# The Need for Psychosocial Interventions in Oncology Care

## ESSAY

In a recent report, the Dutch College of Health Insurances (College van Zorgverzekeringen, CVZ) proposed to remove the costs for psychosocial interventions in oncology care from the basic health insurance repayments. The current essay argues that psychosocial interventions are a valuable addition to the biological treatment of cancer patients. The prevalence of psychosocial problems in cancer patients might be similar to the prevalence in the general population. Psychosocial interventions to treat these problems can be divided in five groups: provision of information, group therapy, training in coping skills, psychotherapy and spiritual/existential therapy. Studies on the effectiveness of these interventions show contradicting results that can be explained by lack of screening for psychosocial problems during recruitment and methodological issues. Furthermore, following the trend in medical cancer treatment. psychological treatment should be more individualized. It is therefore suggested that the CVZ should keep covering these costs in their basic health insurance.

**Keywords:** Cancer, Quality of Life, Psychological Well-being, Psycho-oncology, Prevalence

Daniëlle Starreveld; Research Master student Psychopathology Maastricht University, Maastricht, the Netherlands

d. starreveld@student.maastrichtuniversity.nl

## INTRODUCTION

Due to early detection and the improved (palliative) care the number of patients with a diagnosis of cancer has increased (Meulepas and Kiemeney, 2011). This development leads to more attention to the psychological consequences of the

illness, reflected in the development of psycho-oncology units in cancer centres since the 1980s, increased behavioural research, and the public education in cancer prevention in the 1990s (Breitbart & Alici, 2009). According to Breitbart and Alici (2009), fifty per cent of cancer patients experience psychiatric disorders related to their cancer diagnosis

According to Holland and Gooen-Piels (2000), the general reaction to a diagnosis of cancer can be described in three phases. In the first phase, called the initial phase, patients show symptoms like disbelief, denial or despair. The diagnosis creates a period of crisis that makes it hard to process the important information that is given to a patient during this phase. This phase usually lasts less than a week. The second phase is called *dysphoria*. Dysphoria and emotional turmoil are typical in this phase where patients slowly start to acknowledge their diagnosis of cancer. The thought of the disease intrudes repeatedly and it cannot be banned. Symptoms like anxiety, depression, poor concentration, and insomnia are often seen. Dysphoria usually lasts one to two weeks and diminishes when a treatment starts. The last phase of a general reaction to a diagnosis of cancer is *adaptation*. In this phase, a patient resumes to normal activities and accepts the diagnosis. Patients find reasons to be optimistic. This phase lasts for months and ends with a transition to normal life. The quality of adaption depends on the coping style of a patient, which is formed by previous crisis experiences of a patient. This results in individual differences in the most optimal coping style and indicates that the most optimal coping style for all patients with cancer does not exist. A good coping style results in an adjustment to the diagnosis.

It is this adjustment that creates variety in the response to a diagnosis of cancer between individuals. Different factors influence this adjustment, which can be divided in three factors: society-derived, patient-derived and cancer-derived (Holland & Gooen-Piels, 2000). The *society-derived* variables describe the attitude of a society towards cancer and the treatment. *Patient-derived* variables have three sources: an intrapersonal source determined by the developmental stage and the coping style of a patient, an interpersonal source represented by the social environment of the patient and the socioeconomic and social class of an individual. The final factor that influences the adjustment to the diagnosis cancer is *cancer-derived variables*. The clinical aspects of the disease and the psychological support of nurses and doctors are part of these variables (Holland & Gooen-Piels, 2000).

Due to the increasing numbers of patients with cancer, more patients are affected by the long-term physical and psychological consequences of the illness (Meulepas and Kiemeney, 2011). Despite these increasing numbers the Dutch College of Health Insurances (College van Zorgverzekeringen; CVZ) suggested removing the repayment of the costs for these interventions from the basic health insurance in the Netherlands (van Diggelen & Kroes, 2013). The CVZ suggested that psychological care is integrated in the biological treatment of cancer. Another suggestion is that the best treatment for patients with an adjustment disorder is removing the stress factor, in this case the cancer.

