

SIOG Task Force paper on Quality of Life (QoL) in older oncology patients

*Title*

**Addressing the quality of life needs of older patients with cancer: A SIOG consensus paper and practical guide**

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**Abstract:**

**Around 60% of people living with cancer are aged 65 years or older. Older cancer patients face a unique set of age-associated changes, comorbidities, and circumstances that impact on their quality of life (QoL) in ways that are different to those affecting younger patients. A Task Force of the International Society of Geriatric Oncology (SIOG) recommends and encourages all healthcare professionals involved in cancer care to place greater focus on the QoL of older people living with cancer. This paper summarizes current thinking on the key issues of importance to addressing QoL needs of older cancer patients and makes a series of recommendations, together with practical guidance.**

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Key words: quality-of-life (QoL); older; elderly; oncology; cancer

## **Key message:**

Quality of life of elderly oncology patients should be a key consideration in patient care

## **Introduction**

Around 60% of cancers are diagnosed in older adults, and as many as 60% of people living with cancer are aged 65 years or older.<sup>1,2</sup> Globally, there are geographic and economic factors that affect the number of older people living with and surviving cancers, but data show a common trend for large proportions of people with cancer being older.<sup>3,4</sup> Despite these statistics, older people are still, despite improvements, under-represented in clinical trials of cancer interventions,<sup>5</sup> leading to gaps in evidence and knowledge on best care of older and ageing cancer patients.<sup>6,7</sup>

Older patients are more frequently treated with non-curative strategies. However, age does have an impact on decision making and living with cancer, but the effects and impact of age will differ for each person. Moreover, older patients are often more vulnerable to treatment toxicities, which increases the relevance and value of quality of life (QoL). Quantity, and quality, of life may have other meanings in the elderly, and both should be linked in the decision process to define the optimal cancer management. Is QoL an objective of cancer care, or is it also a way to optimize patient-centred anticancer treatments?

A Task Force, developed by the International Society of Geriatric Oncology (SIOG), proposes here a position paper in order to encourage greater focus on the QoL of older people living with cancer. In the principle of doing good – QoL remains an important objective of every oncology professional when taking care of patients with cancer, whatever their age.

## **What do we mean by ‘older’ or ‘elderly’?**

A number of definitions of ‘elderly’ are applied to describe older patient groups, and these definitions have been shifting and changing in-line with increased longevity.

The World Health Organization (WHO) – which describes ageing populations as those over aged 60 years – highlights that there is no ‘typical’ older person and states that policy should be framed to improve functional ability of all older people.<sup>8</sup>

From a societal point of view, the age of retirement-entitlement is often taken as defining the elderly (usually around 65 years in many countries). In politics, the definition of ages of 70 or 75 years and above are often applied, while in geriatric institutions, the elderly are often defined as those 85 years and older.

In the geriatric sense, a person aged 80-years plus, is more likely than the younger-elderly to present with pathology and to require polymedication.<sup>9,10</sup> In the onco-geriatric sense, given the clinical and psychological impact of cancers, a threshold around 70-75 years might be more appropriate, and may be lower when patients have additional comorbidities or frailties.<sup>11,12</sup>

Patient age is less important than adhering to the principles of a good geriatric evaluation (Table 1). There is a need to distinguish between longevity and life-expectancy (the former relating to a long duration of life/patient age; the latter describing the expected time a person is expected to live), to differentiate between normal and pathological ageing, and to identify age- or disease-related frailties that could be better managed, in older cancer patients.

## **Defining Quality of Life (QoL)**

There are a number of different definitions of QoL – with a notable example being that offered by the WHO: “A state of complete physical, mental, and social well-being not merely the absence of disease” and “an individual's perception of their position in life...a broad-ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment.”

For each patient with cancer, the ideal would be to define, with them, their QoL expectations and aspirations, and to discuss and explore the impact of different anticancer treatment choices on patient QoL – identifying both QoL goals and challenges. This is something that should be discussed at several specific time-points in the course of the cancer:

- at diagnosis – looking at the impact of disease and patient expectations
- during anticancer treatment – reviewing for example side effects or effects of anticancer treatment on cancer-related symptoms
- at the end of life
- in a survivorship-setting in light of life-expectancy.

