Best practices in the management of the psycho-oncologic aspects of head and neck cancer patients: recommendations from the European Head and Neck Cancer Society Make Sense Campaign

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Squamous cell carcinoma of the head and neck (SCCHN) is considered a worldwide health care problem. The majority of patients have a history of alcohol abuse and high-level tobacco consumption; however, SCCHN is also associated with exposure to viruses including human papillomavirus (HPV) and Epstein–Barr virus. A major problem facing SCCHN patients is that their disease is often diagnosed at an advanced stage where treatment options may not be curative, or can have severe post-treatment consequences. Confronted with their diagnosis and treatment options, the patient can express a range of emotional reactions which may lead to maladaptive coping. During the SCCHN patient journey, there are a number of stages where emotional support could be offered. A point of contact should be allocated to help patients navigate these stages and deliver practical emotive support (such as encouraging attendance at hospital appointments, ...
within SCCHN as a health priority. Sense Campaign in raising the prominence of the term head and neck cancer, and few were aware of any preventative measures or early detection strategies. The campaign’s mission is to raise awareness of the disease and ultimately improve outcomes for patients.

Due to continued surgical and therapeutic advances, patients who are diagnosed early with SCCHN have an improved chance of prolonged survival. There is still a significant need to improve these survival rates further. It has, however, become increasingly apparent that patients need emotional support to navigate their cancer journey and successfully integrate back into society and daily life. Emotional support is vital as many people who have been through SCCHN, particularly younger patients, may have impaired physical and psychological well-being.

This article represents an important milestone in the Make Sense Campaign in raising the profile of emotional support within SCCHN as a health priority.

**Key words:** SCCHN, emotional support, psycho-oncology

**foreword**

The European Head and Neck Society (EHNS) has initiated an ambitious program called the Make Sense Campaign to address challenges in squamous cell carcinomas of the head and neck (SCCHN). The campaign’s mission is to raise awareness of the disease and ultimately improve outcomes for patients.

Due to continued surgical and therapeutic advances, patients who are diagnosed early with SCCHN have an improved chance of prolonged survival. There is still a significant need to improve these survival rates further. It has, however, become increasingly apparent that patients need emotional support to navigate their cancer journey and successfully integrate back into society and daily life. Emotional support is vital as many people who have been through SCCHN, particularly younger patients, may have impaired physical and psychological well-being.

This article represents an important milestone in the Make Sense Campaign in raising the profile of emotional support within SCCHN as a health priority.

**introduction**

Genetic, environmental and lifestyle-related factors play a causative role in the etiology and pathogenesis of head and neck cancer. Despite early symptoms, the majority of SCCHN are diagnosed at an advanced stage requiring combined therapies which generate notable complications. Despite intensive therapeutic regimens, approximately half of the patients with locally advanced SCCHN subsequently relapse. Faced with this situation, the EHNS launched a series of activities aimed at improving early diagnosis and outcomes of patients with SCCHN.

In 2008, a survey was conducted in seven Western European countries to assess the awareness of SCCHN in 7250 individuals from the general population [1]. Only 23% of respondents knew the term head and neck cancer, and few were aware of any presenting symptoms. The results of this survey highlighted the potential role for the media in disseminating information about SCCHN to the general population.

In 2010, a second survey was conducted using face-to-face interviews in 104 patients with SCCHN from six Western European countries [2]. Patients were asked how they recalled their journey from diagnosis to post-treatment. The main findings of this survey were emotional shock at diagnosis, difficulties in understanding medical terminology and the need for better emotional support of patients.

On the basis of these two surveys, the EHNS instigated the Make Sense campaign with the following four key objectives:

- To raise awareness of SCCHN in the general population.
- To improve awareness of the signs and symptoms of SCCHN among health care professionals to help them to identify the disease earlier and to aid timely diagnosis and referral.
- To build partnerships with patient advocacy groups and political representatives to prioritize SCCHN in Europe.
- To provide recommendations for better emotional support of patients with SCCHN.

**emotional problems encountered by SCCHN patients**

Studies have reported that patients with SCCHN suffer more frequently from mental health conditions and psychological distress than other cancer patients [3, 4]. Diagnosis of SCCHN can subsequently cause patients emotional distress, psychosocial difficulties or psychiatric disorders [5, 6]. Treatment regimens can also impair their physical and psychological well-being, caused by facial disfigurement and physical disability; for example impaired basic functions, such as communication (speaking), breathing, chewing, swallowing, eating (dysphagia) and drinking. A summary of the keys factors related to emotional problems experienced by patients with SCCHN is shown in Table 1.

