

Symptom Burden, Palliative Care Needs, and Patient-Provider Communication Among Chronic Myeloid Leukemia Survivors

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Background

- People with chronic myeloid leukemia (CML) are living longer, yet they can be challenged by disease complications, adverse effects of treatment, and lifelong drug therapy
- CML symptoms and treatment side effects (SEs) are often chronic, and patients may need care from a multidisciplinary team of specialists

Aims

- The objectives of this study were to examine CML patients' symptom burden, palliative care needs, and experiences with health care team (HCT) communication

Methods

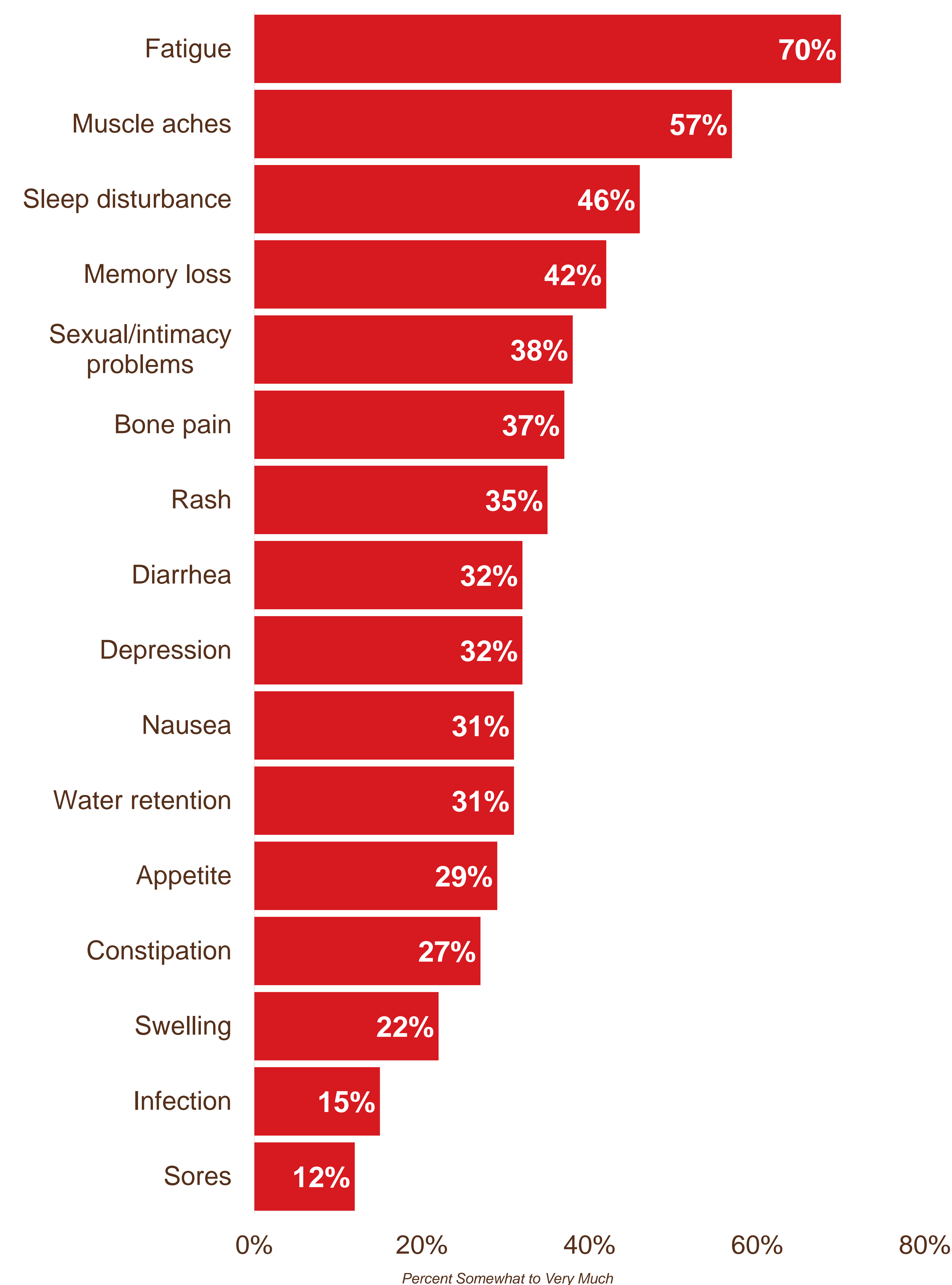
- 310 people diagnosed with CML enrolled in the Cancer Support Community's Cancer Experience Registry and completed questions about CML history, treatment, and symptoms
- Participants rated the extent to which 19 symptoms and SEs interfered with daily life (0=*not at all*; 4=*very much*); ratings were summed into a symptom burden score ($\alpha=.89$)
- Participants also rated 10 items assessing quality of patient-provider communication about SEs (0=*strongly disagree*; 4=*strongly agree*); items were summed into a SEs communication quality total score ($\alpha=.83$)
- Bivariate associations between communication quality and sociodemographic, symptom history, and symptom burden variables were examined; significant variables were included in multiple linear regression analysis predicting SEs communication quality

