

# The “Living With Chronic Neutropenia” Survey: Experiences and Preferences of People Living With Chronic Neutropenia

Anna Ellis, BA; Michele Rhee, MBA, MPH  
X4 Pharmaceuticals, Inc., Boston, MA, USA

Poster #23A

## Background

Chronic neutropenia encompasses different blood disorders characterized by low levels of neutrophils (absolute neutrophil count <1500 for >3 months) that substantially alter the daily lives of affected individuals<sup>1,2</sup>

The current management strategy includes treatment with injectable granulocyte colony-stimulating factor, which may be associated with debilitating side effects, including bone pain and intense fatigue<sup>2-4</sup>

## Objectives

To explore experiences of people living with chronic neutropenic disorders and gather their perspective to understand the unmet need and impact on their daily lives through a virtual survey

## Methods

Respondents were recruited—through direct emails to people living with chronic neutropenic disorders and via outreach to chronic neutropenic disorders Facebook groups—and completed a virtual survey comprising 9 questions

The survey included open-ended narrative responses and severity ratings to assess the impact of chronic neutropenic disorders on daily life, document the frequency and severity of infection, and gather opinions of respondents on interest in and barriers to their participation in clinical studies

## Results

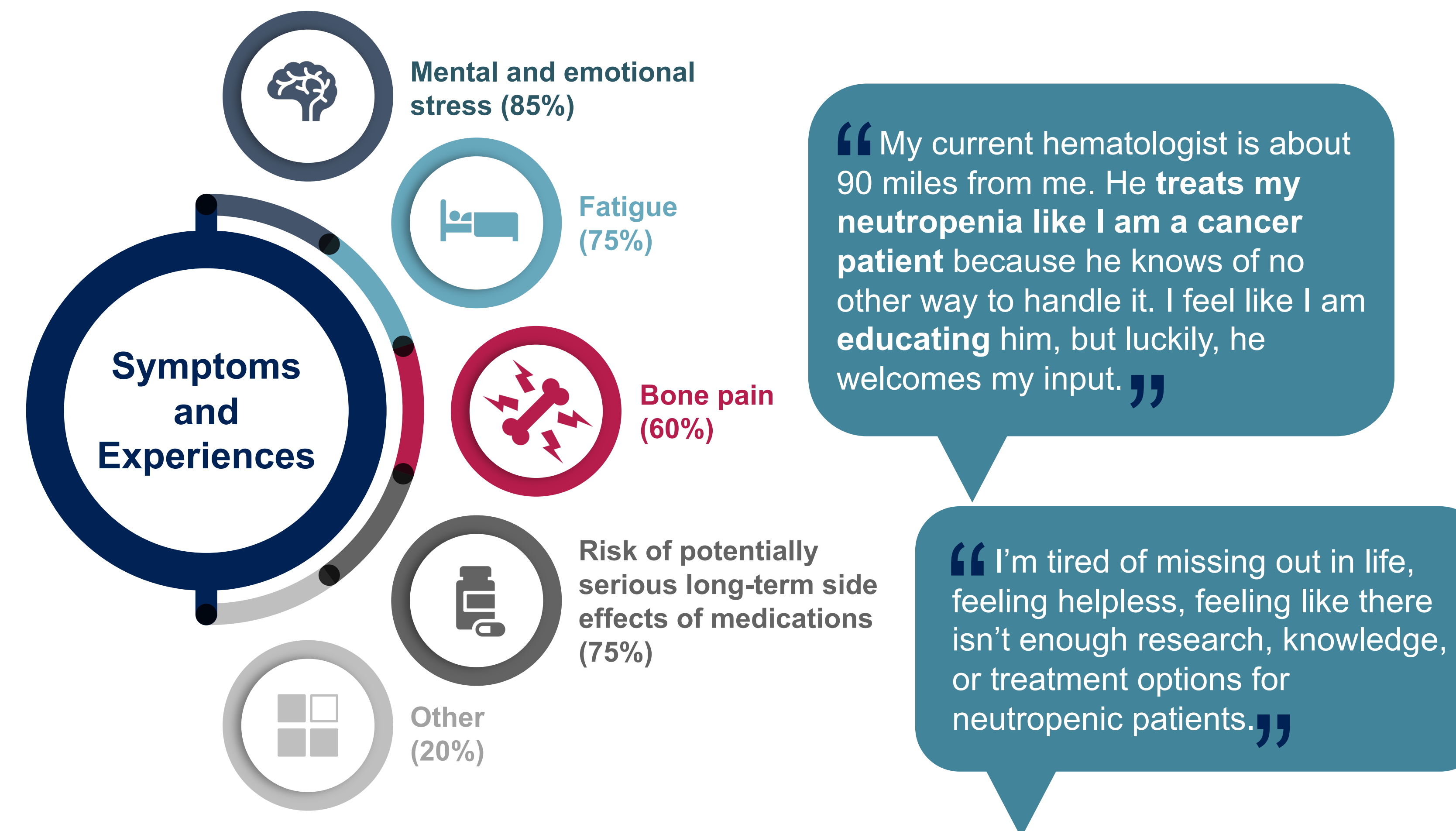
### Respondent Overview

Respondents included	19	1
Adults living with chronic neutropenic disorders		Caregiver <sup>a</sup>
	N=20	
Age range, y	25–62 <sup>a</sup>	
Sex at birth, female, n (%)	15 (75)	
Race, n (%)		
White	15 (75)	
Black/African	3 (15)	
Hispanic/Latino	2 (10)	
Diagnosis, n (%)		
Idiopathic	7 (35)	
Unknown	4 (20)	
Congenital	9 (45)	
Cyclic	5 (55)	
Persistent	2 (22)	
Neither/not sure	2 (22)	
Currently prescribed injectables	4 (20)	

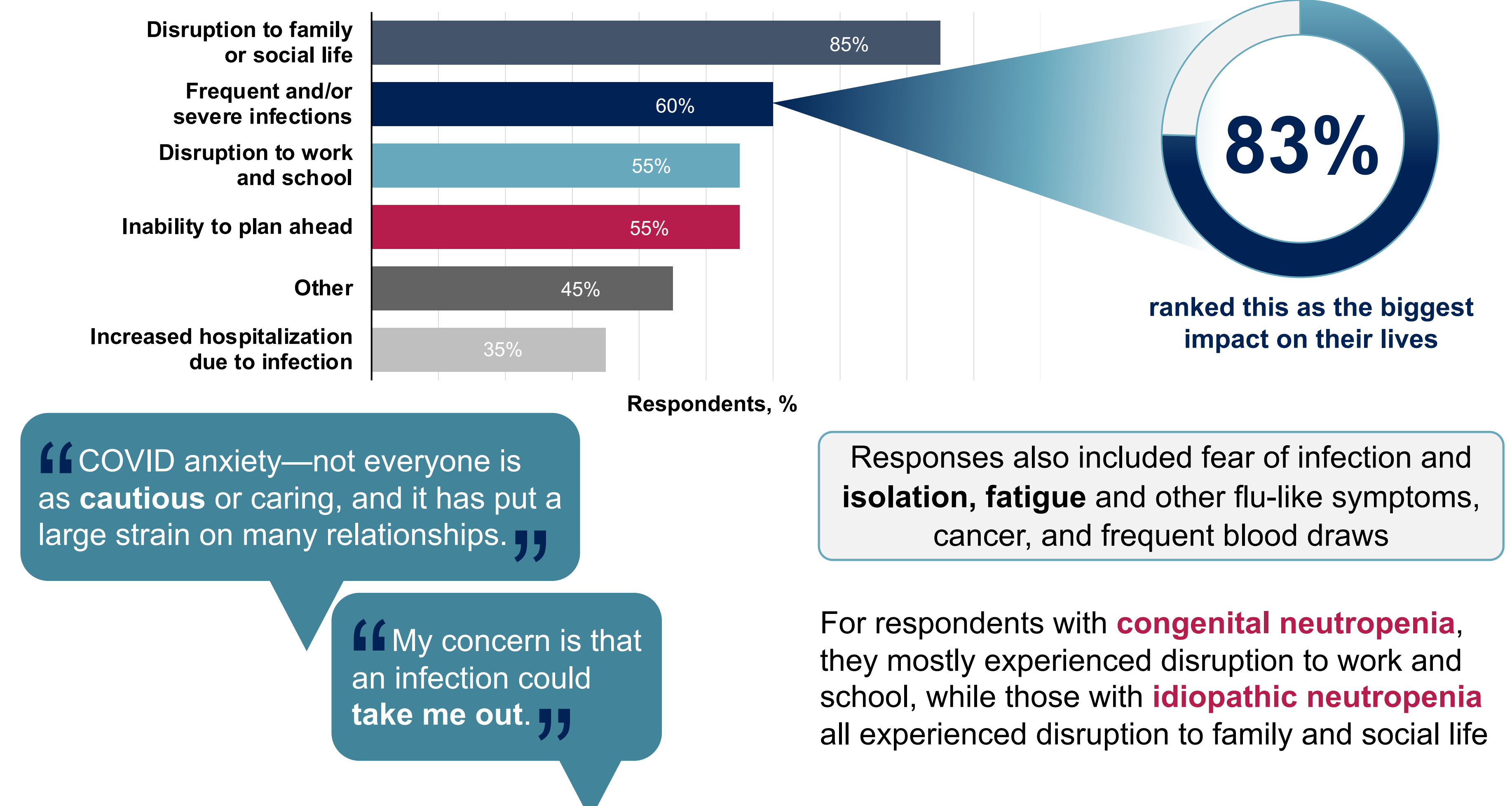
<sup>a</sup>1 parent to a female aged 12 years.

