

Introduction

- Previous research has outlined that stem cell donor ambivalence at multiple points in the donation process is associated with attrition¹⁻²
- Higher ambivalence at time of recruitment has been shown in registrants who believed recruitment staff to be less informative, felt uninformed, and had unanswered questions¹
- Stem Cell Club is a federal non-profit that recruits Canadians as stem cell donors³⁻⁴
- Here, we characterize the commitment level and knowledge of our donors following registration, and their experience registering

Methods

- From 10/16-12/16, newly registered stem cell donors at six stem cell drives run by Stem Cell Clubs in Ontario and British Columbia were invited immediately following recruitment to participate in the survey
- Questionnaires employed the seven-question Simmons Ambivalence Scale (SAS, Cronbachs =0.68)
- Responses were dichotomized for each item to reflect whether participants expressed any ambivalence (1) or no ambivalence(0)
- An ambivalence scale was formed by averaging the dichotomized responses
- A fourteen-question true/false informed consent quiz assessed registrant knowledge according to World Marrow Donor Association suggested procedures for informed consent at time of registration⁵
- Likert scales were employed to assess registrant experience and perceived knowledge

Table 1: Results of the seven-question Simmons Ambivalence Scale (SAS)					
How hard a decision was it for you to register as a potential stem cell donor?	Easy	Moderate		Hard	
	82	17		1	
Did you know right away that you would do it or did you think it over?	Knew right away	Had to think it over			
	81	19			
Many donors have doubts and worries about registering as a donor, even though they go through with it. Did you ever have doubts about registering as a potential donor	Yes	No			
	32	68			
How would you feel if you couldn't donate?	Saddened	Relieved		no opinion	
	57	2		41	
How strongly do you agree or disagree with the statement "I sometimes feel unsure about whether I would go through with donating."?	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
	4	27	15	1	1
How strongly do you agree or disagree with the statement "I would want the transplant patient to get stem cells from someone else instead of from me."?	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
	2	10	42	32	16
How strongly do you agree or disagree with the statement "I would really want to donate myself even if someone else could do it."?	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
	7	29	46	16	2

Table 1: Results of the seven-question Simmons Ambivalence Scale (SAS). Data collected as part of post-stem cell drive survey (n=100, response rate 44%). Answers indicating at least some degree of ambivalence are shaded in beige and bolded.

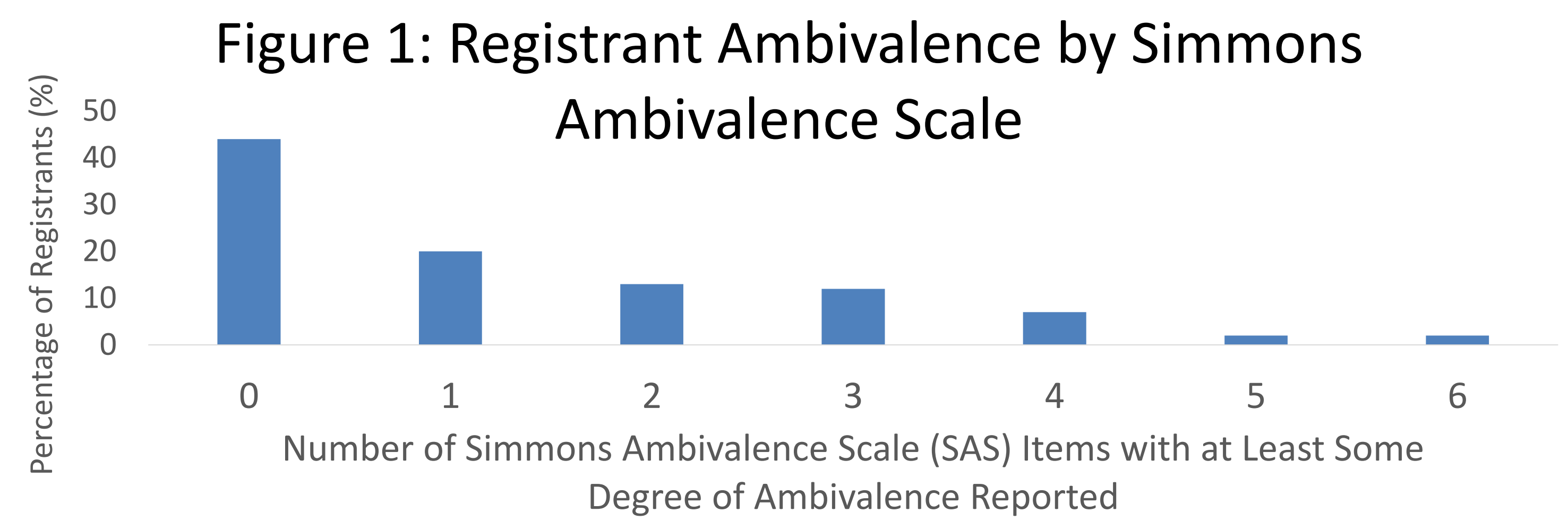


Figure 1: Registrant ambivalence as measured by total score on the seven item Simmons Ambivalence Scale (n=100). Registrants who reported any degree of ambivalence on an item received a score of 1 for that item.



