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RESEARCH PAPER

Person centered care in neurorehabilitation: a secondary analysis

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ABSTRACT
Person centered care has been described as being in its ascendency, despite some of the complexities of embedding it within healthcare systems. The emphasis of research now seems to be moving toward the promotion of cultures of care that support the efforts of practitioners. Informed by some of the principles of positive deviancy, where some of the solutions for change can be found within existing cultures and practices, this paper aimed to identify examples of person-centered care in existing practice. Reporting on a thematic analysis of qualitative datasets from three preexisting projects, we constructed four themes from these data: (1) That patient experience and needs should always be understood in terms of their difficult new reality; (2) the need for a relational orientation in care; (3) the importance of treating trust as a currency; and, (4) efficacy in rehabilitation is co-constructed, and enabled by the efforts of clinicians. Identifying positive examples of care, enacted irrespective of the framework of care they are found within, may provide opportunities to critically reflect on practice. The context for care and the extent to which that context constrains or makes possible person-centered care in practice will also be discussed.

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Person-centredness; qualitative; rehabilitation; thematic analysis; practice

➤ **IMPLICATIONS FOR REHABILITATION**

- Cultures of care are central to enhancing person-centered practice.
- Care begins with recognition of patient's difficult new reality.
- Building trust helps enable capacity for improvement.

The notion of person-centredness within rehabilitation is one that has gained in use and application for a number of years. Person-centered care has been understood to be an important, positive movement within rehabilitation, but has also been historically described as suffering from a lack of definitional clarity [1–4] – this seems to be changing [5]. Some authors have described person-centredness as currently in its ascendency, with theory and practice beginning to cohere around substantive, well defined models, largely associated with nursing [5,6]. Within healthcare more generally, person-centered care has been structured as a counter to a reductionist biomedical focus on disease or trauma, or to the systems, budgets, or staff focus that many hospitals and other healthcare providers appear to operate under [7,8]. When assessing wellbeing and satisfaction, there is little question that person-centered care improves the experience of patients [9], with increasing evidence that relationally orientated care is central to any number of positive outcomes [5,10,11].

Leplege et al. [1] have described person-centered care as a multidimensional concept, capturing various meanings related to who the patient is (including societal understandings of the nature of personhood [4,12,13],) the type of care they need, and differing understandings of patient capabilities [7,13]. Perhaps due to the broadness in many definitions, these meanings can be applied variably, depending on the dominant institutional framework involved [9]. For instance, within contexts where neoliberal economic policy saturate the direction of public services, health and otherwise, person-centered care can be viewed as an avenue to improve features of care such as over or underuse of services, and enhance cost saving measures [9]. When person-centered care is framed in this way, it can be misunderstood as *consumer*-centered care, where the provision of information and choice are prioritized over relational orientations to care and the time and effort needed for this orientation. Further, in these cases, the average patient, rather than the particular patient, remain the focus of treatment. Consequently, person-centered care can risk being superficially layered onto preexisting models of healthcare, rather than changing cultures in ways that best support patient experience [14]. In contrast, references to *patient*-centered care seem to reduce the person to their body and experiences of care within the system, rather than a wider contextualized lens that incorporates an understanding of the whole person [12,15,16].

Such systems-driven and defined applications of 'person-centered care' can end up being associated with metrics and box ticking activities [17]. They may also implicitly rely on the willingness of clinical staff to engage in 'above and beyond' activities that may not be rewarded, nor widely promoted within the wider cultures of healthcare services [6]. Increasing evidence also suggests that bringing true paradigmatic changes forward from philosophies of person-centredness, or lip service to these, to fully implemented practice, will involve changing deep organizational structures and patterns that are highly complex [8]. For this reason, some authors

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have suggested a unified conceptual framework that captures much of the overlap in definitions of person-centered care, and focuses on principles rather than the performance of certain sets of tasks [5,6].

