Memorial Sloan Kettering
Cancer Center

MSK Caregivers Clinic:
A Clinical Service Dedicated to Supporting Cancer Caregivers

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A Vast, Unmet Need…

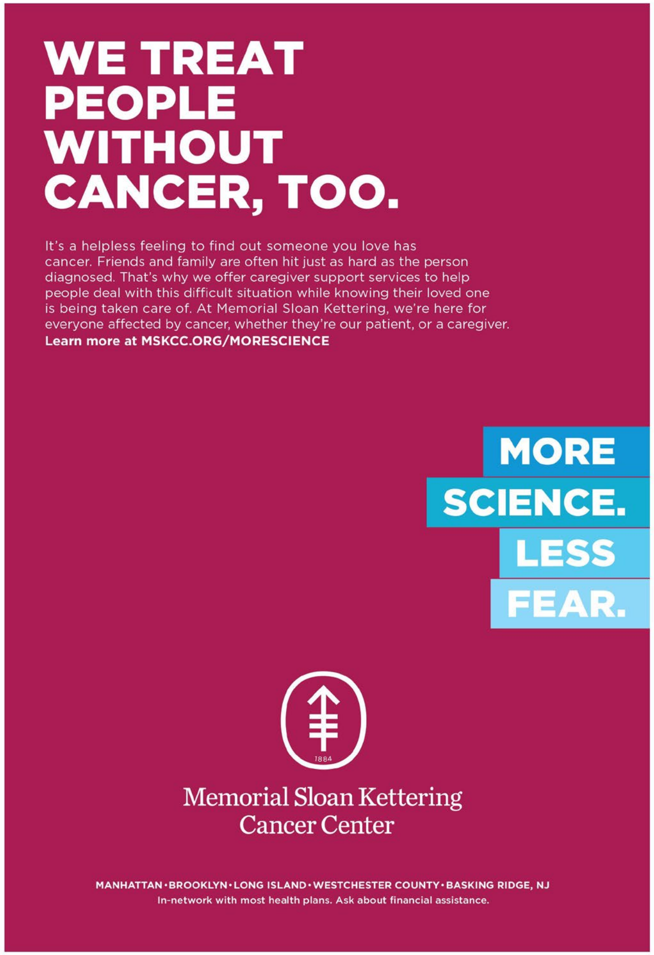
- Diffuse support available for caregivers at MSK, mirrored at cancer centers across the country.
- Desire for caregiver-specific support focused on distress and their own wellbeing (v. support to help caregivers carry out caregiving responsibilities).

Family Care Program

Caregivers Clinic

Family Therapy Clinic

Bereavement Clinic



WE TREAT PEOPLE WITHOUT CANCER, TOO.

It's a helpless feeling to find out someone you love has cancer. Friends and family are often hit just as hard as the person diagnosed. That's why we offer caregiver support services to help people deal with this difficult situation while knowing their loved one is being taken care of. At Memorial Sloan Kettering, we're here for everyone affected by cancer, whether they're our patient, or a caregiver. **Learn more at MSKCC.ORG/MORESCIENCE**

MORE SCIENCE. LESS FEAR.

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MANHATTAN • BROOKLYN • LONG ISLAND • WESTCHESTER COUNTY • BASKING RIDGE, NJ
In-network with most health plans. Ask about financial assistance.