This is fundamental in cancer management, and is not age-dependent.

### **QoL scales and patient-reported outcomes (PROs) and their applicability in oncology**

For older cancer patients, a comprehensive (or cumulative) geriatric assessment (CGA) is the foundation for developing an integrated and coordinated plan for care, treatment and follow-up.

A number of health-related QoL (HRQoL) tools can be used in clinical practice to assess patients' baseline QoL and to monitor and measure changes in QoL. In addition, in recent years, QoL has been recognized (by bodies such as the American Society of Clinical Oncology (ASCO), the European Society of Medical Oncology (ESMO)<sup>13,14</sup> and the US Food and Drug Administration (FDA)) as a key

secondary-outcome criteria when assessing anticancer treatments, particularly when treatment interventions are not expected to alter patient overall survival. Integration of QoL results and other patient-reported outcomes (PROs: standard tools for directly eliciting the patient experience<sup>15</sup>) will become more frequent to support drug efficacy claims for drug labeling.

QoL assessments can also be useful when the expected toxicity of a treatment may impact on anticancer treatment choice. The importance of listening to patients' voices when evaluating the toxicities of oncologic treatments is well recognized, since the healthcare professional evaluation alone may underestimate, or differently judge, the burden and severity of the symptoms.<sup>16,17</sup>

As observers we may collect physiological or biochemical data but some data can only be obtained from the patients. A PRO, like QoL, implies the data come directly from the patient.<sup>18</sup> The issue of integrating PROs with physician-assessed instruments is gaining more and more consensus among healthcare professionals.<sup>19-27</sup> This is particularly relevant in elderly populations, where symptom assessment may be a challenging issue, due to possible communication difficulties, memory issues, or reluctance to explain the suffered toxicities.<sup>28-34</sup> However, in the older cancer patient, PROs have the potential to identify unmet needs such as areas for supportive and palliative care improvement, which may have a resultant positive impact on patients' QoL.

Importantly, many patients themselves may have a preference for anticancer treatments and other interventions that have the potential to improve their QoL rather than their survival.<sup>35</sup>

### ***The EORTC QLQ-C30***

The QLQ-C 30 is one of the most widely used scales for assessing HRQoL in cancer patients, notably in clinical trials. This tool assesses 3 principal fields:

functional and clinical, psychological and social environment.<sup>36</sup> The functional and social environment can be challenged in elderly population, however this questionnaire may not fully meet the needs of elderly patients.

### ***The EORTC ELD 15 / ELD 14***

The QLQ ELD15 was developed as a supplement to the QLQ-C30, to improve detection of age-related differences and factors affecting well-being. It was validated in cancer patients aged  $\geq 70$  years with all cancer types.<sup>37</sup> Its scale structure was later reviewed and modified, which resulted in the validated QLQ ELD14 tool, which includes five scales (mobility, worries about others, future worries, maintaining purpose and illness burden) and two single items (joint stiffness and family support).<sup>38</sup>

### ***Other QoL tools***

Other QoL tools such as the short-form 36 (SF-36) – a generic measure of health status – has some utility in the elderly although it, like many PROs, may not be a suitable tool in people over aged 75 who may require help in providing their inputs to this self-completed questionnaire.<sup>39</sup> The Functional Assessment of Cancer Therapy General (FACT-G) is a general QoL instrument used in cancer patients that can also be used in older persons.<sup>40</sup>

### ***QoL and patient-reported-outcomes (PROs): Should these be used more widely?***

QoL and other PROs allow the measurement of a number of outcomes which have several potential advantages such as:<sup>18</sup>

- identifying negative effects of treatments with a long survival time
- identifying positive effects between treatments with similar survival outcomes
- identifying positive effects between a treatment and best supportive care when the survival time is very limited

- assessing compliance or reasons for non-compliance
- improving communication
- identifying needs for supportive care