Given that historically dominant modes of care still persist alongside shifts toward more person-centered models, it seems important to bolster the latter in ways that create real and lasting change. There is still a strong emphasis on models of care that prioritize the expertise of the clinician over the experience of the patient – especially at the acute level [18] and often dualistically focus care on the body rather than the person [12]. Although some features of acute, episodic situations may mean that a clinician orientated interaction are essential, increases in survivability following trauma or chronic illness, mean most clinician/patient interaction will occur at the chronic level [19,20]. Further, the current demographic make-up of many Western societies, often referred to as the 'ageing society' means a broader focus on chronic health issues is becoming the primary work of healthcare systems [21]. Certainly within the rehabilitation sector, where the vast majority of work is within this chronic setting, there seems very little justification for maintaining systems or clinician-centered practice, when the evidence is weighted toward the benefits of person-centered care.

In order to more fully map person-centered care, the experiences of people within systems where person-centered care has occurred are needed [22]. Following this line of thought, Todres et al. have suggested that such qualitative accounts of people's lifeworlds are necessary to fully understand what works and what does not [22,23]. Further, theories of positive deviance indicate that rather than external (and arbitrary) forces creating and shaping change within a given culture, solutions to problems and difficulties can often be found within the culture itself [8,24,25]. Changing healthcare cultures to a focus on person-centredness can risk focusing on what people are *not* doing, so identifying examples of positive deviance within a given culture or set of cultures and bolstering these, may provide the best avenue for positive change [24]. There has been strong suggestive evidence that 'what works' might be found within organizations – where patients are more successfully recovering from injury or illness or managing their symptoms – and may have something to do with the *existing* efforts of practitioners, even where rhetoric of person-centered care does not exist.

In this paper we aimed to identify and describe patterns of care across a variety of healthcare settings where, irrespective of the philosophical framing of care, person-centered care, valued by patients, was *enacted* and *practiced.* We will focus on patients' descriptions of care that have worked for them, whether it has been defined as person-centered or not.

Methods

Design

This is a secondary analysis of three qualitative datasets, from a University-based research centre that has engaged in over a decade of research seeking to enhance understanding of the interface between clinical practice and patient experience in rehabilitation. Client experience and new ways of working for clinicians are put at the forefront of the Centre's work, in an attempt to enhance rehabilitation among people living with the enduring consequences of injury or illness. This project sought to capitalize on the Centre's existing datasets and research portfolio to gain a wider insight into how person-centered care might be enacted in practice.

Following Heaton's [26] guide to secondary analysis, this project is structured as (1) a supra analysis, and (2) relying on an informal mode of data sharing. The former orientation situates it as transcending the research questions and focus of original studies, while the latter identifies that the primary investigator was not involved in the data collection, nor any previous analysis of the datasets, but was given access to the projects specifically for the purposes of the current project. In order to manage wider concerns about representation and separation of the first author from data generation and project design [27] meetings were set up with researchers from the original projects to discuss coding and interpretation. Further, the second author had oversight of all three projects, and was involved in design, data generation, and analysis, which was drawn upon in the design, analysis, and write-up of this paper.

Projects within the Centre's database were examined by the first author, with twelve identified that (a) sought to capture experiences and perspectives regarding the interface between patients, clinicians, and health services in a rehabilitation context; (b) had a qualitative component; and, (c) data were generated primarily from interviews or focus groups. Three projects were purposively selected from within this group given their rich data targeted to the phenomenon of interest, and that their patient participant base were all recipients of neurorehabilitation. The original purpose and participants of each primary study were:

1. Understanding the construct of patient engagement following stroke: Individual interviews with 19 people who were between 3 months and 6 years post stroke, purposively sampled for a range of impairments and severity. The study also contained focus groups and individual interviews with 18 rehabilitation providers including physiotherapists ($n = 10$), occupational therapists ($n = 3$), social worker ($n = 1$), and field officers ($n = 4$).
2. Exploring the core components of the therapeutic relationship in a neurorehabilitation context: Individual interviews with 14 people experiencing rehabilitation between 1 month and 13 years following a neurological event. The majority had experienced traumatic brain injury ($n = 6$) or stroke ($n = 3$). Focus groups and individual interviews with 14 rehabilitation providers including physiotherapists ($n = 6$), occupational therapists ($n = 2$), psychologists ($n = 2$), and a nurse, speech and language therapist, clinic manager and social worker (n = 1 of each).
3. Improving the outcomes of people with long-term neurological conditions through improved communication and care: 6 individual interviews with people who were purposively sampled across conditions, from a number of neurorehabilitation sites; one interview with a family member carer;

All projects met the ethical guidelines of the Auckland University of Technology. The total dataset was comprised of 40 interviews with patient participants, family members, or carers; three focus groups with patient participants; two interviews with clinicians; six focus groups with clinicians (total $n = 32$). All participants were given pseudonyms distinct to this new project.

