

Joanne S. Buzaglo¹, Clare Karten², Elisa S. Weiss³, Melissa F. Miller¹, Anne Morris¹

¹Cancer Support Community, Philadelphia, PA, ²CTK Consults, Hartsdale, NY, ³The Leukemia & Lymphoma Society, White Plains, NY

Introduction

US prevalence of CML is ~33,990 of Jan 1, 2011 (SEER, 2014). In 2014, there will be an estimated 5,980 new CML cases (American Cancer Society, 2014).

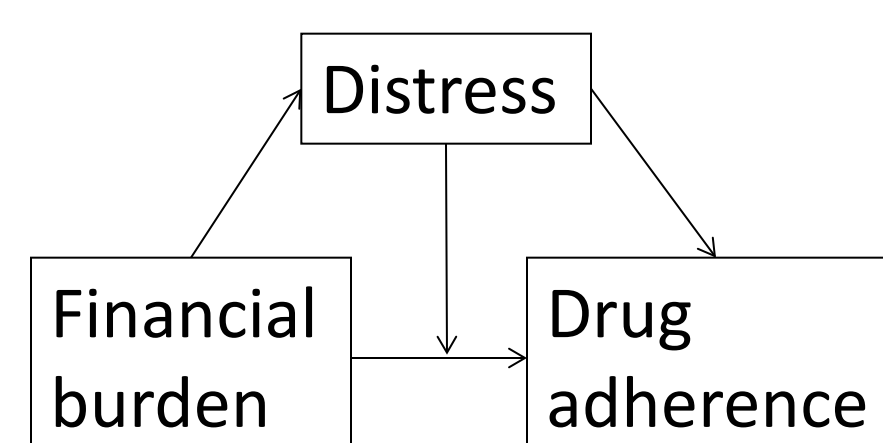
The era of tyrosine kinase inhibitors has transformed CML from an often-fatal disease to one with an excellent prognosis (with ongoing treatment).

Studies have reported the financial burden of CML care is associated with decreased adherence (Dusetzina, 2014).

Poor adherence is associated with decreases in 5-year event-free survival and may occur more frequently than either patients or physicians recognize.

Aim

To characterize treatment adherence among CML patients and define the relationship between financial burden, psychosocial distress, and drug adherence.



Method

The Cancer Experience Registry

Collecting, analyzing and sharing information about the experience and needs of patients and their families throughout the cancer journey.

From October 2013 to June 2014, the Cancer Support Community (CSC) in partnership with The Leukemia & Lymphoma Society (LLS) registered 484 people living with CML to the Cancer Experience Registry.

Registrants were recruited through an outreach program that leveraged CSC's and LLS's networks of community-based affiliates and chapters, online communities, CSC's helpline and LLS's information resource center, other advocacy organizations, social and other media channels.

393 (81%) registrants responded to the questionnaire; the present analysis includes 327 US based registrants.

Results

Sample Characteristics	
Median age	59 years
Female	67%
Caucasian	90%
Black or African American	3%
Hispanic	3%
College degree or higher	51%
Median time since CML diagnosis	4 years
Annual Income	
<\$40K	32%
\$40-79K	31%
≥\$80K	37%