Additionally, a pooled analysis of 39 studies has shown that PRO programmes offer an independent prognostic factor for survival in cancer clinical trials, and many recent studies support this association.<sup>41-44</sup>

QoL parameters such as functional status, pain and loss of appetite are also known to provide prognostic value when considered together with clinical parameters.<sup>45</sup> It has recently been reported that the use of PROs in the setting of patients receiving chemotherapy for advanced cancer had a positive prognostic impact.<sup>46</sup>

The benefit of regular PRO assessment is higher when prompt and appropriate management can tackle the reported symptoms.<sup>44</sup> The earlier recognition of any adverse event could be of higher benefit in the elderly than might be the case in younger or less vulnerable patient groups.<sup>47-50</sup>

The use of new technologies in assessing PROs is burgeoning.<sup>21,51-53</sup> A study of real-time monitoring and web-based reporting of patient-reported symptoms and syndromes, showed that this form of PRO monitoring (electronic or ePRO monitoring) led to fewer emergency room admissions and hospitalizations, and more patients alive at one year when compared with a group not followed in this way.<sup>54</sup>

While the systematic employment of patient-reporting enhances clinician awareness of symptoms usually not investigated, there are still some hurdles to overcome before PRO can be applied widely with older patients.



Some older patients may find difficulties in interpreting questionnaires, due to cognitive impairment or illiteracy, or may be more reluctant to fill in lengthy questionnaires.<sup>29-32</sup> Caregivers might provide help, but this can alter the quality of the answers. The presence of comorbidities could be a confounding factor when assessing the toxicities of a specific treatment, as it could be hard to differentiate the negative impact of the anticancer treatment from the deterioration due to other concomitant diseases.

Nevertheless, the benefits of PROs in cancer management are now clear and new ways of gathering PRO data from older patients should be studied and explored, in order that those benefits reach clinical practice.<sup>37</sup>

### ***The CGA and QoL***

The CGA is defined as a multidimensional, interdisciplinary diagnostic process focusing on determining an older cancer patient's medical, psychosocial and functional capacity, which is used to develop a coordinated and integrated plan for treatment and follow up. In the general geriatric population, it has been shown that CGA plans reduce the risk of hospitalization, nursing home placement, and improve overall survival and QoL.<sup>55</sup>

In elderly patients with cancer, aspects of the CGA which assess functional status (using activities of daily living (ADL) measures and physical performance measures, nutritional condition and depression have been shown to be independent predictors of treatment toxicity and survival.<sup>56,57</sup> . Studies are ongoing to assess the impact of multidimensional geriatric assessment and interventions tailored to the patient, on both HRQoL and patient survival.<sup>58</sup>

Some of QLQ-C30 ELD15 / ELD14 elements appear very similar to parts of the CGA, particularly with regards ADL and IADL. However, specific QoL scales are designed to assess and identify not only what patients are capable of, but how

they feel and what they believe about their capabilities. Good QoL tools – whether they involve self-evaluation or external evaluation should help elucidate how patients feel about and perceive their HRQoL. Highlighting this subtle but important difference between the CGA and the use of QoL tools designed for cancer patients, are the findings of a study in lung cancer patients. The study showed that pre-treatment or baseline global QoL and instrumental ADL (IADL) each had prognostic value for patient survival, while baseline ADL and comorbidities did not predict or prognosticate for survival outcomes.<sup>59</sup>

### **Supporting oncologists – need for QoL and PRO tools**

Oncologists are still in need of proforma QoL tools and clinical practice tools that are not time consuming, which they can use when assessing older patients. Geriatricians can offer expertise and advice to help healthcare teams identify and manage frailty, and all those treating older cancer patients can incorporate elements of the CGA and combine these with QoL criteria when assessing and caring for patients.<sup>60</sup> While there is growing recognition of the importance of QoL assessment in older cancer patients, there is still a need for further studies in the elderly population to help develop time-efficient, relevant tools to support the HRQoL of older cancer patients.

