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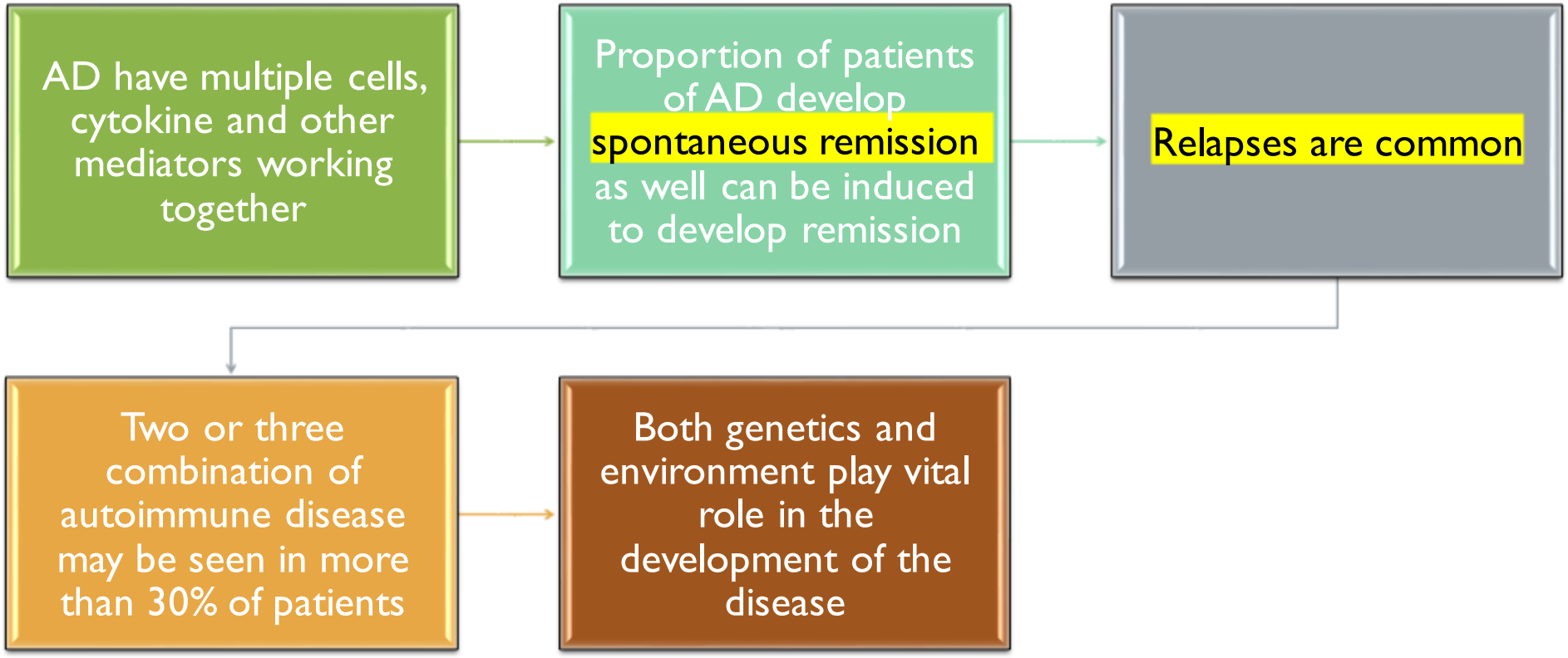
APPLICATION OF EFFORTS TO IMPROVE THE QUALITY OF LIFE IN AUTOIMMUNE DISORDER

SESSION OBJECTIVES:

- Highlight some observations unique to Autoimmune Disorder (Concept of Immunity)
- Understand the dynamic process of Autoimmune disorder to Improve quality of life
- Understand how Autoimmune disease affect the quality of life
- Know what is health related quality of life and what quality of life (QOL) means to patient
- Integrating Palliative care as an approach that improves the quality of life of patients with Autoimmune disorder

OBSERVATIONS UNIQUE TO AUTOIMMUNE DISEASE (AD)



