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## Alexithymia in Cancer Patients: Review of the Literature

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#### **Key Words**

Cancer · Alexithymia · Psychosocial · Neoplasm · Affective symptoms

## Abstract

**Objective:** To summarize the literature on alexithymia in cancer patients. Methods: The empirical literature published between 1972 and January 2010 was searched through MED-LINE, PSYINFO, EMBASE and the Cochrane Library. Key words were: alexithymia, affective symptoms, cancer, neoplasms. Results: The search identified 16 relevant studies which are methodologically problematic and show conflicting results. However, several interesting hypotheses emerge such as a possible link between alexithymia and the immune system, between alexithymia and quality of life, or between alexithymia, anxiety and depression. The question to what degree alexithymia in cancer patients is a trait or a state cannot be answered by these studies. Conclusions: A lack of methodologically sound studies and the large variations of results among studies suggest that the role of alexithymia in patients with cancer deserves more systematic research. Consequently, studies are needed which investigate the nature (state or trait) of alexithymia, its impact on cancer development and progression, as well as its influence on compliance and on the underestimation of psychological distress and psychiatric outcome in cancer patients.

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#### Introduction

Alexithymia, in Greek literally 'no words for feelings', is a term first introduced by Sifneos in 1973 to describe a marked difficulty in verbalizing feelings and a diminution of fantasy of psychosomatic patients [1]. Nowadays alexithymia refers to a multidimensional concept, characterized by cognitive-affective deficits consisting of (1) difficulties in identifying and describing emotions, (2) difficulties in distinguishing between emotions and physical sensations of emotional arousal, (3) reduced imaginative processes, illustrated by a lack of fantasy, and (4) an externally oriented cognitive style (operational thinking) [2].

Research suggests that alexithymia might play a role in the onset or development of several psychiatric and physical health problems such as substance abuse or pathological gambling [3–5], eating [6, 7] and somatoform disorders [8, 9], chronic pain [10], low back pain [11] or kidney failure [12], posttraumatic stress disorders [13, 14] and stress-related disorders in general [15], asthma [16], myocardial infarction [17], inflammatory bowel disease [18], and also cancer [19]. Furthermore alexithymia is suspected to have an impact on treatment compliance and treatment outcome [20].

For several decades there has been a debate on whether alexithymia is to be considered as a trait or a state. According to Freyberger [21], both types of alexithymia can

Prof. F. Stiefel Service de Psychiatrie de Liaison Bugnon 44, CHUV CH-1011 Lausanne (Switzerland) Tel. +41 21 341 1090, E-Mail frederic.stiefel@chuv.ch co-exist: primary alexithymia, considered to be a personality trait and vulnerability factor, and secondary alexithymia, induced by a traumatic event such as a life-threatening disease or exposure to violence. The hypothesis of the two different types of alexithymia, state and trait, has been supported by the different prevalence of alexithymia in medical, psychiatric and healthy populations, but have not been investigated in cancer patients. In the oncology setting some researchers argue that alexithymia might be linked to the onset of cancer, based on the hypothesis of a relationship between personality and cancer and the dysregulating effect of alexithymia on the immune system [22-24]; others suggest that alexithymia might be a reaction to a life-threatening disease. It is important to further investigate alexithymia in cancer patients, for example because of its potential influence on cancer development and progression, on compliance and on underestimation of psychological suffering and psychiatric outcome. The aim of this first review is to summarize the existing literature on this subject and to discuss the clinical and scientific implications of study results.

## Methods

#### Selection of Studies

Studies investigating alexithymia in adult cancer patients from 1972 until January 2010 were eligible for review. Case reports, studies including only benign tumors and articles not published in English were excluded.

#### Study Subjects

Study subjects were cancer patients (aged 18 and over), adult patients with a history of childhood cancer and cancer patients with co-morbid medical illnesses or psychiatric disorders, or healthy controls.

#### Search Methods

MEDLINE, PSYINFO, EMBASE and the Cochrane Library were searched for eligible articles, based on: (1) key word alexithymia, extend all; (2) key word MeSH: affective symptoms, extend all; (3) #1 or #2; (4) key word cancer, extend all; (5) key word MeSH: neoplasms, extend all; (6) #4 or #5; (7) #3 and #6. Filters were used selecting 'only humans' and restricting the search to '1972–current'.

