

Should I or shouldn't I: perspectives regarding the decision-making process on stem cell treatments

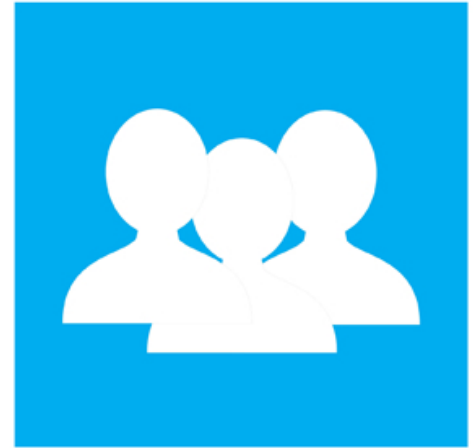
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'No-one here's helping me, what do you do?': addressing patient need for support and advice about stem cell treatments

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Deciphering available information, from both online and other sources, can be difficult for individuals trying to decide whether or not to travel and pay for possible stem cell treatments. Often these individuals seek out advice and guidance from others they perceive to be more knowledgeable on stem cell treatments to help them make their decisions. Interviews conducted by Associate Professor Munsie and colleagues reveal many of the challenges and frustrations patients, carers and professionals - acting as advisors - experience. They also highlight the need to create better resources and call for one-on-one discussions to better support those contemplating alleged stem cell therapies that are yet to be shown to be safe and effective.



What questions & challenges are raised?

Informing the public about stem cell (SC) therapies, specifically the distinction between those that are proven versus those that are not yet a recognised treatment, is an ongoing issue for scientific and regulatory agencies. Patient safety and exploitation are common concerns associated with unproven therapies because they are expensive and often lack evidence they are safe or effective. Many organisations have attempted to limit the demand for unproven treatments by supplying information about SC therapies through printed and online resources and encouraging individuals to discuss therapies with trusted medical professionals. However, navigating information about SCs can be difficult, and many patients and their loved ones look for individuals to talk to and help them better understand their options. In their recent publication, Associate Professor Munsie from the University of Melbourne and her colleagues conducted interviews with Australian patients, carers (caregivers) and professionals contacted for information and guidance, to understand their perspectives on the challenges and shortcomings experienced.

What insight & direction does this give for research policies?

Dr Munsie and her colleagues note that navigating information on SC therapies can be challenging. Marketing by clinics, news stories in the media, online information resources, even the variability of what is allowed by different countries' regulations, all blur people's understanding of what constitutes legitimate and ethical SC research in clinical trials and unproven SC 'treatments' available commercially. It's therefore not so surprising that Dr Munsie and her colleagues' study illustrates that the majority of individuals considering SC therapies seek out individuals with medical or scientific background to better understand SC therapies. However, the authors' study shows that individuals are frustrated with the inaccessibility to knowledgeable professionals and the quality of the guidance, support and advice they are getting from 'accidental advisors'. To better support these individuals and families, the authors propose establishing a dedicated phone-service operated by professionals trained in both patient care and SC science to provide information on SCs, their risks, clinical alternatives and various therapies. The authors also state that healthcare professionals, not just doctors, should have more training and awareness about SC science, concerns about unapproved treatments, and the resources available for medical practitioners and patients. Dr Munsie and colleagues emphasise that these efforts would greatly complement existing information resources on SCs and SC therapies and help to address the unmet needs of many patients and their families.

What background and point are discussed?

Associate Professor Munsie and her colleagues interviewed 24 patients or carers that had participated in unproven SC therapies and 27 individuals who contemplated treatments but did not get them. Twenty professionals were also interviewed, including SC researchers, clinicians and representatives from patient advocacy groups (for example, MND Australia and Cerebral Palsy Alliance). Interviews with patients and carers illustrate that individuals often explore a wide range of information on SC therapies, discuss SC treatments with their clinicians and seek out at least one 'professional' they perceive to be knowledgeable in science or medicine. These 'professionals' range from scientific researchers and medical practitioners to acupuncturists and science students. Dr Munsie and colleagues refer to these professionals as 'accidental advisors', because they are approached for advice due to their line of work but may not have a sufficient understanding of SC therapies or training to counsel individuals and families.

The interviews with patients, carers and professionals reveal several recurring issues and frustrations. Accessibility is a concern raised by some individuals who were greatly frustrated because repeated attempts to contact professionals were never answered. On the other hand, several professionals commented that their work doesn't allow the appropriate amount of time to counsel patients and families. The authors note that in some cases information provided by accidental advisors about the risks, effectiveness and safety of SC treatments was inconsistent with information and resources produced by experts. Surprisingly, interviewed advocacy group representatives were more likely to refer to patient handbooks and professional guidelines than researchers or clinicians. Accidental advisors offered a range of opinions, some supported traveling for SC treatments, several claimed it won't cause any harm, some advised against treatments and other advisors took a neutral position. Individuals expressed frustration when advisors said not to get treatments without any further explanation. People also found it frustrating when advisors were indirect, reluctant to offer advice or encouraged individuals to do more research and make their own decision. Patients and carers perceived this later approach as advisors lacking knowledge on SCs, being disingenuous or attempting to avoid taking any responsibility. The authors note that some advisors did refer people to others if they felt they didn't have appropriate scientific background or counselling expertise. However, other advisors deliberately avoided giving advice, saying that this is the role of a patient's clinician or that there are legal and liability issues about advising on SC treatments.