Patient-Reported Adherence to Oral Medication

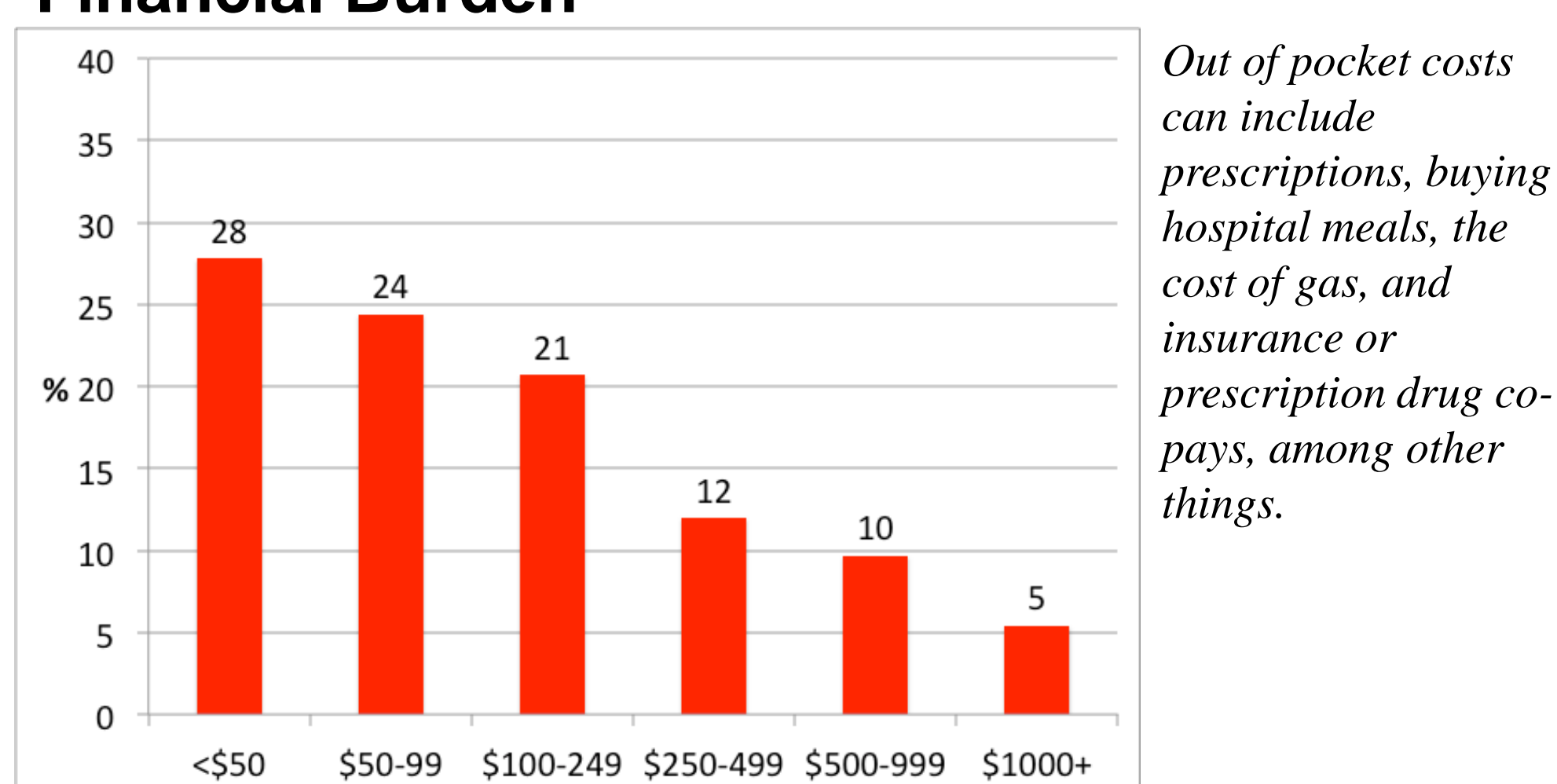
Missed a dose of oral CML medication at least once a month: **19%**

Postponed filling prescriptions: **14%**

Skipped dosages of prescribed CML medication: **10%**

We defined **poor drug adherence** as meeting at least one of the above criteria: **31%**

Financial Burden



Monthly out-of-pocket costs among CML registrants (n=299).

In order to reduce the cost of CML, how often do you...	%*
Postpone seeking psychological counseling or support	23
Delay follow-up on recommendations for complementary treatment (e.g., physical therapy, occupational therapy, nutrition counseling)	17
Postpone doctor's appointments	16
Postpone follow-up screening and/or blood work	12

* Sometimes, often, or always

Results

Because of the medical costs of CML, I have...	%
Used co-pay assistance programs	38
Cut grocery expenses	35
Depleted savings	33
Used pharmaceutical assistance programs	30
Borrowed against or used money from retirement	20
Sold personal property	18
Asked HCP for less expensive treatment	17
Liquidated assets	13
Bankruptcy	6
Foreclosed	4

We defined **financial burden** as having depleted savings or borrowed against or used money from retirement: **35%**

Psychosocial Distress

Using the CancerSupportSourceSM distress screening tool (CSS-15; Buzaglo et al., 2014):

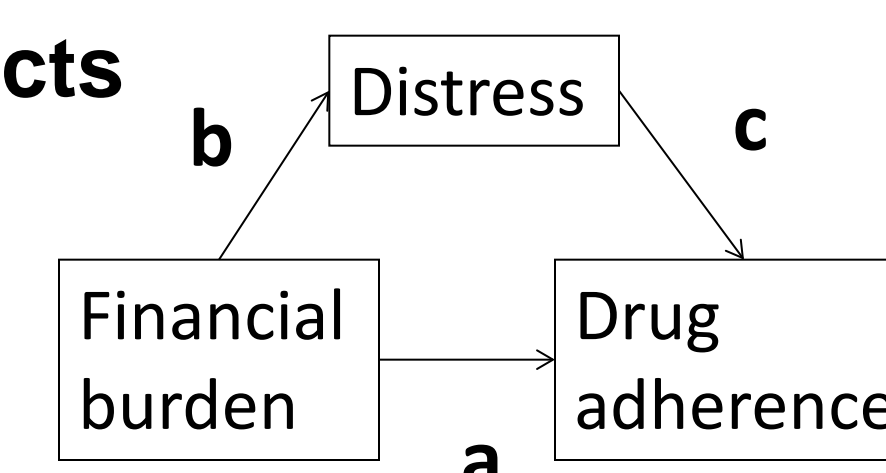
•**45%** CML registrants were at risk for depression (≥6 on 4-item depression subscale)