## Results (cont'd)

### Respondents Reported Multiple Concerns Around Their Chronic Neutropenic Disorders



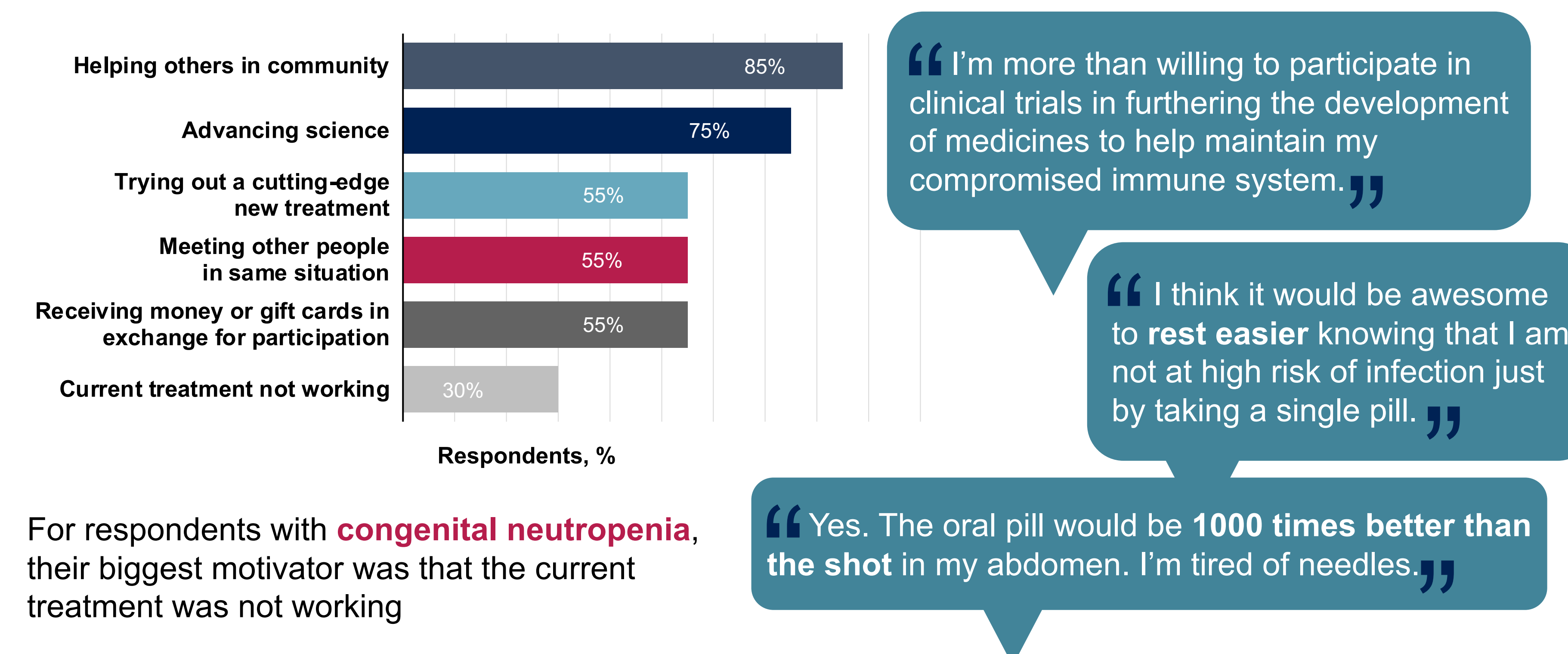
### Psychosocial Experience of Respondents Living With Chronic Neutropenic Disorders