Anxiety and depression can easily develop in SCCHN cancer patients as a consequence of the underlying emotional problems; the majority of these patients may suffer from. However, despite the fact that these patients may face well-recognized medical, psychological and social challenges, they suffer from both a lack of screening for psychosocial disorders and psychosocial support [19]. Studies report a lack of communication, and information given by oncologists regarding patient emotional and social welfare [20, 21], and unmet psychosocial needs that can negatively affect many aspects of their care, from compliance to survival [11].

The lack of support for patients with SCCHN may be responsible for the increased prevalence of depression (22%–57%) and psychological distress compared with patients with other types of cancer [9,10,22]. The same is true for the suicide rate (50.5 per 100 000 person years in the United States), which is more
Table 1. Key factors associated with emotional distress in SCCHN patients

<table>
<thead>
<tr>
<th>Factor</th>
<th>Comments</th>
<th>Evidence</th>
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<tbody>
<tr>
<td>Social class</td>
<td>Poor economic status can impair access to health care services</td>
<td>Tromp et al. [7]</td>
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<tr>
<td>Social stigma</td>
<td>Rejection and stigmatization can be burdensome for patients</td>
<td>Devins et al. [8]</td>
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<td>Life style (alcoholism/addiction to tobacco)</td>
<td>Alcoholism can precipitate depressive disorders</td>
<td>Archer et al. [9]</td>
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<tr>
<td>Diagnosis of disease</td>
<td>Classic responses leading to emotional distress, psychological difficulties and psychiatric disorders</td>
<td>Frampton [5]</td>
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<tr>
<td>Diagnosis of HPV infection and disease</td>
<td>Possible emotions associated with diagnosis of an infection (guilt/fear of transmission)</td>
<td>Hamam [6]</td>
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<td>Lifestyle (adjustments)</td>
<td>High-risk behavior (addiction) or withdrawal from such behavior are correlated with delay and prevention in seeking help for care/compliance with treatment</td>
<td>Moore et al. [14]</td>
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<tr>
<td>Treatment</td>
<td>Consequences of treatment including disfigurement can lead to low self-esteem/body image disorders, problems with communication</td>
<td>O’Brien et al. [15]</td>
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<tr>
<td>Prognosis</td>
<td>Poor prognosis correlated with escape or avoidance strategies and suicidal reactions</td>
<td>Ghazali et al. [17]</td>
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<td>Hodges et al. [18]</td>
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HPV, human papilloma virus; SCCHN, squamous cell carcinoma of the head and neck.

than four times the rate of the general population and the overall cancer population [23].

If the onset of depression is a classic reaction following patient diagnosis with cancer [24], then patient distress levels would correlate with their understanding of the disease and the realization of how treatment will affect their lives [11]. In fact, studies have reported a correlation between the occurrence (and the level) of anxiety/depression and the level of satisfaction with the information given before treatment [20, 25]. Further studies may identify key areas of improvement, which may be specifically important for patients with SCCHN, such as the provision of information regarding support groups, financial advice, the long-term effects of treatment on the ability to work, physical functioning and quality of life (QoL) [20].

definition of emotional support

The term emotional support is commonly used when discussing the needs of cancer patients [26]. For the purposes of this review, the concept of emotional support is defined as a sensitive, empathic and understanding approach to the patient to help them to cope with their disease, and to allow the patient to express and communicate their concerns and feelings (e.g. anxiety, fears, unhappiness and sadness). Emotional support for patients with SCCHN should be delivered in a consistent manner, ideally with a single health care professional being available to the patient throughout their entire journey. This could be a primary health care professional (nurse, physician) with involvement from a mental health care professional (psychologist and/or psychiatrist) as needed. The structure of the typical multidisciplinary team involved during the patient journey is outlined in Table 2. Suggested rules regarding the provision of emotional support are:

- To recognize and respect the individuality, personal preferences and the needs of each patient.

