original article

Is it ethical to advise people to "fight" cancer?

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In January 2014, in his article "Heroic Measures", the New York Times columnist, Bill Keller ignited a fervent debate over how much fight one is willing and should throw into a battle with cancer. The column explored the use of social media by Lisa Bonchek Adams- a women in her thirties suffering from terminal cancer and currently receiving palliative care. Adams chose to come public with detailed accounts of her treatments, her daily struggles and everyday challenges in thousands of tweets and dozens of blogposts. In a rather irreverent tone, Keller notes that "a rapt audience of several thousand follows her unsparing narrative of mastectomy, chemotherapy, radiation, biopsies and scans, pumps and drains and catheters, grueling drug trials and grim side effects, along with her posts on how to tell the children, potshots at the breast cancer lobby, poetry and resolute calls to 'persevere'." Whether Adams is a fighter, clinging to every straw of hope in prolonging her survival or whether the posts are her way of coming to terms with the implacable prognosis is one of the fervent debates around her case. Still, these controversies spurred by the comments of Keller bring to the forefront the pressing questions for psycho-oncology : "What does adaptive coping with cancer mean?", "Does personality in general and a fighting spirit in particular play a role in cancer progression and survival?" "Is promoting resilient psychological traits useful and can they increase the chances of longer survival?"

Attempts to address these questions can be traced back three decades when research on the effect of personality and coping grew in popularity. Thus, research showed that individuals with cancer who displayed a fighting spirit survived longer than those who displayed stoic, helpless or accepting attitudes (e.g. Greer, Morris, & Pettingale, 1979; Greer, Morris, Pettingale & Haybittle, 1990; Morris, Pettingale, & Haybittle, 1992; Pettingale, 1984; Tschuschke, Hertenstein, Arnold, Bunjes, Denzinger, & Kaechele, 2001). Fighting spirit describes the optimistic framing of cancer as a challenge rather than a burden and the determination of fighting and not allowing the disease to take control over the person's life (cf. Coyne & Tennen, 2010). Other traits associated with fighting spirit seemed to prolong survival. Denial - in the form of minimising the impact of cancer (Garssen, 2004, p. 328)- is associated with longer survival in metastatic melanoma and in metastatic breast cancer (Butow, Coates, & Dunn, 1999; Butow, Coates, & Dunn, 2000). Optimism – in opposition to pessimism- was proven as a helpful trait and was associated with longer survival in younger patients recieving palliative radiation treatment (Schulz, Bookwala, Knapp, Scheier, & Williamson, 1996). Even when fighting spirit did not seem to contribute to disease-free survival, its reversed counterparts, namely hopelesness and/or helplesness still played a negative role on survival rates (Watson, Homewood, Haviland, & Bliss, 2005). Finally, the work of Lydia Temoshok suggested that there might even be a "cancer-prone" (type C) personality, characterized by supression of emotions, self-sacrifice, self-blaming and need for cooperation, which would correlate with the

progression of different cancer types (Temoshok, 1987; Temoshok et al., 1985). Briefly, the figure of the succesful cancer survivor, as depicted in the psycho-oncological literature seemed to be a bold, outspoken and optimistic person, highly commited to defeating cancer.

However pervasive this steretypical cancer fighter might be, a closer analysis of research regarding the connection between positive personality traits and cancer reveals that such a relation is, in fact, shaky (Coyne & Tellen, 2010). A large systematic review found little convincing evidence that fighting spirit and helplesness/hopelessness would affect survival (Petticrew, Bell, & Hunter, 2002). Similar conclusions were reached by Nakaya et al. (2010) who in a large prospective cohort study showed virtually no association between personality traits (extraversion and neuroticism) and breast, corpus uteri, ovary or prostate cancers (N = 4631 with a follow-up span of 30 years). Watson, Haviland, Greer, Davidson, and Bliss (1999) failed to prove an effect of fighting spirit over survival, even though they did find a significant risk of death at 5 years in women scoring high on depression, helplessness and hopelessness scales. Finally, another longitudinal study found no evidence of an association between the incidence of breast cancer and personality traits such as anxiety, depression, optimism, or Type C personality traits (Bleiker, Hendriks, Otten, Verbeek, & van der Ploeg, 2008). What these studies have in common is their carefully planned prospective designs (or inclusion of longitudinal studies only- in Petticrew systematic review), recruitment of large samples and rigorous control of confounds.