## Data Collection and Analysis

All abstracts were read by two of the authors (V. Forni and A.M.M. de Vries) who decided independently from each other whether the articles could be included in the review. If it was not possible to include or exclude a study based on the abstract, the full text was evaluated before making a decision. In case of doubt a consensus with the last author (F. Stiefel) was planned; however, it was not necessary to organize such a consensus.

The articles included were evaluated by the first author (A.M.M. de Vries) and classified as follows: (A) population, pa-

tient number, characteristics, diagnoses; (B) study design, main research questions, main hypothesis; (C) instruments used to measure alexithymia; (D) statistical analysis performed; (E) outcome and main conclusions.

## Results

## Included Studies

A total of 375 non-duplicated references were identified. First, studies in which alexithymia was not measured were excluded (316), and then articles on patients without cancer (7), with benign tumors (1), children with cancer (4), case reports (2) and book chapters (4). Of the remaining 41 articles, 25 were excluded since they were not written in English, leading to a final selection of 16 studies. Study characteristics and results can be found in the online supplementary table (www. karger.com/doi/10.1159/000330888).

## Study Designs and Concepts of Alexithymia

Twelve studies investigated alexithymia as a primary and four studies as a secondary objective. Different study designs were used, controlled and uncontrolled, prospective and retrospective, cross-sectional and longitudinal. All studies used a concept of alexithymia based on the first definition by Sifneos in 1973 [1]. Only three studies [25–27] assessed all dimensions of alexithymia with their instruments; the different dimensions measured and instruments are listed in table 1.

## Alexithymia and Outcomes

# Sociodemographics and Medical Characteristics of Patients

Five studies focused on cancer patient characteristics and prevalence of alexithymia [26, 27, 32–34]. Of these studies, three found no differences in alexithymia scores between men and women [32–34] and one study reported a higher prevalence in men having survived childhood cancer [27]. One study identified a higher prevalence of alexithymia in older cancer patients [26], which was not confirmed by two other studies [33, 34]. Education was not related to alexithymia in patients with cancer [33]. Cancer patients showed a higher mean score on the Toronto Alexithymia Scale than healthy controls,

Dimensions	DCPR <sup>1</sup>	BVAQ <sup>2</sup>	TAS <sup>2</sup>	SSPS <sup>3</sup>	SPSS-R <sup>3</sup>	MMPI-A <sup>4</sup>
Difficulties identifying and describing emotions	+	+	+	_	+	_
Difficulties distinguishing between emotions and physical sensations of emotional arousal	+	+	+	-	-	-
Reduced imaginative processes	+	+	-	-	+	_
Externally oriented cognitive style	+	+	+	_	+	_
Number of studies included in this review using the instrument	2	1	9	2	1	1

Table 1. Dimensions of alexithymia and their measurement with frequently used instruments

DCPR = Diagnostic Criteria for Psychosomatic Research; BVAQ = Bermond-Vorst Alexithymia Questionnaire; TAS = Toronto Alexithymia Scale; SSPS = Schalling-Sifneos Personality Scale; SPSS-R = Schalling-Sifneos Personality Scale – Revised; MMPI-A = Minnesota Multiphasic Personality Inventory – Alexithymia scale. <sup>1</sup> [28]. <sup>2</sup> [29]. <sup>3</sup> [30]. <sup>4</sup> [31].

while patients with benign tumors did not differ from controls [32]; however, it has to be noted that the number of patients included were between 5 and 8 in this study. One study found that 26% of patients with different types of cancer qualify for alexithymia (no control group) [26]. Finally, in a study comparing colorectal cancer patients to patients with cholelithiasis, the prevalence of high-level alexithymia was 34 and 35%, respectively [27].

## Type and Stage of Cancer

All studies specified the type of cancer, but none compared alexithymia scores of different types of cancer. Eight studies provided information about staging, without including the stages in the analysis [23–26, 33, 35–37]; one specified that curative cases were included [34] and seven provided no information about the stages [19, 22, 27, 32, 38–40].

## Treatment Variables

Information on treatment was mentioned in four studies [25–27, 37]; only van Dijk et al. [27] reported that radiotherapy (yes or no), surgery (yes or no) and occurrence of cancer (second malignancy or relapse) were not associated with the total alexithymia scores. In four studies alexithymia was assessed before cancer diagnosis, but no information was provided about the existence of other diseases or treatments [19, 23, 24, 36]. Two studies specified whether patients were in palliative or curative treatment [33, 35], one that alexithymia was assessed before surgery [38], one that patients underwent surgery and that analyses were controlled for adjuvant therapy [34], and four provided no information about treatment [22, 32, 39, 40].