The question arises whether the CVZ is right to propose removing the costs for these interventions from the basic health insurance, or whether these interventions are in fact effective and should be available as basic health care. Therefore, the present review describes first the prevalence of psychological problems in cancer patients. Second, the available psychological interventions, and finally discusses the effectiveness of these interventions

#### PREVALENCE OF PSYCHOSOCIAL PROBLEMS IN CANCER PATIENTS

Most studies about psychiatric disorders report the prevalence of depression, anxiety disorders, and psychological distress in oncology patients (Aass, Fosså, Dahl, & Moe, 1997; Minagawa, Uchitomi, Yamawaki, & Ishitani, 1996; Okamura, Yamawaki, Akechi, Taniguchi, & Uchitomi, 2005). According to Derogatis et al. (1983), the prevalence of psychiatric disorders in cancer patients is 47%. This prevalence is three times as high as the prevalence of psychiatric disorders in the general population. However, Van't Spijker, Trijsburg, and Duivenvoorden (1997) performed a metaanalytical review of 58 studies after 1980 and found much smaller differences between cancer patients and the general population. Their results described a prevalence of depression disorders in up to 46% for cancer patients. A comparison with the general population resulted in a d-value of 0.20, which indicates a small difference between the prevalence of depression in both populations. A prevalence of 1 to 49% is reported for anxiety disorders. Psychological distress is measured by 5 to 50% of the cancer patients. Both prevalence ratings did not differ from the prevalence of anxiety disorders and psychological distress in the general population. Van't Spijker et al. (1997) suggested that these findings were more robust because they compared different studies where Derogatis et al. (1983) only described one study.

Furthermore, van't Spijker et al. (1997) described that the prevalence of depression in oncology patients does not significantly differ from the general population when only the studies after 1987 were considered. Van't Spijker et al. (1997) explain this finding as a consequence of an attitude change towards cancer since the 1980's. Patients were better informed and the medical treatment for cancer was improving. The diagnosis of cancer is at an earlier stage and therefore the average patient's age at the moment of diagnosis is lower than before the 1980's. Early detection in turn resulted in better prognoses, which lead to less psychosocial problems. Therefore, it is suggested that the prevalence of psychosocial problems in oncology patients is comparable with the general population in recent times. In a more recent study completed by Kadan-Lottick, Vanderwerker, Block, Zhang, and Prigerson (2005), 251 advanced cancer patients were recruited. The prevalence of psychiatric disorders was determined through questionnaires on major depressive disorder, generalized anxiety disorder, panic disorder and post-traumatic stress disorder. The prevalence of these psychiatric disorders was not significantly different from the general population, confirming afore-mentioned results.

There are thus conflicting conclusions regarding a higher prevalence of psychosocial problems in patients with cancer (Derogatis et al., 1983) versus no differences in prevalence (Kadan-Lottick et al., 2005; van't Spijker et al. 1997). However, it should be taken into account that methodological issues (i.e. the use of two different questionnaires to determine depression) could explain the conflicting

numbers on the prevalence of psychosocial problems (Ciaramella & Poli, 2001). Other factors that could lead to conflicting results are the used definitions of depression, the time since the diagnosis of cancer, history with depression and treatment for cancer (Newport & Nemeroff, 1998). It thus remains unclear whether or not the prevalence of psychosocial problems in cancer patients is heightened compared to the general population. The CVZ based its opinion that oncology patients should not be treated differently from the general population on the studies of Kadan-Lottick et al. (2005) and van't Spijker et al. (1997). Future research is necessary to shed light on the true prevalence.

#### PSYCHOLOGICAL INTERVENTIONS FOR CANCER PATIENTS

A variety of psychological help is available for patients with cancer. Examples are psycho-education, cognitive behavioural therapy, client-centred and experiential psychotherapy, psychotherapy, systemic family therapy, group therapy and music therapy (de Haes, Gualthérie van Weezel, & Sanderman, 2009; Hart, 2009). The hierarchy of psychological interventions by Cunningham (1995) describes different forms of available therapy (see Fig. 1). The bottom of this hierarchy should be available for every patient. The top of this hierarchy consists of intensive therapy for patients who need elaborate mental health care.