- To understand and appreciate the psychological effects on the patient of the transition from health to illness.
- To avoid interjecting clichés, such as ‘Don’t worry’, ‘Take it easy’ or ‘Everything will be all right’.
- To avoid negative criticism, judgmental attitude and facial expressions that may indicate rejection of the patient behavior.
- To listen to the patient and provide compassionate and realistic counseling and care.
- To provide an atmosphere that invites the patient to discuss their feelings, and present a caring attitude.

recommendations for better emotional support during the patient journey

Recommendations for the provision of emotional support should be placed in the context of the SCCHN patient’s journey. The emotions, thoughts processes, and aspirations of the patient during this journey were described in the about Face 2 study [2]. These features and the recommendations for the required emotional support from the health care professional at each stage of the SCCHN patient journey are outlined in Figure 1 and detailed below.

before diagnosis

Before diagnosis, patients have been described as being in a state of ‘blissful ignorance’. However, even at this stage, we can identify two different approaches to coping that should be considered:

- The patient may present with an adaptive coping mechanism by seeking medical information on the internet, from family or friends, others patients or patient’s associations. Seeking medical help or earlier medical consultations during this prediagnosis phase can be considered rational behavior as long as the patient is not overwhelmed by anxiety or depression.
- On the contrary, a maladaptive coping mechanism would be suspected when the patient has intrusive thoughts, hyper
<table>
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<tr>
<th>Health care professional</th>
<th>Diagnosis and patient evaluation</th>
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\(^a\) Radiation oncologists do not directly deal with chemotherapeutic agents, but do however have also to deal with the acute toxicity of combined therapies.

\(^b\) Psychologist or psychiatrist.

GP, general practitioner; SCCHN, squamous cell carcinoma of the head and neck.
vigilant behavior and defense mechanisms, such as denial, or feigning of physical or psychological signs or symptoms, which might result in avoiding or delaying medical consultation.

Maladaptive coping strategies are often displayed at other stages during the patient treatment journey (summarized in Table 3). Before diagnosis, the patient is unlikely to be involved in psycho-oncologic support; however, health care professionals should identify maladaptive behavior as soon as possible in order to refer the patient to the psycho-oncologic team.

at diagnosis

The diagnosis of cancer is an extremely important stage for the patient, and while the emotions, thoughts and aspirations at this stage of the patient journey are documented (Figure 1), there will be patients that show evidence of maladaptive coping [27].

Maladaptive coping following diagnosis with cancer can result in mood disorders such as depression, feelings of despair and can be associated with risk of suicide; patients can also present with feelings of mistrust toward proposed treatments.
This can be explained by a gap between the medical reality (having a curable cancer, due to the availability of better non-surgical therapies and surgical advancements) and the patient’s sometimes pessimistic perception of their medical condition (the disease is incurable). With an increasing subset of patients having a more favorable prognosis and the recent innovations in head and neck cancer treatments, more patients are surviving their cancer and, therefore, emotional support is vital in enabling them to have productive and fulfilling lives. Studies have shown that less optimism and active coping may explain delays in seeking medical consultation and support [7]. However, patients with SCCHN tend to be more fatalistic and passive. Overall, some step-by-step guidelines for communication skills with patients diagnosed with SCCHN can be used by doctors to provide the correct level of emotional support [28].

**communicating the diagnosis of SCCHN**

Besides communicating bad news and informing the patient that their treatment may require combined therapies, the practitioner needs to decide how to deliver diagnosis and the appropriate level of information so as not to overwhelm the patient. This is considered as one of the most stressful duties of the physician in oncology [29]. Studies have shown that an oncologists’ discomfort caused by apprehension related to the delivery of bad news is one of the most important barriers to successful conversation [30] and often results in patient dissatisfaction [31]. Good communication skills are therefore key to successful dialog with the patient [32]. Key steps when communicating with the patient are as follows:

- Eliciting (i) the patient’s main problems; (ii) the patient’s perceptions of these problems; and (iii) the physical, emotional and social impact of the patient’s problems on the patient and family.
- Tailoring information to the needs and requirements of the patients; checking patient understanding.
- Eliciting the patient’s reactions and concerns to the information given (open questions are more suitable to elicit feelings and understanding).
- Determining how much the patient wants to participate in decision making (where treatment options are available).
- Discussing treatment options so that the patient understands the implications of their use, and the benefits to their long-term health.
- Maximizing the chance that the patient will follow agreed decisions about treatment and advice about changes in lifestyle.

