

Existential aspects are neglected in the evaluation of support-intervention in breast cancer patients

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To the Editor,

In number 2 in 2011, *Acta Oncologica* published several papers from the Nordic Cancer Rehabilitation Symposium. In that issue, Helle Ploug Hansen and co-workers stressed that the effects of a support-intervention as measured by quantitative questionnaires cannot be properly interpreted without taking into account parameters such as human interaction, the organization or the staff, i.e. parameters not formalized in the intervention program [1].

We agree and would like to discuss the necessity of including existential aspects in the evaluation of support programs for breast cancer women, as this is seldom done in a systematic way, despite the fact that most of the cancer patients go through an existential crisis [2–5]. Our arguments are based on our own current experience of randomized breast cancer women's experiences of a support program.

Despite substantial improvements as regards survival prospects, a breast cancer diagnosis still exerts a significant impact on quality of life (QoL) due to uncertainty and strong negative emotions. In order to support these women, different support programs have been tested, with psychological, psychosocial and/or physical focus [6–9]. Even internet support groups have been studied [10]. Generally, the emotional impact has been evaluated with validated

instruments such as HAD (Hospital Anxiety and Depression Scale), Beck scale (a depression inventory) or STAI (State and Trait Anxiety inventory). The psychosocial effects and the general effects on QoL have been evaluated with instruments such as the EORTC QLQ-30, POMS (Profile of Mood State) or FACT/FACIT (The Functional Assessment of Cancer Therapy) with variable outcomes [6–9]. Recent meta analyses and systemic reviews have indicated methodological weaknesses in many studies [6–9].

However, evaluations rarely include existential or spiritual aspects, as they are seldom a part of the commonly used QoL questionnaires, despite the fact that existential crisis greatly contribute the patients' suffering [2–5].

In many evaluations, the participants are encouraged to provide spontaneous comments on the intervention, besides the validated instruments, but these responses are seldom used in a systematic way for improvement of the intervention, as open-ended responses are more cumbersome to summarize.

Our own experience

As a part of a randomized one-week long psycho-educational rehabilitation study, which was supplemented with relaxation, massage, qi-gong and art

therapy, the 191 participants were asked open-ended questions, besides the formal evaluation of mood, fatigue and QoL by the aid of HADS, Norwegian fatigue questionnaire, and QLQ-30. Two open-ended questions were specifically about: 1) “What did you appreciate most (as regards the rehabilitation week)?”; and 2) “Which aspects were the most negative ones?”

The written answers were analyzed using content analysis, where words and sentences were coded, categorized and summarized [11,12]. The coding was made by two of the authors separately (C.L., P.S), with a good agreement (92%) as the statements were rather explicit. In the few cases with partially different coding (8%) the answers were discussed and total agreement was achieved [11,12].

Results

Based on the question “What did you appreciate most?”, four categories were inductively crystallized: 1) existential aspects (n = 163 statements); 2) the actual content of the program (n = 111 statements); 3) staff attitude (n = 54 statements); and 4) others (n = 65 statements, including milieu and catering).

The impact of existential aspects were striking as those statements made up for the largest category (n = 163). In short, following descriptions were made: Sharing the same experience of a life-threatening disease was the most frequent one (n = 77). In general it is difficult to fully share a cancer experience with healthy people, why being in a group of persons with the same, deeply existential experience was described as a relief. Thirty responses were related to one’s own existential awareness concerning the need for own, uninterrupted time and space for existential thoughts, e.g. time for reflexion over life priorities. Also, the quietness was frequently mentioned, giving rise to joy and harmony (n = 23). Twenty respondents found existential inspiration from the support intervention, as it was turning their outlook on life into a more positive one, making them dare to believe in life again. Thirteen of the respondents also underlined the existential meaning of being acknowledged and “cared for” in their struggle with both practical but also life-and-death issues as exemplified by the answer of patient CT + RT17: “*To stay in a quiet and beautiful milieu, be together with persons with similar experiences and illnesses, taking part in a good and varied program making you dare to hope for a future*”.

As regards, “Which aspects were most negative?”, 12/62 statements were about unmet existential needs.

Discussion

The analysis of the participants’ spontaneous comments on the most important outcome (the most

appreciated aspects) reveal that the largest group of statements could be categorized as existential, and these issues do partly, but not totally coincide with the questions in FACIT-sp12 (the spiritual domain) [3]. The fact that existential issues were the most frequently stated ones is an important finding as psycho-educational interventions have so far only been evaluated with psychological or QoL instruments. Important aspects of the perceived benefit in the form of improved existential well-being are therefore probably not detected. Even in the current study, the focus was on psychosocial support; still it resulted in a perception of existential well-being, as described by the patients in the open-ended responses.

Such differences in intentions versus outcome are not uncommon: studies show that there tends to be a discrepancy between what information the profession think they have given and what the patients believe that they really have heard [13].

To summarize, studies show that existential issues are generally rated as important by cancer patients and this dimension comprises issues such as meaning, awareness of values in life, need of positive outlook, need for nature and relationships with fellow persons [2–5]. FACIT-sp12 covers at least partly these issues, as the first part (eight items) are measuring a sense of meaning and peace, whereas the other part (four items) focus on the role of faith in illness [3].

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