Analysis

We used thematic analysis following Braun and Clarke's [28,29] six phase approach, taking a critical realist ontology in relation to the data [30]. Critical realism treats knowledge and experience as mediated and constructed through language, while acknowledging the material and social structures and mechanisms that generate phenomena. The data were treated as a single data set, with the research question guiding analysis at every phase, this being: "In what ways have patients experienced person-centred care being enacted in their healthcare." The first author familiarized himself with the data, taking casual observational notes about their content. This was followed by inductive research question informed coding, at both semantic (descriptive) and latent (interpretative) levels. Themes were then constructed from these codes and their associated data, first, by establishing candidate themes, which were tested for their utility in telling the story of the data, then reviewing and finalizing themes. Both authors discussed the content of codes and candidate themes using thematic maps to make sense of them. We generated four themes from the data that described the *doing* of person centered care, and the ways in which it can be experienced by patients. Both patient and clinician data informed the construction of themes, however, data extracts from the patient participants will be prioritized in the analytic section of this paper, and hereafter references to 'participants' are to patients, unless otherwise identified. This decision was made to emphasize that the implications of care, poor, indifferent, or otherwise, often fall on the patient [22].

Results

We generated four salient themes related to accounts of person-centered care in practice within the dataset. Each theme cohered around a central organizing concept – or the key idea than underpins the thematic explanation of the data [29]: (1) That patient experience and needs should always be understood in terms of their difficult new reality; (2) the need for a relational orientation in care; (3) the importance of treating trust as a currency; and, (4) efficacy in rehabilitation is co-constructed, and enabled by the efforts of clinicians.

"So there's all this danger, you know, you don't sort of realise until you get home" – a difficult and unstable new reality

This theme describes the lived context that necessitates rehabilitative care according to our participants. All participants spoke of the ways patient's lives and self-identities are radically changed by the experience of a new, and often sudden, impairment or range of impairments. As a consequence of these changes, the world was often presented as more risky, troubling, and unfamiliar. This was evidenced not only in the ways that cognitive, physical, and emotional impairments impacted participants lives, identities, and those around them, but also having to manage and understand the processes of rehabilitation and the foreign nature of clinical and gym spaces. These are features of the rehabilitation 'landscape' often taken for granted by clinicians.

Participants also spoke of the impact of their condition(s), and the initial sense of confusion, struggle, and emotional trauma that came with the clash between the impact of their injury or illness on the expectations, hopes, and embodiments of their reality – a biographical disruption [31,32]. For a number of participants, this change to their lives was constructed as overwhelming, not easily integrated into their preexisting identity. One participant spoke of the intensity of these early weeks, and the suicidal ideation this resulted in:

> "Certainly the dealing with the shock and change and challenge of perhaps the highlight for me, in that first 3 weeks anyway, was going through a phase when I truly, really wanted to die. It was in conscious and rational choice. I choose to die, death is the best option" (George, Study 1, 65, Person post-stroke).

Navigating successfully through the new reality their illness or injury had created was marked as an important feature of this early period, with George providing a more extreme example of the need for good navigation. Many participants spoke of depression, anxiety, and anger at the changes their condition had effected upon them that they often found difficult to articulate to those around them. However, as their first environment was often hospital based, many participants also described being 'protected' from the full extent of their new reality, until after they had left more intensive care:

> "Because in hospital, in 2 months, I never considered myself as sick. That may seem strange and it wasn't until I got home that I realised how ill I had been. They sort of treat you like mushrooms in there and keep you in the dark. It wasn't until I got back onto the internet and started reading about other people's experiences and the fact that I was having trouble coping with some things, so it was only then that I realised 'oh gee I had been crook'" (Joseph, Study 1, 70, person post-stroke)

Joseph's description of slowly coming realize the full impact of his stroke was another common thread within this theme. Participants described moments of increasing awareness, when their difficult new reality was suddenly clear to them. This gain in clarity was commonly described as traumatic, with various mechanisms (such as denial) referred to by participants to manage it. Clinicians and researchers have described these processes in various ways – referring to them as insight deficits or shifts in self-identity [33].