- Christen U, von Herrath MG. Initiation of autoimmunity. *Curr Opin Immunol.* 2004;16:759–67.
- Zhang J. Yin and yang interplay of IFN-gamma in inflammation and autoimmune disease. *J Clin Invest.* 2007;117:871–3.
- Topfer F, Gordon T, McCluskey J. Intra- and intermolecular spreading of autoimmunity involving the nuclear self-antigens La (SS-B) and Ro (SS-A) *Proc Natl Acad Sci U S A.* 1995;92:875–9

The disease process is dynamic and fluctuates between worsening and improvement

Both clinical and immunopathological features vary within the patients' population of the same autoimmune disease (syndrome)

No single autoantibody or clone explains all the clinical manifestation in an AD with few exceptions

No single defect has been demonstrated to be responsible for driving Ads

OBSERVATIONS UNIQUE TO AUTOIMMUNE DISEASE (AD)

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OBSERVATIONS UNIQUE TO AUTOIMMUNE DISEASE (AD)

- ✓ the basic pathological processes mediating AD are now largely delineated.
- ✓ The most interesting inference which emerges from these observations is that a**utoimmunity and immune response (IR)** involved in AD are **not unidirectional** and **one-step response**.
- ✓ The autoimmune process is a **dynamic process, progressing from one end of lower affinity to higher affinity response and changes over a period of time**

