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# EXPRESSING DISTRESS IN PATIENTS WITH ADVANCED CANCER

Literature  
review

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## Keywords

Network between emotions and topics,  
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Advanced stage cancer,  
Disclosed emotions

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## JEL Classification

I12; I23; I31

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## Abstract

*Negative emotions (distress) are recognized as part of the psychological profile of patients diagnosed with advanced stage cancer. However, most patients are not accustomed to verbalize feelings towards their physician, and generally towards family and medical care personnel. The purpose of this paper is to analyze the expression of emotions by patients in advanced stages of cancer, respectively the means by which they get to express emotions. To this respect, we identified the most common types of emotions expressed, or metaphors used by patients to describe their emotions and topics that trigger emotions. Words and phrases most commonly used are in relation to: fear, anxiety, depression, guilt, negligence, concern. They are uttered in order to depict the network created between disclosed emotions and topics on health status, symptoms, adverse effects and therapeutic choice, patient privacy, and social and family issues.*

## Introduction

Negative emotions (distress) are recognized as part of the psychological profile of patients diagnosed with advanced stage cancer, revealed by verbal or non-verbal communication (Zabora et al., 2001; Stark et al., 2002; Ryan et al., 2005).

World Health Organization defined palliative care (WHO, 2002) as an on-going “approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment, and treatment of pain and other problems – physical, psychosocial and spiritual”.

Terminal cancer means having an incurable cancer with no chance for the patient to be cured and it will soon lead to death.

The occurrence and long-term persistence of negative emotions, like anxiety and depression, in advanced cancer patients may influence their perception on life quality (Grabsch et al., 2006). Psychological distress, induced especially by those two types of emotions, was related to 27% increased risk of cancer death in a large sample size from the Scottish Health Survey (SHS) which is periodically performed, every 3 to 5 years (Chida et al, 2008; Hamer et al., 2009). In Hamer study performed on 12,880 patients vs. 337 persons in the control group, there was a strong correlation between distress and cancer site only for lung cancer mortality.

However, most patients are not accustomed to verbalize feelings towards their physician, and generally towards family and medical care personnel.

A consequence of distress is the dropout phenomena from cancer or depression treatment due to fatigue, delirium, cognitive impairment, side-effects from antidepressant drugs and chemotherapy (Wells et al., 2011). The qualitative research may endeavour to define the adherence to treatment or its lack, depending on gender, age, race, socio-economic status.

## Aim of the study

The purpose of this paper is to analyze the expression of emotions by patients in advanced stages of cancer, respectively the means by which they get to express emotions. To this respect, we identified the most common types of emotions expressed, or metaphors used by patients to describe their emotions and topics that trigger emotions. The method used to explore the patients’ “inner voice” is the qualitative research by semi-structured interviews.

## *Intrapersonal and Interpersonal Emotions*

The change in perception of body image in patients with low rectal cancer that benefit of a permanent stoma after abdominoperineal resection can

negatively influence the quality of life (QoL) (de Campos-Lobato et al., 2011). The depth of the effect of physical aspect changes is more profound in breast cancer women (Adams et al., 2011).

In young adult cancer patients, distress was correlated negatively to family and social support (Kumar and Schapira, 2013) with a frequent use of “dejected” and “frustrated”.

Although it was not found any difference in the severity of emotions reported to the financial status, people with lower economic status did manage to express more often their distress, and thus, to receive and perceive more empathy from their oncologists than those with a higher economic status (Pollak et al., 2010).

## *Topics-Related Emotions*

Narrative communication allows to unveil the deep feelings of cancer patients. The importance of this status is to verbalize those emotions, especially the negative ones. Some studies have shown a longer survival in breast cancer women while they have been psychologically supported. Words as “worried”, “afraid”, “depressed”, “nervous” expressed negative emotions like anxiety, fear, depression, anger.

In single young adult cancer patients, the family role in caregiving and psychological support helps their child to cope with the cancer, to reduce the feelings of profound loneliness and emotional distress (Kumar and Schapira, 2013).