For a number of participants, it was the orientation by clinicians toward simple tasks that highlighted how different their bodies and lives had become. Goal setting was often described as depressing or disempowering as a consequence, with broader long-term hopes deferred for their immediate clinical needs:

> "That was hard because I was quite unrealistic at the beginning. I remember the first time the therapist at the hospital talked about setting goals, I said something about tramping again perhaps swimming perhaps even playing golf again – she said, "What about getting up in the morning and getting dressed?" and I thought, "Hell's teeth we're on a different page here" and my heart sank a bit" (Andy, Study 2, 68, person post-stroke).

Although it is not uncommon for clinicians to propose longer-term goals in the rehabilitation process, the early emphasis tends to be on independence and daily living functioning – likely due to safety and discharge concerns [34]. However, even as rehabilitation progresses, practitioners can privilege certain goals over others, demonstrating discomfort when patient priorities do not match their orientations [35]. These practitioner privileged goals can tend toward physical function, the short term, and be conservative regarding future outcomes – and may result in patients deeming their own goals "unrealistic." Mismatches between patient and practitioner goal setting in our data, often went in the direction of the practitioner's biases, with their expertise used to justify this.

Comparisons were routinely made between the clashing of two realities, the impact the differences had on patients self-identity, and the difficulties they had processing these differences. For instance:

> "I'm not a person to sit around and do nothing. This has been a hell of a shock because I've always worked with my hands and doing things. So, suddenly boom, you know, can't do it anymore, because when I first went to hospital, like I was carried in. Couldn't walk. Couldn't talk. Couldn't go to the bathroom. Couldn't do anything" (Paul, Study 1, 68 person post-stroke).

Needing time to process the impacts of a stroke, head injury, or other illness, was often confounded where there were cognitive effects, but these were not described as the defining characteristic of their experience. Within the accounts of Paul and others, it was the suddenness ("boom") of the change that was most profound, undermining their sense of self, and something not often recognized by those around them providing care [36,37].

The process of returning home was commonly identified by clients and clinicians alike as a movement toward independence, however, most clients spoke of this period as extremely difficult, fraught with a sense that everything had changed for them [19,38]. Those people who acted in a support role also spoke of feeling overwhelmed, having to deal with a new world that made even the familiar risky:

> "No. You just sort of get excited thinking we are going to go home, it's going to be wonderful." You get home and then there's all these obstacles and stuff like, oh we had to have when we first got home ACC had to install a thing around the fireplace which is blocked up but because he's lost peripheral vision and that as well and depth there's that little step he kept. So there's all this danger you know, you don't sort of realise until you get home. And then if you have got nobody there to support, to sort of like turn to it's a nightmare" (Anna, Study 3, Parent of child with head injury).

Similar to Anna's "nightmare", metaphorical language such as "new terrain", "a whole different world" pervaded the data, describing what had once been a safe and familiar environment – the home. New obstacles were identified that made previously simple tasks, such as walking to collect the mail, problematic. When rehabilitation was begun, it was almost always described in similar terms, with many participants speaking about the lack of familiar landmarks within the new reality:

> "The first session that I did with all of the different therapists was, I was going into the great unknown, I had no idea what was being set down or what was maybe going to be set in place for me" (Finau, Study 2, 59, person post-stroke).

Practitioners viewed positively by participants, were described as *guides* through the difficult new reality, giving clear information about the severity of their condition, pathways to provide improvement, and warnings about the limits and constraints their condition placed on them. Understanding the centrality of a patient's difficult new reality did not mean practitioners assumed that the patient was vulnerable or incapacitated [13]. What seemed essential was a sense that these guides both understood the wider terrain of the difficult new reality, but also the individual needs of those attempting to navigate it. More personalized, engaged care of patients was always described in terms of the relational orientation of a practitioner, even above their skills or knowledge. It is this area that our next theme describes.

Theme 2: "I mean I've only known them all of two weeks but you'd swear I'd known them for six months" – relational orientation in care

The second theme we constructed spoke directly to the notion of the therapeutic relationship [39] and its creative and generative scaffolding of rehabilitation [40]. Within the dataset, participants spoke of 'success' with a patient as moving beyond a set of tasks (and sometimes even initial clinical outcomes), treating the relationship between patient and clinician as the priority. The therapeutic alliance was understood not simply as a welcome addition to rehabilitation, but as the basis of it.

