

Side effects at the time of rehabilitation as reported by 316 breast cancer survivors in response to an open question and a structured, closed questionnaire

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Background and aim

Our knowledge of side effects after breast cancer and its treatment is generally based on observations close to treatment. Much less is known about side effects months or years after treatment. When quantifying the side effects we assessed whether answers reported in an open question yield results comparable to answers obtained by a structured, closed questionnaire among Danish breast cancer survivors at the time of rehabilitation.

Rehabilitation Centre Dallund

RcDallund is the first and only centre in Denmark offering rehabilitation to cancer survivors after end of cancer treatment as a residential programme. Each week 20 cancer survivors stay at rcDallund for 6 days. RcDallunds annual capacity is 700 patients.

The rehabilitation is a coordinated effort with several specialists. The programme consist of physical, psychological, social, work related and spiritual issues. The programme is varied between lectures, group based dialogs, individual consultations, physical activity and creative activities. Each survivor can choose one consultation with one of the specialists.

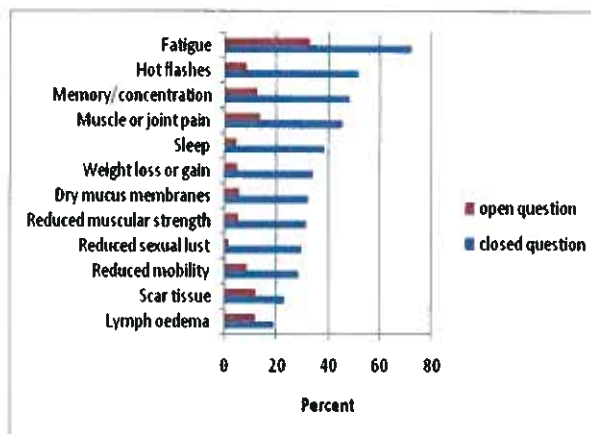
Materials and methods

Before their stay at rcDallund, each survivor received a set of open questions related to the stay. One of the questions was: Do you have impediments, complications or side effects following your illness or treatment? The survivor also received the Dallund Scale, which is a highly structured one page questionnaire qualified to disclose the survivors need of rehabilitation. The scale contains the possibility of checking 29 different physical complications. All 329 breast cancer survivors attending Dallund during 2007 received both the open question and the closed questionnaire and 316 (96%) answered both questionnaires.

Schedule

Time	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
7.30 - 8.30		Breakfast	Breakfast	Breakfast	Breakfast	8.00: Breakfast
9.30 - 13.00	Arrival and registration	Late effects* Doctor and nurse	Psychological reactions to cancer* Psychologist	*Diet, health and healthy habits** Dietician	9.30-10.00 Motivation and change	9.15 - 9.45 Check out
10.00	Welcome and presentation of the programme	Or Physical activity* Physiotherapist	Or Physical activity and relaxation* Physiotherapist	Or Physical activity* Physiotherapist	11.00-12.30 Individual plans for the future	9.45 - 11.15 Goodbye to Dallund
11.30	Walk around the lake in groups of 3	10.50-12.30 The two groups switch	10.50-12.30 The two groups switch	10.45-12.30 The two groups switch		
12.30		Lunch	Lunch			11.30 Lunch
14.00	Presentation	14.00 - 18.30 Back to work? Social worker	13.45-15.30 Body and art* Art therapist	Individual consultations Massage	13.30-16.00 Talk about individual plans in groups	12.15 Departure
16.00	Guided tour around the castle	13.15-16.00 Individual physiotherapy Physiotherapist	Or Cancer and sexuality* Sexologist			
18.00		16.00-17.45 The two groups switch Dinner	16.00-17.45 The two groups switch Dinner	18.30 "Who is the owner of life" Clergyman	18.00 Banquet	
19.30	Staging and music Musicians		Creative activities			

* The participants are split up in two groups and switch activity after the session.



Results

In the figure the most common side effects are presented. Both the number of different complications and the frequency of side effects picked up by the open question are significantly less than those reported on the Dallund Scale. An example is the frequency of fatigue where 33% vs. 72% reported fatigue in the open question and the Dallund scale respectively. The question on lymph edema, muscle- or joint pain and reduced mobility was reported in the open question but 32%-46% of those did not report it in the closed questionnaire. In the open question the second and third most common side effect, "pain" and "the arm" reported by 19,6% and 14,9% respectively, was not an option in the closed questionnaire.



Discussion

In the open question it seems that many of the women underreport their side effects. The reasons can be that they are unable to remember the side effects, they cannot concentrate about writing them down or they do not think of the symptoms as side effects and they maybe therefore underreport them. On the other hand it is possible that the side effects are over reported by the closed structured questionnaire. For lymph oedema, scar tissue and fatigue the frequency reported by the open question is 62%, 51% and 45% of the frequency of the closed questionnaire and may be the side effects that the breast cancer survivors are most aware of. Survivors who reported fatigue in the open question had all but one reported it in the closed question. This was not the case for the other side effects.

Conclusion

Frequencies of side effects were much lower assessed by an open question compared to a questionnaire with 29 possible physical side effects. When side effects are registered by cancer survivors we will not recommend to ask them to write the side effects in an open question without an interview with a health professional. The frequencies of side effects in a closed, structured questionnaire, including several possible complications, are much higher and reflect the actual side effects we see among breast cancer survivors better than the open question.