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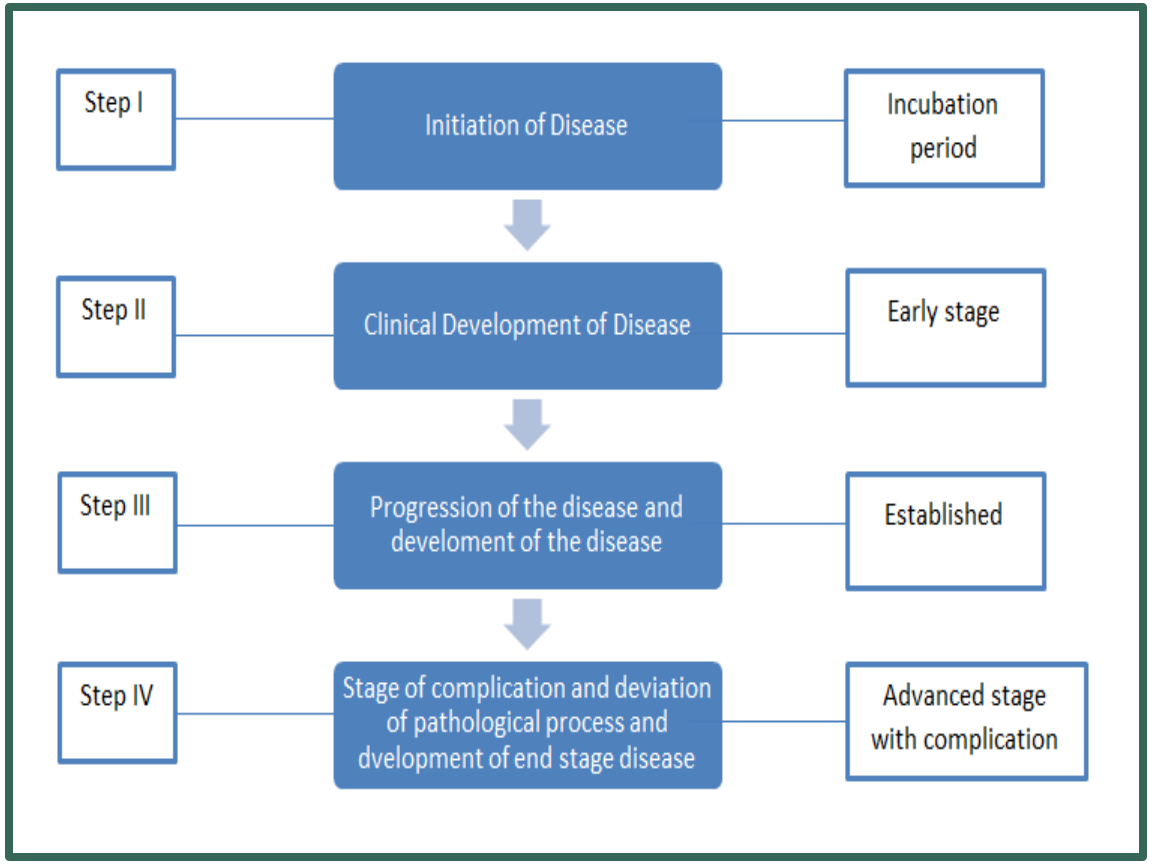
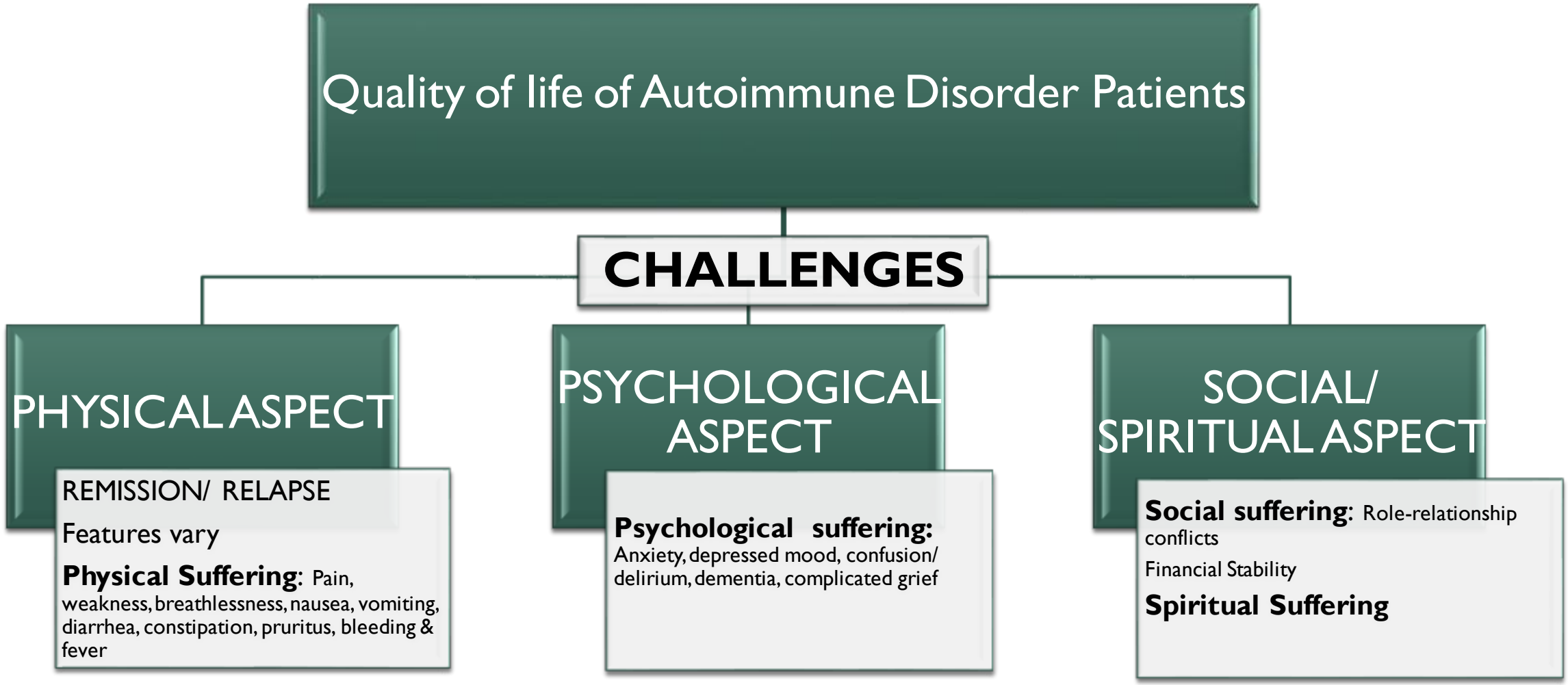
AUTOIMMUNE PROCESS IS A DYNAMIC PROCESS



- ✓ Autoimmune disease is not a one-step process.
- ✓ It moves through stage of preclinical evolution to fully established disease
- ✓ The cells, cytokines, and other pathological process differ through these stages.
- ✓ Reversibility is best seen in first two steps

- https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3523489/

HOW DOES AUTOIMMUNE DISEASE AFFECT THE QUALITY OF LIFE?