As with theme one, examples of what patients experienced as good and bad care and therapy were deployed in interviews, with hospital experiences often portrayed more negatively than outpatient rehabilitation. This would typically be discussed in terms of the volume of clients hospitals had to deal with, as compared with the greater time community therapists could spend with clients. For instance:

> "So I just think they were just a hospital organisation of course. There wasn't much emotional buy-in. There was no real relationship. Maybe because they had so many people coming through, they just, they haven't got time. I think if you don't bond to your PT, to your therapist you know, you don't get as much as you should out of it. If they're aware when you walk in tired or you're down" (Andrew, Study 2, 52, person post-stroke).

The need to have a "real relationship" with health professionals was described by almost all of the participants as being at the heart of rapid improvement [41]. Much of this entailed a familiarity developed over time, but the "bond" was consistently constructed as something that could be established quickly, and gave momentum to progress – even in the highly transitory space of acute wards. Knowing they were not simply a task to be fulfilled or ticked off, was described as giving patients a sense that their needs were important, that their difficult new reality had been recognized. In contrast, being treated as just another number, seemingly without consideration for their unique needs could have the opposite effect:

> "The same things happens in the hospital you've got consultants coming around you've got the doctors coming around. They will invariably say "I've got other patients to see" and you feel like saying "don't forget I'm one of them. You have still got to meet my needs" (Paula, Study 3, 20, person with idiopathic intracranial hypertension).

Having needs met through clinicians being wholly present in the time available, especially for those patients with communication or cognitive difficulties, was marshaled as a contrast to standard clinician accounts of 'expertise', 'experience', or 'evidence' as doing the work of rehabilitation (see Kayes et al. [42], for critique of this sort of account). Where 'expertise' and technical, disciplinary knowledge was privileged, this appeared to result in clinicians treating their clients as a set of tasks, or parts of a body needing to be repaired. However, where relational practice was constructed as legitimate rehabilitation work, this appeared to contribute to a more human approach to care. This was described as inevitably leading toward client engagement and participation in clinical decision making.

Rehabilitative therapy can occur at any number of levels: physical, cognitive, affective, or spiritual, but the emphasis of care in rehabilitation is often on physical and cognitive improvement in order to achieve independence [43]. Many participants identified that what seemed to be a dead end of improvement in the physical sphere could result in unacknowledged possibilities across others [1]. June, for instance noted:

> "Well it's the caring and the, yes that's it. It made me feel good. I sort of felt 'oh my god I've got all these things wrong with me, what must these girls think?' But as soon as we were talking and they said 'just do it if you want to' and all this and I felt good, I thought I wasn't pressurised that I had to do it […] They were understanding. They said 'we understand what you have got and when you can do it, you do it. And you've got your bike if you feel you can do more on your bike'" (June, Study 2, 72, person with Multiple Sclerosis and Rheumatoid Arthritis).

June argued several times that she had been positioned as a 'problem case' by various therapists and specialists. She commented that her dual diagnosis of Multiple Sclerosis and Rheumatoid Arthritis had resulted in slow progress in her rehabilitation and had made her feel like a burden on the health system. What seems important in her account is the construction of self-worth she gained from her time in rehabilitative care. That she was still involved and engaged in her rehabilitation over a long period of time indicates the value she ascribed to the care she received. Her physical recovery and adaptation may have come slowly, but it was *continuous*, due to the efforts of her therapists. Unfortunately, such positive accounts of clinical openness were not typical, with most accounts indicating that engagement was often not viewed as a two way process, co-constructed within the clinical relationship, as it is increasingly understood to be [44] Practitioners described positively by participants appeared to engage with patients beyond the task or program, motivating them through the relationship built up between them. Many of the patient participants spoke of the various ways they could tell if a health professional was interested in their care, and the impacts that had on their various recoveries. Sam described it the following way:

> "It's all about making you feel interested that, or you're wanted, if you know what I mean? If you're just a therapist talking to me and you got no, ahhh you're pretty low key, and it's just a job for you, it's going to make life a lot difficult for me personally. But in that the people here they treat you as a family member really it's quite good quite nice" (Sam, Study 3, 25, person with head injury).

