

Local attitudes in the treatment of low prognosis head and neck squamous cell carcinoma

Herman Karl Borg Xuereb, Anthony Dimech, Kenneth Muscat

Abstract

The incidence of head and neck carcinoma in Malta is 2.44 per 100,000 population, with 5-year survival rate of 20%. International studies have however shown that head and neck squamous cell carcinoma (HNSCC) carries an average 30% survival rate. The cost of treatment of low prognosis HNSCC patients in Malta is roughly €62,500 per year per person and considering that 7 patients out of those diagnosed are treated curatively annually, the total cost would increase to nearly half a million Euros per annum. In view of this, one is bound to ask the question whether not treating patients with a 30% survival rate is justifiable, especially in view that surgical and oncologic treatment can result in severe disfigurement and poses great physical and psychological stress on patients. No studies about local decision-making with respect to HNSCC have been published. This study set out to explore this issue from the ethical point of view, taking into account a number of variables with respect to treatment and the patient factors. A pre-determined set of questions was formulated and these questions were tackled by ten medical professionals, nine of which had direct contact with HNSCC patients. Issues such as informed consent, old age, quality of life, social variables, autonomy, healthcare rationing, medico-legal problems and past experiences with patients have been identified and discussed with reference to the local situation. It was noted that the majority of interviewed professionals (70%), still emphasised the need to provide full treatment for low prognosis HNSCC.

Keywords

Ethics, squamous cell carcinoma, head and neck cancer, decision making.

Introduction

Head and neck malignancy is the sixth most common cancer in the world. Head and neck squamous cell carcinoma (HNSCC) is the most frequently encountered type. The incidence of head and neck carcinoma in Malta is 2.44 per 100,000 population with 5-year survival rate of 20%,¹ although several studies have shown that HNSCC generally carries a 30% survival rate.²⁻⁴ The TNM staging method is used by many clinicians to determine the aggressiveness and severity of cancer, on which a treatment plan can be devised from established protocols. However, the Western world tends to be more legally and scientifically oriented and often finds difficulty in taking ethical moral decisions in such cases.⁵

Although decisions with respect to head and neck cancer are not very different from the ones taken for other cancers, a differentiating feature is that head and neck cancers tend to present late and they would entail radical surgery with subsequent disfigurement and dysfunction which significantly impinge on the quality of life of the sufferer. Several factors need to be considered when it comes to decision making, including informed consent, counselling, treatment withdrawal, end-of life issues as well as the patient's personality, social, cultural and family background.

Health care in Malta is limited by its budget. This leads to prioritization and rationing in health care, whether this being implicit or explicit.⁶ One also has to keep in mind the direct (medications, services, therapies, tests, etc.), indirect (productivity, disability, etc.) and intangible (often psychosocial) costs of health.⁷ Based on breakdown cost calculations, if one considers all medical personnel involved in the care of HNSCC patients and adds up routine costs of procedures, hospital stay and follow up, a conservative estimate for treating a single HNSCC patient in one year would be around 62,500 Euros.

Social justice including the fair distribution of health care resources is possibly the most important issue in bioethics.⁸ Access to health care across borders,

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poverty, age and ethnicity are all important to consider when planning health care distribution. Fortunately, poverty is not much of an issue for Malta since everyone is entitled to free health care, irrespective of his social status. Age discrimination can be a problem as seen in the Britain, where age is given importance with respect to treatment provision.⁹ In recent years, Malta has seen a significant influx of irregular immigrants which posed a new challenge for our country. Other minority groups such as the homeless face similar problems in that they tend to get marginalised by the people with consequent social, political and possibly health detriments.¹⁰

Two models of care representing the two extremes of modern day medical practice can influence decision-making, management and the doctor-patient relationship. These are 'evidence-based medicine' and 'patient-centred medicine'. Evidence-based medicine integrates the best clinical knowledge of a medical practitioner acquired through experience and clinical practice with current evidence-based medicine in the care of individual patients.¹¹ This approach tends to disregard the individuality, emotions and preferences of patients in the decision-making process.¹² Patient-centred care takes into consideration the patient as a person with his or her individual ideas, emotions and expectations, and merges these aspects with a common goal in terms of care, health promotion and enhancement of the doctor-patient relationship.¹³

Methodology

When compared to other countries, the number of medical professionals involved in the management of HNSCC in Malta is small. In this study, a set of qualitative face-to-face video-recorded semi-structured interviews were created. In these interviews, the interviewee had to identify himself before being asked a set of 14 open-ended questions in sequence (Table 1). Both Maltese and English versions were available. The subjective and elaborated responses were then recorded digitally on a laptop computer. These were later transcribed and the data analysed.

The interviewees were all hospital-based professionals, and all the interviews were conducted on hospital grounds. Each was provided with three documents. The first served as a general introduction to the study, the second was a consent form and the third consisted of the questions to be asked. All interview recordings were deleted once the replies were analysed.