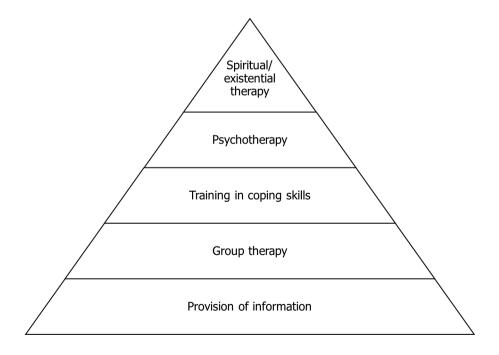


Figure 1: The hierarchy of psychological interventions of Cunningham (1995).

#### **Provision of information**

Provision of information is at the bottom of the hierarchy proposed by Cunningham (1995). This type of psychological care focuses on providing information for cancer patients. An example is psycho-education. According to Gualthérie van Weezel and de Jong (2009) the provision of information helps patients adjust to their new situation. Health care providers explain which difficulties cancer can cause and how to deal with these difficulties. This intervention is a direct effect of the development of psycho-oncology in 1980's. Since the 1980's, more attention was given to the patient and his or her involvement in the treatment. A patient needed to be informed about the diagnoses of the disease to make a decision about treatment. This is thought to lead to a heightened feeling of control over the situation, which could help patients cope with their illness.

# **Group therapy**

One level higher on the hierarchy is group therapy. This form of therapy aims to assist individuals in admitting the effects of the disease and to show their emotions to the individuals around them (Cunningham, 1995). Patients come together to talk with each other. The idea behind this intervention is that individuals live and learn in groups during their lives. When an individual receives the diagnosis cancer the patient can have the experience that he or she is alone. The group experience returns when these individuals talk with other individuals that are going through the same process. Patients remember that they are not alone (Pet, de Ruiter, & Barkmeijer, 2009). Effects of group therapy are an improvement of the psychological wellbeing and decrease of depressive and anxiety symptoms. Altogether this leads to an increase of quality of life, better coping and mental adjustment to the disease (Weis, 2003).

## Training in coping skills

Provision of information and group therapy should be available to the majority of the cancer patients, whether they experience psychosocial problems or not (Cunningham, 1995). However, training in coping skills is a more intensive therapy suited for patients who developed some form of psychosocial problems after a diagnosis of cancer. This type of therapy is less frequently used and placed on the third level of the hierarchy of Cunningham (1995). An example of this type of intervention is cognitive behavioural therapy (CBT). The aim of CBT is to develop new cognitive skills that help patients to adjust better to the disease.

CBT in oncology care is based on the idea that the personal meaning of the disease determines how a patients copes with the disease. As noted before, every patient has his or her own coping style to adjust to the diagnosis cancer. When a patient does not adjust well to the diagnosis of cancer emotional and behavioural problems arise. This is caused by wrong associations that patients have about cancer. An example of a wrong association is: "I have cancer, nothing can be done to save me." In CBT, patients identify existing associations, thoughts causing these associations and inspect whether or not these thoughts are correct together with

a therapist. The incorrect thoughts are rectified (Schroevers, van der Lee, & Pet, 2009).

# **Psychotherapy**

Cunningham (1995) places psychotherapy on the second level of psychological care for patients with cancer. Psychotherapy is based on psychoanalytical grounds. It assumes that in the human psyche conscious and unconscious processes work together. The unconscious processes influence the behaviour of an individual. Examples of unconscious processes are defence mechanisms that help to protect an individual from situations that are too threatening to handle. A diagnosis of cancer is an increased threat to life, which most patients can process themselves. Yet, some patients need extra help to cope with this increased threat and psychotherapy can be a solution. During this therapy the patient and the therapist build a confidential relationship. Together they will work out which defence mechanisms are used by the patient and where they come from. With the knowledge of these repressed thoughts, the therapist and patient work to adjust the defence mechanism to cope with the life threatening disease (van Schoonheten, Gualthérie van Weezel, & Ploegmakers-Burg, 2009).

## Spiritual/existential therapy

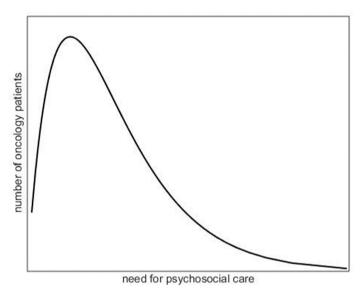
The top of the hierarchy for psychological interventions describes spiritual/ existential therapy (Cunningham, 1995). The basic idea behind this therapy is that an individual puts all attention to the here and now and tries to identify the physical and emotional feeling related to the illness. It gives patients the opportunity to determine the current emotions elicited by the diagnosis of cancer while ignoring emotions from the past or emotions that are expected by others. The aim of the therapy is to label current emotions and deal with them. The therapist leads a patient in this process (Vedder & Maas, 2009).