Moving forward, there should also be more trials to help practitioners choose the right PRO instrument for a specific question to be addressed - and instruments should be easy, specific, comparable and validated. Appropriate tools could also help define the intensity of the supportive care needed throughout the patient's journey according to the baseline reporting of symptoms.

### **The importance of the patient perspective**

Patients are often best placed to evaluate how much benefit may be derived from more intensive anticancer treatments offering longer survival vs better QoL in

their later years.<sup>61,62</sup> Age may play a role in treatment decisions,<sup>63</sup> but decision-making must be shared between the patient (accounting for their preferences and expectations) and the patient's healthcare team. It is essential to consider various aspects of a patient's profile: functional, psychological, lifestyle preference and the day-to-day situation and circumstances.

One size does not fit all. The organization Europa Donna - The European Breast Cancer Coalition - advocates that all women should have access to appropriate screening, treatment, follow up, and access to clinical trials regardless of age. However, we cannot forget that stage of life does have an impact. For example a cancer diagnosis will have a different impact on an older person compared with a younger person. Older patients may have freedom from the family responsibilities of younger patients (although may have responsibility for a spouse or partner), and may be retired with free time and independence.<sup>64</sup> However, they are also more likely to have other physical impairments, and may or may not have anyone who can easily care for them at home. Such factors need to be taken into consideration and healthcare teams must understand the point of view of the patients - their concerns, expectations, needs, short and long term goals. It is not necessarily true that younger people have a greater desire to continue their life- it depends on whose life we are considering.

### ***Ask the patient what QoL means to them***

Patient and physician goals may differ, and older cancer patients may have different preferences to those usually expressed by older patients without cancer – typically wanting more information and wanting to play a bigger role in decision making.<sup>65</sup>

Physicians may believe they are acting in the best interests of patients but they may not have really listened or asked the patient about their needs and preferences. Goals need to be aligned between patient and physician and various studies shows that this is not always the case.<sup>60,66,67</sup> The health care

team needs to have a dialogue about length of life and QoL. Is independence and staying at home more or less important for the patient? Clinical trials and using new drugs may seem to provide new options that doctors want to try. Patients may or may not be interested in this. They may not be interested in extending their life by 3-6 months if it means a poor QoL during that time, or hospitalization instead of staying home with loved ones. On the other hand, some patients may wish to participate in clinical trials and this should not be prohibited because of age. Again, careful assessment of each patient is required.

### **Caring for the older oncology patient – the importance of MDT care**

Gerontologists and geriatricians by definition work in a field where multidisciplinary care is the norm. (Table 2) A future goal may be to look to encourage double-boarded, or at least double-trained oncologists and geriatricians.

A multidisciplinary team (MDT) and multiprofessional approach to patient care offers the best means to manage all aspects of the patient's health and the impact of treatments on health and QoL.<sup>68,69</sup> The make-up of such a team may vary according to the patient's needs and the cancer centre's availabilities. Opportunities to share physicians, pharmacists and other supportive-care providers are possible through cross-meeting organisation.<sup>70,71</sup>

Key to MDT care is defining the team and the roles of the team members – while ensuring that care is not fragmented across the team. Core to good MDT care for the older patient should be an agreement within and across the MDT as to the importance of QoL and defining and adapting QoL goals according to the patient's QoL aspirations.

The MDT should agree which team members will assess QoL and with which tools – with tools chosen according to their validity and practicality – including considerations such as whether they are available for use in different languages.

### **Challenges and hurdles of QoL evaluation in the older cancer patient**

Elderly patients may have a number of confounding comorbidities, symptoms and compliance issues which impact on their QoL and the evaluation of QoL.

#### *Implementation of QoL and PRO assessments*

Inability to use digital devices (internet, phone, connected devices, etc) may reduce PRO programme implementation in the elderly and yet such tools could be used to instruct patients, and for the communication and interpretation of results, with lowest impact on PRO efficacy. The electronic revolution means that increasingly more older people are becoming connected and so this hurdle may be reduced in the near future.

#### *Compliance issues*

Fatigue is common in cancer patients and can have an impact on QoL and the process of its evaluation. Cognitive disorders and self-assessment limitations may contribute to a low level of QoL evaluation performance. Education, as well as care-giver and professional accompaniment may lead to improved adherence.

