

What do cancer patients need? (in the Czech Republic)

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Amelie z.s. is an NGO that offers complex psychosocial care free of charge to people with all kinds of oncological diagnoses in all stages of the disease as well as to their loved ones. It provides services of psychologists, social workers, activation program, peer support, and it is also engaged in raising of public awareness. Amelie also offers a volunteer program in several hospitals in different regions of the Czech Republic.

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Introduction

Psychosocial care for cancer patients reduces patients' discomfort and improves quality of life. At the same time, it reduces the cost of cancer treatment. Psychooncological care is provided in some of the Complex Oncology Centres and in some hospitals in the Czech Republic. The capacity of clinical psychologists, working with oncology patients, and social workers, who are also in the health care field, is, according to our experience, insufficient. So far, there was no research of psychosocial needs of oncology patients in the Czech Republic, which would clarify the areas and issues in which the help to this group of people is most needed.

Aims of the survey

- 1) identify psychosocial needs of cancer patients and
- 2) measure the importance of the needs for the patients

Findings of the survey can help professionals see opportunities for the improvement of services provided to cancer patients and their families.

Methods

1) Interviews with 8 patients

The objective of the 8 in-depth interviews was to identify frequently mentioned psychosocial needs of cancer patients to obtain a basis for preparation of the "Questionnaire mapping the needs of cancer patients".

2) Cancer patients needs questionnaire

The "Cancer patients' needs questionnaire" was created and distributed in electronic form among respondents through patient associations and other organisations and individuals. The questionnaire examined the importance of 36 needs divided into three categories: 1) psychological needs, 2) needs related to social, legal and financial issues, and 3) needs related to healthcare. Respondents rated the importance of the needs on the scale from 1 ("no importance") to 6 ("very important").

Respondents:

- 253 respondents, 87 % women and 12 % men, age 22-83 years (the average age 55)
- 21 % currently undergoing oncology treatment, 79 % not currently being treated
- the majority of respondents were women with breast cancer (54%)

