The Challenges of Chronic Myeloid Leukemia (CML) Survivorship for Community-Based Providers

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Learning Objectives
After this presentation, attendees will be able to:
• Describe the challenges that treating people with CML present for community-based providers
• Explain the CML survivorship issues that community-based providers face
• Explain the ongoing survivorship needs for CML patients at different ages

CML Statistics
• According to Surveillance, Epidemiology and End Result’s (SEER) 2011 statistics
  – Number of people currently living with CML is growing
  – Number of deaths per year has declined
• With introduction of Gleevec, survival rates have greatly improved

ACCC Pre-Survey
• Challenges for small-population cancers
  o 22% of physicians correctly identified
  o 18% of pharmacists correctly identified
  o 14% of nurses correctly identified
  o 4% of administrators correctly identified
• Increased prevalence of CML survival
  o 40% of physicians recognized
  o 6% of nurses recognized
  o 18% of pharmacists recognized
  o 8% of administrators recognized
Survivorship Definition

• An individual is considered a cancer survivor from the time of cancer diagnosis through the balance of his or her life

NCCS (National Coalition of Cancer Survivorship) and the NCI (National Cancer Institute) Office of Cancer Survivorship definition

What has changed for CML Patients?

• Gleevec
• Ongoing monitoring
• Second and third generation tyrosine kinase inhibitors (TKI’s)
• Adherence to drug therapy and drug compliance
• Long term side effect management
• Treatment costs

Challenges that CML Presents for Community-Based Providers

• Complex care
• Psychosocial
• Finances
• Patients diagnosed in accelerated phase; different survivorship concerns
• Length of care
• Patient’s age needs to be considered
How Can Community-Based Providers Address and Manage These Issues More Effectively?

Complex Care

• Healthcare team needs to work with patients to
  – Schedule regular visits
  – Continue to monitor for treatment response
  – Assess support services
  – Follow up if medication is not obtained
  – Monitor drug compliance

Complex Care [cont.]

• Use ACCC’s ASK (Answers, Solutions, and Knowledge) forum
• Use the ACCC small population cancer webpages
• Use LLS Resources
Psychosocial

- Ongoing treatment
- Don't “look” like they have cancer/Have the “good kind of cancer”
- Anxiety/Depression
- Education about costs, side effects, compliance

Finances

- Cost of drug
- Insurance
  - Insured-Can patient afford co-pay?
  - Underinsured- Can patient afford to pay?
  - Uninsured?
- Increase knowledge of financial resources due to cost of CML treatment

Accelerated Disease

- Optimal therapy for patient?
- Better understanding of why current therapies are not working
- Can consult other hematologists without travel
Length of Care

- Ongoing treatment and monitoring required
- Ongoing side effect management
- Building partnership with healthcare team
- Look to advocacy organizations and web for continuing education

Who Has CML?

Jason Blake, age 38
Erin Zammett-Ruddy, age 33
Ryan O’Neal, age 70
Kareem Abdul-Jabbar, age 64

CML and Age

- Average age at onset is 66
- Most cases of CML occur in adults
- Only about 2.4 percent of new leukemia cases in children aged 0-19 years are CML
- Slightly more than 1 percent of all cases of CML are in children aged 15-19 years
CML and Age [cont.]

- Due to nature of treatment for CML, each patient should to be assessed for long-term needs
  - Insurance coverage/payment for the drug
  - Choice of three drugs for newly diagnosed
  - Shared care of oncologists and PCPs

Megan
Children and Young Adults

• Treatment will continue their entire lives
• Many concerns arise including
  – Social lives
  – Interruptions in schooling
  – Peers
  – Dating
  – Marriage
  – Fertility

Adults

• Caring for family members (children or parents)
  – How to juggle taking care of yourself and someone else
  – Getting to the doctor’s office for testing while coordinating other’s activities
• Saving for retirement
Older Adults

- Quality of life
- Medicare coverage concerns
- Care for other health issues- comorbidities
- Management of multiple medications

Resources

- NCCN Guidelines for Patients (nccn.com)
- ACCC ASK on CML forum
- Medscape
- LLS CME programs (www.lls.org/CME)

LLS Resources

- Information Specialists (800) 955-4572/infocenter@lls.org
- Assistance with Clinical Trial searches
  - Call our Information Specialists (800) 955-4572 or visit www.lls.org/clinicaltrials, and click on TrialCheck®
- Local Support Groups www.lls.org
- Online CML Chats www.lls.org/chat
- Peer-to-Peer Support www.lls.org/firstconnection
- CML discussion board www.lls.org/discussionboards
- Co-pay Assistance Program/Patient Financial Aid www.lls.org/finances
- Local Education Programs www.lls.org/programs
LLS Resources [cont.]

- LLS Website [www.lls.org](http://www.lls.org)
- Education Materials [www.lls.org/resourcecenter](http://www.lls.org/resourcecenter)
- Patient/Healthcare telephone/web education programs
  - [www.LLS.org/programs](http://www.LLS.org/programs) for more information and to register
  - Dr. Michael Mauro will present *CML: An Expert Discussion about Diagnosis and Treatment* on Oct. 25th from 1-2 pm
  - CML program scheduled for January

References

- Chronic Myeloid Leukemia. The Leukemia & Lymphoma Society. In production, 2011.

References [cont.]