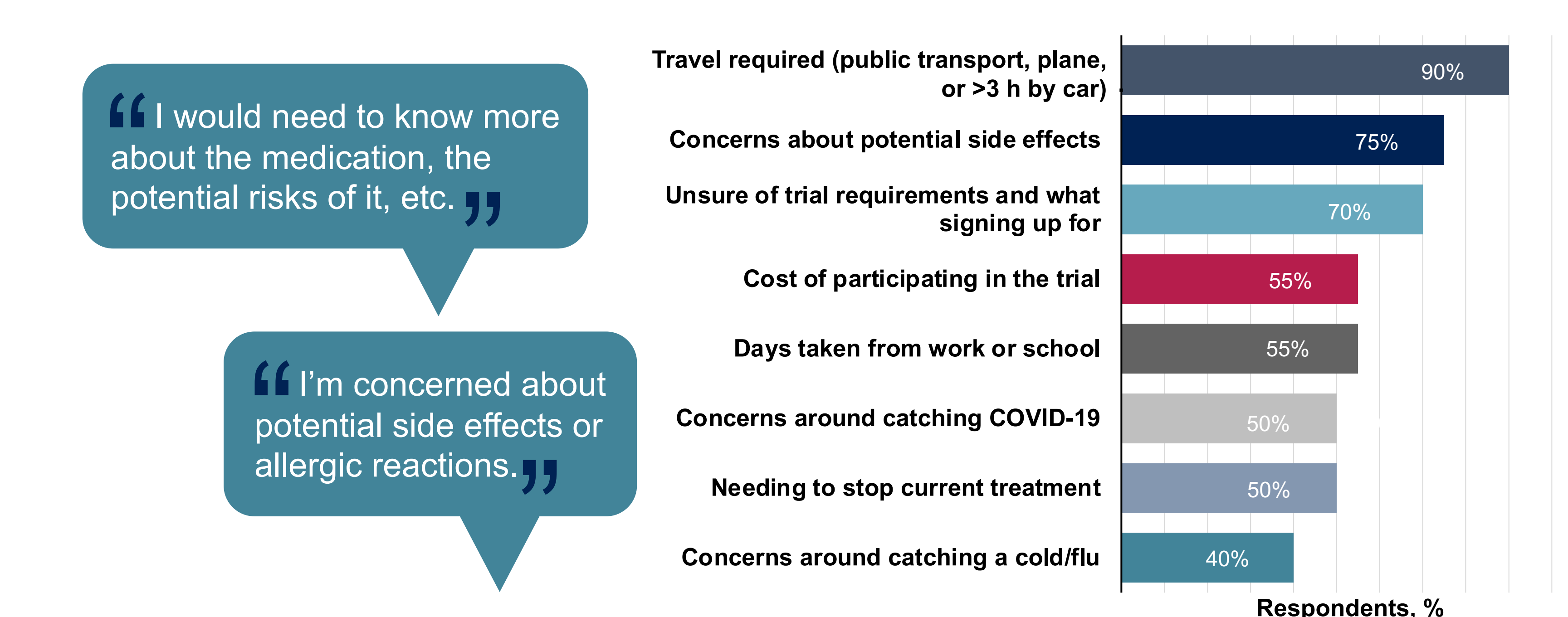
### Participation in Clinical Trials for Chronic Neutropenic Disorders With Oral Medication as a Potential Treatment Option



### Motivation for Participation in Clinical Trials



### Biggest Barriers to Participation in Clinical Trials<sup>a</sup>



<sup>a</sup>Other responses included overnight stay at a hospital or medical center (25%), potentially receiving a placebo (25%), impact on a care partner (eg, family or friend; 20%), physically going in a hospital medical center (10%) and being the parent of a child with neutropenia (10%).

## References

1. Dale DC, et al. *Blood*. 1993;81(10):2496-2502. 2. Newburger PE, et al. *Semin Hematol*. 2013;50(3):198-206. 3. Dale DC, et al. *Blood Advances*. 2022;6(13):3861-3869. 4. Anderlini P. *Curr Opin Hematol*. 2009;16(1):35-40.

## Disclosures

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