#### *Factors possibly affecting QoL and maintenance of QoL during and after therapy*

Neutropenia and anaemia affect QoL. Age > 65 is considered as the major risk of febrile neutropenia, and in order to avoid any excess mortality, adapted anticancer treatment. The use of granulocyte Cell Stimulating Factors (GCSF) and prophylaxis should be discussed for each patient.<sup>72</sup> Anaemia is a common

issue in elderly patients and is one of the major causes of QoL worsening in cancer patients. Its assessment, monitoring and management should (strictly) follow accepted guidelines for anaemia management, (and aim for QoL enhancement).<sup>73</sup>

Nausea and vomiting impact on QoL. Although patients are usually protected against chemotherapy-induced nausea and vomiting, in the elderly, attention should be paid to the level of emetogenicity of chosen anticancer treatments, as well as to patient factors affecting emesis risk to prevent any deterioration. Antiemetic prophylaxis and education are areas that need to be developed in the elderly setting.<sup>74</sup>

Many other symptoms pose challenges and hurdles and affect QoL in the elderly. Neuropathy and walking ability are relevant for older patients and might be considered because of their impact on mobility and autonomy.<sup>75</sup> These include pain (which may not be well expressed or may be under recognised in older patients),<sup>76</sup> changes in sexual function and drive (which may be given low attention in the elderly), and social and psychological disorders, all of which can lead to poor quality of daily living. The assessment and management of such factors is crucial in order to improve quality of care and QoL.

### **Tailoring the approach to elderly cancer patients – identifying subgroups with particular QoL needs**

Elderly cancer patients are a very heterogeneous group. However they do have in common a decreased functional reserve, a higher likelihood for multiple and more severe comorbidities and also multiple concomitant medications with a higher risk of interactions and side effects often linked with polypharmacy.<sup>9,10</sup>

To evaluate QoL in these complex patients many challenging questions arise:

- Is the cancer the leading disorder regarding survival?
- Which disorder is leading on the symptoms and affecting the QoL the most?
- Will the patient tolerate the potential treatment's side effects and what could be its impact on the QoL?
- What aspects count the most for the QoL of an individual elderly patient?

The clinicians' aims should be similar to the patients' aims.

Decisions regarding treatment-intensity are a frequent challenge and are influenced by the type of cancer, the clinical setting, and the patient's performance status and comorbidities. But that same decision should also vary based on the patient's baseline QoL and the estimated risk of impacting the QoL with a specific treatment.

We face the risk of under-treating some patients and over-treating others. Many elderly cancer patients are faced with a palliative setting where symptom control and QoL play the major roles.<sup>77</sup>

For the elderly population we need to look beyond tumour stage, and more carefully at the patient: assessing their performance status, comorbidities, polypharmacy, functional status, mobility, nutritional status, mental health, cognitive status, social situation and also their individual QoL.

### ***More trials needed in older patients***

There is an underrepresentation of elderly patients in oncology trials, which is also reflected in QoL evaluations. In fact, as described in this paper, the methodological challenges related to the QoL assessment are intensified in elderly cancer patients, due to the potentially:

- higher proportion of cognitive disorder and illiteracy, limiting patient interpretation of the questionnaires

- higher compliance issues on filling out long questionnaires
- higher comorbidity incidence – with confounding effects on assessment of the real impact of cancer and/or its treatment on QoL
- higher risk of missing data throughout the several assessment in different time-points.

Although QoL assessments have been increasing in clinical trials over the last decades, in clinical practice, many clinicians lack the training/skills for QoL assessment, and therefore struggle to select an assessment tool or to interpret/act on the subsequent relevant data.

Another challenge commonly reported is the limited time and resources to perform a QoL assessment. However, such assessment plays a very important role in the upfront treatment decision. It may save time and resources down the line and it also improves the communication between patient and clinician.