Results

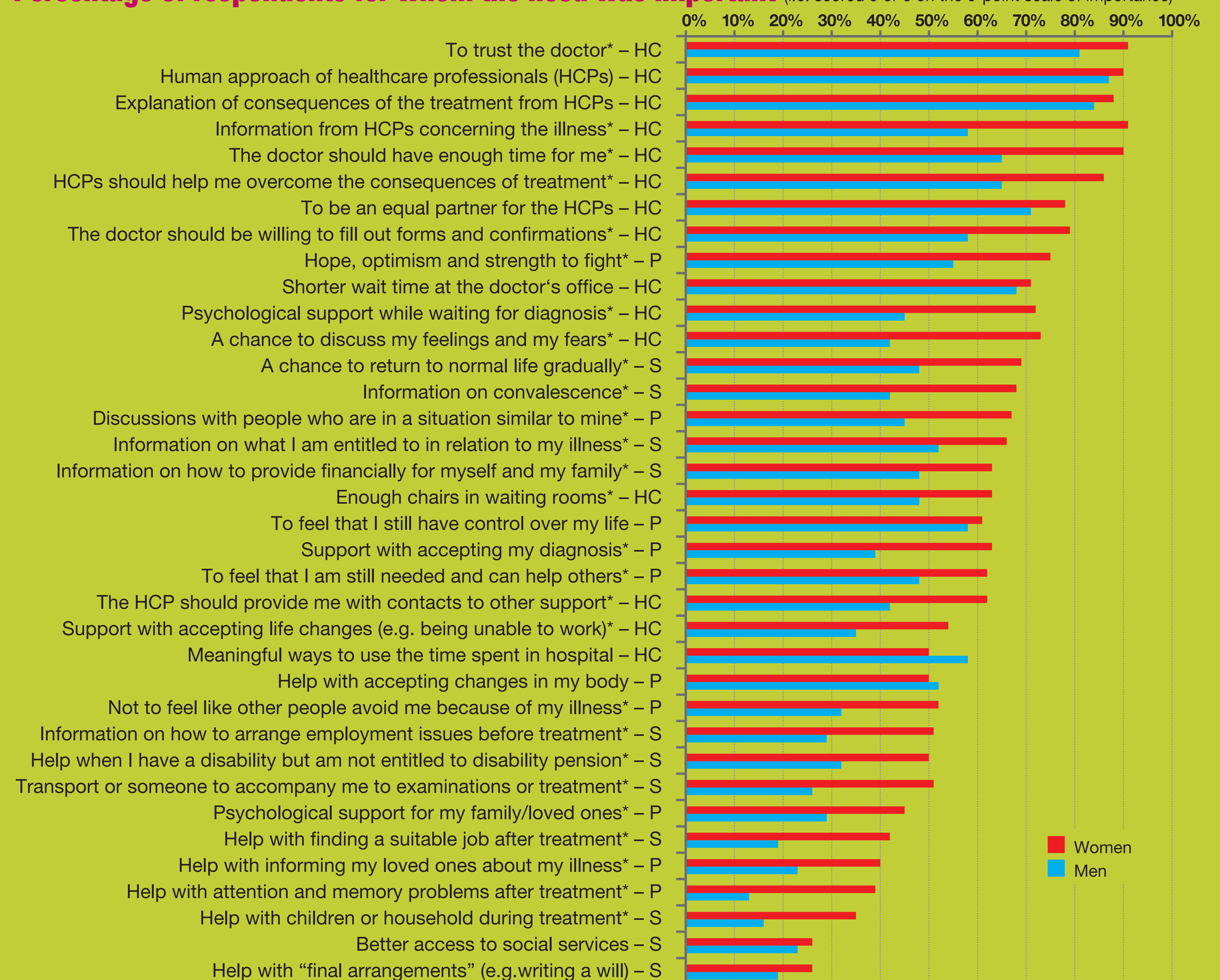
Outcomes of the interviews analysis

Respondents frequently mentioned needs associated with healthcare system. They were also reflecting possible cause of their illness and repeatedly said that their cancer was probably related to their previous hectic way of life and long-term stress, e.g. "I led a very hectic life. I had two jobs and ran from one to the other. Plus the family, a husband and two children – it was very stressful." The experiences vary depending on the stage of the illness. Respondents stated that help – professional support as well as the help from their loved ones – is usually most intense during the initial stages of diagnosis and treatment but is lacking in the post-treatment period.

Importance of the needs (see the Chart)

- The needs related to healthcare were considered as most important by our respondents, occupying the top 8 positions (see the Chart).
- Patients need especially good relationship and good communication with HCPs.
- Further, they need psychological support and an opportunity to discuss and share their experiences.
- They also need to have enough information on what the patient is entitled to, especially in the period after treatment
- Women perceive most of the needs as more important than men.

Percentage of respondents for whom the need was important (i.e. scored 5 or 6 on the 6-point scale of importance)



HC – Healthcare need; P – Psychological need; S – Social and financial need; * indicates a significant difference in the need's importance for men and women

Conclusions

- **For patients, a way in which HCPs communicate with them is crucial:** For cancer patients in the Czech Republic it is the most important to feel comfortable within the health system. Given the fact, that good communication between the patients and their doctors has an impact on the success of the treatment, this aspect of the treatment should be given much more attention.
- **Patients need psychological support:** It is estimated that approximately 20% of cancer patients suffer from depression or anxiety in some stage of their illness. Regrettably, psychological support does not constitute an integral part of care commonly provided to cancer patients at present.
- **Patients need to know what kind of state help they are entitled to**
- **There is a lack of support in the period after the treatment:** Once cancer treatment ends, people have to return to their ordinary lives, and often to work as well. Patients themselves as well as the others (their employer, family and friends) often have unrealistically high expectations concerning the speed of recovery and are taken by surprise when their health problems and negative emotions continue. People are often surprised by the fact that probably the most difficult period comes at the moment when they and their loved ones think that "the worst is over".
- **Stressed by stress:** Patients are looking for the causes of their disease and trying to act in a way to prevent further development of the disease. They realize that stress has negative health consequences. In a situation that is inherently threatening, aside from the experienced stress, also feelings of guilt for experiencing that stress are added.

Further direction of research

- The research has shown that it is easiest to reach women with breast cancer from the entire population of cancer patients. Therefore, the results can be difficult to generalize to other groups of patients and there is a risk that the needs of other patients may remain unheard.
- We have identified the needs of patients and how important they are. However, we do not know the extent to which these needs are met and in which way they are met (e.g. self-help, state aid, NGO services etc.)
- Cancer always affects the entire family system of the individual and the experience of this disease has a particularly strong impact on the main caregiver. Further research should therefore focus on the needs of the loved ones of oncology patients.

Examples of Amelie's activities:

Tai Chi

Individual consultation

Art therapy

Pilates

Healthy cooking