Some reasons for treatment discontinuity are offered by the patient concerns related to cancer – emotional strike while diagnosis or prognosis disclosure, and the requirement to be adherent to treatment –, rising care demands, social and financial issues, employment, depression treatment-dissatisfaction, informational – misunderstandings, instrumental (including transportation problems), cultural (language communication problems) and discrimination from providers, and health care team problems (Wells et al., 2011; Anderson et al., 2008).

The “guilt” as a result of introspection is retrospective as well as prospective search. The patient expressed guilt related to circumstances like his negative thoughts or actions – “have done something wrong or evil” (Puchalski, 2012).

Other patients felt that having cancer made them to “desire to be closer to God, deepening relationship with Him” (Puchalski, 2012).

Distress was seen when speaking about symptoms and functional concerns, and experiencing health care system support (Anderson et al., 2008).

Irrespective of gender and age, any major physical changes determines negative distress. While the patient chooses a certain treatment in order to survive, the impact might be reproduction, sexual function or identity self-perception (Kumar and Schapira, 2013).

In about health of oncological patients, the distress was very strongly perceived while they got the medical diagnosis and/or were informed about the treatments (Anderson et al., 2008).

The assessment of depressed affect may outline the maladaptive behaviour in cancer patients, as self-neglect or abusive behaviours directed towards the loved ones (Massie, 2004).

Patients felt hopeless (Hagerty et al., 2005) when they perceived the doctor to be nervous or uncomfortable, or when the doctor used technical communication, euphemisms and giving the good news before the bad ones. Their “not hopeful state” was associated to future health and life, and to their perception upon unmet needs and value of life (Puchalski, 2012).

### Discussion

In case of cancer, the adaptation to this life-threatening disease associated with decreased quality of life is shaped by a network that comprises family and friends that come in with a positive emotional support, and the physician and each of the health care team members that encourage and provide information about the disease every time the patient needs.

Just as for cancer patients in advanced stage, terminal cancer patients openly expressed their distress in relation to death and dying in very rare situations.

Patient concerns rise from a combination of barriers that yields a negative influence on patient behaviour and doctor-patient relationship (Wells et al., 2011; Anderson et al., 2008).

A complex medical care pattern recognizes the oncologic patient as a whole person with a history of chronic illness that intermingles in a unique manner each and all biological, psychological, social, and spiritual dimensions (Delgado-Guay, 2008). Psychosocial and spiritual inquiries that contour the bio-psycho-socio-spiritual model should be part of the same frame arising from the doctor-patient relationship (von Gunten and Higginson, 2006).

The medical team should receive training in order to make the differences between experience, expression, and control of anger (Zabora et al., 2001).

Palliative medicine is prepared to address both patient and family needs, social and spiritual demands, and emotional distress (Engel 1977; Sulmasy, 2002).

### Conclusion

Words and phrases most commonly used are in relation to: fear, anxiety, depression, guilt, negligence, concern. They are uttered in order to depict the network created between disclosed emotions and topics on health status, symptoms,

adverse effects and therapeutic choice, patient privacy, and social and family issues.

The empathic behaviour on the part of the oncologist is stimulated by the multiple expression of patients' distress, as seen in low-income patients, who also perceive a more empathic attitude from their physicians.

The endeavour to explore the inner behind the chronic disease will reveal thoughts, motivation, attitudes and finally the personal touch on the patient behaviour.

