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HEALTH AND REHABILITATION RESEARCH INSTITUTE

Summary of findings

Exploring engagement in rehabilitation for people with stroke

Why we did this study

Engagement is commonly said to be important for getting the best rehabilitation outcomes. However little is understood about what it means to people with stroke, or what helps or hinders their engagement. This study aimed to better understand what engagement is in the context of stroke rehabilitation and what might help or hinder this engagement. We hope these findings will help rehabilitation practitioners better understand and promote engagement.

What we did

We wanted to talk to people who had received rehabilitation services following stoke, their family members and health practitioners providing stoke rehabilitation. We interviewed 23 people (12 men and 6 women) who were between 3 months and 6 years post stroke. They ranged in age from 48 to 83 years. We also interviewed four of their family / whanau members and held focus groups and individual interviews with 27 rehabilitation practitioners who were involved in providing stroke rehabilitation.

Who we are:


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AUT UNIVERSITY AND LAURA FERGUSSON REHABILITATION

What we learnt about engagement in stroke rehabilitation:

Engagement is a complex process

Engagement in stroke rehabilitation was considered difficult to describe and was often talked about as being something intangible, an elusive concept. What was clear however is that engagement is viewed as a dynamic two way process where both the patient and practitioner have a crucial role to play. However stroke related changes such as cognitive or communication impairments can make engagement difficult and could be misinterpreted by practitioners.

Connections were important

Engagement appeared to involve a process of connection between the rehabilitation practitioner and patient; and between the patient and the rehabilitation tasks. For some patients, the relationship with their practitioner was the critical ingredient that helped them engage in therapy, while for others, what was more important was feeling that the rehabilitation tasks were relevant, meaningful and supported their goals.

> *It's a relationship really and creating that trust and the feeling valued as a person, that your point of view is important, that the person [therapist] wants to work with you to achieve what you need to. (Person with stroke)*

> *His understanding is that the exercises that he's doing is just for him to get better but he doesn't really understand like say for example on the treadmill he doesn't understand why he has to – like what will the treadmill do to help with his stroke? (Family member)*

Other key engagement processes

A number of processes appeared to underpin making connections including: KNOWING, ENTRUSTING, ADAPTING, INVESTING and RECIPROCATING. These processes were relevant to both the person with stroke and the practitioner.

KNOWING was about the practitioner really getting to know the patient, what was important to them, and understanding who they are. However, it appeared equally important for the patient to know the practitioner, at both a therapeutic and human level.

ENTRUSTING: Trust is something that needs to be built. The patient trusts their practitioner has professional skills and will use them to do what is required to meet their needs. As the practitioner demonstrates their abilities, patient trust increases.

ADAPTING was about the practitioner responding to the needs of the individual, adapting their way of working to ensure "fit" with the patient, making changes and modifying their approach through the course of rehabilitation in response to patient needs and preferences. For the patient, adapting refers to the process of adapting to the rehabilitation environment, to their impairment, to their altered sense of self.

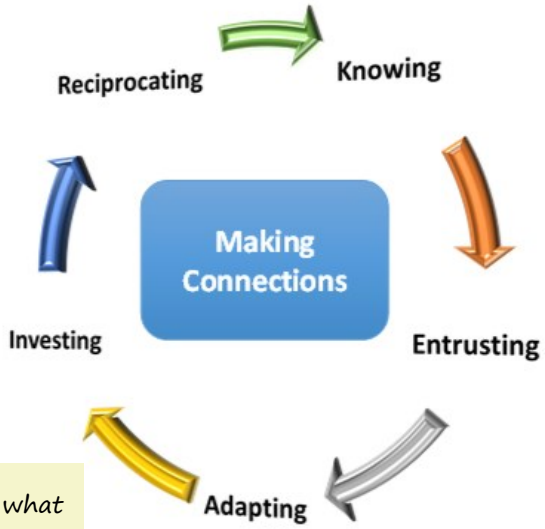
INVESTING: The practitioner and the patient both need to invest themselves in the process. Rehabilitation requires emotional and physical commitment from both parties.

RECIPROCATING: Engagement is reciprocal. Practitioner engagement appeared just as important as the patients' engagement. This involved both parties being enthusiastic, interested and emotionally invested in the process.

Reciprocating: I think the person who's coming to see you – if they're enthusiastic you're going to be enthusiastic... but hopefully the therapist who's dealing with you – if they're keen you're keen (Person with stroke)

Knowing: The basic thing is just seeing, sussing out how the person is acting and how they're feeling and listening to what they're saying. (Person with stroke)

Investing: It's just as much of a thrill for you to see them succeed. I think sometimes more thrilling for us because we appreciate the steps along the way and you know we get, well some of us, get quite carried away. (Therapist)



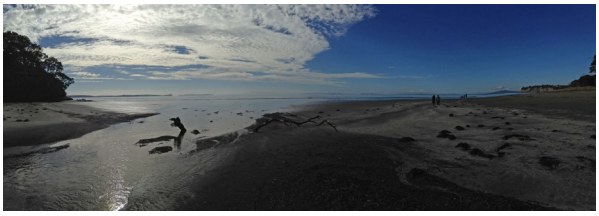
Entrusting: I think they engage so much more when they trust the therapist or whoever it is that they're working with, and that they believe in the person that they're working with, and they believe that the person they're working with wants things for them. (Therapist)

Investing: She cared about what happened to me. (Person with stroke)

Adapting: The therapist and their listening and their flexibility in being able to work with me ... [their] attitude and skills, that helped me through, and persistent—being persistent; and their attitude that 'we can do it'. And eye contact—that made me feel like they really are caring—they care about me, not just in it for the job—but they are in it for me. (Person with stroke)

Adapting: If that again isn't the patient's goal, if they want to just get on and do something, I think we have to adapt ... the whole purpose is about them achieving what they need to achieve (Therapist)

Entrusting: You have to trust they're telling the right things to do. It was all totally foreign to me. So you have to believe that they know what they're doing. (Person with stroke)



Our conclusion

- Engagement is a two way process which involves both the patient and practitioner. It is a dynamic process changing within and across sessions. It does not just happen but requires perseverance, ongoing effort and explicit strategies.
- Connections are crucial; connections between the patient and the practitioner, and between the therapy tasks and the patient goals, hopes and aspirations. The therapeutic connection between the patient and practitioner appears to be fundamental as it provides the foundation to build other connections.
- Facilitating patient engagement requires skill and effort from the practitioner. It requires them to adapt their ways of working and be flexible in their approach ensuring this is the approach the patient needs.

Where to from here?

We have shared our findings at conferences and workshops attended by rehabilitation professionals. This study has also informed our undergraduate and postgraduate teaching. We have found that simply talking about engagement with practitioners has promoted them to reflect and critically think about how they could actively work to facilitate engagement with their patients. We will continue to seek opportunities to present our findings to relevant groups. This study has informed ongoing research projects which aim to integrate these findings into rehabilitation practice, and optimise rehabilitation outcomes following stroke.

Thank you

We would like to extend our warmest thanks to *AUT University and Laura Fergusson Rehabilitation* for funding this research, and to all the individuals who gave their time to support the project. In particular we would like to acknowledge the contribution of participants who shared their experiences, thoughts and ideas about engagement in rehabilitation following stroke.

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