Rehabilitation of patients living with advanced cancer

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Presentation is based on published literature and own experience from CARECA project, and from Pirkanmaa and Karina Hospices

CARECA - Cancer Rehabilitation and Pathway Care Projects

The project “Careca” (www.lssy.fi) supervised by Dr R Nurminen in based on collaboration with Cancer Society of South Western Finland and Turku University of Applied Sciences. The project is scheduled for 2010–2016 and is divided into four parts:

2) The quality of life of cancer patients during the hole cancer pathway (2011–2016)
3) Peer support in cancer rehabilitation (2012 – 2016)

Thus far 17 master theses, one doctoral dissertation (to be published in the autumn 2014), other 15 scientific and professional publications, and 15 posters at ECRS in 2012 and 2014 has been published.

At Pirkanmaa Hospice rehabilitation is integrated in the care of all patients (personal communications with Dr T Surakka)
INTRODUCTION

- Patients with advanced cancer have several symptoms and impairments
  - disease-related (↑ with advancing disease)
  - treatment-related (↑ with increasing number of treatments)
  - distress and depression is often worsening symptoms
- **Common physical symptoms**: pain (up to 70-80%); dyspnea (up to 60-70%); fatigue (up to 75%); neurological impairment (cancer-induced, treatment-induced); symptoms due to bone metastases (pain, pathological fractures, disability); lymphedema, etc.
- Research has shown the need for rehabilitation in patients with advanced disease, but its underuse as well
- Reasons for underuse of rehabilitation in this patient population
  - lack of knowledge about the benefits of rehabilitation
  - lack of referrals (by oncologists)
  - lack of resources etc.
Rehabilitation and advanced cancer – own experiences

- By offering information and peer support, it is possible to help the rehabilitee to accept cancer as a part of life; improve coping-skills; enhance the sense of coherence and empowerment.
- The goal of rehabilitation is to help persons to regain control over many aspects of their lives and remain as independent and productive as possible.
- Rehabilitation can improve the quality of life for people with cancer and their families by:
  - improving physical, social and psychological strength
  - helping the person with cancer to become more independent and less reliant on the caregivers
  - helping the person with cancer to adjust to actual, perceived, and potential losses due to advanced cancer
  - lowering the number of hospitalizations.
Goals for rehabilitation in patients with advanced disease

In patients living with cancer as chronic condition, the rehabilitation goals are usually different than in patients after treatment with curative intent.

- The prognosis should be taken into account (e.g., metastatic breast cancer vs. metastatic pancreatic cancer)
- Relevant goals for rehabilitation in this patient population are e.g.,
  - improvement of function
  - improvement of quality of life
  - reduction of the burden of care.
- The goals and means should be individually tailored and re-evaluated often enough.
Multidisplinary approach is needed in patients with advanced cancer

- We need to take care of physical, psychosocial, cultural, and existential and spiritual needs.
- Individual preferences and needs are to be taken into account.
- Different modalities to be utilized, including
  - Physical therapy (dyspnea, pain, mobility, lymphedema)
  - Exercise therapy
  - Occupational therapy
  - Psychosocial support/psychoterapy
  - Use of cultural elements (art, painting, literature, music etc.)
  - Peer support
  - Etc.
- The most investigated field is the physical rehabilitation.
Some research results and own experiences on rehabilitation in patients with advanced cancer
Physical rehabilitation and advanced cancer

- Physical exercise is a suitable approach for maintaining physical capacity in cancer patients with incurable and advanced disease (1).
- A leading cause of emotional distress in cancer survivors is physical disability (2).
- Comorbidities are statistically significant associated with the rehabilitation needs. Moderate to severe comorbidity has shown to be associated with a need of rehabilitation in the emotional, family-oriented and financial areas, as well as participation in physical-related rehabilitation activities. (3)

Excercise interventions and advanced cancer (Systematic review by Beaton et al., 2009)

- **Heterogeneity:**
  - Interventions used very variable (yoga, aerobic exercise, resistance exercise, multidimensional programmes)
  - Different intervention periods, inconsistent outcome measures etc.

- **Key findings:**
  - The evidence shows the enhancement of QoL (level A).
  - Support for exercise effects in improving physical performance (level C)
  - Important to communicate this benefit to the patients and relatives.
  - Important to clarify the goals: To maintain or even improve the function in order to retain independence with mobility and transfer.

- **Conclusions:**
  - There is no agreement on optimal exercise parameters.
  - There is limited evidence concerning the safety of exercise.
  - Future research (large-scale RCTs) could identify optimal and safe exercise parameters.

