
QUESTION 18
DID YOU KNOW THAT IT IS IMPORTANT TO MAINTAIN PHYSICAL ACTIVITY DURING THERAPY?

82% of the sample was aware of the importance to maintain physical activity during oncologic therapy.
QUESTION 19
DID YOUR PHYSICIAN RECOMMEND TO MAINTAIN A CERTAIN LEVEL OF PHYSICAL ACTIVITY, EVEN IF YOU FEEL TIRED?

46.2% of physicians did not recommend to maintain a certain level of physical activity.

Answered question: 836
Skipped question: 71
QUESTION 20
DID YOUR PHYSICIAN/ONCOLOGIST
ADVICE YOU TO IMPROVE YOUR APPETITE AND
TO ALLOW FOR ADEQUATE NUTRITION?

Almost 2/3 of physicians
did not give any advice to
improve patients’ appetite

Answered question  830
Skipped question  77
QUESTION 21
DID YOU KNOW THAT TAKING VITAMINS OR ANTIOXIDANTS CAN HAVE NEGATIVE EFFECTS ON YOUR THERAPY?

57% of the patients did not know about the potential negative effect of taking vitamins or antioxidants during therapy.

Answered question 830
Skipped question 77
QUESTION 22
DID YOU KNOW THAT
IF YOU TAKE ANY VITAMINS OR ANTIOXIDANTS
YOU NEED TO INFORM YOUR THERAPIST?

56% of the patients did not know they had to inform therapist in case they took vitamins or antioxidants.

Answered question 830
Skipped question 77
QUESTION 23
DID YOU KNOW THAT PERSISTENT LACK OR LOSS OF APPETITE OR WEIGHT LOSS CAN BE CAUSED BY THE TUMOUR?

69% of the sample knew that persistent loss of appetite could be caused by the tumour.

- Answered question: 827
- Skipped question: 80
QUESTION 24
HAVE YOU EVER HEARD ABOUT “CACHEXIA”?

73% of the patients didn’t know the word “cachexia”
QUESTION 25
DID YOUR PHYSICIAN/ONCOLOGIST GIVE TO YOU OR YOUR RELATIVES ANY INFORMATION ABOUT CACHEXIA?

92.4% of the sample did not receive any information about cachexia

Answered question: 827
Skipped question: 80
QUESTION 26
IS THE TOPIC OF ‘FOOD’ WORRISOME FOR YOURSELF AND YOUR FAMILY?

61% of the sample is worried by the “food” problem

- No: 39%
- Just a bit: 30%
- Quite a bit: 21%
- Very much: 10%

Answered question: 805
Skipped question: 102
QUESTION 27
DO YOU FEEL TO HAVE BEEN ‘FORCED TO EAT’ BY YOUR FAMILY OR CAREGIVER?

Almost half of the patients (42 %) thought to be somewhat forced to eat

Answered question 710
Skipped question 91
QUESTION 28
DID LOSS OF OR REDUCED APPETITE INFLUENCE YOUR MOOD?

- No: 34%
- Just a bit: 35%
- Quite a bit: 23%
- Very much: 8%

66% of the patients felt their mood was influenced by appetite loss.

Answered question: 805
Skipped question: 102
QUESTION 29
DID PROBLEMS RELATED TO EATING HABITS INFLUENCE YOUR DAILY LIFE AND SOCIAL INTERACTIONS WITH OTHERS?

60 % of the patients felt their eating habits had an impact on their social interactions.

Answered question 805
Skipped question 102
• **Patients** and **physicians** have significantly different perspectives on cancer-related nutritional issues.

• Although **patients** are aware that weight loss negatively impacts on disease-related and quality-of-life outcomes, they are not aware about cachexia, nutrition support options, and the potential negative impact of vitamins and anti-oxidants supplementation during active treatments.

• **Patients** are willing to receive more information on how to manage cancer-related nutritional issues.
• **Physicians** are prevalently not focused on nutrition as primary/relevant aspect of their activity. They are not:
  ✓ regularly checking weight/recording weight loss
  ✓ providing information about weight loss management, appetite improvement and promotion of energy balance
  ✓ referring patients to a nutrition HCP

• A significant gap still exists between objective patients’ needs and current patient information

• **Patients associations** may play a fundamental role in prompting interventions aimed at filling this life- and health-threatening gap.