## Comparison with Controls

Four studies found no statistically significant difference in alexithymia mean scores between patients and controls for patients with breast cancer [35, 36] and for patients with different types of cancer (breast, lung, colon, prostate, ovarian and other) [40]; in one study no differences in alexithymia mean scores were observed in men with medical diseases (such as cancer) and with psychosomatic or psychiatric disorders [22]. Differences between cancer patients and controls were observed for women with breast cancer, who showed significantly higher alexithymia scores [19, 39], and for women with cervical dysplexia, who showed a higher prevalence of alexithymia (42.5%) than healthy women (12.8%) [24]. One study reported that male survivors of childhood cancer had a lower proneness to alexithymia than the healthy population, while females did not differ from healthy controls [27].

## Pain

In one study global alexithymia scores were not related to pain, but the alexithymic factor 'difficulty identifying feelings' predicted experience of pain and was associated with the dimensions of intensity, interference and quality of pain [33]. Dalton and Feuerstein [40] found that chronic non-cancer pain patients had significantly higher alexithymia scores than cancer patients. None of the other studies assessed pain.

## Quality of Life

Quality of Life (QoL) has been found to be influenced by the level of alexithymia in patients with colorectal cancer [34]: patients were divided into a high alexithymia (HA) and a low alexithymia (LA) group; before surgery, QoL was higher in LA patients than in HA patients, but after surgery the results inversed, with HA patients having higher QoL than LA patients. Despite an initial improvement in QoL in the HA group, both groups ended with lower QoL after surgery. The authors hypothesized that the 'reassuring effect' of surgery may be different for LA or HA patients and that QoL was influenced by the level of alexithymia. The study also included a control group of patients with cholelithiasis: in both LA and HA groups, patients improved significantly in QoL after surgery. The authors concluded that the 'reassuring effect' of surgery is different in colorectal cancer patients and cholelithiasis patients and that the influence of alexithymia levels seems not to depend on the severity of the disease.

#### Immune System

A statistically significant correlation has been found between alexithymia and certain lymphocyte clusters; the authors concluded that alexithymia seems to favor the development of cervical dysplasia through influence on the immune system [23, 24].

## Psychopathology

In 1989, Todarello et al. [19] found no correlation between alexithymic traits of cancer patients and psychopathology (anxiety, phobias, obsessive compulsions, psychosomatic disorders, depression or hysteria), but several subsequent studies show different results. In one study both depression and anxiety were significantly associated with HA mean scores in cancer patients, but alexithymia was only found to be positively correlated with anxiety, explaining 12.6% of its variance [37]. In another study depression and anxiety of breast cancer patients were positively correlated with total alexithymia scores at baseline and at 6-month follow-up [38]. Variance in follow-up alexithymia was explained by baseline alexithymia (22%) and changes in depression (12%) and anxiety (4%). A third study found that in cancer patients meeting the Diagnostic Criteria for Psychosomatic Research, alexithymia was correlated with higher avoidance and depression, lesser well-being, more physical symptoms, decreased leisure activity, difficulties of adjustment, lower interpersonal support and more cancer worries [25].

## Conclusions on Alexithymia and Outcome

Regarding the results of studies on alexithymia and outcome, several hypotheses can be drawn. Studies on the impact of sociodemographics showed inconsistent results due to large variations in study design. Nonetheless one might conclude that in cancer patients alexithymia seems not to vary between men and women [33, 34, 36] and between patients with different levels of education [33]. In contrast, alexithymia might have a different development in boys or girls facing cancer [27]. Not enough is known about a potential relationship between type and stage of cancer, treatment variables and alexithymia. In studies comparing the prevalence of alexithymia in cancer patients and controls, inconsistent results are also reported, but pain, which is frequent in cancer patients, seems to be related to alexithymia [33, 40]. Furthermore, alexithymia might influence QoL in patients with colorectal cancer [34]. One group demonstrated that alexithymia seems to favor the development of cervical dysplasia through influence on the immune system [23, 24]. Finally, alexithymia is found to correlate with psychopathology, such as anxiety or depression [25, 37, 38]. No study addressed the consequences of alexithymia for patients with cancer with regard to treatment outcome.