**expected emotional reactions from the patient at diagnosis**

Patients diagnosed with SCCHN can experience many different emotional reactions and feelings after diagnosis: shock, disbelief, anxiety, distress, anger or guilt and fears associated with the diagnosis and the consequences of the treatment: hopelessness, loss of meaning and purpose in life, tears, denial, apathy and uncertainty about the future [8,14]. Following diagnosis, patients may experience poor concentration, difficulty in processing all of the information, variations in mood and sleep disorders.

**how the physician should react**

The treating physician should have a positive attitude and provide empathy, openness and reassurance. The physician can propose two options, one in which the patient is involved in the decision-making process and how their illness is managed, the other in which the patient relies completely upon the doctor’s decisions. At each step, the doctor needs to check the patient understanding regarding the level and detail of the information given. To prevent the patient becoming overwhelmed by the emotional impact of the situation, it has been suggested that

<table>
<thead>
<tr>
<th>Milestone</th>
<th>Evidence of maladaptive coping</th>
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<tr>
<td>Before diagnosis</td>
<td>Hypervigilance, Intrusive thoughts, Factitious disorders, Denial, denegation, Avoiding/delaying medical consultation</td>
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<tr>
<td>At diagnosis</td>
<td>Depressive disorder/despair, Mistrust of treatment proposals, Gap between medical reality (potentially curable disease) and patient perception of the medical condition (pessimism), Suicidal ideations</td>
</tr>
<tr>
<td>During treatment</td>
<td>Excessive denial, Fatalism, Depressive disorders, Avoidance/refusal of potentially curative treatment, Seeking exclusively alternative treatment options (complementary medicine)</td>
</tr>
<tr>
<td>After treatment</td>
<td>Avoiding medical follow-up, Continuation of alcohol and tobacco abuse</td>
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SCCHN, squamous cell carcinoma of the head and neck.
the oncologist follows three steps when communicating with the patient [33]:

- Create a good interpersonal relationship and switch the clinician-dominated model to the patient-centered relationship by using mutual trust, warmth, genuineness, acceptance, reflection, validation and legitimization.
- Exchange information with the patient about biomedical and psychosocial problems including diagnosis, history of illness, treatment options, risks and benefits and alternatives without forgetting concerns, patients’ personality, hopes and faith.
- Facilitate beneficial patient behavior by educating the patient to improve decision making and promoting treatment compliance.

**communication and provision of information about pretreatment and treatment**

The treating physician should provide realistic information without overwhelming the patient with too much medical information; signs of maladaptive coping, such as denial, may also be expected. A difficult issue is the short interval from diagnosis to treatment planning [11]. While the patient is trying to cope with the shock of diagnosis, they are faced with a series of medical and/or surgical appointments which may generate conflicting information, or which may be challenged by information obtained via the Internet. Again, it has been suggested to follow the established steps proposed in the ‘SPIKES protocol’ [34, 35]:

- **Step 1: Setting.** Before discussing treatment, create an appropriate setting that provides privacy, patient comfort, uninterrupted time, sitting at eye level and inviting significant others that can assist the patient during the consultation.
- **Step 2: Perception.** Elicit the patient’s perception of his or her problem and treatment.
- **Step 3: Invitation.** Obtain the patient’s permission to disclose the details of the medical condition and medical treatment.
- **Step 4: Knowledge.** Provide knowledge and information to the patient regarding treatment and check regularly for understanding; avoid medical ‘jargon’.
- **Step 5: Empathize.** Empathize and explore emotions expressed by the patient after they have listened to the treatment regimen or procedures.
- **Step 6: Summarize.** Provide a summary of what has been said to the patient and negotiate a strategy for treatment and follow-up.

**expected emotional reactions from the patient**

The period between diagnosis and the start of treatment is often a critical time as patients may avoid communicating specific symptoms, fears or emotional distress [14, 36]. Patients with SCCHN in particular may not only fear dying but also fear surviving with treatment-related disabilities, disfigurement and dysfunction [11]. In addition, patients may fear a loss of autonomy, addiction or the inability to cope with the disease or treatment-related outcomes. It is therefore vital that support is provided at this stage, if optimal outcomes are to be achieved through the appropriate use of treatments.