Being "low key" or simply relying on expertise over relationship (e.g., "it's just a job for you") was described by many as barrier to care being experienced positively. Depth of relationship (or perception of such) was constructed by participants as providing the potential to enable greater engagement, engender motivation, and support a willingness to participate in tasks that seemed difficult or mundane, and promote confidence to do more than the patient thought possible – something we will return to in theme 4. Some participants described a sense of reciprocity, with this way of working having the advantage of meeting the needs and goals of the clinician:

> "She took her time and explained it all to me and that made it easier for me to try and help her out. Try and do the things she wanted to do. You know I would have crawled over hot coals for her and it's just the way she. It was just her mannerisms I suppose. I don't know whether it's something you can teach" (Michael, Study 2, 68, person with stroke).

Almost all of the participants described this relational orientation as intangible, and therefore complex to teach. However, some key ingredients to a relational practitioner can be identified from their accounts that highlight the importance of the clinician in creating a context where this sort of relational care can occur. First, a willingness to spend time with clients, building a relationship as part of the 'duty' of care. Second, a willingness to engage with the person as a person, irrespective of whether outcomes follow a 'normative' pathway to independence. Third, a willingness to be responsive and adapt to the individuals in their care, not attempting to quickly categorize them or force them into a protocol driven process. One feature of this relational orientation will be discussed in the next theme: recognizing the value of trust within care.

Theme 3: "I think it's important to gain the faith of the person that you are dealing with" – a currency of trust

Structured around accounts of experience with therapy, this theme identified one of the key components of relational care - trust. Following a significant health crisis, and the fundamental life changes this enveloped them with, patient participants often spoke of the initial leap of faith that was necessary to trust their doctors/therapists and the care they offered. The metaphor of currency is used, as participant accounts collectively constructed a notion of trust as something that persists beyond dyadic arrangements, and can be gained, lost, or transferred to other practitioners and contexts. It also reflected talk of trust's protective effects, and its ability to 'purchase' hope and confidence.

A number of people explicitly used the language of trust to describe their experiences of good therapy. This was often presented as being a product of vocational competence, and a willingness of professionals to use that competence in ways that were tailored to meeting the unique needs of the individual. For example, Nigel made the following comments:

> "Just with what's going on with me, physically. If I have issues, posture, I'm doing an exercise wrong, just be straight with me and explain to me, say "you are doing that wrong it should be done this way." Which I find with her, she is very good. Just trust, I guess which is how I used to work with my customers. You build that trust up" (Nigel, Study 3, 36, person with head injury).

Nigel positioned himself as highly engaged and involved in his rehabilitation, so assurance that his efforts were not being wasted were considered a priority. Many participants spoke similarly about getting good information, and this providing them with some degree of control over their new reality [45]. The construction of trust as 'built up' over time was often deployed by participants, and in Nigel's account this was a product of providing the right information, or evidence of skill, at important times.

For some participants, competence and confidence in skill were the key ingredients needed for a trusting relationship with health professionals. For others a more relational orientation toward vocational competence seemed apparent:

> "I guess like I can only speak for myself, but once I've spoken to the person a couple of times and sort of get where they are at, and know that they are just being straight up with me and they are doing their job and whatnot, then you sort of feel like you can relax and it's not something that comes instantly, you know some people it does but other people it might take a couple of sessions to get the feel for them" (Pauline, Study 2, 50, person with head injury).

Although many participants described vocational competence helping with the initial faith in a health professional, it was generally not enough to *sustain* the trust needed for a positive experience of rehabilitative care. Like Pauline, many participants spoke of their care improving as a direct consequence of time spent with clinicians who appeared to recognize that engagement was a two way process [44]. However, health professionals losing patient's trust, especially at the earlier stages of care, was described continually throughout the data, with many, very detailed accounts deployed as examples. Often what was apparent in these stories was the sense that a need to build trust was not important for the professional, with a task-orientated approach dominating:

> "He was all like "I'm the doctor" pretty much. And then I was just like, oh yeah I just don't like doctors like that. And it really bugged me how doctors, how we just accept it kind of. How people accept that doctors are like dicks pretty much, but it shouldn't be like that. Like my dad is an accountant and I don't see how it's any different from an accountant. Like if he was to treat his clients like that or if he was rude or he didn't listen or he was like, it just wouldn't happen" (Paula, Study 3, 20, person with idiopathic intracranial hypertension).