WHAT IS QUALITY OF LIFE?

- ✓ Health related **quality of life (QOL)** is not the absence of disease or suffering but is largely a response to a series of life events that influence quality and quantity of life.

Dulaney C, Wallace AS, Everett AS, Dover L, McDonald A, Kropp L.Defining Health Across the Cancer Continuum. Cureus. 2017;9(2):e1029. [PubMed: 28357161]

WHAT IS QUALITY OF LIFE?

- ✓ **QOL c**an also be defined as a *subjective evaluation* of life as good or satisfactory overall
- ✓ Individuals may have a disease yet not be "ill" or experience a reduction in perceived QOL.
- ✓ Similarly, there are individuals without disease who complains of being "ill" and have poor QOL.

Ventriglio A, Torales J, Bhugra D. Disease versus illness: What do clinicians need to know? Int J Soc Psychiatry. 2017;63(1):3–4.
Durkin T Disease versus illness: one patient's definition. J Med Pract Manage. 2011;26(4):233–5.
Helman CG. Disease versus illness in general practice. J R Coll Gen Pract. 1981;31(230):548–52.

WHAT IS QUALITY OF LIFE?

- ✓ QOL is one of the important outcome measures in clinical trials and the most important determining treatment utility (cost effectiveness).
- ✓ QOL is the principal outcome to palliative care interventions.

Naik H, Howell D, Su S, Qiu X, Brown MC, Vennettilli A, et al. EQ-5D Health Utility Scores: Data from a Comprehensive Canadian Cancer Centre. Patient. 2017;10(1):105–15.

Lara-Munoz MC, Ponce de Leon S, de Ramon la Fuente J [Conceptualization and measurement of the quality of life of cancer patients]. Rev Invest Clin. 1995;47(4):315–27.

Kassianos AP, Ioannou M, Koutsantoni M, Charalambous H. The impact of specialized palliative care on cancer patients' health-related quality of life: a systematic review and meta-analysis. Support Care Cancer. 2017.

Conrad R, Mucke M, Marinova M, Burghardt A, Stieber C, Cuhls H, et al. Measurement of Quality of life in Palliative Care: Evidence for Criterion-Oriented Validity of a Single-Item Approach. J Palliat Med. 2017;20(6):604–10.

Song MK, Happ MB. Generating high quality evidence in palliative and end-of-life care. Heart Lung. 2017;46(1):1–2.

WHAT DOES QOL MEAN TO PATIENTS?

- ✓ Patient perspectives when queried about QOL include the following perspectives:
  - ✓ Fulfilment of personal goals,
  - ✓ good control of physical symptoms,
  - ✓ emotional well-being,
  - ✓ the ability to lead a normal life and maintain a sense of self,
  - ✓ sociability (role within the family and society),
  - ✓ existential and transcendent fulfilment,
  - ✓ finding meaning in life,
  - ✓ adaptability or resiliency,
  - ✓ changing values or recalibration of goals with the disease trajectory

Edlund M, Tancredi LR. Quality of life: an ideological critique. Perspect Biol Med. 1985;28(4): 591–607.

WHAT DOES QOL MEAN TO PATIENTS?

- ✓ In this sense, the **World Health Organization** definition as
- ✓ *"an individual's perception of their position in life in the context of culture (family and society) and value system in which they live and in relation to their goals, expectations, standards and concerns"*.