#### Alexithymia: Trait or State?

#### Primary Alexithymia

Nine studies did not address the question of primary alexithymia [25-27, 33-35, 37, 39, 40]. Two studies concluded that alexithymia could not be identified as a predisposing factor for the development of cancer either in women with breast cancer [36] or in men developing different kinds of cancer over a period of 10 years [22]. Five studies, conducted by three different research teams, found that alexithymia is a trait that could be part of a cancer-prone personality [19, 23, 24, 32, 38]. One group [19, 23, 24] measured alexithymia in apparently healthy women without physical symptoms prior to routine gynecological cancer screening. By comparing those who were affected by cervical dysplasia with those found to be healthy, the authors concluded that alexithymia is a personality trait and that it plays a role in the development of cervical dysplasia. Carta et al. [32] replicated these results using a very small sample size (n = 8, n = 5). The third research team [38] investigated the absolute and relative stability of alexithymia from the day before surgery for a first cancer to a follow-up at 6 months; they found no absolute but a relative stability of alexithymia, supporting the view that alexithymia is a personality trait rather than state-dependent.

The distinction between primary and secondary alexithymia, its possible co-existence and its absolute and relative stability is especially important for the oncology population, for which a cancer-prone personality has been hypothesized. While a 'trait' is a stable characteristic of personality that cannot be specific to a somatic disease, the cancer-prone personality characteristics are by definition specific. Therefore the cancer-prone personality traits would have to be distinct from alexithymia, at least with regard to some dimensions (e.g. difficulties identifying or expressing certain feelings, such as anger, but not others, as has been hypothesized) [23, 41].

## Secondary Alexithymia

Ten studies did not address the question of secondary alexithymia [19, 22–26, 33, 36, 37, 39]. Six studies concluded that alexithymia could not be considered as secondary based on their data [27, 32, 34, 35, 38, 40]. Of these studies, three [34, 35, 40] found no difference in alexithymia scores between cancer patients and healthy controls. One study [27] found a gender effect for the influence of childhood cancer on alexithymia scores in adults; whereas female survivors showed no differences, male survivors were less alexithymic than the healthy population. The fifth study [38] considered that alexithymia could not be state-dependent because of its relative stability. Finally, one study concluded that alexithymia was not secondary, since its onset was observed prior to the development of cancer [32].

## Conclusions on Primary and Secondary Alexithymia

In conclusion, although some studies did not identify alexithymia as a predisposing factor for the development of cancer, several others did; especially the distinction between absolute and relative stability has provided information suggesting that alexithymia might be a personality trait in patients with cancer. On the contrary, none of the studies supported the existence of secondary alexithymia in cancer patients. Limitations in study design, however, do not allow firm conclusions to be drawn on the prevalence of primary and secondary alexithymia (or the co-existence of both) in the cancer population.

## Discussion

The small number of studies included in this review, some of them conducted by the same group of researchers, demonstrates a feeble interest for the investigation of alexithymia in cancer patients. This may be due to the large evidence for biological origins of this disease; for other disorders, such as psychosomatic or psychiatric disorders, the origin is less clear and interest in psychologi-

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cal risk factors, such as alexithymia, is stronger. However, as with any other disease, biological factors do not exclude an influence of psychological factors contributing to onset or development of the disease – or to outcome, including psychosocial adjustment – as illustrated by studies on alexithymia in the development of cervical cancer, which is known to be related to stress [23, 24] and how stress is perceived and coped with [25].

Studies on alexithymia in cancer are methodologically problematic, since important information which might have an effect on the prevalence of alexithymia is often lacking - such as identification of stages of cancer, type of treatment and existence of alexithymia before the development of cancer - and designs often do not include a control group or show weaknesses concerning the measurement of alexithymia. This last point is illustrated by the fact that alexithymia, as trait or state, is not perceived by the patient but measurement is mainly based on selfreported questionnaires. Interestingly, a recent controlled study with heart-transplanted patients showed that the concept of emotional inhibition, a conscious emotionfocused coping strategy, partly overlaps with a self-report measurement of alexithymia but not with an observerrated measurement of alexithymia [42]. The results suggest that emotional inhibition and alexithymia are distinct phenomena even though they share certain features. Alexithymia is a difficult concept to measure because of dimensions such as 'impoverished fantasy life' - which has been found to be linked to social desirability which can influence answers [29] - and because of the difficulties associated with the measurement of personality constructs. A multidimensional measurement might therefore be necessary to assess the entire construct. As new methodologies and experimental approaches to measure alexithymia are used in other fields [43], this should also be done in oncology.

