



Psychological support of esophageal cancer patient?

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Abstract: Important questions are still open about psychological aspects in esophageal cancer (EC) and about the related psychological support. How to cope with the cancer diagnosis and poor prognosis: a psychological counselling may be a valid option to personalize the communication to patients with a poor prognosis. How to cope with long chemoradiotherapy: after neoadjuvant therapy, patients know that curative process is not completed, and they perceive the severity of the neoadjuvant side effects, considering themselves “fragile” and far from a healthy condition before the major surgery they are going to undergo. Therefore, this is a particularly crucial point when psychological support may be useful. How to cope with change of nutritional habits: esophagectomy for cancer strongly impairs nutritional function in the early postoperative period and feeding Jejunostomy impairs emotional function. How to cope with sleep disturbances: most cancer patients report disturbed sleep after cancer diagnosis and/or following cancer treatment. Psychological intervention aims to identify underlying concerns worsening sleep quality. How to cope with postoperative complications: the occurrence of such complications reduces patient’s satisfaction and has a negative effect on doctor-patient relationship. How to cope with long-term functions impairment: EC patients need a plan for the future.

Keywords: Psychological support; esophageal cancer (EC); esophagectomy; quality of life

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Esophageal cancer (EC) and psychological status

EC is associated with poor prognosis and significant impact on patients’ habits and wellbeing. Overall, cancer diagnosis and treatment deeply affect both physical and psychological status (1-5). Patient commonly experience high levels of stress and anxiety, depressive and psychosomatic symptoms (1). The direct consequences of this psychological imbalance may be the adoption of maladaptive coping strategies (1,6-8) that are associated with poor clinical and survival outcomes (9-12). In patients with lung cancer, an increased risk of mortality has been related to depression (12), which may arise in

around 40% of cancer patients (13). In patients with EC, a recent study showed an increased risk of mortality in patients with new-onset psychiatric morbidity following esophagectomy (14). The importance of the psychological status in cancer patients is underlined by a comprehensive review study focused on breast cancer, which suggested an association between cancer outcome and some psychological factors (including emotion constrain and depression) (15). In patients with EC, symptoms and surgical treatment (with a not-negligible morbidity rate) often result in life-altering consequences (such as fatigue, eating difficulties, pain and impaired bowel functions) that deeply affect quality of life (16,17). For all these reasons, psychological status may be

considered a key variable in EC patients' outcome.

EC and health related quality of life (HRQL)

Esophagectomy is part of the standard treatment for early and locally advanced EC, but this surgical intervention is also associated with high risk of severe postoperative morbidity (18). Centralization of EC surgery can overcome this issue thanks to the high experience and expertise of the surgical staff, resulting in decreased morbidity and mortality in high volume centers (18,19). Nevertheless, the surgical aspects of esophagectomy can affect HRQL (16,17) which has arisen as an important outcome measure.

According to WHO, health is a state of complete wellbeing that goes beyond the mere absence of disease/infirmity, while quality of life is "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (20,21). Thus, HRQL refers to patient's perceived health (22).

The definitions of health and HRQL permit a global care, and all patients' features should be considered in order to achieve a good condition. Nowadays, patients are frequently asked to evaluate their condition and to express their satisfaction, becoming active participants in the cure process and in its effects on lifetime. Asking patients to participate in this process entails the intervention on all barriers to a "health condition", taking care of additional aspects (i.e., psychological and social) beyond physical status.

In EC patients several aspect of HRQL are impaired at the different stages of the disease. A systematic review showed that global HRQL was significantly worsened in the early postoperative period after esophagectomy (23). Moreover, a prospective study suggested that postoperative pain (and its relief) was related to early postoperative HRQL (24). Several peculiar, and apparently secondary, aspect of EC management may influence HRQL outcomes. As example, the request of hypnotics during ICU and surgical ward stay (as indirect measure of sleep disruption) has been associated with poor postoperative HQRL (25). Furthermore, patients receiving jejunostomy reported poor emotional function at 3 months after surgery (26). Therefore, we believe that candidates to esophagectomy for cancer mat benefit from psychological support.

EC and patients' psychological needs

Thus, health status, HRQL and psychological well-being

are closely connected, and an inclusive treatment of EC should focus, beside on the results of surgery, chemotherapy and radiotherapy also on HRQL and psychological well-being. These two domains may be considered the starting point when the patients is taken in charge by and oncological multidisciplinary team since they may prepare the patients to cope with the diagnosis and challenges that the EC treatment pose.

