

Linking Multiple Myeloma Patients and Families With Telephone Support: A Unique Pathway for Caller Referral



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Introduction

- The Cancer Support Community (CSC) represents a global network of non-profit, community-based organizations that provide evidence-based programs to patients and families.
- People affected by cancer are often unaware that psychosocial services exist. While 40% of patients experience significant levels of distress, fewer than 10% of patients utilize psychosocial supportive services.
- As oncology social workers, we are challenged to identify as many touch points as possible for patients and families to access psychosocial services whether in a hospital environment or out in the community.
- Critical access points for psychosocial care that are often overlooked are pharmaceutical patient assistance programs. These programs are provided to assist patients in gaining access to, and reimbursement for medications. Such programs are often limited in knowing how to help patients and their families with complex psychosocial needs. Social workers frequently refer patients and families to these programs, and yet, we do not consistently cultivate the opportunity to get reciprocal referrals.
- CSC, with Onyx Pharmaceuticals, Inc., an Amgen subsidiary, established a new industry standard for patient access programs. Through this program, CSC is assisting and empowering patients with multiple myeloma, caregivers, and family members, who are referred directly by the Onyx Pharmaceuticals 360™ (Onyx 360) patient assistance program.
- Patients, family members and caregivers who contact or enroll in the Onyx 360 patient support and services program can be referred to the CSC Cancer Support Helpline for information about and referral to local, regional and national resources, short-term support and counseling related to stress management, personal or family issues and practical support for managing day-to-day treatment and survivorship issues.

By providing highly personalized assistance to help patients and caregivers identify and address critical needs, CSC is able to link callers with a community of support and help them live better lives.

Key Features of the Cancer Support Helpline®

- Helpline launched in April 2012 and is staffed with licensed mental health professionals specially trained in telephonic health and psycho-oncology.
- Open Monday-Friday, 9 am-8 pm EST to manage both inbound and outbound calls.
- Spanish language available and Live Chat.
- Callers include patients, caregivers/family and friends, healthcare professionals, other advocacy organizations, industry partners.
- Call center management system and database.
- Services include: Distress screening, referral and follow-up, Treatment decision counseling (Open to Options), Coping skill/problem-solving development, Short-term supportive counseling, Disease-specific education and referral, Referral to local, regional, national resources including mental health, Provision of educational materials, End-of-life care planning and support, Online support group enrollment and referrals for assistance for Practical resources.