•On average, they reported overall moderate levels of distress (sum of 15 item ratings: mean=23, SD=14 (range 0-60))

Using the Impact of Event Scale (Horowitz et al., 1979):

•**37%** reported clinically high levels of stress-related intrusive ideation about the financial cost of cancer (>13)

Main Effects



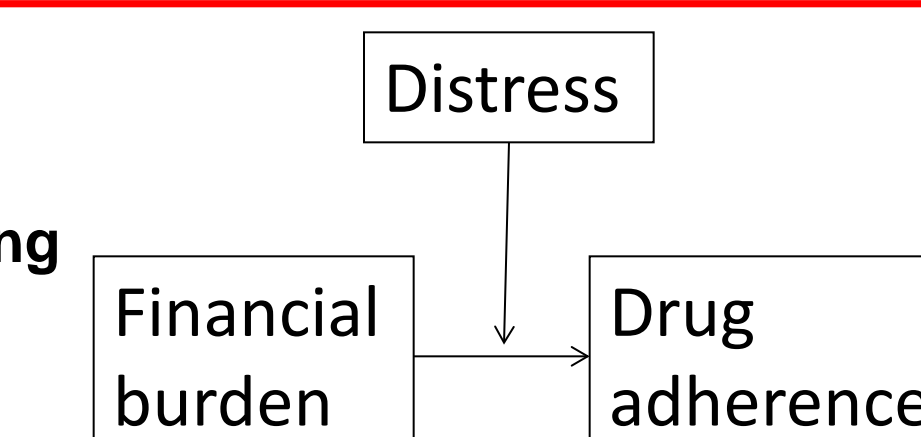
a. Financial burden was significantly associated with poorer drug adherence [OR=2.8 (95% CI=1.6, 5.1), p=0.001].

b. Financial burden was significantly associated with greater distress defined as: (1) intrusive ideation about the financial cost of care (p<0.001); (2) overall distress score (p<0.001); and (3) risk for depression (p=0.001).

c. Greater distress had no effect on drug adherence after controlling for financial burden.

Results

Interaction effect on % reporting poor drug adherence.



At risk for depression	Financial burden	
	No	Yes
No	21%	32%
Yes	18%	57%

Being at risk for depression significantly modified the relationship between financial burden and drug adherence (p=0.019), such that financial burden was significantly associated with poorer drug adherence among those at risk for depression [OR=7.6 (95% CI=2.8, 20.9), p<0.001]. Financial burden had a modest impact on drug adherence among those not at risk for depression [OR=1.3 (95% CI=0.5, 3.7), p=0.60], but the association was not statistically significant.

Conclusion

The number of individuals living with CML is growing, and many incur a financial burden that may negatively affect treatment outcomes and reduce quality of life. A significant number also experience psychosocial distress. These findings suggest that psychosocial distress and financial burden may have a greater impact on treatment adherence than financial burden alone. Implications for future research and practice so that patients fully benefit from CML therapy include the development and evaluation of interventions that enhance patient-clinician communications, psychosocial distress screening and referral, and financial counselling and assistance.

Acknowledgements

Thank you to Pfizer Oncology, the inaugural sponsor of the Cancer Experience Registry: CML

Thank you to our Advocacy partners: The Leukemia & Lymphoma Society, The National CML Foundation and The Max Foundation.

References

- SEER Program (www.seer.cancer.gov). Prevalence database: "US Estimated 36-Year L-D Prevalence Counts on 1/1/2011". NCI, DCCPS, SRP, Data Modeling Branch, rel. 4/2014, based on the 11/2013 SEER data submission.
- American Cancer Society. cancer.org/cancer/leukemia-chronicmyeloidcml/detailedguide/leukemia-chronic-myeloid-myelogenous-key-statistics.
- Buzaglo et al. JNCCN, 2013.
- Dusetzina SB, Winn AN, Abel GA, et al. Cost Sharing and adherence to tyrosine kinase inhibitors for patients with chronic myeloid leukemia. *J Clin Oncol*. 2014 Feb 1;32(4):306-311.
- Horowitz et al, *Psychosom. Medicine*, 1979.