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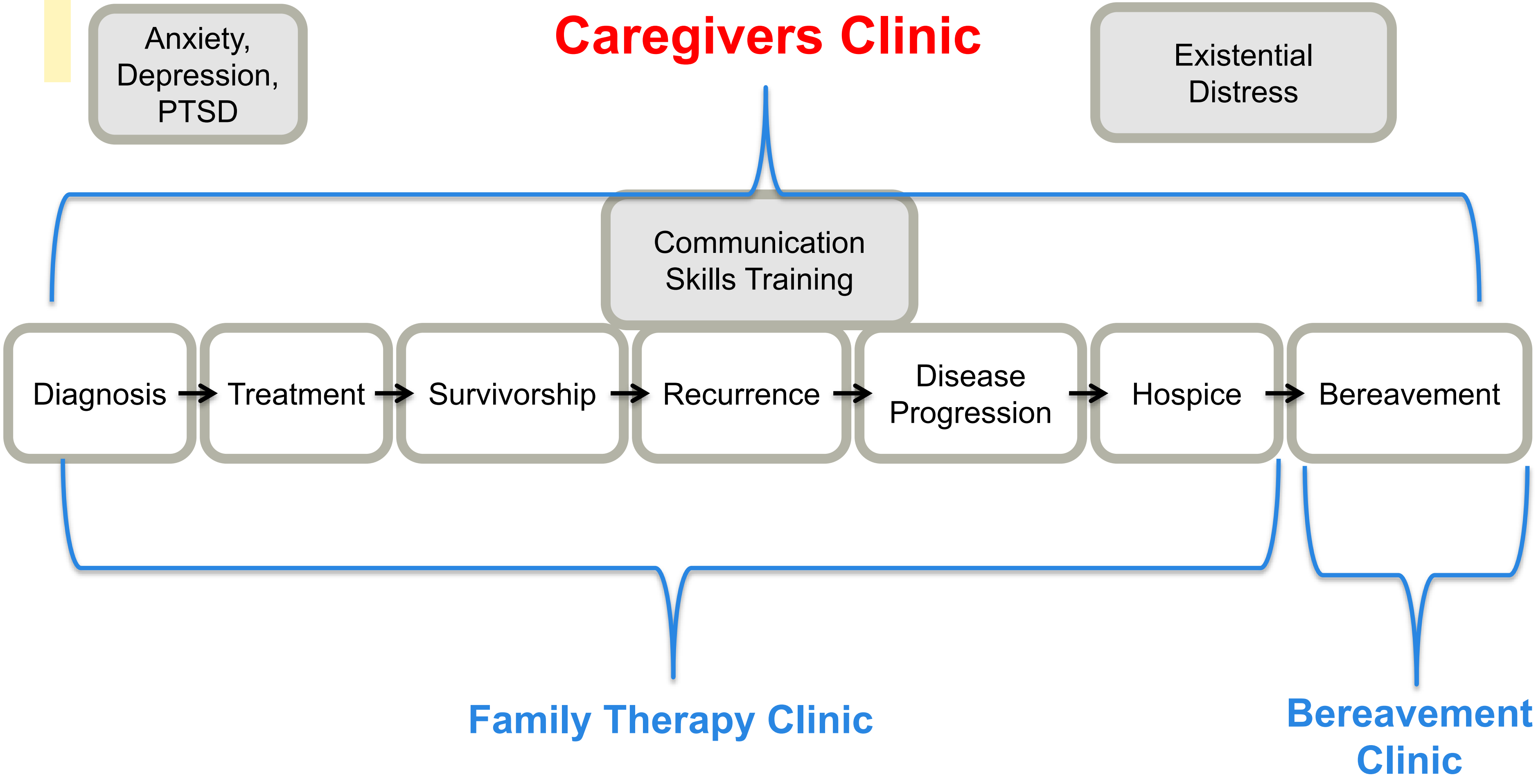
Family Care Program