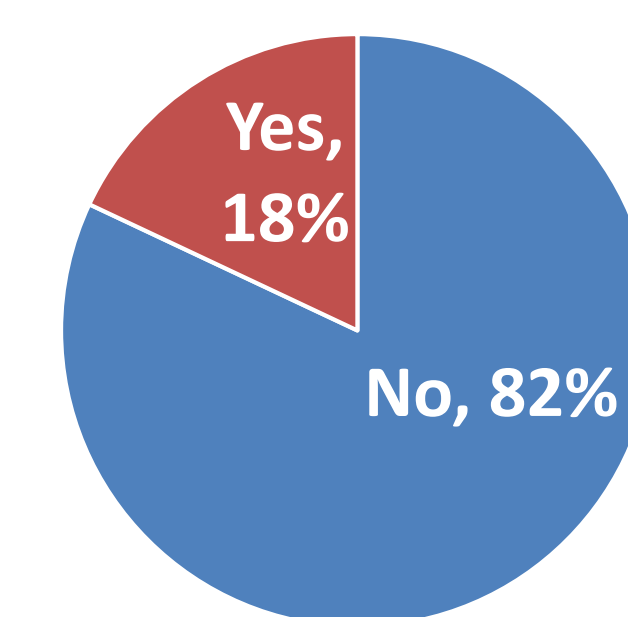
Figure 2: Performance on variables known to be associated with registrant ambivalence (n=100 registrants, reflecting 44% survey participation rate); a) Registrant perception of their knowledge prior to and following the stem cell drive. Significant improvement was seen in self-reported knowledge by Wilcoxon rank sum test (p<0.001); b) Registrant perspective on whether recruiters were knowledgeable; c) Percentage of registrants following the stem cell drive who had remaining unanswered questions about stem cell donation.

Table 2: Results of the fourteen-question informed consent quiz

	% Responding FALSE	% Responding TRUE
Donors are paid in exchange for their stem cells	97	3
All stem cell donations involve surgery under anesthetic	96	4
Donors who have blood-born and transmissible diseases (such as HIV or Hepatitis) are allowed to donate stem cells	93	7
Once committed to save a patient's life, donors are not allowed to withdraw from the program	91	9
Potential donors on the Onematch database need to inform Canadian Blood Services when their contact information changes	9	91
Stem cell donors can direct their donations to a patient of their choice	88	12
Everyone who joins OneMatch will have the opportunity to donate stem cells	85	15
Swabs collected at stem cell drives are stored with OneMatch for future additional testing	15	85
Donors could be saving the life of a patient who could be in any country, anywhere in the world	17	83
A registrant's medical information (HLA markers, medical history) will be shared with other stem cell donor databases around the world, but their personal information (name, contact information) will be kept strictly confidential	83	17
Donors are informed of the identity of the person who will receive their stem cells before the donation	80	20
Everyone can register to donate stem cells	68	32
Pain is a common side effect of stem cell donation	40	60
Prior to donating stem cells from blood, the donor is given injections of a growth factor to move stem cells from their bone marrow into their blood	41	59

Table 2: Results of fourteen-question informed consent quiz. Questions assessed topics presented in the informed consent checklist developed by Rosenmayr et al. (2003) for use at time of initial recruitment onto a volunteer registry. Data collected as part of post-stem cell drive survey (n=100, response rate 44%). Correct answers are shaded in beige and bolded.

Figure 2c: Did you leave the stem cell drive with any unanswered questions?



Results

- Of the 228 stem cell donors registered during the study stem cell drives, 100 (44%) completed the post-drive survey and consented to be included in this analysis
- 88% of participants reported feeling at least moderately informed about stem cell donation, 90% agreed or strongly agreed that recruiters were very knowledgeable, and 18% reported unanswered questions following the drive
- Mean SAS score was 0.19±0.22, with 44% of participants scoring 0/7, 20% scoring 1/7, and 36% scoring 2/7
- Mean informed consent quiz scores were 82±13%, with the lowest scores on questions regarding donation process and side effects

Conclusions

- In summary, we describe the ambivalence of donors recruited by Stem Cell Club, and our performance on metrics known to influence ambivalence
- These data will guide quality improvement efforts, including revisions to our recruiter training program to improve registrant experience and address observed registrant knowledge gaps
- Study recruitment remains ongoing
- Future analyses will stratify by gender and self-reported ethnicity

Acknowledgements
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References

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