Depression may also occur at different stages, for example before the diagnosis of cancer is made [37], and during or after treatment [16, 38]. Emotional reactions may also be delayed, with patient reactions to the diagnosis sometimes occurring during the treatment. The patient may react in a fatalistic way without expressing emotion, particularly when the patient’s disease is associated with the factors such as high alcohol intake or smoking.

Patients may also develop feelings of hopelessness and a loss of meaning in life [14]. Therefore, clinicians need to address patient’s concerns and fears about the proposed treatment. Exploration of the patient’s beliefs and discussion of the different treatments can help the treating physician to decide the amount of information to give to the patient. While the impact of treatment and QoL relating to disfigurement/dysfunction have been well studied, psychosocial perspectives remain less well investigated and understood [15]. Personal identity, social networks and intimate relationships are often profoundly changed by treatment regimens [15], and the patient is often unable to realize or anticipate what QoL will be like post-treatment.

**how the treating physician should react**

- Determine the level and amount of information that is appropriate for the patient.
- Assess the capacity of the patient to understand the medical information being provided (regarding emotional and cognitive parameters).
- Discuss benefits and potential side-effects of each therapeutic regimen in an honest manner.
- Ask the right questions in order to select the most appropriate treatment for the patient by balancing oncological advantages versus QoL.
- Assess the role of the patient in the decision-making process and their ability to give informed consent, taking into account cognitive faculties.
- Explain the treatment regimen to the patient and the importance of compliance; respect ambivalence, refusal and difficulties that the patient might express about this choice.

**during treatment**

Follow-up during the treatment is an important part of medical care and numerous challenges for the treating physician require attention:

- Avoiding and preventing any somatic complications that would interfere with the recovery process.
- Checking the patient remains compliant to the treatment regimens and procedures [39].
- Screening for emotional distress using tools such as Distress Inventory for Cancer version 2 (DIC2) and the Hospital Anxiety and Depression scale (HADS) [38].

**after treatment**

Follow-up post-treatment from both a medical and psychological perspective is important to consider. Following the end of treatment, a major challenge for the treating physician is how to support the patient in the post-treatment phase. Support may include:
The post-therapeutic period remains a time where the patient is vulnerable. The treating physician should show diplomacy and persuasion to emphasize compliance to follow-up programs to secure optimal outcome [40]. Preventive rehabilitation programs [41] or self-care rehabilitation can alleviate the burden of side-effects connected with concomitant chemoradiotherapy, though this has not been confirmed in all studies [42].

Fear of recurrence following treatment is a major patient concern and is often associated with psychological distress [43]. Surprisingly, this is not frequently discussed in the outpatient setting and the prevalence of this fear is estimated to be around 35% [17]. Actively screening for fear of recurrence (e.g. emotional support, cognitive techniques) might therefore help to reduce patient concerns [18].

In summary, at all stages of the SCCHN patient’s journey, screening of psychological distress can be carried out by the multidisciplinary team, ideally by a designated member. Emotional support can be initially provided by the multidisciplinary team, however if subsequently additional more technical emotional support is needed, referral to the mental health professional or a psycho-oncologic unit should be made.

**HPV-related SCCHN**

Human papillomavirus (HPV) is an emerging factor associated with the development of SCC of the oropharynx (OPC) [44, 45]. Patients with HPV-associated OPC are generally younger, in good general health and are not associated with the classical history of tobacco and/or alcohol abuse. While research and published literature concerning psychosocial distress in patients with HPV-related SCCHN remains scarce, some authors suggest that this subset of patients might be at a similarly high risk of psychosocial distress as is reported in SCCHN patients associated with more classical risk factors (alcohol and tobacco use) [11].

**communicating the diagnosis of HPV-related head and neck cancer**

Coping mechanisms and adjustment to the disease and treatment may be hindered by the fact that patients with HPV-related head and neck cancer might feel guilt related to the cause and transmission of HPV (i.e. sexually transmitted infection). This may therefore be a great source of distress among these patients, especially while they are trying to understand the implications of HPV infection and its relation to their cancer. Moreover, patients will also have to deal with the reactions of their partner and family.