- ✓ "Those who report the very poorest QOL will be least likely to have met their own '...goals, expectations, standards and concerns'"

Skevington SM, O'Connell KA, Group W. Can we identify the poorest quality of life? Assessing the importance of quality of life using the WHOQOL-100. Qual Life Res. 2004;13(1):23–34. [PubMed: 15058784]

EVIDENCES THAT PALLIATIVE CARE IMPROVES QOL

A meta-analysis of recently published studies which measured the effect of specialist palliative care services in various locations (hospital, hospice or community setting) on QOL

8 studies, 3 of which had a small but statistically significant difference favoring palliative care and four studies had nonsignificant differences.

The effect size (by SMD) was 0.16 (95% confidence interval 0.01–0.31).

By sensitivity analysis the SMD was 0.57 (95% confidence interval-0.02 to 1.15).

For patients receiving specialist palliative care early the effect size was 0.33 (95% confidence interval 0.05–0.61).

Gaertner J, Siemens W, Meerpohl JJ, Antes G, Meffert C, Xander C, et al. Effect of specialist palliative care services on quality of life in adults with advanced incurable illness in hospital, hospice, or community settings: systematic review and meta-analysis. BMJ. 2017;357:j2925. [PubMed: 28676557]

EVIDENCES THAT PALLIATIVE CARE IMPROVES QOL

- A second study analysed 10 palliative care studies
- 3 were randomized controlled trials
- The quality of the studies was moderate to low, and the great majority of patients had cancer
- The effect size was estimated in half of the studies which was 0.27.
- The effect size was greater in the observation studies than the randomized trials

Catania G, Beccaro M, Costantini M, Ugolini D, De Silvestri A, Bagnasco A, et al. Effectiveness of complex interventions focused on quality-of-life assessment to improve palliative care patients' outcomes: a systematic review. Palliat Med. 2015;29(1):5–21

EVIDENCES THAT PALLIATIVE CARE IMPROVES QOL

A third study measured QOL at the EOL using the Good Death Inventory

Of the 10 domains, 3 were improved (favourable place, maintained hope and pleasure, living in a comfortable environment) with an effect sizes of 0.1, 0.1 and 0.09 respectively.

The benefits were greater in those with worse performance score (ECOG 3 and 4) with an effect size of 0.54.

Yamagishi A, Sato K, Miyashita M, Shima Y, Kizawa Y, Umeda M, et al. Changes in quality of care and quality of life of outpatients with advanced cancer after a regional palliative care intervention program. J Pain Symptom Manage. 2014;48(4):602–10. [PubMed: 24703945]

EVIDENCES THAT PALLIATIVE CARE IMPROVES QOL

These population-based effect sizes may seem disappointing regarding the benefits of palliative care on QOL.

The effect size seemed in certain cases to be less

However, the population standard median differences are made up of individuals who dramatically improve-

- **those who have modest improvements**
- **those whose QOL remains stable or those that worsen.**

Certain groups appear to benefit more than others.

Those seen earlier by palliative care had greater improvement in their QOL.

Those with poor performance score at the EOL benefitted more than those with good performance scores though this is likely related to the questionnaire used to measure QOL and perhaps regression towards the mean.

Hageman WJ, Arrindell WA. Establishing clinically significant change: increment of precision and the distinction between individual and group level of analysis. Behav Res Ther. 1999;37(12): 1169–93. [PubMed: 10596464]

40 million people are in need of palliative care each year

78% of adults in need of palliative care live in low- and middle-income countries

