

# **Family Caregiving Issues that Cancer Survivors and their Caregivers Face**

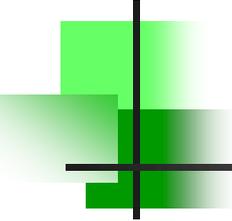
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# State of Knowledge of Caregivers in Survivorship

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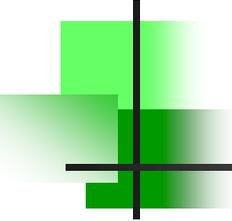
- Increased demand due to advances in treatment and health care – more survivors, older survivors
- More outpatient and care at home responsibilities
- Family caregivers get lost in care system - recognition of role largely absent
- Caregivers are not part of the health team or patient's survivorship plan of care
- Families use few community resources, do not know how and when to access
- Most prevalent are breast and prostate studies



# State of Knowledge...

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- We have few longitudinal studies of needs - 3,5,8 years
- 50-65% caregivers employed and under 65
- Spouses provide most care
- Know a lot about burden, distress, and depression but not in the survivorship period; fear of recurrence major
- 5 years post diagnosis still assisting patient with distress
- Caregivers and patients have interdependence but caregivers have unique unmet psychosocial needs



# State of Knowledge....

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- Few studies on caregiver social relationships or occupational circumstances
- Few studies on interventions for caregivers in survivorship, fewer still dyadic
- Only 25% of all get training
- Little consideration of effect on comorbidities
- At 2 years post-diagnosis, 33% need help with own coping

# Gaps About Caregiver Care in Survivorship

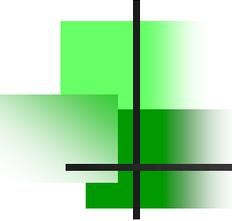
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- Knowledge and skills that caregivers need
- How to help families provide care, need care coordination
- Changes in role across post-treatment for residual and late effects
- Quality of care given by caregivers (patient outcomes, safety)
- Unnecessary care vs appropriate care by caregivers
- Late and long term effects on caregiver outcomes
- Should interventions be motivational and emotional regulation rather than CBT?
- Coordination and transition of cancer care (primary care and oncology). What works best?

# Caregiver Responses in Survivorship

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- Anxiety (38% 2 year, 21% 5 year)
- Depression (38% 2 year, 21% 5 year)
- Burden - higher periods than others
- PTSD
- Lack of social support
- Lifestyle changes (27% 2 year)
- Stress and distress/fear of reoccurrences (37%)
- Spiritual needs are heightened

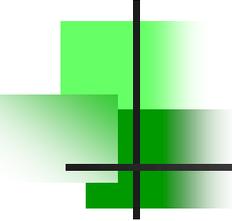


# Caregiver Responses

## 2 Years Post-diagnosis

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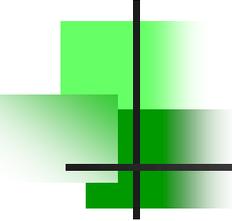
- Financial challenges
- Lifestyle changes
- Challenges to employment
- Unsure about follow-up patient care when patient referred to primary care
- Who is in charge? Role of caregiver unclear
- Want clear set of expectations across transitions
- What resources are available?
- Quality of life at 2 years predicted quality of life at 6 years



# Information Needs

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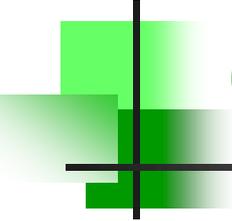
- 78% feel have inadequate information
- Prognosis for recurrence and disease progression
- Late effects and residual effects (expectations of future)
- Coping with the uncertainty
- What care do patients currently need?
- Where do I go?
- How to provide emotional support
- Support and community resource availability
- Impact on patient (sexuality, body image, work, health)



# Caregiver Tasks of Care Residual and Late Effects

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- Decision-making/problem solving
- Symptom management, monitoring, interpreting, action, residual and late effects (50-75%)
- Providing emotional support - for anxiety, uncertainty, depression, anger
- Administering medication (33%) - responsibility for complex oral medications schedule
- Coordinating care
- 43% perform complex tasks without prior preparation
- Ensuring follow up care



# Risk Assessment for Caregiver Situation

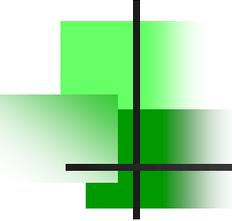
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- Caregiver's own physical health/chronic disease
- Caregiver's own mental and emotional health (depression, anxiety)
- Caregiver's multiple other roles (work, family, social) - competing demands
- Decisional and family conflicts
- Difficult transitions in care
- Complex follow up needed (include psychosocial needs)