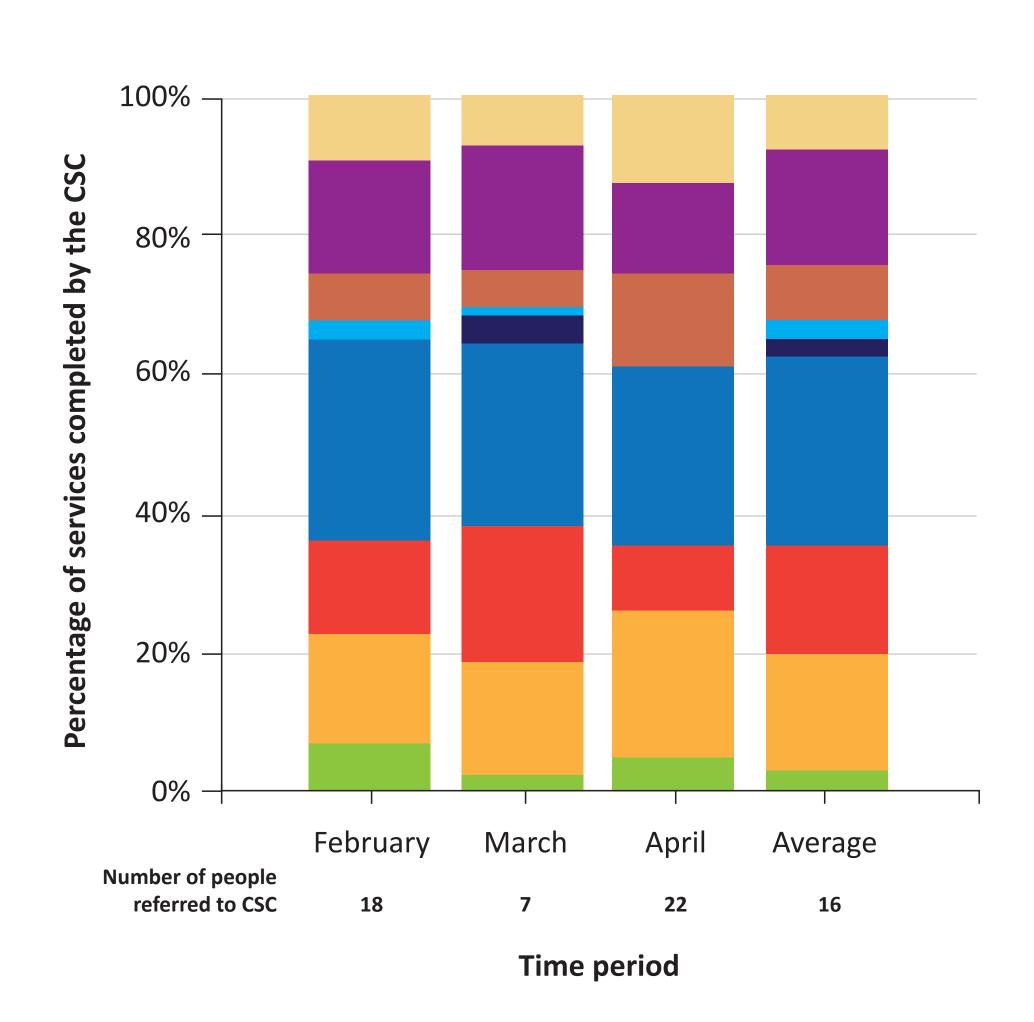
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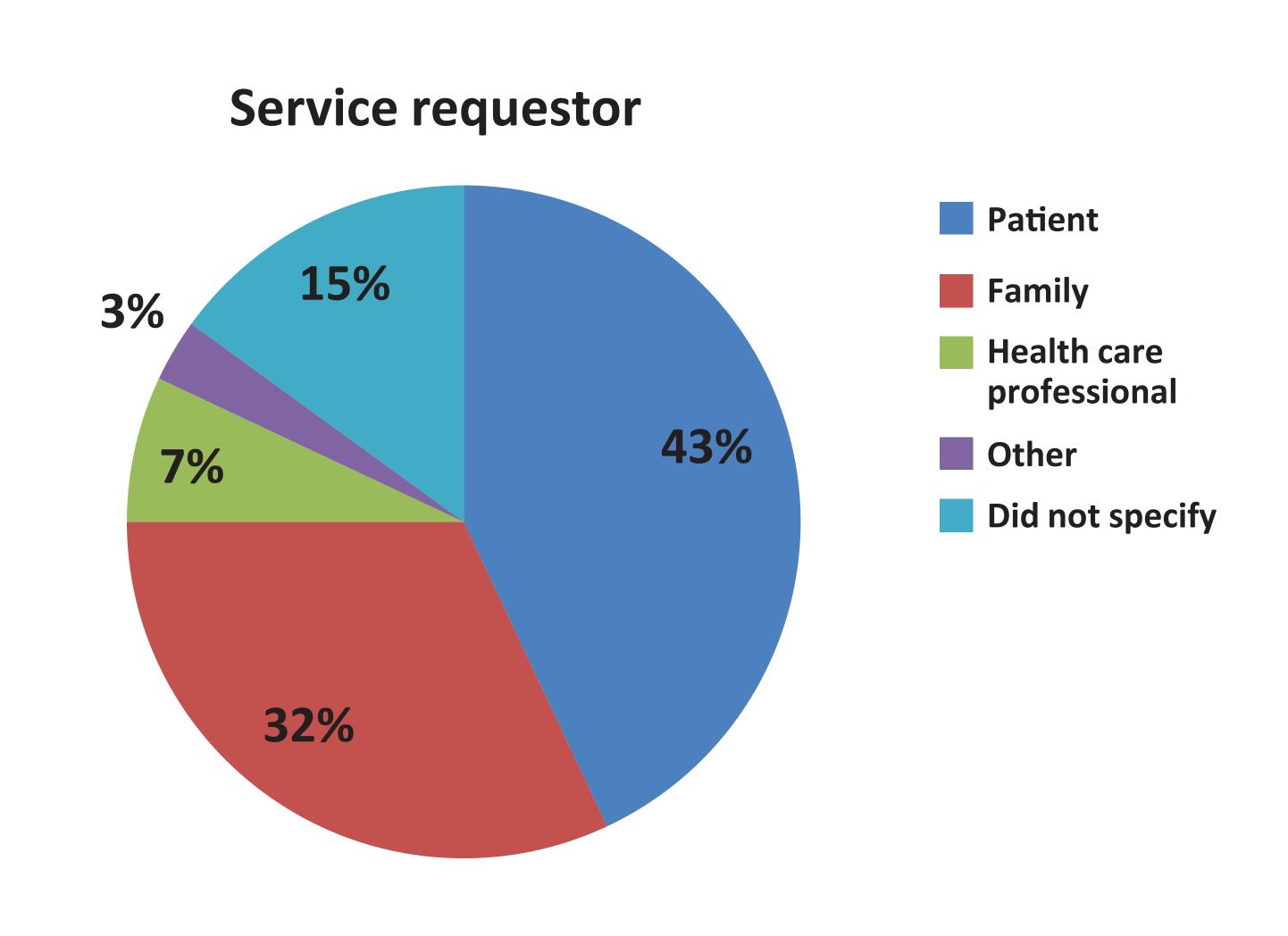
- A multidisciplinary, multi-organizational team was mobilized by the Onyx 360™ team to outline the steps to establish formal pathways referrals for psychosocial services taking into account industry regulations and standards of care.
- Extensive planning, cross-training between call centers staff, continual program evaluation and refinement as well an enthusiastic company champion are essential elements for a successful program.
- Skilled oncology social workers address concerns such as transportation and often more significant issues such as end of life care planning and family distress.

Results

• Services completed by the CSC from February 1, 2014 to April 30, 2014 after referrals from Onyx 360 are shown below







Recommendations and Best Practices

- Do not assume that patients and family members will automatically take advantage of referral for supportive services.
- Initially, there was a limited caller response to being offered the option for a warm transfer or referral for follow-up by a CSC Helpline Counselor. In response, CSC developed 4 brief screening questions to better engage the caller in identifying social, emotional or practical concerns. This has increased caller acceptance of the referral by approximately 30%.
- On a scale of 0 to 10 (0 being lowest, 10 the highest), how would you rate...
- Your level of concern about practical issues such as home care, transportation, finances, etc.?
- Your level of concern about family, work, or home life?
- Your level of concern about emotional issues or coping with multiple myeloma?
- Your overall level of distress today?

Conclusion and Future Directions

• It is clear that patients and family members value and are highly satisfied by a 'whole patient' approach to the standard pharmaceutical patient assistance program. This program also illustrates the feasibility and importance of formally integrating referral agreements among community-based organizations and industry partners to ensure quality care.