Anxiety, Depression, PTSD

Caregivers Clinic

Existential Distress

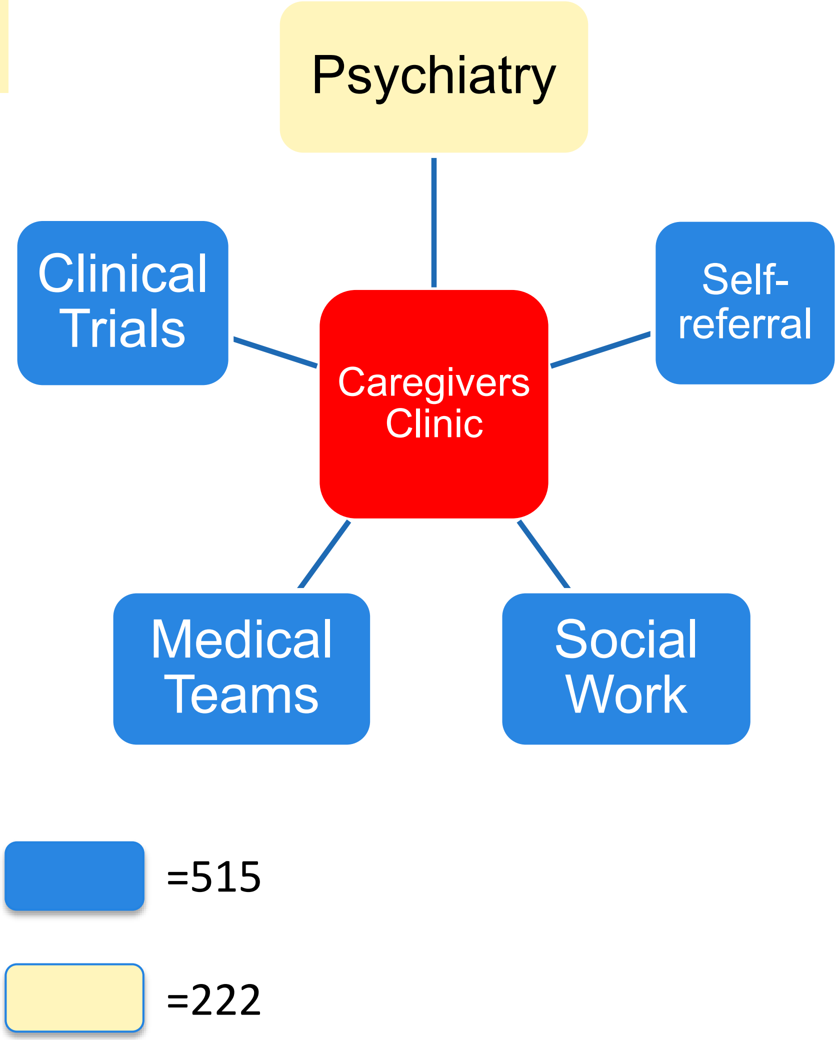
Communication Skills Training

Diagnosis → Treatment → Survivorship → Recurrence → Disease Progression → Hospice → Bereavement

Family Therapy Clinic

Bereavement Clinic

Referral Sources (November 2011-2021)



Psychiatry

Clinical Trials

Caregivers Clinic

Self-referral

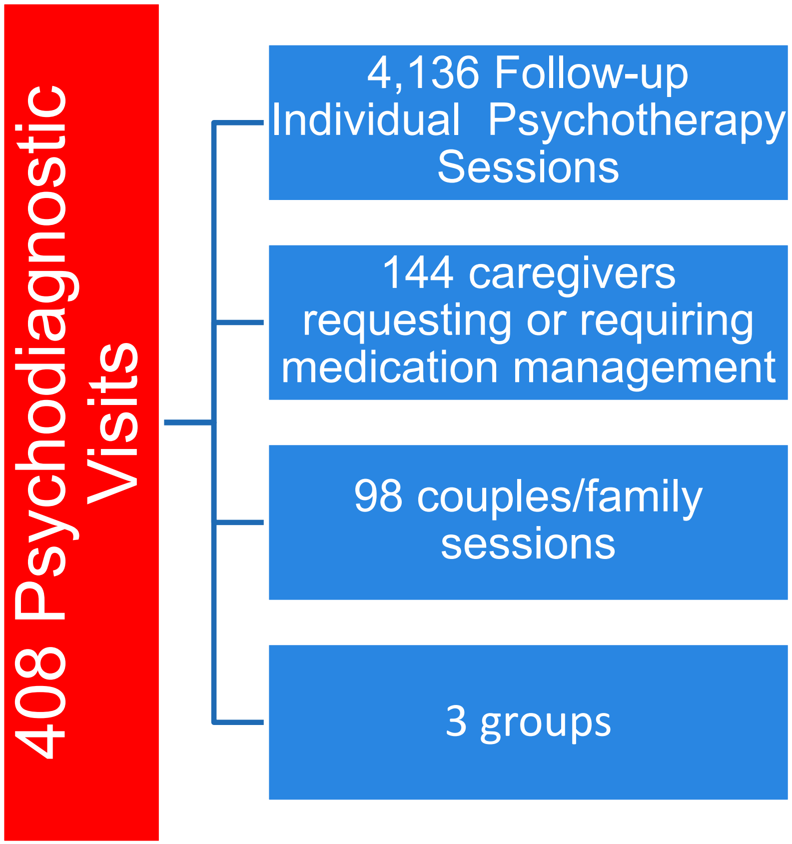
Medical Teams

Social Work

🟦 =515

🟨 =222

Referral Outcomes



408 Psychodiagnostic Visits

- 4,136 Follow-up Individual Psychotherapy Sessions
- 144 caregivers requesting or requiring medication management
- 98 couples/family sessions
- 3 groups

Clinic Administration

comments and controversies

Documentation of Caregivers as a Standard of Care

Allison J. Applebaum, PhD[1,2]; Erin E. Kent, PhD[3,4]; and Wendy G. Lichtenthal, PhD[1,2]