Physical exercise for cancer patients with advanced disease: A Randomized controlled trial (Oldervoll et al., 2011)

- Cancer patients (n=231) with life expectancy ≤ 2 years were randomized to physical exercise group (PEG; n=121) and a control usual care group.
- PEG group exercised under supervision 60 min twice a week for 8 weeks.
- Primary outcome was physical fatigue; secondary outcome was physical performance measured by Shuttle Walk Test (SWT) and hand grip strength (HGS) test.
- No significant effect was observed in physical fatigue, but physical performance was significantly improved after 8 weeks of physical exercise.
- Conclusion: Physical exercise might be suitable approach for maintaining physical capacity in patients with advanced disease.

Oldervoll LM et al., The Oncologist 2011;16:1649-1657.
Own experiences on rehabilitation at Cancer Society of Finland (CSF) in patients with advanced disease

- CSF is organising approximately 45-50 rehabilitation courses including 800 – 900 participants each year.
- Kela (Social Insurance Institution of Finland) is also organising cancer patient rehabilitation for about the same number of patients (with focus on patients ≤ 65 years).
- Only minority of courses organized by CSF (and none by Kela) target patients with advanced disease (4-5 courses/year).
- Key forms of support during the course for patients with advanced disease are cognitive and psychosocial support and various forms of peer support.
- In addition, there are peer-support groups and internet-based groups for patients with advanced disease.
Own experiences on rehabilitation at Cancer Society of Finland (CSF) in patients with advanced disease

- The structure of the adaptation training course (appr. 5 days):
  - coping with everyday life
  - physical training
  - health
  - sexuality
  - psychological wellbeing
  - social wellbeing.

- Multidisciplinary team is always involved (oncologist, oncology nurse, palliative care nurse, physiotherapist, rehabilitation nurse, dietician, psychologist, music therapist, sexuality counsellor, voluntary workers, etc.).

- Small group of patients and their relatives or loved ones (appr. 10 subjects) to facilitate peer support.
Own experiences on rehabilitation at Cancer Society of Finland (CSF) in patients with advanced disease

- Participants usually report receiving benefits from rehabilitation.
- However, many patients still report that they have not been offered rehabilitation they would have needed.
- Difficulties and problems experienced:
  - Advancing disease may prevent the planned participation.
  - Deteriorating physical condition may be a limiting factor during the rehabilitation course.
  - Peer support may be difficult if there are patients with different status of the disease.
- Future plans: smaller and more flexible groups; outpatients rehabilitation interventions closer to home; better integration of families and other loved-ones in the rehabilitation process; continuous patient education instead of fixed courses.
Rehabilitation in palliative care

- Integration of rehabilitation into palliative care and continued efforts to increase clinicians’ awareness and acceptance of rehabilitation benefits and expertise are needed (1).
- For patients with advanced cancer, exercise can decrease anxiety, stress and depression, while improving levels of pain, fatigue, shortness of breath, constipation, and insomnia (2).
- Rehabilitation can even have positive effects on morbidity and mortality. Patient should be encouraged to participate in rehabilitation programs. (3)

Mobility and physical therapy in palliative care – own experiences

- Moving is one of persons basic needs and basic rights.
- Dependence of other persons is many times the most frightening and also the most important reason for a person to wish to die.
- It is important to focus on the existing resources.
- Physical activity can alleviate pain in some occasions.
- The ability and possibility to do things yourself is very important to be able to keep your dignity.

"It is important NOT to do things for the patients, but together with the patient."
“I was outside yesterday a for a couple of hours. It would be so nice to go out again…”
“It was so sweet, I enjoy a lot to be able to go outside.”
“It is so much easier to breathe outside.”

Special thanks to Pirkanmaa Hospice
"In the beginning it was awfull to be helped by other persons"...

"Indeed, now I can be proud, that I can manage all my daily activities here without help."

"It is very important to be able to keep your dignity."

Special thanks to Pirkanmaa Hospice
Rehabilitation of patients in palliative care – own experiences

- In addition to physical and psychosocial rehabilitation, patients in palliative care setting benefit from different other forms of rehabilitation.
- Spiritual and social needs can be met with certain kind of focus group meetings.
  → Patients, nursing staff, family members and volunteer workers can share thoughts of hope – e.g., hope for good care and continuing good life.
- Our experience on helping the patients to focus on existing life strongly includes rehabilitation and occupational therapy as part of good palliative care.
Depression, anxiety, physical, mental and emotional changes of patients living with advanced cancer

Results and experiences based on CARECA Project

Foto Janne Nurminen
DEPRESSION

- **Depression** is a distressful disorder characterized by feelings such as sadness, apathy, guilt, hopelessness, and irritability that persists consistently for more than two weeks and negatively affects one’s daily activities and relationships.
- Depression may occur near the time of diagnosis or anytime during or after treatment.
- The diagnosis of depression is based on mood-related, cognitive, physical, and behavioral symptoms.
- As many as 15% to 25% of people with advanced cancer experience depression.
ANXIETY AND FEAR

- Many people with advanced cancer experience *anxiety*, with fears triggered by the uncertainties related to advanced cancer.
- *Fear* of death is often the primary concern.
- Many patients have fears for:
  - pain
  - progression of disease
  - treatment-related adverse effects
  - losing control over future life decisions
  - becoming dependent on others
  - having changes in relationships dynamics to others
Depression, anxiety, mental and emotional changes

We may overlook these mental and emotional symptoms while focusing e.g., on the physical effects of cancer and cancer treatment.

