



SEPTEMBER 2022 MM FIGHTERS! MEETING

Psychosocial Issues in Multiple Myeloma: Patients and Caregivers

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What is Psycho(social)-Oncology?

“clinical specialty that addresses the emotional and psychosocial concerns associated with cancer”
- APOS



Source: www.mskcc.org

What Quality of Life Issues Matter in

MMM

Physical independence	Psychological well-being	Social functioning	Relationships with family/significant others	Role function/changes
Sexual function	Work life	Disease-related symptoms	Treatment side effects	Finances
Leisure/fun	Body image	Education about disease and treatment	Support/coping mechanisms	Planning for the future

Osborne, T. R., Ramsenthaler, C., Siegert, R. J., Edmonds, P. M., Schey, S. A., & Higginson, I. J. (2012). What issues matter most to people with multiple myeloma and how well are we measuring them? A systematic review of quality of life tools. *European Journal of Haematology*, 89(6), 437-457.



What Matters to You Today? Patients + Caregivers

Changing roles

Interplay between caregiver and patient during the journey with multiple myeloma

Evolutions in the course of care

Challenges in chronic illness: staying ill too long, or resistance to reclaiming health

Not the only patient

When caregivers are patients themselves

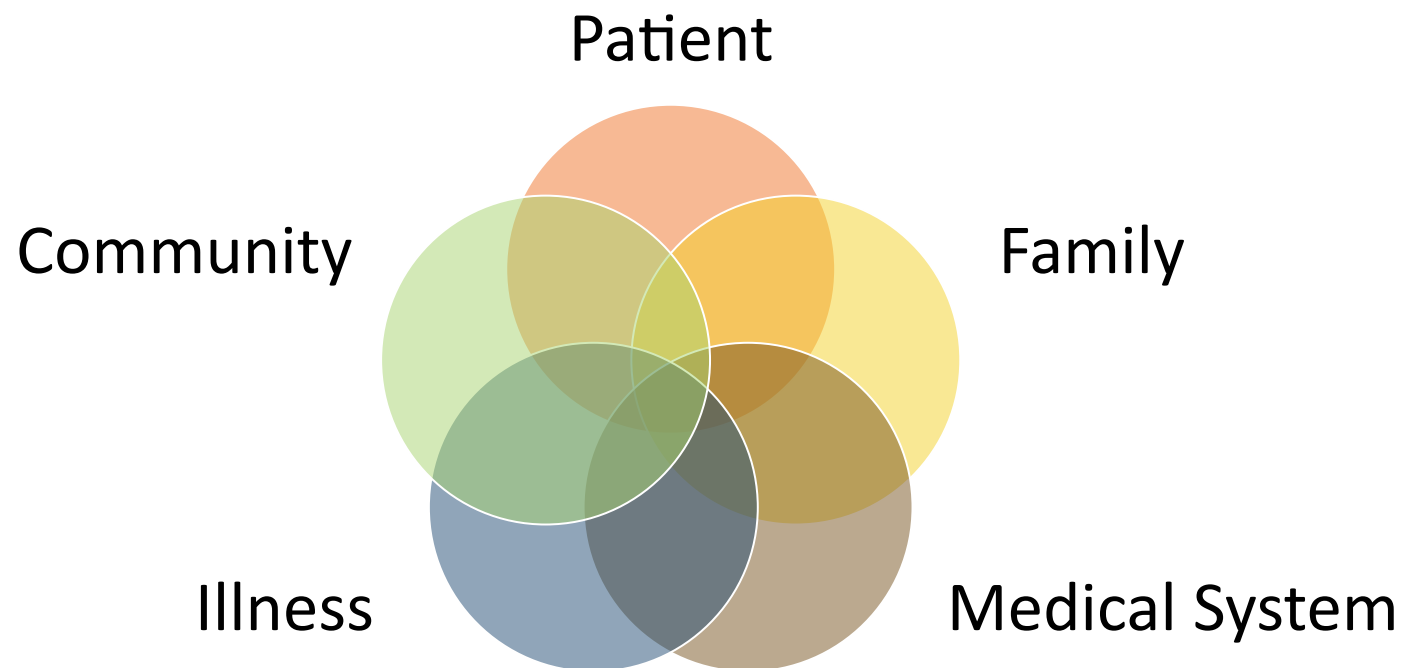
Journeying alone?

Special challenges for multiple myeloma patients living alone

What Impacts Coping with Cancer?