Thus, the main questions are, what are EC patients' needs? And can we consider these problems reasons to provide for psychological support for EC patients? Using a search procedure through combined terms (EC; psychological well-being; quality of life) on this topic to identify specific articles concerning EC patients' needs, several key points arose. These relevant questions are still open about psychological aspects in EC and about the related psychological support:

- (I) How to cope with the cancer diagnosis and poor prognosis;
- (II) How to cope with long chemoradiotherapy;
- (III) How to cope with esophagectomy in term of:
 - (i) Change of nutritional habits;
 - (ii) Sleep disturbances;
 - (iii) Postoperative complications;
 - (iv) Long term functions.

How to cope with the cancer diagnosis and poor prognosis

After a cancer diagnosis has been reached, the patient should receive complete information about his/her disease and its consequences (including life changes, treatments and prognosis), and this is often the first challenge for the patients and for the health providers (27). Thus, focusing on health communication is necessary in order to understand patient's representation of illness and therapy. In fact, often patient's limited knowledge of cancer diagnosis and treatment options can couple with fear and lead to misunderstandings (28). Attention to communication can also make health providers enhance patient's compliance and adherence to scientific recommendations. Diagnosis of neoplasm communication is a critical situation, so much that physicians should not ignore the importance of personalized emotional support involving patient's family, too (29,30).

As a matter of fact, providing information enhances patient's ability to cope with his/her illness (by reducing personal uncertainties and raising a sense of personal control) (31) and adherence to treatments (by offering an

overlook of procedures, timing and consequences) (32,33). However, an effective communication should take into account patient's point of view, including information needs, cultural level and their satisfaction on received information (34,35). These aspects seem to be relevant throughout the whole therapeutic process, especially at the diagnosis, as they are often recalled by survivors with emphasis (36). Despite their wish to be informed about all aspects of disease and treatment, it is noteworthy that health care providers are often not able to fulfill such information needs (31,37-39).

The importance of a good communication is even more stressed in patients receiving care for aggressive neoplasms (including EC), because of the severe prognosis (40,41) and the drawbacks of the surgical treatments (i.e., high morbidity and reduced HRQL) (23-25,42). EC patients would like to receive information on both short-term (surgical side effects) and long-term (recovery, quality of life and survival) issues (32,43,44), but the communication is hampered by clinicians who underestimate patients' needs or find stressful the communication of uncertain prognosis (45).

Perceived receipt of information has been investigated mainly in North-European EC patients undergoing esophagectomy, whereas little is known in South Europe or in EC patients before final decision on treatment strategy (32,45). A recent Italian study underlined the importance of: (I) experienced health care providers (satisfaction on information about treatment was lower in patients with no previous contact with a tertiary referral center); (II) psychological counselling to patients with a poor prognosis (satisfaction on the information about disease was lower in candidates for palliative treatment); and (III) provision of personalized information (global quality of life and social functioning were lower in patients receiving written information). In fact, patients should have the possibility to ask question and to be reassured.

How to cope with long chemoradiotherapy

One of the treatment options for esophageal tumors is chemoradiotherapy which can be indicated with curative intent in neoadjuvant and/or adjuvant settings or in palliative treatment (46). There are different perioperative chemotherapy regimens: platinum-based with 5-fluorouracil/calcium folinate or oral fluoropyrimidines, epirubicin, cisplatin and 5-FU or paclitaxel and carboplatin (47). Moreover, radiation therapy is a fundamental part of treatment for most of EC patients and combination therapy has shown a superior overall survival when compared

with radiation alone. In a definitive setting, when the goal is the treatment of the primary cancer or its metastasis, chemotherapy is the only acting therapy and the patients understand its importance. Even if some regimes can be better tolerated, patients are burdened by side effects of chemo and radiotherapy in these nutritionally compromised patients. Late toxicity is not only an important issue that could impair HRQL, but also dose-limiting toxicity is considerable for patients undergoing pre-operative therapy regimens (48). In fact, interruption of treatment, in a pre-operative setting or adjuvant setting, can be stressful for patient because of the curative process is interrupted while the cancer is advancing. Initially the treatment suggested by physician was the "arm" against neoplasm, when the "arm" can no longer be used, patient is defeated in his/her representation.

Furthermore, HRQL is considered an outcome measure in oncology and it is analyzed in studies concerning efficacy and effects of chemoradiotherapy regimens. A recent randomized study reported no statistically significant difference in postoperative HRQL in EC patients receiving neoadjuvant therapy plus surgery *vs.* surgery alone (49), despite HRQL decreased during chemoradiotherapy. Some aspects (physical function, emotional function, fatigue, eating problems and global quality of life) deteriorated 1 week after neoadjuvant chemoradiotherapy, while all patients reported a decreased HRQL at 3 months after surgery, followed by a continuous gradual improvement. While some aspects (global quality of life, emotional function and eating problems) returned to baseline levels during follow-up, it is noteworthy that physical function and fatigue were still impaired at 12 months. Similarly, Basco and colleagues showed that some HRQL dimensions, such as fatigue, dyspnea, deteriorate during the treatment for EC (50). A further study investigating the impact of chemo and radio treatments on HRQL among early-stage EC patients showed that those received only surgery performed better in physical and social functioning compared with patients who underwent surgery and concurrent chemoradiotherapy (51).