The hierarchy of psychological interventions of Cunningham (1995) suggests that there is a fitting psychosocial intervention for every patient with cancer. It also suggests that most patients do not need specialised mental health care as long as they receive valid and understandable information. Other patients need more assistance to adjust to the illness. Yet, the question remains whether or not these interventions really improve the adjustment to the diagnosis of cancer.

## EFFECTIVENESS OF PSYCHOSOCIAL INTERVENTIONS

Meyer and Mark (1995) reviewed several studies on psychosocial interventions in oncology care and concluded that psychosocial interventions have a positive effect on cancer patients. It improves the emotional and functional adjustment and symptoms related to the illness and medical treatments are decreased. However, some studies described no effect or a small effect, whereas others described large

effects. There are several explanations for these contradicting findings. First, inclusion criteria differ between studies. None or limited inclusion criteria resulted in a high heterogeneous group of participants of which some already adjusted to the disease. Psychosocial interventions will have a small effect on these patients and distort the effect size of the intervention seen in patients who are in need for psychosocial care (see fig. 2). Second, some interventions have a small effect, do not work, or only work in a small group of patients that makes it difficult to detect an effect (Ross, Boesen, Dalton, and Johansen, 2002). Third, a comparison of different single intervention studies leads to a comparison of heterogeneous variables (i.e. measurement type and participants) and differences in methodology (i.e. the use of a control condition and randomization).



**Figure 2:** Distribution of the number of oncology patients and their need for psychosocial interventions. Most patients with cancer are on the left side of this distribution, representing no or a low need for psychosocial interventions corresponding to the lowest level of the hierarchy by Cunningham (1995). Few patients are on the right side of the distribution, representing that they need psychosocial interventions and could benefit from psychosocial intervention on the higher levels of the hierarchy by Cunningham (1995).

Rehse and Pukrop (2003) addressed the third problem in a meta-analysis on the effectiveness of psychosocial interventions for patients with cancer. A measurement of quality of life (QoL) was constructed to reduce the problem of heterogeneous variables from different studies. Results indicated that psychosocial interventions have a positive effect on QoL in adult patients with cancer. Based on these results, Rehse and Pukrop (2003) suggested that psychosocial interventions should be part of the standard care for cancer patients, which is in line with the proposal of Cunningham (1995). The costs of implementation are low in comparison with the high benefit of a better quality of life for cancer patients. However, more research is needed to tailor psychological treatment to the individual patient's needs.

According to Tamagawa, Garland, Vaska, and Carlson (2012), there is not a single, most optimal psychological intervention for every patient with cancer. It is suggested that psychosocial characteristics of an individual are moderators for the effect of a psychosocial intervention. These moderators can be divided in four categories. The first category is *personality traits*, i.e. optimism. Individuals who score low on optimism benefit more from psychosocial interventions in comparison with individuals who score high on optimism. The second category is *mental and psychical quality of life*. Patients who experience physical limitations before the start of their treatment experience more benefits from the intervention compared to patients who do not experience physical limitations. *Social support* is the third category. When a patient experienced less social support than the psychosocial interventions had more effect. The final category is *self-efficacy*. The moderating effect of this category is two-sided. Individuals with low-levels of self-efficacy benefit from interventions, but high levels also benefit from some interventions (Tamagawa et al., 2012).

The author believes that many studies suffered from severe methodological challenges. Screening for psychosocial problems of patients with cancer would yield encouraging effectiveness results in future studies. A recent study by Rykov (2008) is an example that showed that screening can have positive effects on the reported effect size of psychosocial interventions. Rykov (2008) summarized experiences of a group-based music therapy for patients with cancer who were not diagnosed with psychosocial problems or reported them to a physician. Based on personal stories, Rykov (2008) concluded that this type of therapy is empowering and provides the oppurtunity to experience a feeling of control that was lost since a diagnosis of cancer. The sample of this study was self-selected, reflecting patients on the right side of the distribution of oncology patients and their need for psychosocial interventions (fig. 2). The results showed that psychosocial interventions can have positive effects in patients who wanted more help to cope with their diagnosis. This interest plays an important positive role in the effect of an intervention (Carlson & Bultz, 2008). No interest in an intervention might result in opposite effects, such as more distress (de Moor et al., 2002).