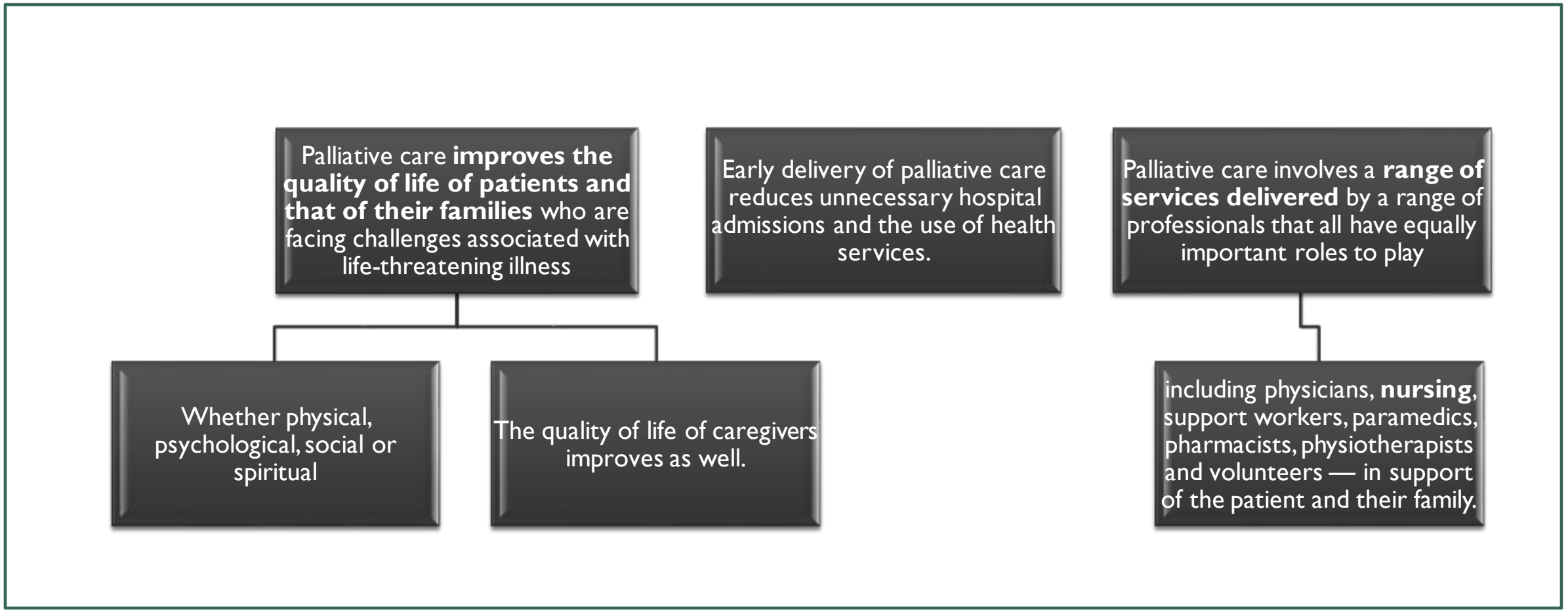
Worldwide, Only **14%** of people who need palliative care currently receive it

The global need for palliative care will continue to grow as a result of the ageing of populations and the **rising burden of noncommunicable diseases** and some communicable diseases.

Adequate national policies, programmes, resources, and training on palliative care among health professionals are urgently needed in order to improve access.