For example

• People with untreated depression or anxiety may be less likely to continue healthy habits and take their cancer medication because of fatigue or lack of motivation.
• They may also withdraw from family or other social support systems, which means they won’t ask for the needed emotional and financial support to cope with cancer.
• This in turn may result in increasing stress and feelings of despair.
Physical changes affect your body image and mood

- Both cancer and cancer treatments may change your physical appearance.
- There may be severe changes in your body image due to advanced cancer, such as
  - hair loss, weight gain or weight loss
  - scars from surgery
  - rash, typically a result of drug therapies
  - physical changes due to surgery (mastectomy, amputation)
  - need for a stoma, catheters etc.
  - fatigue or loss of energy; due to severe fatigue you can give up activities that you once enjoyed.
Mental and emotional changes associated with advanced cancer

Depending on the seriousness of the illness and the prognosis you may need to change your plans and realize the possibility of dying.

Advanced disease is frightening and has a profound effect on how you view your life. It is not unusual to experience many different emotions; sometimes it may be difficult to figure out exactly what you are feeling.

Many people with advanced cancer describe feelings such as: anger; a feeling of lack of control; sadness; fear; frustration; guilt; a change in the way you think about yourself and the future.

Self-Image and Cancer

A diagnosis of advanced cancer is always unwelcome and causes many changes in your life. All changes, however big or small they appear to others, affect how you see yourself and how you relate to others.
As an example of special techniques: Music therapy/voice control

- Music therapy ≠ listening and enjoying music.
- Music/voice therapy is possible in all stages of palliative care.
- Music therapist is a member of a palliative care team.
- Music/voice therapy can alleviate physical and psychological anxiety. It may help the patient to find words.
- Music experience/music therapy can also alleviate pain (opioids).
- The most common technique used is ”toning”, which means singing of long vocals (you can have effects on heart rhythm and breathing).

”Voice as a bridge to death”


Personal communication with music therapist Virve Niemeläinen, Cancer Society of South Western Finland, Turku, Finland, is acknowledged.
Patients’ experiences from music therapy

- "What a surprise!" "This is refreshing and relaxing"
- "It is so wonderful that I still can experience this in my life"
- "This helped me to forget my poor condition for a short moment"
- "During the therapy I remember items that I have not been able to remember for a very long time"
- "When you sing, I feel fibrations in my legs" (says a patient who can not move any more). "It is a similar feeling that I feel when my pain medication is starting to help."

Personal communication with music therapist Virve Niemeläinen at Cancer Society of South Western Finland, Turku, Finland, is acknowledged.
Other special items that need to be taken into account in rehabilitation of patients with advanced cancer

- Family life and how to talk about advanced cancer
- Relationships with friends and relatives
- Special needs related to childhood and cancer
- Advanced cancer and workplace discrimination
- Advanced cancer and the insurance problems (e.g., health insurance and travel insurance)
- Sexuality and advanced cancer
  - Maintenance of sexual and reproductive health
  - Sexual problems and finding support for sexual and reproductive concerns
  - Being single with advanced cancer and sexual relationships
Some thoughts for the future...

- Institute of National Health and Welfare (THL) published in May 2014 the 2nd part of national Cancer Control Plan in Finland including recommendations on prevention, early detection, rehabilitation, and research and education.

- The key recommendations on rehabilitation included the following:
  - Rehabilitation should be individually tailored (based on screening).
  - Rehabilitation should be available during the whole cancer continuum (from prehabilitation to palliative care).
  - Each patient should have an individual rehabilitation plan.

- CSF performed in 2013 – 2014 a survey on the knowledge and experience of rehabilitation. The results revealed that patients did not know much about rehabilitation. There were specific information needs for nurses and doctors as well. Rehabilitation plan was done only for very few patients (less than 10%).

- Much work is thus needed!
Conclusions

- In parallel with increasing cancer incidence and improved treatment options, there are more and more patients living with cancer as a chronic condition.
- Rehabilitation is needed in all steps of cancer continuum, also in patients living with advanced disease.
- Goals in patients living with cancer as a chronic condition are usually different from those in patients after curative treatment and need to be individually tailored.
- In general, the same rehabilitation methods as used in patients after curative treatment can be utilized also in patients living with advanced disease.
- The most investigated area is physical rehabilitation, which has shown to improve physical performance. More data is needed particularly on different methods of rehabilitation and adverse effects.
- **Rehabilitation is effective also in patients with advanced disease It can prevent disability and improve QoL.**