Despite grey evidence, media and promoters of alternative medicine repeatedly stressed the importance of displaying a fighting attitude and other personality traits that would presumably increase the chances of a favorable prognosis. Suppose that these psychological traits predict not only psychological adjustment to cancer but also disease free survival. For cancer sufferers, not having them would mean a psychological incapacity of choosing the "right" over the "wrong" thinking at the expense of precious months or years of survival. Put another way, it would send the message that "brave and good people defeat cancer and that cowardly and undeserving people allow it to kill them" (Diamond, 1998, p. 52, cited in Coyne, Stefanek & Palmer, 2007). Also, the state-of-the-art in psycho-oncological research tells little as to whether these personality traits have cumulative effects in predicting cancer onset and progression. Also, it is not known if more protective traits can compensate for these 'bad' ones. Hence, after a detached, scientific analysis of the available data, what advice should we give to people facing the burden of cancer? Should they strive to keep an optimistic, fighting stamina? Is psychological adjustment a good-enough outcome or should they hope to also increase survival?

Although these questions bear considerable ethical dilemmas for professionals, the idea that the mind must have some control over the body is appealing. Not surprisingly, psychosocial interventions aimed at fostering adaptive attitudes that would, subsequently, increase psychological adjustment and (why not?) disease free survival were welcomed. Probably the most well-known and the most controversial study of the effects of psychotherapy on cancer survival rates suggests that group intervention aimed at exploring ways of coping with cancer and expressing feelings not only enhanced better psychological outcomes but also led to an average of 18 months longer survival in women receiving the intervention compared to the control group (Spiegel, Bloom, Kramer, Gottheil, 1989). Similar interventions seemed to increase survival at 6 years follow-up (Fawzy et al., 1993) and even at 10 years follow-up (Fawzy, Canada,

& Fawzy, 2003). Overall, according to Spiegel (2012), there were 8 controlled trials showing some survival benefits (besides psychological ones) of psychosocial interventions for different cancers and across cancer stages compared to 6 trials showing no benefits in terms of survival (3 of them did not showed improvement in psychological outcomes either). Still, positive findings largely come from underpowerd studies with poor adherence to the Consolidated Standards of Reporting Trials (CONSORT) standards, with no aprori asumptions regarding survival, no intention-to-treat analyses as well as some inappropriate data analyses, all of which inflated the probability of type 1 error (Coyne et al., 2007). Additionaly, claims regarding possible psychoneuroimmunological mechanisms through which psychosocial interventions would positively impact immunological functioning in cancer, were not investigated in these trials and therefore cannot be deemed plausable. On the contrary, more rigurously conducted reviews were less likely to find positive effects of psychosocial interventions on survival and suggest untested mechanisms of influence (Lepore & Coyne, 2006).

Putting it all together, the evidence regarding psychological traits associated with cancer and the presumable effects of psychosocial interventions on survival suggests a preccipitation of psycho-oncolgy to claim territories which are yet far from being conquered. This leaves room for the aggressive marketing of psychological ' recepies' to fight cancer in the ' right' way, in lay publications and in some scientific circles alike. The struggles of cancer patients to follow these scripts for success can be extremely burdening and may have paradoxical effects. Trying to be optimistic when one doesn't feel like, displaying the famous ' fighting attitude' in order to meet the expectations of self and the others, struggling not to feel anxious or depressed even if the person is collapsing on the inside can lead to loosing confidence in one's ability to influence the course of cancer and place a huge baggage of undeserved and unjustified guilt. In this context, Spiegel's affirmation, although very well intended, that 'in our desire to be respected members of the oncology community, we have often minimized a natural ally in the battle against cancer – the patient's physiological stress-coping mechanisms'(Spiegel, 2012, p 588) seems rather ironic. Thus, as Coyne et al. (2007) points out, if psychological interventions do not prolong survival, acknowledging it would remove some of the blame felt by persons with cancer.

These issues should lead to a serious debate as to future direction of psycho-oncology. If it strives to still search for potential benefits of psychosocial interventions on survival, more attention should be devoted to designing adequately controlled trials . Even if interventions and personality traits do prove to influence survival, the field faces the challenge of finding good answers for the questions regarding the ethical implications of such discoveries. Should patients with cancer prone personality traits be advised to enroll in therapy? Would cancer development be more under their personal control and if so, could they be held (at least partially) responsible for the outcomes? Until we find answers to such provocative questions, the field should devote itself to understanding the mechanisms by which these interventions influence psychological outcomes. Also they should focus on refining and tailoring existing interventions as to maximize their potential psychological and psychosocial benefits that may seem, at a superficial analysis, less intriguing or challenging. Tackling patients' emotional distress, boosting their social functioning and self-management skills (psychological

management of pain, fatigue, nausea etc.), facilitating a better quality of life and quality of death should be regarded as being equally important psychosocial outcomes as prolonging survival.

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