PALLIATIVE CARE IS CRUCIAL IN IMPROVING QUALITY OF LIFE

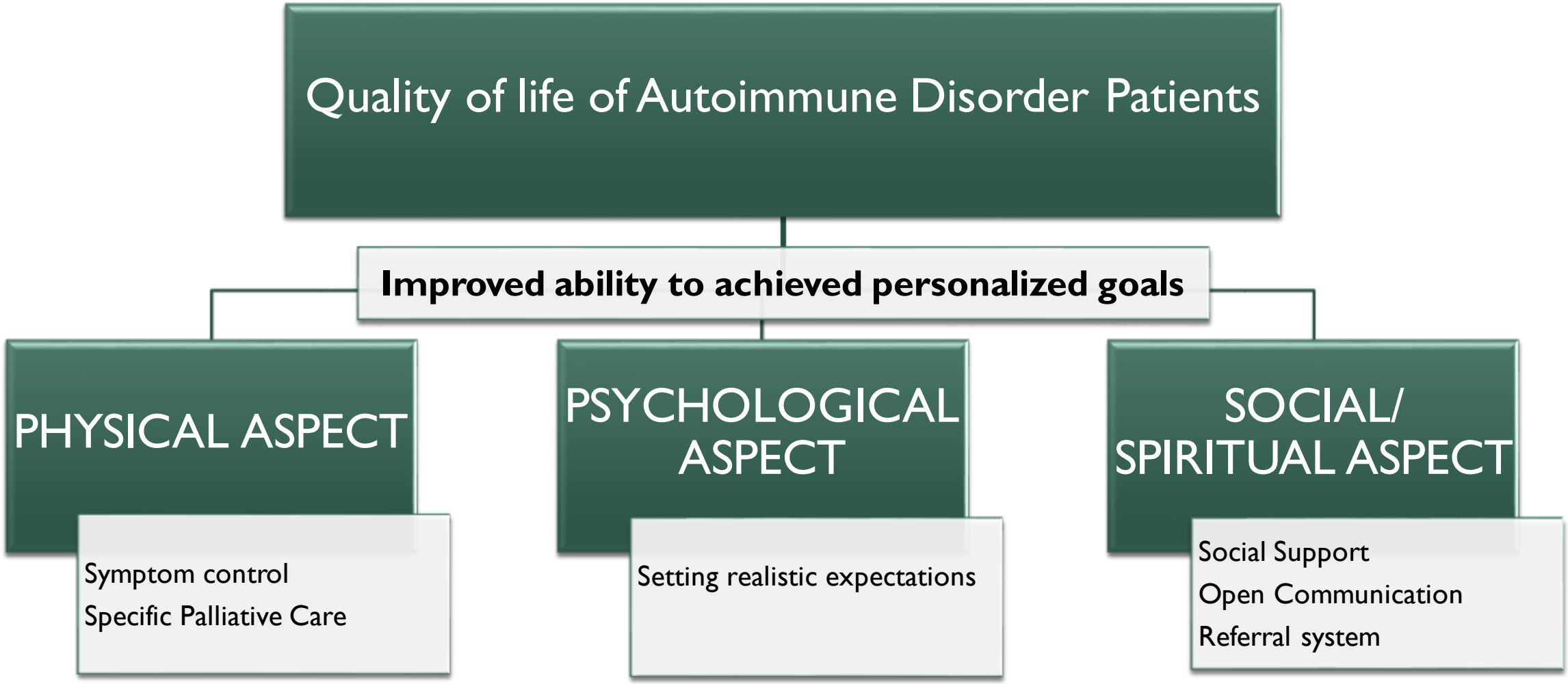
WORLD HEALTH ORGANIZATION (WHO), 5 AUGUST 2020



PALLIATIVE CARE IS CRUCIAL IN IMPROVING QUALITY OF LIFE

WORLD HEALTH ORGANIZATION (WHO), 5 AUGUST 2020

PALLIATIVE CARE ENHANCES PATIENT'S QUALITY OF LIFE



National health policies and systems often do not include palliative care at all

Training on palliative care for health professionals is often limited or non-existent

Lack of awareness among policy-makers, health professionals and the public about what palliative care is, and the benefits it can offer patients and health systems

Cultural and social barriers, such as beliefs about death and dying

Misconceptions about palliative care, such as that it is only for patients with cancer, or for the last weeks of life

Misconceptions that improving access to opioid analgesia will lead to increased substance abuse

SIGNIFICANT BARRIERS: THE UNMET NEEDS OF PALLIATIVE CARE

WORLD HEALTH ORGANIZATION (WHO), 5 AUGUST 2020

WHAT CAN HEALTHCARE SYSTEM DO??

Palliative care is most effective when considered early in the course of the illness

Early palliative care not only improves quality of life for patients but also reduces unnecessary hospitalizations and use of health-care services

Providing palliative care should be considered an ethical duty for health professionals

A sustainable, quality and accessible palliative care system needs to be integrated into primary health care, community and home-based care, as well as supporting care providers such as family and community volunteers