The COVID-19 pandemic has highlighted a national caregiving crisis that existed long before 2020.[1] More than ever before, the approximately 6 million Americans who serve as family caregivers to patients with cancer are an essential extension of the health care team.[2] Caregivers' responsibilities are growing; today's shorter hospital stays and shift toward increased outpatient care have left them with significant responsibilities and little to no preparation for this role. As a result, caregivers are at increased risk for psychiatric morbidity, including anxiety and depression,[3-7] and physical health conditions, including poor immune functioning, cardiovascular disease, and sleep difficulties.[8-13] This significantly affects their capacity to provide high-quality care to patients and can lead to poor bereavement outcomes for those caregivers whose loved ones die.[14]

This distress commonly experienced by caregivers has the potential to be mitigated or prevented with proper psychosocial support. However, too often, access-to-care barriers interfere with caregivers receiving critical support services. Although there are many systemic contributors to caregiver underutilization of mental health services, in this commentary, we highlight the importance of establishing an infrastructure to facilitate the screening and support of caregivers. Specifically, we argue that streamlining documentation procedures is an addressable barrier to improving caregiver care. We propose that standardizing the establishment of separate medical records for caregivers at the time that patients' records are generated will facilitate the provision of the support that caregivers often need to maintain their role as fundamental members of the patient care team.

The benefits of providing psychosocial care to caregivers from the time of diagnosis through bereavement are vast and well-documented.[15-19] Formally supporting caregivers has the potential to improve caregiver mental and physical health, to improve patient outcomes, and to reduce the financial toll of care in the long-term.[15-17] Over the past decade, there has been a notable increase in the development of psychosocial interventions focused specifically on addressing the needs of cancer caregivers.[20] This has been driven, in part, by funding opportunities and recognition from major health organizations that supporting family caregivers is a critical component of patient-centered care.[21-25] As a result, there has been significant progress in moving the state of the science of psychosocial support for caregivers forward, and there is increased recognition that meeting caregivers' support needs is critical.

Despite these developments, standardized documentation of caregiver identity in medical institutions is limited. Currently, the only regulations mandating routine documentation of caregiver information are through the Caregiver Advise Record and Enable (CARE) Act, which has three main provisions, requiring hospitals to (1) record the name of a family caregiver on the medical record of the care recipient who is admitted for treatment, (2) inform the family caregiver when the care recipient is to be transferred or discharged, and (3) provide the family caregiver with education and instruction of the medical tasks they will need to perform for the patient at home. To date, the CARE Act has been signed into law in more than 40 states, the District of Columbia, Puerto Rico, and the US Virgin Islands.[26]

Although the CARE Act has led to the addition of caregivers' contact information in hospitalized patients' medical records, there is no consistent or specified location for this or any other caregiver-related data, nor does it apply in the outpatient setting. Without standards for *how* and *where* to track information about caregivers, significant challenges emerge. For example, notes from support services (eg, social work) delivered to caregivers are often included in the patient's medical record. This practice presents several issues. First, both privacy and confidentiality of caregivers are potentially compromised when any such information is included in the medical record of patients. If caregivers are in receipt of support services from providers who bill (eg, psychologists) without the patient present for the encounter, placing that note in the patient's medical record assumes that the patient is billed for the services and can read about what was discussed when accessing their own records. If the patient dies, continuing to document and bill under the patient's record is more complicated and leads to the following questions: Where should bereavement

Author affiliations and support information (if applicable) appear at the end of this article.

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- Caregivers receive ICD-10 diagnoses; insurance carriers are billed (except when caregivers seen by fellows)
- Sessions via telepsychiatry since March 2020
- Pace tailored to caregiver needs
- Rely heavily on empirically supported interventions

Challenges of Meeting the *Extraordinary* Demand for Care

Wait times/pace of sessions

- Staffing via externs/interns/postdocs
- Referral to clinical trials
- Caregiver-to-Caregiver Mentoring Program

Cost of care

- Follow-up sessions provided by fellows/trainees are free of charge, but diagnostic visits are always billed
- Philanthropic support

Caregivers living out of state

- Temporary licenses
- Referral to Social Work/Community based organizations

Telemedicine

- Addresses many historic barriers to psychosocial service use among caregivers
- Ease of access has created a new challenge of meeting the demand for care

Next Steps

- Integrating distress screening (e.g., CancerSupportSource®-Caregivers (CSS-Cg)) across MSK
- Mini-registrations for all MSK caregivers
- Expansion of peer support through the Caregiver-to-Caregiver mentoring program

Thank You!

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