Table 1: Questions asked during each interview

Interview questions	
A	Do you think the subject has been explained adequately to you?
B	Do you think it is relevant to the local setting?
C	How often do you see such cases per year?
D	Do you think it is ethical to withhold treatment for low prognosis Head and Neck cancer patients and only offer palliative treatment?
E	Yes/no: on what grounds?
F	In your experience is the amount of suffering incurred by the patient during and after the treatment justified?
G	Do you think that the expense incurred by treating these patients is justified where the same money may be used for other groups of patients with a better prognosis?
H	How expensive do you think the treatment of one patient might be?
I	God forbid, if you had to be in such a situation what type of treatment if any would you prefer?
J	Should you be involved in this decision making process?
K	Do you think you are involved in the decision making?
L	In your experience do you recall any specific patients in this prognosis group who unexpectedly fared really well or really badly?
M	Did these episodes affect your clinical decision making vis a vis the management of subsequent patients?
N	Any further comments?

Results

10 medical and para-medical staff (7 males and 3 females) were interviewed, with a mean age of 43.7 years (29-53 years). Their respective professional backgrounds are displayed in Figure 1, and the mean professional working years was 20.6 years. Each interview lasted a mean of 12 minutes. Nine of the professionals interviewed had direct daily contact with HNSCC patients.

Figure 2 shows the results of nine of the eleven questions that were asked. With respect to Question C, the mean incidence of HNSCC estimated by the respondents was 11.7 cases per year.

When asked whether or not it would be ethical to withhold treatment for low prognosis Head and Neck cancer patients and only offer palliative treatment (Question D), which is central to this study, 3 agreed to

withhold treatment and 7 considered this decision unethical. However, 7 respondents emphasised that informed consent should always take priority.

Figure 1: Professions of interviewees (n=10)

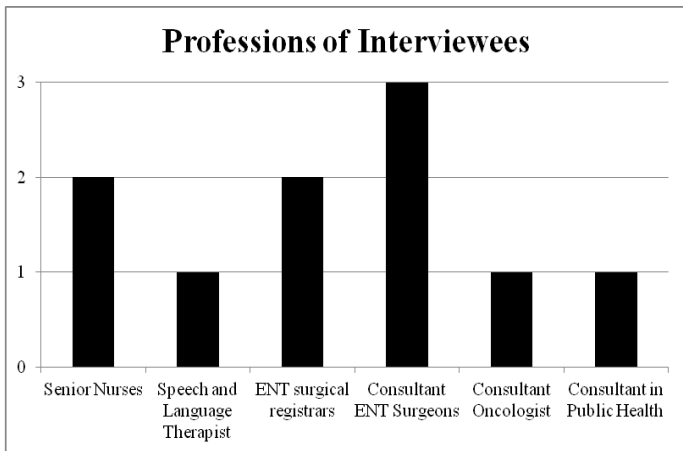
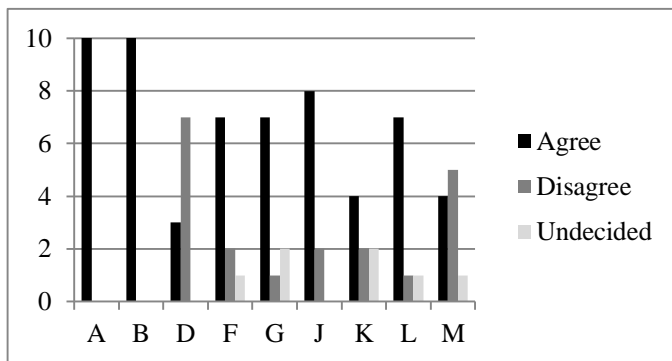


Figure 2: Responses to nine of the eleven questions asked in the interview. Answers to Questions C, E, H, I, J and N were more elaborate and the data could not be adequately presented graphically



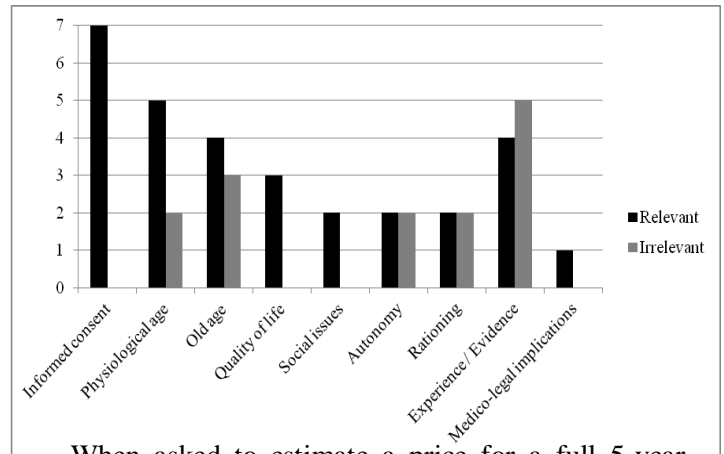
Regarding Question E, of those who would withhold treatment, one mentioned that although the patient should preferably take part in the decision-making process, this may not be true in all cases. For example when the patient has a low IQ or other co-morbidities interfering with the treatment plan, the doctor may decide for the patient. One also argued that patients would endure much suffering if administered the full treatment, so might as well opt for palliative care alone.