Most studies focus on the prevalence of alexithymia in cancer patients compared to healthy controls and produce contradictory results. While alexithymia has been frequently investigated in patients with chronic pain [10, 40], especially in patients with pain as a somatoform disorder [11], only one study [33] addressed the issue of pain and alexithymia in patients with cancer, reporting that the difficulty of alexithymic subjects to identify emotions predicted pain and some aspects of pain perception. More recently, the same authors published a study adding evidence to the importance of the role of alexithymia in predicting the variance of pain intensity, pain interference and pain quality in patients with cancer [44]. Independently of intervention group (6 months psychological

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intervention or control group) or time, alexithymia was found to be related to a more severe pain experience. Pain should therefore be systematically included in studies on alexithymia.

With regard to other outcomes, only one study [34] addressed the possible influence of alexithymia on QoL, indicating a different outcome for QoL of cancer patients undergoing surgery depending on baseline scores of alexithymia; this study concluded that surgery had a more reassuring effect in patients with higher alexithymia at baseline, explaining their higher QoL after surgery. Two studies [23, 24] investigating the possible role of alexithymia on the immune system found that alexithymia may be a mediating factor with regard to stress, coping with stress and development of some types of cancer. In addition, several studies indicate the potential impact of alexithymia on psychopathology, adjustment to disease and other important outcomes for patients with cancer, such as leisure activities, interpersonal support or cancer worries [25, 37, 38]. Again, treatment outcome, compliance and psychosocial outcome should be systematically assessed in studies on alexithymia in cancer patients, since its role on different outcomes might have important clinical implications.

Because of the potential role of alexithymia in cancer development, one of the most important questions concerning alexithymia in the cancer population is whether it is a state or a trait; a majority of the studies were not designed to answer this question or could not answer it because of methodological weaknesses. This is a difficulty not limited to research concerning alexithymia and cancer, but is also found with other personality constructs in medical and psychiatric disorders. While some studies [19, 23, 24, 32, 38] concluded that alexithymia in cancer patients might be a personality trait, others [22, 36] found that primary alexithymia was not a predisposing factor for the development of cancer. Since there may exist an absolute and relative stability of the construct, as has been demonstrated in research on alexithymia in patients with depression [45, 46], this distinction should be addressed in future studies on alexithymia in oncology.

With regard to secondary alexithymia – considered as a state and a reaction to a traumatic event, such as cancer – six studies [27, 32, 34, 35, 38, 40] concluded that alexithymia was not secondary, but their design does not allow confirmation of this statement. For example, one study [32] showed that secondary alexithymia was not present since alexithymia existed prior to the development of cancer; however, the existence of primary and secondary alexithymia is not mutually exclusive. Despite the fact that alexithymia, especially secondary alexithymia, is of clinical importance for the psychiatric and psychotherapeutic approach to cancer patients, the literature on this subject is still very scarce. As noted in a recently published tribute to the work of the co-founder of the concept of alexithymia, John C. Nemiah, the importance of life events in the development of psychological processes intimately related to the formation of psychological or bodily symptoms is widely recognized, but investigating this process has proven to be challenging [47]. A recent study with cancer patients has shown that a multicomponent psychological intervention was able to reduce alexithymia [44], and other studies are currently under way to further evaluate whether psychotherapeutic approaches can influence alexithymia in cancer patients [48].

Since the role and the biological and psychosocial consequences of alexithymia might vary across the medical and psychiatric populations, there is a need for research specifically investigating alexithymia in cancer; in this respect, research on specific somatic diseases, such as dermatology, or on single psychological aspects, such as work-related stress, has provided valuable insight into the role of alexithymia [49, 50].

In conclusion a clear need exists for prospective and controlled studies – based on psychometric instruments which reflect the clinical concept – addressing questions which surpass the sole issue of prevalence of alexithymia in cancer patients. Some evidence on alexithymia and its role in or impact on cancer development and other dimensions that are intrinsically linked to cancer, such as psychosocial variables, has been produced during the past decades and calls for further investigation.

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The authors declare no potential conflicts of interest.

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