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Editorial

Special Issue: We are human – an invisible and fundamental aspect of rehabilitation in acquired brain injury

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The fact that acquired brain injury (ABI) rehabilitation services are made up of human beings supporting other human beings is not often considered in research or practice. In this special issue of Brain Impairment we are delighted to be able to share the work of academics who are engaging with this aspect of ABI rehabilitation. As editors, when we met in 2018 at the 41st annual conference of the Australasian Society for the Study of Brain Iimpairment (ASSBI), we were struck by how several presentations, although using slightly different language, were all touching on the same aspect of rehabilitation - human connection. Despite consensus and anecdotal evidence that human connection is a critical component of rehabilitation, there is remarkably little written in the literature to help us unpack, reflect on and harness human connection. Human connection is therefore not only 'invisible' in itself but also in developments in rehabilitation research and practice. As a first step, we would like to encourage service managers, researchers and clinicians to consider the value of human

connection within service provision, to explore new ways of researching which allows human connection to come to the fore, and to celebrate the experience and power of human connection in our therapeutic relationships.

In this special issue we invite you, the reader into the world of the invisible and immeasurable - human connection. We have a diverse range of authors and topics ranging from those reflecting individual lived experience, through therapeutic relationship, to wider social discourses. Although the focus for each author is discrete we feel that each contribution adds to this continuum as each part cannot exist without each other; the individual experience is always relational and social in an ever changing and powerful sea of meaning. The first author in our edition, Dixon sets the scene and in a way 'says it all'. Through sharing his own experience of rehabilitation services following his stroke, he reflects how living following an ABI is isolating and at times rehabilitation services can be part of the problem when people are not seen or heard, compounding the issues people are facing. On the other hand, the moments when 'safe' spaces are created through meaningful, trusting relationships, where people tap into their human knowing and work as equal partners, are very powerful. They allow exploration of vulnerability and possibility (Galvin and Todres, 2013) and the development of a confidence in self and future life. Dixon also highlights the importance of language; the effect on identity and social possibilities which is a key theme running through this issue. Wilson and colleagues invite us into Te Ao Māori (a Māori, the indigenous people of New Zealand, worldview), emphasising the relational and reciprocal processes that are needed to support effective rehabilitation which is often provided from a non-Māori, often western-centric, perspective. They not only provide insights into how meaningful connections can be formed but also the power within Te Ao Māori of whānau (extended family, community) and wairua (deep sense energy, spirit)

highlighting the human energy and life possibilities that can be released when approached in the right way.

Our next three papers focus on the therapeutic relationship itself. Williams and Douglas in their pilot study in community rehabilitation show how recognising the person beyond their condition, reciprocity, being non-judgmental and occasionally the use of humour, allow people to feel part of the rehabilitation process and give them the confidence to try new things which at first seem overwhelming. Again, they highlight that the language we use is key as realities and possibilities are created by connection through authentic communication tailored to the individual and the collabrative work of therapy. Kayes and colleagues in their study on engagement in stroke rehabilitation discuss the fundamental importance of reciprocity within a trusting relationship to support the person to overcome the existential challenges they are facing after a stroke. This involves emotional work not only on the part of service user but also the provider and when a safe space is held, choice and a sense of freedom can be created. Gordon and colleagues in their appreciative action research study into meaningful relationships on a stroke ward share that although existing, they are rarely recognised or actively developed. Their research has shown that through using an appreciative approach staff can become sensitised to meaningful rather than just transactional relationships and develop opportunities for them to occur more often. This process of sensitisation occurs through staff being supported to develop their curiosity, their awareness of their felt sense and embodied knowing, to 'ignore the pressure to do and feel how you are' leading to a sense of freedom to act which is very energising. In essence, this study highlights the importance of not only recognising and actively engaging with recipients of care as human, but also creating the context for staff to be, feel, and embody what it means to be human.

Our next group of papers move us from the individual therapeutic encounter to group and wider relationships and societal understandings. Using single case experimental design, Moorhouse and colleagues compare participation in art therapy and sports discussion groups in a long-stay, secure ABI/mental health unit. Their work draws attention to the complexity behind the statistics where the consequences of organic injury coincide with mental health challenges, prior experiences, personality and activity preferences. The success of both kinds of groups and the recognition that they offer differing opportunities provide preliminary evidence of the importance of offering a range of well-planned groups aiming to meet individuals "where they are at". The value of focussing on the personal journey of the individual is further emphasised by D'Cruz and colleagues. They develop their previous work on the role of narrative storytelling following acquired ABI by examining the engagement of storytelling facilitators with storytellers within the context of a storytelling advocacy programme. Analysis of the facilitators' data demonstrates how the role and the relationships formed supported humanising practice as identified by the the eight dimensions of the Humanisation Framework (insiderness, agency, uniqueness, togetherness, sense-making, personal journey, sense of place and embodiment). They also emphasise the importance of starting with the self and seeing how we can change to enable others, rather than expecting others to fit into our predetermined systems. This message is carried forward by Mah and colleagues in their paper when they invite us to think 'otherwise' and learn from service users about what they understand by 'paediatric concussion'. They remind us that rather than creating and living in our separate realities, we need to develop a shared reality and 'dance together' to provide responsive and effective services. Bourke in his personal reflection on employing a support worker highlights the need for people with ABI to be supported to learn

how to manage the complex and intimate human relationships on which their way of life and at times their lives may well depend.

Our final two clinical opinion papers widen the focus beyond the person living with ABI to recognise that as humans we are all interconnected through relationship and that family members have a great deal of existential and practical work to carry out themselves when a relative has an ABI. Whiffin and Ellis-Hill highlight that the invisible narrative work which family members undertake as they develop the meaning of ABI in their lives can go in many more, and more positive directions; developing the more limited discourse of loss which has been reported previously. Holloway and Ellis-Hill complete this edition by highlighting that what family members following severe ABI value most is service providers who are not only experts in ABI but most importantly companions who recognise and can reach across into the paradoxical parallel universe they find themselves in so they are not alone. This brings us full circle to the message of Dixon at the start of this edition.

From the papers in this edition, it can be seen that being human and forming human connections is not just a case of being nice or friendly; relationships form the basis of the reality and awareness that is created by each person at an existential level at every moment (Ellis-Hill et al., 2021). Through the types of relationships we form and language we use we either shut down or open up possibilities in life. By focusing on human relationship as the fundamental aspect of rehabilitation services we can ensure that services move beyond a narrow focus of the technical, visible aspect of care, to ensure we do not limit the vision and life possibilities of people with ABI. Taking a humanising approach, we understand that professionalism is based on professional technical expertise within the context of human relationship. We are all humans together and can draw on our wealth of human knowing to

create safe spaces, where we can gain trust in our embodied as well as intellectual knowing (Todres, 2008) and learn together to create responsive services which are highly valued by those who are using them. In this edition we have introduced the area of human connection in ABI services and work in this area is just beginning. There are many areas which we have not been able to touch on including the need for staff to experience safe spaces themselves in the workplace to carry out the emotional work of ABI service provision and the development and mainstream acceptance of research approaches which can address and honour humanising practice. We hope this special issue will inspire readers to carry out work in this field and take the work forward.

References

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