Lastly, another challenge is that about 25% of patients in a palliative care setting are unable to complete a QoL questionnaire.<sup>78</sup> That could be due to poor eyesight, fatigue, poor performance status or cognitive impairment. In such cases the clinicians may only rely on the judgement of relatives and carers, with all their limitations. More needs to be done to support and facilitate better collection of QoL data by members of the healthcare team.

A list of patients in whom QoL assessments may be challenging, but in whom such assessments are particularly relevant, is given in Table 3.

### **Task Force recommendations and guidance on supporting good QoL in elderly cancer patients (see also Figure 1)**

- Quality of life (QoL) considerations should be a fundamental component in cancer management, whatever a patient's age



- Decisions about cancer screening, treatment and care should never be based on chronological age alone
- There is a need to differentiate between normal and pathological ageing and to identify frailty in older cancer patients
- Health related quality of life (HRQoL) tools such as the EORTC QIQ-C30 and ELD-14 should be used together with a comprehensive (or cumulative) geriatric assessment (CGA) to develop an integrated and coordinated plan for care, treatment and follow-up for elderly patients with cancer
- QoL assessments should be performed at baseline and repeated at regular intervals
- The healthcare team caring for the elderly patient with cancer should discuss the impact of different treatment choices on patient QoL across the course of the cancer – at diagnosis, during treatment, during survivorship and at the end of life – taking into account patient preferences which may include treatments and interventions that have the potential to improve QoL rather than survival
- The care and management of the elderly patient should be provided by a multidisciplinary team (MDT), comprising as a minimum oncologists, surgeons, radiotherapists, geriatrician (general, oncology), pharmacists, palliative care specialists, nurses, physiotherapists, onco-psychologist, dieticians/nutrition professionals and other different supportive-care providers
- There should be more opportunity for elderly patients to take part in research studies and randomised clinical trials devoted to QOL
- There is a need for more studies using patient-reported outcomes (PROs), to explore and define the QoL and oncological benefits of addressing the needs of elderly patients with cancer
- Systematic geriatric screening and assessment of older cancer patients, including QoL assessments is feasible and can have a significant impact on the detection of unknown geriatric problems, leading to geriatric-appropriate interventions and adapted treatments that support improved QoL and potentially improve their survival
- Assessing and addressing QoL should not be perceived as time/resource consuming. It helps tailor the best treatment strategy and therefore has the potential to save far further time and resources down the line

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**Figure 1. Task Force recommendations on a management decision tree focusing on QoL in elderly cancer patients**

Table 1 Evaluating the older patient with cancer: principles of geriatric evaluation and care.

- Obtain diagnostic certainty (disease and domains of QoL)
- Identify comorbidities and estimate their severity
- Identify and manage any geriatric syndromes
- Assess and address medical-social factors
- Identify required resources
- Estimate survival prognosis
- Prioritize issues
- Propose a therapeutic programme (oncology and non-cancer)
- Establish a comprehensive care plan

Table 2 Healthcare professionals\* who should be part of an elderly-oncology-patient, QoL-focused, multidisciplinary team (MDT), with team make-up tailored according to patient needs. [*Within any MDT, an individual (or a core team of healthcare professionals) should be designated responsible for a patient's overall care.*]

- Medical oncologist
- Geriatrician
- Palliative medicine specialist
- Oncology nurse practitioner (in countries were available; oncology nurse for other countries)
- Pain specialist
- General practitioner
- Nutritionist
- Psycho-oncologist
- Social worker (financial, family needs, disability expenses (eg wheelchairs etc.))
- Physiotherapist
- Pharmacist
- Important consultants to the oncology team such as:
  - Dermatologist
  - Cardiologist (trained in cardiotoxicity of oncological treatments)
  - Neurologist
  - Pneumologist
  - Endocrinologist
  - Surgeon
  - Radio oncologist
  - Nephrologist
  - Psychiatrist
  - Ear, nose and throat specialist (ENT)
  - Rheumatologist
  - Ophthalmologist
  - Sexual health specialist
- Allied health professionals in the community and in hospitals
- Care-home staff
- Self-help and support groups, patient advocacy associations
- Clerics (or spiritual helper)
- Volunteers

\*The MDT should be trained in specific care of cancer patients.