Seven medical professionals emphasised the need to provide full treatment for low prognosis HNSCC. One based his reasoning that a prognosis of 30% is very much similar to other types of cancers which would normally still merit treatment. Two interviewees pointed out that the patient should be looked at and treated holistically and not only from the cancer point of view. Another interviewee stated that every patient is entitled to treatment because we do not know who will survive or not, and one should never consider the social value of the patient when it comes to deciding to opt for surgery

or not. Finally, the need to avoid providing the patient with falsely high expectations was brought up.

When asked to elaborate further on their answer to Question E, a number of considerations were mentioned by the interviewees and are shown in Figure 3.

Figure 3: Incidence of considerations as mentioned by interviewees when asked to elaborate on their answer to Question D



When asked to estimate a price for a full 5-year treatment of a patient with HNSCC (Question H), a mean price of €37,222 was quoted (range €10,000-€100,000). One interviewee could not estimate a price.

Question I placed the clinical profession in the patient's seat. Three would accept the full treatment, two preferred palliative care, four were undecided and one preferred not to be treated. Many argued that there were a lot of variables that needed to be considered, mainly age and social issues such as family.

When asked to provide further comments, eight of the interviewees agreed that patients form an important part in the decision making process and that multidisciplinary teams (which are lacking locally) are of utmost importance in the holistic management of patients. There was the need of standard paramedical protocols and audits aimed at assessing survival and quality of life. Furthermore, the more experienced surgeons tend to favour conservative treatment.

Discussion

Question D was by far the most important, and on which this study is actually based. The responses were essential for evaluation of the local decision-making process. In some situations, informed consent requires care and skill to be extracted properly. However, it is close to impossible to explain all the outcomes so that the patient can make a truly informed choice. Being faced by a distraught patient does not help either. Sometimes doctors try to soften the blow by putting some details aside. Furthermore, many times the relatives direct the physician on what to say, when and how to say it.¹⁴ This has been the norm for many years, whereby non-disclosure of sensitive information to the

patient regarding serious or terminal illness was considered taboo.¹⁵ On the other hand, safeguarding the right to autonomy is a prerequisite in showing respect for human integrity.¹⁶ Combining disclosure with autonomy requires good negotiation techniques, merging the physician's medical knowledge with the cultural factors underlying the family's and patient's views.¹⁷

Physiological age was considered more important than old age by the majority of interviewees. This is understandable as age-related physiological changes and co-morbidities expose the elderly to certain risks. For many elderly patients, it is the way they live their final years that matters most rather than by how many years they can prolong life.¹⁸ A multidisciplinary team may help to improve quality of life of such patients, which is very reasonable in this regard. In addition, psychological interventions which target social support are important in diminishing treatment-related side-effects.¹⁹

Seeing how a small number of medical professionals are aware of so many ethical issues, one can identify an element of egalitarianism and utilitarianism as well. Decisions are often based on a combination of morals, intuition and evidence-based medicine. Intuition in itself can be useful in some situations, but not so in others.²⁰ Rationality and consistency may be challenged in the face of a decision harassed by variables such as worry, risk aversion and perception of danger.²¹

Traditional healthcare ethics often call for a more paternalistic approach, which may conflict with the modern ethical principles of autonomy and transparency in decision-making.²²

Expensive interventions have forced doctors to shift their approach from the individual to the wider community.²³ Health responsibility comprises both a personal and a social aspect. This led to the concept of co-responsibility, which indicates the subjects and objects of health responsibilities, and considers responsibility as being different from prioritization of treatment methods.²⁴

The element of solidarity in health care is strongly defended and is based on three factors. **Emotional bonds** should exist among interacting members of the group, which are united by **universal goals and ideals**. There must also be an element of **sacrifice** within the group. More recently, the criteria which define solidarity have been extended to include responsibility for health, communal health benefit, acknowledgement of utilitarian ideas which promote the common good and sacrificing one's own care so that others may benefit.⁵

Conclusion

This paper was part of the first author's Master of Arts in Bioethics at the University of Malta. It portrays

that the majority of professionals interviewed agree that it is unethical to withhold treatment for low prognosis HNSCC patients. However, not treating is by no means not caring. Indeed those who chose not to treat at the outset based their decision on a holistic view of the patient and the possible consequences of the actual treatment, which included more suffering and the risk of giving false hopes. Finally, the principles of the common good and justice ensured that fairness ruled over the distribution of health care resources.²⁵

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