Good examples of building trust certainly included seeing results and having those results placed within an understandable framework, but having a therapist who listened, rather than prescribed, and being a stable positive presence that they could rely on in the navigation of their difficult new life was primary to the continued accumulation of trust.

In order to clarify the differences in therapy, good professionals were often described using terms such as putting clients at ease, or making them feel relaxed, with participants identifying the ways this might occur:

> You know about them. They know about you. You've got to feel relaxed in their presence you know. Just as I say I found it hard that they know all about me and I know nothing about them. I think it would be nice if you could know this person is this, they've done this, this is their training, they've been here so many years. They've worked with stroke people. To make you feel at ease straight off. Just to complete strangers, you get sick of meeting strangers. You actually get sick of professionals in your life" (Brian, Study 1, no age given, person post-stroke).

Knowledge about a practitioner, their history, their skills, and their personhood, all shaped the way a patient experienced care. Although most participants spoke about the relationship being professional rather than personal, an increasing awareness of how a clinician worked, and the experience and knowledge they could use to guide clients, helped engender trust. Relying on expert status to justify decisions was considered a feature of poor care. Therapists and doctors alike who continually maintained a professional distance were portrayed as impacting the therapeutic relationship in a negative fashion – disrupting any trust vocational competence might otherwise enable. This is consistent with Austin et al.'s critical reflection on the professional 'boundary' metaphor and the need for more dynamic and fluid conceptualization that allows for reciprocity in sharing of self as a therapeutic tool in its own right [46].

Maintaining trust was not always about a relationship with an individual health professional. A number of participants noted trust could occur within the context of healthcare teams, where there was often a degree of transferability or sharing of trust. This transferability could also occur in the movement of a patient from one care provider to another. The continuum of care is a well understood concept within healthcare, with transitions often being problematic [21]. Links and communication between various forms of care provider are thought to enable smoother transitions, and in several cases, there seemed to be a similar effect with trust being passed from one professional to another:

> "I don't know if it's the usual practice but my physio at [inpatient rehabilitation facility] had actually took me out one day to the community practice, and we met them, and I actually saw my physio and the physios there talking to each other and getting really excited and talking about all these new plans for me and stuff, and it was sort of like just really important to see that handing over. I knew that the seeds had been sown and sort of thing and that I wasn't just going into a place that completely didn't understand me and I had to build my whole sort of yeah" (Sam, Study 3, 25, person with head injury).

Within many accounts, the 'contagiousness of trust' was considered a mitigating effect throughout care. Those clinicians that went outside "usual practice" and attempted to bridge gaps in care not only garnered trust for themselves, but also seemed to contribute their trustworthiness to others within their teams, and to the next line of professionals in a patient's care. Sam's excitement at moving into a new facility can be set in contrast to accounts of abandonment, which were prevalent through the data and in the broader literature [38,47,48]. When reflecting on positive experiences, clinicians were also described as acting in ways that supported and shored up patient's capabilities, seen as enhancing and being enhanced by trust.

Theme 4: "she tends to make you believe in yourself a lot more than you normally would" – enabling efficacy

This theme is built on accounts that seemed to act as a counter to existing discourses of self-efficacy and independence that continue to define therapy [43]. In particular, these related to what was commonly described as the task orientations of therapists, and the prioritization of notions of patient adherence to and compliance with rehabilitation tasks. Instead of a patient's ability to accomplish tasks and move through the rehabilitation process being understood as an internal characteristic, almost all clients and some therapists spoke of a relational production of efficacy. This perspective constructs the role of therapists and significant others as enhancing or enabling efficacy, or a sense of autonomy, the patient may not have, or feel capable of, especially at the beginning of the rehabilitation process. In this way the concept seems to be closely affiliated with theories such as the relation-inferred self-efficacy component of the tripartite model of efficacy (i.e., they believe in me, therefore I believe in me) [41,49] and relational autonomy [14,50].