# Risk Factors for Negative Caregiver Situation

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- Lack of choice in becoming a caregiver
- Serious late effects expected
- Older adults with multiple complex comorbidities
- Poor communication
  - Patient to caregiver
  - Patient, caregiver, provider
  - Provider to provider
  - Capacity to care
  - Young caregivers



# Recommendation: Provide Resources

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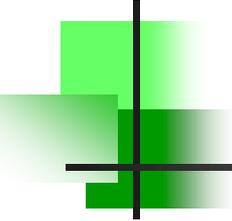
- Cancer Support Community
- Training materials for caregivers at various phases (Bootcamp for caregivers)
- Training of professionals
- Community education (e.g. community colleges)
- Stress management programs
- Use of peer networks, social media, and support groups
- Use of technology- remote follow up and consultation

# Resources:

## Tools to Support Caregivers

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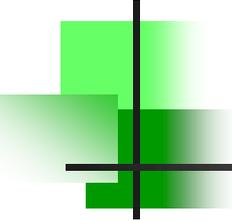
- Use internet as a source of information; 78% looked up condition
- Assistive Devices – medication dispensers, PDA/ video clips, AARP for elderly
- NCI websites, ACS website
- Cancer center's links to resources
- ASCO / Cancer Care Consortium
- Peer support programs
- AARP resources- video clips on care components
- Develop toolbox of interventions and resources



# Health System Issues

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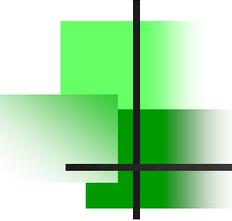
- Who cares and whose responsibility / recognition of caregiver role?
- Benchmarks for successful caregiver survivorship
- Guidelines for survivorship care - by diagnosis and age
- Standards of care and guidelines for psychosocial concerns - include in survivorship care plans
- Measurement of quality of care provided by caregivers
- Health professional education - what support do caregivers need?



# Health Professional Roles

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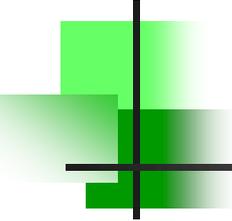
- Need to assess ongoing care needs and strategies on the caregiver considering:
  - Demands – hours of care, level of care
  - Expected duration and level of care needed
  - Caregiver's availability / capability to care
  - Existing knowledge and skills needed
  - Available resources
  - Living arrangements (caring from a distance)
  - Caregiver competing demands
- Need to consider the caregiver as part of the team



# Research Recommendations

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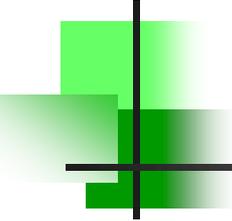
- Caregiver surveillance at intervals of survivorship
- Identify high risk situations - referrals. Can we impact?
- Vulnerable caregiver populations - rural, racial and ethnic
- Measures should be examined
  - Quality and safety of patient care / caregiver care
  - Coordination of patient care by caregiver
  - Instruments to capture caregiver role
  - Patient outcomes
  - Caregiver health outcomes
- Family navigation in survivorship centers (Psychosocial)  
Coaches



# Research Recommendations

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- Do interventions targeted to caregivers affect employment (caregiver and patient)?
- More dyadic studies
- Caregivers 25% make employment changes
- Health care utilization by caregivers during survivorship
- What lasting lifestyle changes are of value?
- Develop toolbox of assessments across survivorship phases to capture high risk experiences

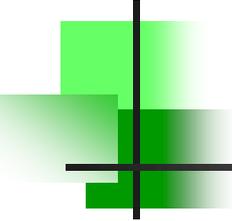


# Policy

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- Look at effect of role on use of services and wellbeing
- CARE Act type to instruct and support caregiver at end of treatment and into survivorship
- Tax credits and social security credits for survivorship
- Work place accommodations should be considered
- HB 2505- Credit for Caring Act (RAISE) - Support
- Big questions: Who should pay? Need data to support
- Family Caregiver Support Program needs funds
- Try models of practice of interdisciplinary delivery

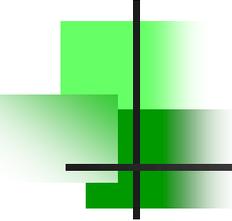
Family caregivers are  
the hidden cancer care  
team members - we  
need to recognize their  
value and include them!



# References

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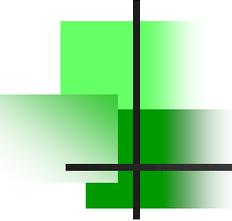
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