All these findings suggest that a psychological support might be useful in preparing patients to cope with neoadjuvant chemoradiotherapy for EC. In fact, in the long-term cancer survivors in general, there are not evidences on interventions or treatments cause HRQL improvement or distress reduction (52). On the other hand, these findings (49-51) point out that the critical stage for HRQL in EC patients is after the neoadjuvant therapy,

both considering physical and emotional functions. Indeed, from a psychological point of view, after neoadjuvant therapy, patients' HRQL is impaired by the disease and by the treatment. Patients know that curative process is not completed, and they perceive the severity of the neoadjuvant side effects, considering themselves "fragile" and far from a healthy condition before the major surgery they are going to undergo. Therefore, this is a particularly crucial point when patients' resilience is critically stressed. If they are not supported enough, they can be not able to prepare themselves to the surgery, to comply medical advices, to manage the preoperative period, to image the perioperative period, too, in order to cope with it using adequate resources.

How to cope with esophagectomy

In term of change of nutritional habits

Patient who undergoes an elective esophagectomy has multiple reasons and time points for developing nutrition risk. Esophageal injury or disease often inhibits food passage from the mouth to the stomach with resultant weight loss. Moreover, esophagectomy patients who will receive preoperative chemoradiation therapy may experience more weight loss and recover only some of their lost weight prior to surgery. So far, few studies investigated food and eating issues in patients who received esophagectomy. In an Australian study, patients reported a "journey of adjustment, grieving and resignation" (53) in their long-term relationship with food and eating after major upper gastrointestinal surgeries. It is noteworthy that such attitude suggested a coping process similar to patients with chronic illness. These findings suggested that health services should be remodeled in order to provide ongoing management and support to such patients (53).

In an Italian study, receiving jejunostomy during esophagectomy was associated with poorer emotional function at 3 months after surgery (26), thus candidates to feeding jejunostomy during esophagectomy may benefit from additional psychological support.

In conclusion, esophagectomy for cancer strongly impairs nutritional function in the early postoperative period. For this reason, we designed an ongoing randomized control trial aimed to investigate the effect of the nutritional counselling on HQRL after esophagectomy for cancer (ClinicalTrials.gov NCT01738620). The main endpoint was the impairment in quality of life between discharge from hospital and 1 month after surgery, as measured by

EORTC C30 instrument (appetite loss; global quality of life). We hope to define a supporting protocol to help EC patients to cope with the nutritional impairment due to esophagectomy.

In term of change sleep habits

Patients receiving esophagectomy can be prone to postoperative sleep disturbances due to treatment-associated aspects, including: (I) postoperative pain (54); (II) nasogastric tube in place for the first 7 to 10 postoperative days (55); and (III) postoperative stay (at least 2 days) in the ICU (56).

In addition, sleep disruption often occurs after cancer diagnosis and is further exacerbated during treatment process (57), thus psychological counseling may help in managing cancer-related anxiety.

In a recent study, psychological counseling alone significantly reduced the proportion of patients reporting impaired sleep latency (58). The psychological intervention focused on identifying "worries, concerns and regrets" that hampered sleeping onset and/or maintenance, in order to find the most appropriate intervention for each patient (58). The findings of the study suggested that psychological support, alongside with sleep adjuvant measures, should be offered whenever possible to improve sleep quality of hospitalized patients (58).

In term of postoperative complications

Esophageal surgery is a complex procedure that is hampered by high risk of morbidity and mortality when compared with other surgical procedures (56,59). Since postoperative complications may heavily affect HRQL outcome (25), providing information on surgical morbidity is therefore crucial in doctor-patient communication and in obtaining informed consent (60), and failure to do so often leads to litigation (61,62). Although patients usually understand most components of the consent for surgical procedures, there are still controversial aspects such as adverse events and unexpected complications. It is unclear whether postoperative morbidity is effectively disclosed in preoperative consent (63), while it is generally recognized that patient's perception and surgeon's perception do not overlap (64). Postoperative morbidity impacts on patient's satisfaction and consequently on doctor-patient relationship (65).

In term of long-term functions

Thanks to the improvements in cancer treatments and prognosis, the increasing number of cancer survivors

has gathered attention on their participation to the work class (66). In fact, cancer survivors face the risk of job loss, inability of resume the former job or unemployment, which can lead to financial loss as well as social and work disability (67-70).