Table 3 Elderly cancer patients with particular QoL needs.

- Isolated patients

- Patients with cognitive impairments/complaints
- Patients with mood/psychiatric disorders
- Patients with difficulty expressing themselves
- Patients with altered functional autonomy
- Hospitalized patients
- Nursing home patients
- Patients with chronic diseases / several comorbidities
- Patients undergoing active treatment with specific treatments
- Patients with very advanced cancer and minimal anticancer treatment options

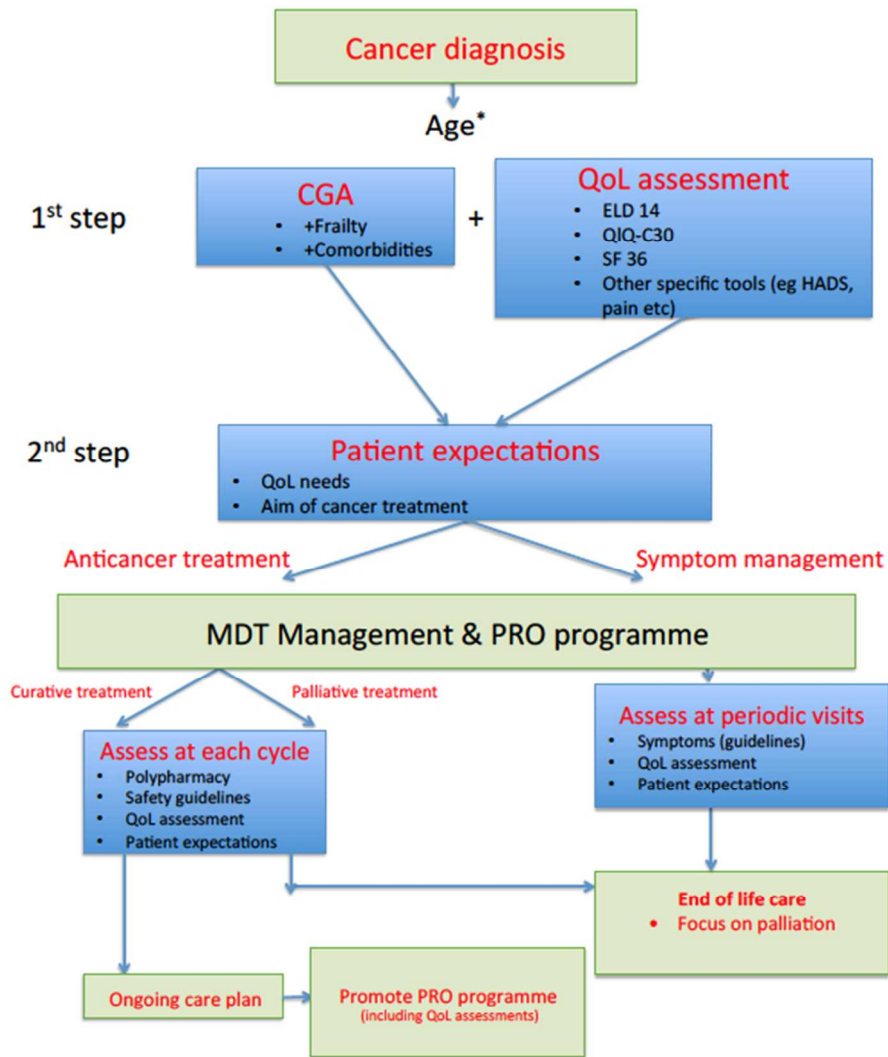


Figure 1. Task Force recommendations on a management decision tree focusing on QoL in elderly cancer patients

Footnote: \* Elderly age ~75 or age 70 if frailty and comorbidities. CGA: comprehensive geriatric assessment; ELD: EORTC elderly cancer patients QoL tool; HADS: hospital anxiety and depression score; MDT: multidisciplinary team; PRO: patient reported outcome; QoL: quality of life; SF 36 : short-form 36 items

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