



In Pursuit of “Informed Hope” in the Stem Cell Discourse

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To cite this article: Joanne Reimer , Emily Borgelt & Judy Illes (2010) In Pursuit of “Informed Hope” in the Stem Cell Discourse, The American Journal of Bioethics, 10:5, 31-32, DOI: [10.1080/15265161003754072](https://doi.org/10.1080/15265161003754072)

To link to this article: <http://dx.doi.org/10.1080/15265161003754072>



Published online: 10 May 2010.



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information and vibrant conversations about their research and about science more broadly.

Finally, funding streams need to be created that can support small portions of the scientists' and ethicists' time, which can then be specifically devoted toward participating in this promising form of public engagement. Again, building in-house staff expertise and infrastructure will allow for this valuable resource (time) to be used in a way that allows for maximum engagement within the practical constraints that will inevitably arise here.

Given the typical orientation of the research community, arguments in favor of investing in social media engagement will be strongest when backed by data. Further work needs to be done not only to develop a richer literature demonstrating best methods and the potential impact of this form of social media engagement, but also, at a more basic level, to educate stakeholders about the relevant metrics and the thresholds for demonstrating success.

Returning to the context of stem cell tourism, rapidly expanding social media seem to be playing a vital role in its growth, further suggesting that this could be an effective place for scientists and ethicists to join the conversation. Engaging in an open discourse with patients and their social networks via social media not only can provide a means for exploring what is and is not known about stem cell transplantation. It can also be helpful in other ways, for example, by providing a venue to air patient perspectives on decision-making involving untested interventions, or by revealing additional unanticipated but vitally important issues. In the long run, social media engagement can serve as a useful tool for facilitating the sort of egalitarian exchange that is necessary to build understanding and trust between the scientific and ethics communities and the public. ■

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Murdoch and Scott's cogent analysis in “Stem Cell Tourism and the Power of Hope” (2010) describes how the potential for stem cell therapy (SCT), the low moral standards of some entrepreneurial companies, and the hopes of individuals converge to undermine informed discourse between patients, their advocates, and researchers. These factors contribute to current trends in medical tourism. Zarzeczny and Caulfield (2010) add another dimension to the discussion in their thorough consideration of the duty that physicians bear when faced with questions about medical tourism for the treatment of childhood disorders. In our opinion, both papers appropriately support the need for open dialogue, but fall short of actually extending the direction of information flow from the end-beneficiaries—people affected by conditions potentially treatable with innovative therapies—to researchers and clinicians. We argue that discourse that is truly bidirectional will temper unmitigated trust and blind faith that may be harmful, and will contribute to a comprehensive knowledge base promoting informed hope, au-

tonomy, a respect for different values and well-grounded decision making.

The suggestion that there is a need for clinicians and scientists to think carefully about how they “counsel” patients interested in SCT (Murdoch and Scott 2010) is meritorious in a unidimensional sense. However, it perpetuates a separation between basic science, clinical science, and the people research serves that, as Anderson (2009) argues, has carried on too long. In 2004, Chalmers wrote, “Because clinicians share with patients the front lines where uncertainties are encountered in practice, patients must obviously help define how to deal with these quandaries” (Chalmers 2004, 476). Arguably, the uncertainty of SCT demands that the values and perspectives of patients be heard if medical tourism is to be understood. An inherent benefit of such bidirectionality will be respect for autonomy, both for persons affected by diseases and for their networks. If Tewarie (2009) is correct in predicting that rapid advancements of stem cell science will require that ethical and social

Acknowledgments: The authors' work is supported by the Stem Cell Network 20R44220, CIHR/INMHA CNE number 85117, the British Columbia Knowledge Development Fund (BCKDF), and the Vancouver Coastal Health Research Institute (VCHRI).

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barriers be surmounted to enable treatment, it is indeed vital to engage patients to inform relevant debates.

As a case in point, research to date pertaining to SCT for spinal cord injury (SCI) has focused predominantly on the basic sciences, yet a number of authors (e.g., Anderson 2004; Estores 2003; Furlan and Fehlings 2006; Hammell 2007) underscore patient priorities for functioning and advocate for the consideration of these priorities in bench to bedside translational studies. Even less is known about patients' perspectives on SCT research for SCI (Abma 2005; Downey and Geransar 2008). Data that we have collected using focus groups and interviews with affected individuals who are greater than 18-months post-injury and people in their extended networks suggest that there is consensus between stakeholder and provider perspectives in at least two areas: (1) an imperative to guard against any further loss in function from new therapies, and (2) the need for more accurate and consistent dissemination about research results (Reimer and Illes 2009). Contrary to our expectations, results to date suggest that early adopters of new stem cell therapies are likely to be people with chronic thoracic SCIs who describe an impatience with their current situation, anticipate opportunities for change, and weigh benefits over risks. In contrast, people with chronic cervical SCIs describe a sense of pragmatism about their life situation and weigh risks over benefits. Both groups report that, in retrospect, they would not support decision making for experimental therapy at the time of acute injury. We note that the acute stage is target for at least one pending clinical study in California (Geron 2010).

In the Zarzeczny and Caulfield article "Stem Cell Tourism and Doctors' Duties to Minors," the authors note that parties have different perspectives on stem cell tourism but the article focuses primarily on the perspectives of physicians and parents, with little discussion about the perspectives of the minors themselves. Age-appropriate discussion with minors is considered good practice in medical decision making and treatment, as these authors highlight (Zarzeczny and Caulfield 2010). By focusing on the tension between physicians and parents (and perhaps the courts), however, the article misses the potential for minor patients to be productively engaged in deliberations.

Challenges of unregulated SCTs persist, but it is especially in this context that parents, physicians, and policymakers must not lose sight of the harm that exists in excluding children and adolescents from decision making and self-determination, even passively or unintentionally. The authors rightly highlight the physician's role in educating parents about stem cell tourism, but they stop short of a critical step—encouraging and engaging in age-appropriate communication with young patients about risk and benefits of SCT. Mutually informed communication between physicians, parents, and patients fosters not only awareness of the risks and benefits of SCT but also the developing autonomy of minors. In a recent study with adolescent cancer survivors, for example, the participants asserted the right of minors to be informed about their condition and participate in decision making, although they also em-

phasized the importance of parental involvement (Pousset et al. 2009). It behooves all players—physicians, parents, and policymakers—to pause and remember pediatricians' recommendations for active listening (Zarzeczny and Caulfield 2010).

In conclusion, we emphasize that communication needs to be a two-way street. Given the investment and speed at which SCT is advancing both along traditional scientific trajectories as well as on the less regulated tourism platform, this bidirectionality has never been more important. Whether the stakeholders are adults or children, meaningful therapy will only be realized when it is responsive to individual values and priorities and situated in the context of hope that is fully informed. ■

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