A Dutch study investigated problems and expected care as reported by 30 patients within 1 year after esophagectomy (71). Physical problems (i.e., early satiety and fatigue) were common but decreased over time, while patients also felt depressed and afraid of metastases and death. Interestingly, they expected professional care for disease-related physical problems but not for psychosocial problems, which were managed in their own social network (71).

A Swedish study provided a long-term perspective on quality of life and new life adaptation after esophagectomy for cancer (72). Patients struggled in the recovery period (the theme “When moving on becomes a struggle” efficaciously captured their own experience) and adverse symptoms were still present long time after surgery. The main barriers to adaptation were connected with nutrition problems and diarrhea (which affected patient’s social and emotional levels beyond physical perspective), and with a feeling of losing control of life (resulting in anxiety and fear about the future) (72).

Therefore, EC patients may benefit from a supportive care program that focuses on their physical, mental and social needs, in order to improve the management of the remaining symptoms but also “to take control of their new life” (72).

Psychological burden of EC

Depression and anxiety (73), post-traumatic stress disorder (PTSD) (74), fear of recurrence (75), and return-to-work and financial issues (76) are among the psychological consequences of living beyond cancer (52). Typically, these conditions are underdiagnosed and undertreated, despite the availability of effective psychosocial and drug interventions (52). Although cancer survivors, over time, tend to return to former levels of activity and productivity, many experience distress (52). Distress occurs on a spectrum extending from adjustment disorders that are just below the threshold of mental disorders to diagnosable psychiatric illnesses (e.g., a major depressive episode) (77).

In particular, diagnosis and treatment of EC often lead to complex life changes involving physical, social, and emotional features. An Irish study outlined some important emotional/cognitive themes among EC survivors (“coping

with a death sentence”, “adjusting to and accepting an altered self”, and “the unique benefits of peer support”) and their caregivers (“the carer as buffer”, “representations of recovery and recurrence”, and “normalizing experiences through peer support”) (78). Such patients and their caregivers require comprehensive support in adapting to the consequences of diagnosis and treatment of EC, with peers playing an important supportive role (78). Interestingly, a Swedish study summarized patients’ experience of supportive care in the theme “The need for a guiding light in the new life situation” (79). Patients’ opinions highlighted the importance of a combined support of both healthcare system and social network, which should provide clear information, help in navigating the healthcare system (and overarching the gap between in and out-patient care) and indications for a plan for the future (79).

All these finding and considerations suggest the need for the development of a comprehensive supportive care program that is focused on patient’s needs after this life-changing event (79).

Conclusions

Important questions are still open about psychological aspects in EC and about the related psychological support.

- (I) How to cope with the cancer diagnosis and poor prognosis: Information about the disease is unsatisfactory in candidates for palliative treatment. A psychological counselling may be a valid option to personalize the communication to patients with a poor prognosis. Global quality of life and social functioning are lower in patients receiving written information. Patients need personalized information and should have the possibility to ask question and to be reassured.
- (II) How to cope with long chemoradiotherapy: from a psychological point of view, after neoadjuvant therapy, patients’ HRQL is impaired by the disease and by the treatment. Patients know that curative process is not completed, and they perceive the severity of the neoadjuvant side effects, considering themselves “fragile” and far from a healthy condition before the major surgery they are going to undergo. Therefore, this is a particularly crucial point when patients’ resilience is critically stressed. If they are not supported enough, they can be not able to prepare themselves to the surgery, to comply medical advices, to manage the preoperative

period, to image the perioperative period, too, in order to cope with it using adequate resources.

- (III) How to cope with esophagectomy in term of:
- (i) Change of nutritional habits: esophagectomy for cancer strongly impairs postoperative nutritional function, and jejunostomy affects emotional functioning. Candidates to such surgical procedures should receive additional psychological support to face these difficulties.
 - (ii) Sleep disturbances: sleep disruption often occurs after cancer diagnosis and is further exacerbated during treatment process. A psychological intervention focused on identifying “worries, concerns and regrets” that hampered sleeping onset and/or maintenance may help in identifying the most appropriate intervention for each patient.
 - (iii) Postoperative complications: these affect patient’s HQR and satisfaction, thus providing appropriate information is crucial in doctor-patient communication and in obtaining informed consent.
 - (iv) Long term functions: EC survivors can experience job insecurity, adverse symptoms and long-term psychosocial problems. Moreover, psychological burden of EC involves both cancer survivors and their caregivers. They need a comprehensive support program (involving healthcare system and their social network) to adapt to the new life conditions.

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Footnote

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