Trust and Transparency in the Communication About Stem Cells for Spinal Cord Injury

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The paralysis occurring as a result of spinal cord injury (SCI) is a devastating condition for which there are currently no available treatments. Enormous interest in stem cell transplantation as a potential regenerative therapy for the injured spinal cord has arisen. While the safety and efficacy of cell transplantation approaches for SCI are still being established, many for-profit centres around the world have been offering stem cell interventions to individuals with spinal cord injury (ISCI). Such interventions, which are often marketed as treatments, are not licensed in Canada or the United States and typically have limited to no preclinical substantiation of their effectiveness. ISCIs who are interested in experimental stem cell interventions may be influenced by many factors including the media, their families, for-profit stem cell clinics, and their doctors at home. In the end, ISCIs must decide where and in whom to place their trust to make decisions about their health care. The present study examines how the trust relationship between physicians and ISCIs is affected by the discussion of stem cell interventions for SCI and the nature and role of trust in these decisions. Semi-structured interviews were conducted with ISCIs and physicians who provide care for ISCIs, exploring perspectives about the patient-physician trust relationship specifically. Interviews were transcribed verbatim and analyzed using a thematic analysis approach. Analysis revealed that both patients (n=18) and physicians (n=12) express a range of perspectives on how discussions about stem cell interventions can both strengthen and pose challenges to trust in the patient-physician dyad. ISCIs expressed that trust was strengthened when physicians had caring, attentive and positive attitudes as well as a high level of knowledge and scholarship. Reluctance of physicians to communicate about stem cells and perceived lack of physician knowledge posed challenges to trust from an ISCI perspective. Physicians stressed the importance of transparency and understanding the patient's perspective to enhance trust. Physicians also identified that the clinical reality of treatment choices and pressure from external information sources such as family, friends and clinics abroad challenge trust. Finally, both ISCIs and physicians commented on the variability of information sources about stem cells interventions, and the difficulty that they have navigating them. Overall, the findings suggest that transparency should be privileged over silence. Better information tools will be a vital resource for trusted communication between physicians and patients about the rapid evolution of biotechnology and for their interactions about stem cells.

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