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### References

- [1] Adams E, McCann L, Armes J et al. 2011. The experiences, needs and concerns of younger women with breast cancer: a meta-ethnography. *Psycho-Oncology*. 20:851–861.
- [2] Anderson W.G., Alexander S.C., Rodriguez K.L., Jeffreys A.S., Olsen M.K., Pollak K.I., Tulskey J.A., and Arnold R.M. 2008. “What concerns me is...” Expression of emotion by advanced cancer patients during outpatient visits. *Support Care Cancer* 16(7): 803–811. doi:10.1007/s00520-007-0350-8.
- [3] Chida Y, Hamer M, Wardle J, Steptoe A. 2008. Do stress-related psychosocial factors contribute to cancer incidence and survival? A systematic quantitative review of 40 years of inquiry. *Nat Clin Pract Oncol*;5:466–75.
- [4] de Campos-Lobato LF, Alves-Ferreira PC, Lavery IC, Kiran RP. 2011. Abdominoperineal resection does not decrease quality of life in patients with low rectal cancer. *Clinics*. 66(6):1035-1040.
- [5] Delgado-Guay MO, Bruera E. 2008. Management of pain in the older person with cancer part 1. *Oncology*; 22(1): 56–61.
- [6] Engel GL. 1977. The need for a new medical model: a challenge for biomedicine. *Science*; 196: 129–136.
- [7] Grabsch B, Clarke DM, Love A, McKenzie DP, Snyder RD, Bloch S, Smith G, Kissane DW. 2006. Psychological morbidity and quality of life in women with advanced breast cancer: a cross-sectional survey. *Palliat Support Care*; 4:47–56. [PubMed: 16889323].
- [8] Hagerty R.G., Butow P.N., Ellis P.M., Lobb E.A., Pendlebury S.C., Leigh N., MacLeod C.,

- and Tattersall M.H.N. 2005.Communicating With Realism and Hope: Incurable Cancer Patients' Views on the Disclosure of Prognosis. *J Clin Oncol* 23:1278-1288.
- [9] Hamer M., Chida Y., Molloy G.J. 2009. Psychological distress and cancer mortality. *Journal of Psychosomatic Research* 66 (3):255–258.
- [10] Kumar A.R., and Schapira L. 2013.The impact of intrapersonal, interpersonal, and community factors on the identity formation of young adults with cancer: a qualitative study. *Psycho-Oncology* 22: 1753–1758. DOI: 10.1002/pon.3207.
- [11] Massie MJ. 2004. Prevalence of depression in patients with cancer. *J Natl Cancer Inst Monogr*; 32: 57–71.
- [12] Pollak K.I., Arnold R., Alexander S.C., Jeffreys A.S., Olsen M.K., Abernethy A.P., Rodriguez K.L., and Tulskey J.A. 2010.Do patient attributes predict oncologist empathic responses and patient perceptions of empathy? *Support Care Cancer* 18(11): 1405–1411. doi:10.1007/s00520-009-0762-8.
- [13] Puchalski C.M. 2012.Spirituality in the cancer trajectory. *Annals of Oncology* 23(3): iii49–iii55, 2012. doi:10.1093/annonc/mds088.
- [14] Ryan H., Schofield P., Cockburn J., Butow P., Tattersall M., Turner J., Girgis A., Bandaranayake D. & Bowman D. 2005.How to recognize and manage psychological distress in cancer patients. *European Journal of Cancer Care* 14:7–15.
- [15] Stark D, Kiely M, Smith A, Velikova G, House A, Selby P. 2002. Anxiety disorders in cancer patients: their nature, associations, and relation to quality of life. *J Clin Oncol*; 20:3137–3148. [PubMed: 12118028].
- [16] Sulmasy DP. 2002.A biopsychosocial-spiritual model for the care of patients at the end of life. *Gerontologist*; 42(3): 24–33.
- [17] von Gunten C.F., Higginson I. 2006.The Future of Palliative Medicine. In: *Textbook of Palliative Medicine*. Bruera E., Higginson I.J., Ripamonti C. and von Gunten C. (eds.). New York: CRC Press, Taylor & Francis Group; pp:77-82.
- [18] Wells A.A., Palinkas L.A., Qiu X., Ell K. 2011.Cancer patients' perspectives on discontinuing depression treatment: the “drop out” phenomenon. *Patient Preference and Adherence* 5: 465–470.
- [19] WHO (2002). National cancer control programmes: policies and managerial guidelines, 2nd ed. Geneva, World Health Organization.
- [20] Zabora J., BrintzenhofeSzoc K., Curbow B., Hooker C. & Piantadosi S. 2001.The prevalence of psychological distress by cancer site. *Psycho-Oncology* 10:19–28.