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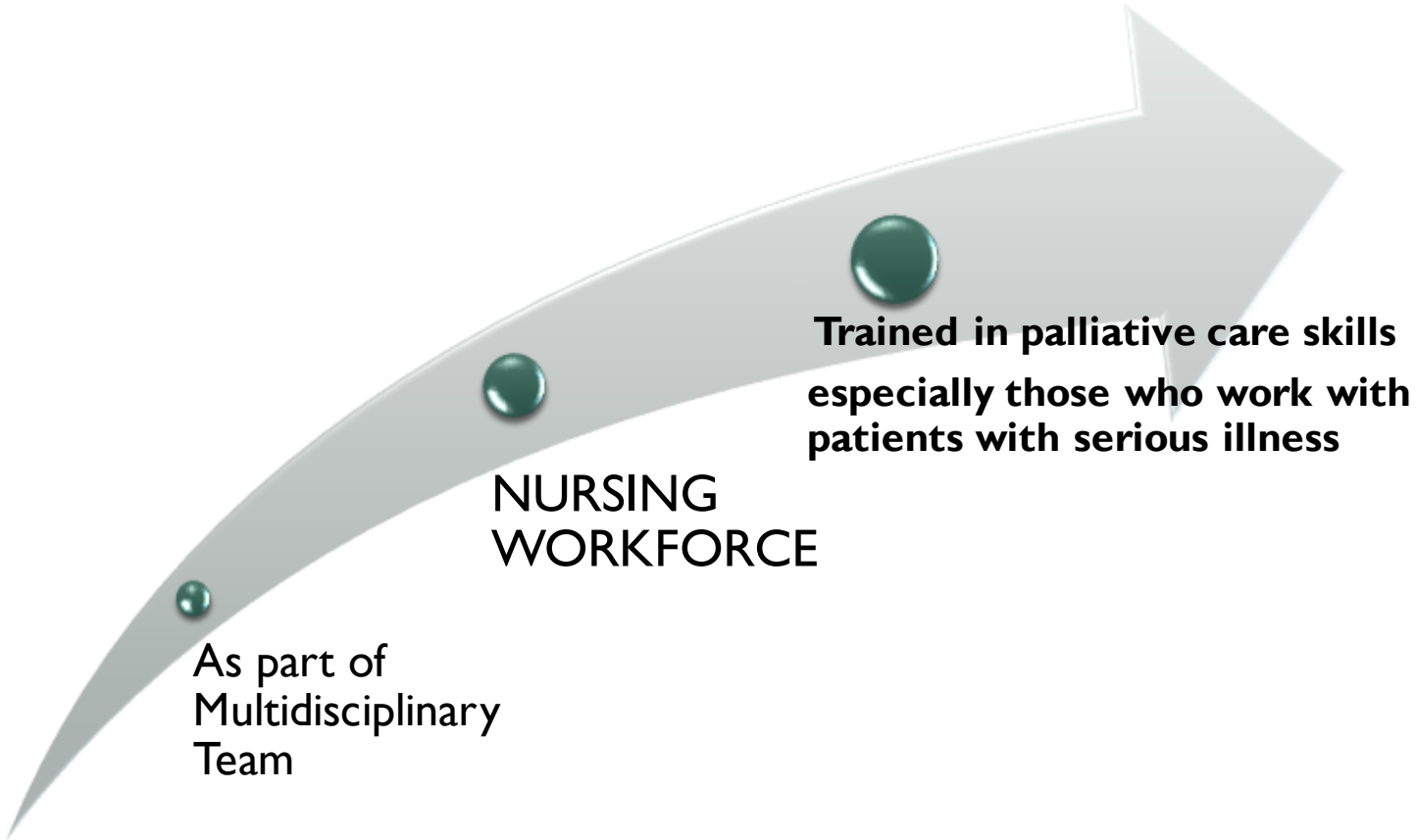
WHAT CAN NURSES DO??



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INTEGRATING NURSING PALLIATIVE CARE & SYMPTOM RELIEF

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IS PALLIATIVE CARE = SUPPORTIVE CARE???

Supportive care also called comfort care, palliative care, and symptom management

Morstad et al found that the term PALLIATIVE CARE evoked more negative emotions and was less favored by patients

Can One live a normal life with autoimmune diseases???

Your Call as a Nurse…

Start making a difference…NOW!

THANK YOU FOR LISTENING ☺