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The Power of Personal Narrative: A Reply to “The Reality of Relapse: Impact of Cancer Relapse on Survivorship Interventions and Patient-Reported Outcomes Data”

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To the Editor

We appreciate the letter from Dr. Sansom-Daly and colleagues and fully agree with their suggestion: relapse among adolescents and young adults (AYAs) with cancer greatly contributes to the prevalence of missing data.[1] Indeed, censoring patients at the time of relapse is a limitation of clinical oncology research that is not limited to AYAs; rigorous studies designed to capture the perspectives of patients with advanced cancer are needed in pediatric, AYA, and older adult populations.

While our referenced “Resilience in Adolescents and Young Adults” study is a victim of this same limitation, the point of our analysis was to underscore methods to optimize patient participation among those who remain enrolled.[2] We made no suggestion that AYA cancer survivors were “more easily engaged” in research, nor did we intend to imply that “more research contact” promoted completion of data. In fact, we highlighted several studies where frequent e-mail- and phone-based contacts were costly, cumbersome, and/or ineffective in optimizing data collection.[3,4] Similarly, Dr. Sansom-Daly and colleagues describe up to 15 reminders per patient questionnaire in their own data collection processes.[1] Rather, we demonstrated that patients who participated in 1:1 semistructured interviews were more likely to complete corresponding quantitative surveys than those who were asked to complete surveys alone (without the interviews). Our conclusion was that inviting patients to share their personal narrative may have led them to feel more valued and engaged, in turn encouraging their prioritization of the research itself.

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Although patients with relapsed disease were removed from the study at the time of relapse, this finding may have been true for them, too. Indeed, the power of personal narrative has been described in other literature bases, including bioethics and bereavement.[5,6] For AYAs with cancer, it may be of additional importance because patients of this age already struggle with their autonomous and social development.[7] Personal narrative may facilitate the integration of a cancer diagnosis into a patient's identity and facilitate a process of meaning making and coping. Anecdotally, several patients who were removed from our study for relapsed disease requested continuing with the interviews, even if their data were not used. One patient's explanation: "The interviews make me feel heard."

Adolescence and young adulthood is hard. Adding a diagnosis of cancer to the physical, social, and emotional developmental challenges of this age is undoubtedly harder. We fully agree with Dr. Sansom-Daly and colleagues that additional research is needed among patients of this age must include those with relapsed, recurrent, or refractory disease, as well as survivors who struggle with the uncertainty of if or when their cancers will come back. We simply propose that giving these patients the opportunity to share their stories in their own words will help us to successfully understand and ultimately help them.

REFERENCES

1. Sansom-Daly UM, McGill BC, Anazoda A, Plaster M, Maguire F, O'Dwyer C, Ellis SJ, Robertson EG, Cohn RJ, Wakefield CE. The reality of relapse: Impact of cancer relapse on survivorship interventions and patient reported outcomes data. (In press).
2. Rosenberg AR, Bona K, Wharton CM, Bradford M, Shaffer ML, Wolfe J, Baker KS. Adolescent and young adult patient engagement and participation in survey-based research: A report from the "Resilience in Adolescents and Young Adults with Cancer" study. *Pediatr Blood Cancer*. 2016; 63:734–736. [PubMed: 26681427]
3. Harlan LC, Lynch CF, Keegan TH, Hamilton AS, Wu XC, Kato I, West MM, Cress RD, Schwartz SM, Smith AW, Deapen D, Stringer SM, Potosky AL. Group AHSC. Recruitment and follow-up of adolescent and young adult cancer survivors: The AYA HOPE Study. *J Cancer Surviv*. 2011; 5:305–314. [PubMed: 21274648]
4. Richards J, Wiese C, Katon W, Rockhill C, McCarty C, Grossman D, McCauley E, Richardson LP. Surveying adolescents enrolled in a regional health care delivery organization: Mail and phone follow-up—What works at what cost? *J Am Board Fam Med*. 2010; 23:534–541. [PubMed: 20616296]
5. Zaner RM. On evoking clinical meaning. *J Med Philos*. 2006; 31:655–666. [PubMed: 17162733]
6. Germain A, Mayland CR, Jack BA. The potential therapeutic value for bereaved relatives participating in research: An exploratory study. *Palliative Support Care*. 2015 Oct 29:1–9. [Epub ahead of print]. PMID 26510786.
7. Zebrack B, Isaacson S. Psychosocial care of adolescent and young adult patients with cancer and survivors. *J Clin Oncol*. 2012; 30:1221–1226. [PubMed: 22412147]