Participants

	N = 310	M/n	SD/%
Age (years) (n = 256)		57	12
		Range: 23–84	
Non-Hispanic White (n = 303)		269	89%
Female (n = 303)		203	67%
Disease Status (n = 304)			
<i>Hematologic remission</i>		199	66%
<i>Cytogenetic remission</i>		125	41%
<i>Molecular remission</i>		190	63%
<i>Initial response, no longer responding</i>		8	3%
<i>No response to treatment</i>		3	<1%
More than one provider manages CML (n = 306)		268	88%
Satisfied with care coordination (n = 268)		193	72%

Results

Daily Interference of CML Symptoms and Side Effects



- Symptoms causing greatest interference with daily life included fatigue (70%), muscle aches (57%), sleep disturbance (46%), loss of concentration/memory (42%), problems with sexual or intimate relations (38%), and bone pain (37%)

CML Side Effect Management and Communication with Health Care Team (HCT)

	% of Respondents
Satisfied with HCT communication [†]	94%
Believed it was easy to contact the HCT with questions/concerns [†]	93%
Believed HCT takes enough time to address concerns [†]	92%
Felt confident in their ability to cope or get help with treatment SEs [†]	87%
Satisfied with communication about treatment SEs [†]	86%
Believed HCT prepared them to manage treatment SEs [†]	78%
Wanted more help managing long-term SEs*	59%
Wanted more help managing short-term SEs*	51%
Potential SEs at least somewhat affected treatment choice [†]	41%
Did not report the full extent of their symptoms/SEs to their HCT [†]	19%

[†]Percent Somewhat to Very Much; *Percent Yes

- More than half of CML respondents wanted more help managing short-term (51%) and long-term (59%) side effects
- Almost one-fifth of respondents (19%) did not report the full extent of their symptoms and SEs to their health care team

Patient Factors Associated with Health Care Team Communication Quality

Predictor	Semipartial <i>r</i>	<i>p</i>
Felt confident in their ability to cope or get help with treatment SEs	.32	<.001
Did not report the full extent of their symptoms/SEs to HCT	-.33	<.001
Wanted more help managing short-term SEs	-.22	<.001

Significant associations only are displayed

- Regression analysis indicated that three predictors explained 55% of the variance in a composite variable assessing the quality of HCT communication about SEs ($R^2=.55$, $F(4,261)=75.33$, $p<.001$)
- Poorer HCT communication quality was associated with less confidence in coping with SEs, more holding back from telling the HCT about SEs, and wanting more help managing short-SEs and symptoms
- Wanting more help managing long-term SEs and greater symptom burden were associated with poorer HCT communication quality at a bivariate level only

Implications and Conclusions

- People with CML experience significant symptom burden and want more support with managing the symptoms and side effects of their illness
- Patient satisfaction with health care team communication by itself is not a successful marker of effective symptom management, as even satisfied CML patients wanted more support in coping with short- and long-term side effects
- The study findings support the need for comprehensive CML symptom management during survivorship care, which may include integrated palliative and supportive care resources

Acknowledgments

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References

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2. Cella, D., Nowinski, C. J., & Frankfurt, O. (2014). The impact of symptom burden on patient quality of life in chronic myeloid leukemia. *Oncology*, 87(3), 133-147.

- The Registry is for all cancer survivors and caregivers, but also includes 10 disease-specific surveys.
- Findings contribute toward advancing research, health care and policy.
- Over 12,000 cancer survivors and caregivers are registered in the Cancer Experience Registry.

Learn more or join the Registry at www.CancerExperienceRegistry.org