Cancer Care Ecosystem

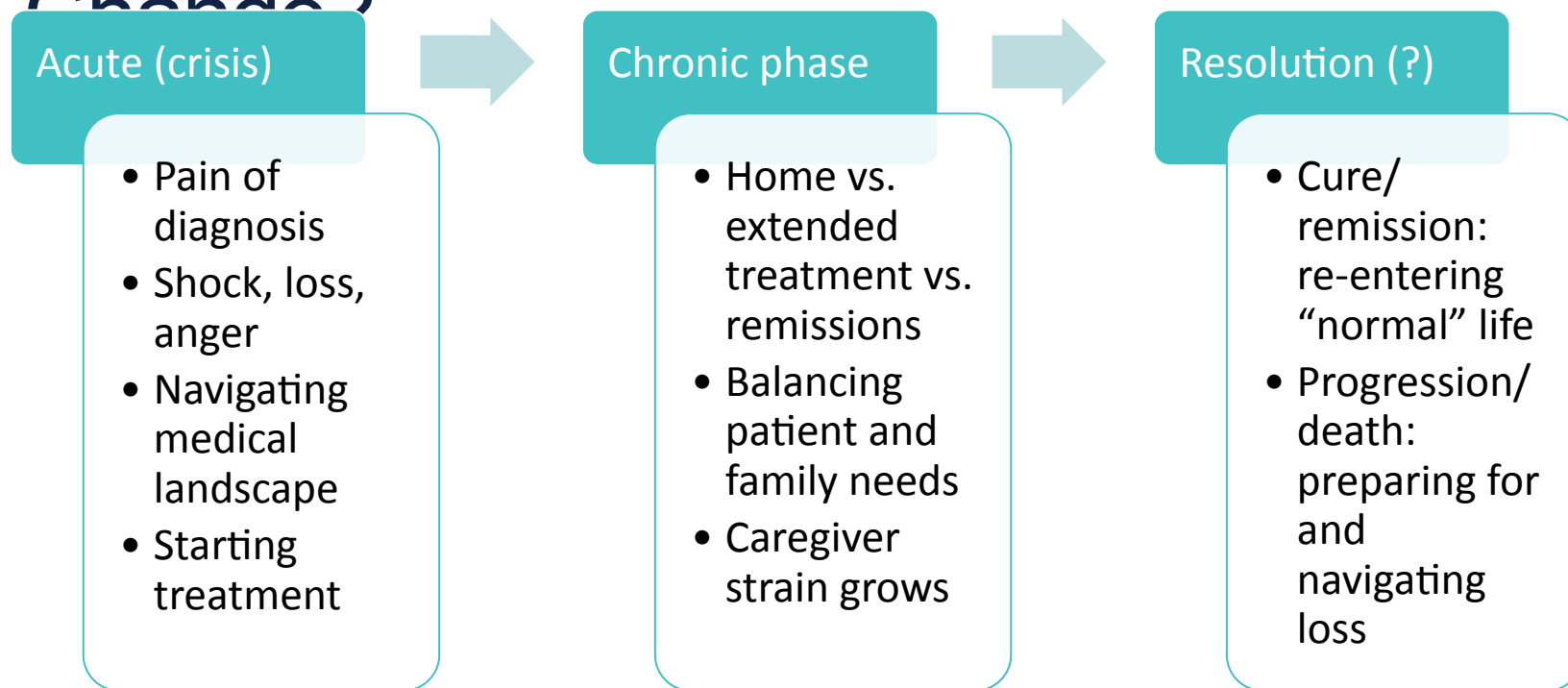


Under Stress, We All Regress

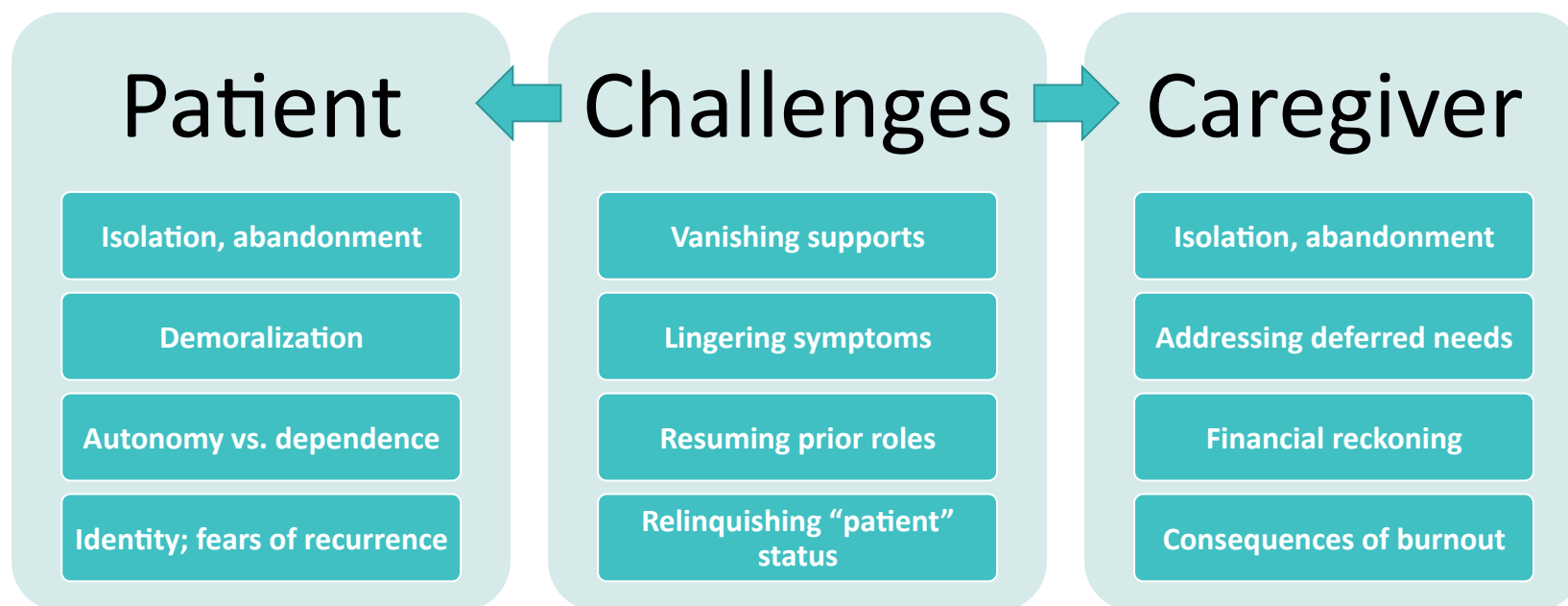
- Serious illness threatens individual and family stability
- Extreme circumstances may drive more extreme versions of ourselves
- Even healthy families move toward less healthy interaction styles



How do Patient and Caregiver Roles Change?



Returning to “Normal” After Treatment





What if Cancer Progresses?

Patient struggles

- Autonomy vs. seeking support
- Death anxiety
- Existential conflicts
- Caregiver struggles
 - Hypervigilance
 - Overprotection
 - Criticism
- Communication struggles
 - Protecting each other from distress
 - Emotional/physical intimacy
 - Individual and shared grief

Navigating MM Alone

- Unique challenges
 - Logistical
 - Emotional
 - Access to treatments/transplant
 - Overall survival?
- Recommended strategies
 - Connect with others
 - Friends, family, support groups
 - Make space for self-care
 - Plan responsibilities ahead

**Also applies to caregivers with their own
medical needs**



Sources:

1. Ríos-Tamayo, et al. LIVING ALONE WITH MULTIPLE MYELOMA: THE NEXT-GENERATION CHALLENGE. HemaSphere: June 2019 - Volume 3 - Issue S1 - p 658
2. Myeloma UK (myeloma.org.uk)



Strategies for Patients & Caregivers

Seek psychoeducation

- Therapeutic alliance
- Skills and knowledge
- Self-reflection and adaptive coping

Address mental health issues

- Clinical depression and anxiety in 20-30% of cancer patients, maybe more in caregivers
- We all need space and time for self-care
- Mindfulness meditation is a great place to start. UCLA Mindful: <https://www.uclahealth.org/marc/ucla-mindful-app>

Communicate

- Avoid avoidance
- Individual or couples' therapy

Maintain, repair, or build new connections to meaning

- Life beyond the scope of cancer care
- Seek supports, in native communities or support groups



Experiential Exercise: Meaningful Moments

"List one or two experiences or moments when life has felt particularly meaningful to you – whether it sounds powerful or mundane. For example, it could be something that helped get you through a difficult day, or a time when you felt most alive. And say something about it."



Thank You. Questions?

National Suicide & Crisis Lifeline: 9-8-8

FHCC Psychosocial Oncology:
<https://www.seattlecca.org/services/psychiatry>

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