## DISCUSSION

Research about the prevalence of psychosocial problems and the effectiveness of psychosocial interventions in oncology patients led to contrasting results. These contrasting results are also seen in studies about medical treatments for cancer. When clinical trials in oncology care are compared to clinical trials for other diseases, results indicated significant differences in oncology research. The life-threatening aspect of cancer and quick development of innovative treatments make it easier to start with early-phase trials. However, most of these studies have small sample sizes and no control conditions leading to heterogeneous results, the absence of clear answers and no knowledge on the long-term side effects of medical treatments of cancer (Hirsch et al., 2013).

According to Bernards (2013), the term cancer does not describe a disease that is equal for every patient. It might seem that every form of lung cancer is the same, but this is not the case. Every patient is different because cancer is caused by an individually unique mutation in the DNA. Therefore the medical treatment of cancer has to be individualized. An example of this is the treatment of a melanoma. Patients with a specific genetic mutation receive a specific kind of medication that gives them a better chance on survival. In the near future it should be possible to treat most forms of cancer according to this mechanism: an individual combination of medication based on the DNA of the patient.

Recent developments in the medical treatment of oncology acknowledge the fact that every person is unique. The fact that every patient is unique also needs to be acknowledged in the psychosocial care for cancer patients. There are patients who receive a diagnosis of cancer and develop psychosocial problems because of it (van't Spijker et al. 1997). In order to prevent that these problems get unbearable for patients, screening these problems is necessary. In this way patients at risk are detected at an early stage and effective interventions can be offered immediately.

Another question remains whether these psychosocial interventions should be available for all patients with cancer. One could vote in favour of this statement because every patient goes through a general reaction process to a diagnosis of cancer (Holland and Gooen-Piels, 2000). However, a recent study by Rykov (2008) indicated that a group-based music therapy had very positive effects in a self-selected sample of patients with cancer. Moreover, de Moor et al. (2002) indicated that offering a psychosocial intervention to patients who are not interested in it has detrimental effects. These unfavourable effects would plead to offer psychosocial interventions only to the patients who are in need of it.

The CVZ proposed to remove the costs for psychosocial interventions in cancer treatment from basic health insurance. This proposal could be defended by the indication that the prevalence of psychosocial problems in patients with cancer is similar to the prevalence of psychosocial problems in the general population (van't Spijker et al., 1997). Following this reasoning it seems clear that psychosocial interventions are not important in cancer care and that these costs could be cut from the basic health insurance. Furthermore, it is not clear whether or not these interventions are effective (Ross et al., 2002). Yet, it is important to note that small effects might disappear in meta-analyses and that it is likely that not every patient would benefit from a psychosocial intervention (Tamagawa et al., 2012) This is a critical factor that may well have distorted reviews about the effectiveness of psychosocial interventions (Meyer & Mark, 1995; Ross et al., 2002).

Even though the scientific research is not conclusive about the beneficial effects from psychosocial interventions, it should not be forgotten that there are patients in need of psychosocial care. Until it is not clear who benefits from these interventions and who does not, psychosocial interventions should be available for those who search for it. Rykov (2008) showed that psychological interventions are very effective in patients who ask for them. But when the costs of these psychological interventions are removed from the repayment list of the basic health insurance,

these individuals might not be able to use them. Less patients participating in interventions means less research on the subject. And that means that the real effect and the real importance of these interventions will stay unknown.

So, the prevalence of psychosocial problems in patients with cancer might be similar to the prevalence of psychosocial problems in the general population. Moreover, contradicting results do not offer clarity on the effectiveness of psychosocial interventions for every cancer patient. Even though these uncertainties exist, the CVZ should offer a repayment for psychosocial interventions in oncology care from the basic health insurance. The effects of these interventions can be priceless for the patients who need them. Insurance companies should not deny this form of help to patients that are experiencing a difficult and uncertain time in their life and are asking for help in coping with cancer.

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