As there are no established protocols for informing patients with head and neck cancer of their HPV status, questions might be raised during diagnosis between the patient and physician [12]. For example the association with HPV and disease could be related to specific sexual activities (e.g. oral sex), or unprotected sex with multiple partners [46], issues that are not part of the usual discussion between the oncologist and the cancer patient.

Negative psychosocial outcomes from HPV testing and disclosure remain to be studied, especially how this type of information is disclosed to the patient, the amount of information they wish to know, and the educational resources which are available to explain the facts about HPV in SCCHN [13].

**expected emotional reactions from the patient**

In the case of HPV-related cancer diagnosis, the emotional response of the patient may differ from the usual emotional reaction associated with SCCHN related to tobacco and/or alcohol abuse. Therefore, the suggested emotional support recommended to these patients may differ from the support provided to patients with SCCHN related to classical causative factors.

The existing literature on HPV-infected patients with cervical cancer supports the concept that patients with HPV-associated OPC need education to address issues such as self-criticism, guilt and problems with intimacy/interpersonal relationships [47]. When HPV testing is carried out, it should be accompanied by evidence-based and patient-centered counseling to minimize negative psychosocial outcomes and ensure health promotion [47].

**how should the treating physician react**

Physicians may be confronted with the dilemma between their duty of honesty and transparency in providing information and counseling to the patients, and the difficulties in sharing information concerning sexually transmitted infections with the patient (unskilled, not prepared). Physicians need to find the balance between respecting patient confidentiality with providing the required information to other members of the multidisciplinary team.

**conclusion**

Patients with SCCHN are at a high risk of developing emotional problems at all stages of their disease, and therefore need a support network that closely follows them throughout their journey. Patients do not usually express their emotions spontaneously in front of the oncologist, and there is evidence that patients with SCCHN request less and receive less support from psycho-oncologists [4]. It is imperative that a system is put in place to provide emotional support to SCCHN patients throughout their cancer journey and to encourage them to comply with their ongoing treatment to achieve optimal outcomes. This support could come in the form of one designated health care
professional that monitors the patient on an ongoing basis, or as part of an integrated multidisciplinary team management approach. Health care professionals must be aware of this reality and be able to implement psychological interventions during the patient journey. Therefore, for SCCHN patients, the development of psychosocial interventions can be useful in order to improve psychological outcomes and avoid maladaptive coping such as avoiding medical follow-up and continuing their tobacco and alcohol addiction [48].

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references

Prognostic factors for diffuse large B-cell lymphoma in the R(X)CHOP era

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Background: The introduction of rituximab (R) to conventional CHOP chemotherapy for newly diagnosed diffuse large B-cell lymphoma (DLBCL) led to an unequivocal improvement in survival, establishing RCHOP as the standard of care. Still, nearly 40% of DLBCL patients will eventually die of relapsed disease. Efforts to improve outcomes by addition of new biologic agents (X) to the RCHOP backbone are underway. In this era of R(X)CHOP, it is imperative to develop prognostic and predictive markers, not only to identify patients who will suffer a particularly aggressive course, but also to accurately select patients for clinical trials from which they will most benefit.

Design: The following review was undertaken to describe prognostic factors in DLBCL, with emphasis on markers that are accurate, relatively available, and clinically applicable in 2014.

Results: The International Prognostic Index retains its validity in the era of RCHOP, although with limited ability to predict those with <50% chance of long-term survival. Gene expression profiling has provided novel insights into the biology of DLBCL and led to the development of immunohistochemistry (IHC) algorithms that are in routine practice. Identification of a ‘double-hit’ (DH) lymphoma by fluorescent in situ hybridization with aberrations involving MYC and/or BCL2 and BCL6 genes has important implications due to its extremely dismal prognosis with RCHOP. Other markers such as the absolute lymphocyte count (ALC), serum immunoglobulin free light chains, vitamin D levels, serum cytokines/chemokines, and imaging with positron emission tomography (PET) have all shown promise as future predictive/prognostic tests.

Conclusions: The future for new treatment options in DLBCL is promising with current clinical trials testing novel targeted agents such as bortezomib, lenalidomide, and ibrutinib as the ‘X’ in R(X)CHOP. Predictive factors are required to select and randomize patients appropriately for these trials. We envision the day when ‘X’ will be chosen based on the biological characteristics of the tumor.

Key words: lymphoma, non-Hodgkin, large cell, double hit, prognosis

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