As discussed in theme 1, participants would often draw on descriptions of themselves prior to their difficult new reality, in order to make sense of their current experience. Johnnie, for instance, commented on his identity as a 'fixer':

> "I knew before I met her that, all my life I had been a 'fix it yourself, if I haven't got one I'll make it' sort of thing, I am always fixing things and I recognised quite early on that this was something I wasn't going to be able to fix myself. I needed some help. So I leaned on people pretty heavily I suppose" (Johnnie, Study 3, 52, person post-stroke).

The independence imperative that seems to drive much acute and rehabilitative care [51], often made little sense to patient participants as they experienced their difficult new reality. Like many of the participants, Johnnie's accounting for the important features of his rehabilitation experience set his care within a web of supportive personal and therapeutic relationships. In contrast to his experience, individualistic expectations of self-motivation, self-advocacy, and even pressure to make decisions, were described by participants as exhausting and occasionally as soul-destroying. Participants also spoke of being unable to see past the new limitations on their capabilities in the earlier stages of their rehabilitation, noting, in particular, the absence of self-belief. Some clinicians were framed as giving something of themselves to their clients, to enable the necessary motivation to enter into rehabilitative programs:

> "You sort of get the feeling that yes you can do the things she teaches you yeah and she I don't know she tends to make you believe in yourself a lot more than you normally would" (Heather, Study 2, 56, person with head injury).

Reliance on this type of care was commonly described by participants as making them more capable of achieving certain goals and more stable in their responses to the difficult new reality they faced. In contrast to neoliberal discourse and policy that places the burden of response to care and adhering to rehabilitation on the patient, and seems concerned that dependence on carers can undermine a patient's capacities to improve [52], most patients spoke of the opposite effect in their lives. Harold, for instance, spoke of his therapist's ability to shift his emotional and mental state when he felt unable to do so:

> "I think the therapist and their listening and their flexibility in being able to work with me if I wasn't quite feeling there or involved, they had the ability to change it. And that I understood what was required of me in what they were saying. And caring. They have a lot of energy and positive feedback and that spurred me on. This isn't bad at all. I can do this. If they're positive in their energy and the material they give me, and it's not the same thing every day. And it's interesting. I would never have thought of that. In the past I've done things I would never have done. It made more sense so I think it's, the therapists' attitude and skills that helped me through and persist" (Harold, Study 1, 72, person with stroke related communication difficulties).

It was common for patients to describe these sorts of effects, speaking of drawing on the energy, and belief, and value the practitioner invested into them. Similar to the effects described in relation-inferred self-efficacy [49], confidence expressed in their practitioner and their practitioner in them, enabled greater confidence in themselves and their capabilities:

> "I think it took it me a good twenty minutes to make one cup of tea and she just sat there she said "take your time" and. "don't rush it and think about what you are doing" and that sort of thing and she would use her own hand expressions like she'll say "look at your hands and open your fingers imagine opening your fingers and stuff like that and grabbing a cup" and I'd sort of just watch her movements and my hand moves with her sort of thing those sorts of things you know she took the time to actually physically show me how I should hold a cup and stuff like that um she's got the patience there "hurry up, you're doing well, put your hand over here, do this" and she's really quite patient. I tend to think she is cos it took a good 20 minutes to just make one cup and now I can probably do 5–7" (Elsa, Study 3, 50, person with head injury).

Elsa's account speaks to the intensiveness of supported efficacy at various points, here it was described in terms closer to new learning than relearning the task of tea-making. These sorts of accounts did not suggest that growing independence was taken off the table. There was still a focus on empowerment, and increasing self-efficacy in daily living tasks within Elsa and other's stories. However, the recognition that this occurred within various layers of relational dependence, and was not the goal of rehabilitation, was what stood out. In fact, a number of participants spoke of having to rely *more* on their physiotherapists as their condition improved, as a tendency to overextend became common:

> Sometimes my therapist said "look you are pushing too hard" because he said it is not going to benefit you, it is going to make you tired. And I have learnt, you know, it's just a matter of "OK I am in your hands and if you are saying I am going too hard, tell me how to go"? I think that is pretty important." (William, Study 1, 64, person with stroke related communication difficulties).

It can be easy to see where such accounts might impact on the decisional autonomy of a patient. However, in the interview with William and others within the dataset, the description of events was not one of withdrawal of autonomy, but where the capacity to make good decisions was supported when the tendency might be to "push too hard." The difference between decisions being made with or without the full involvement of clients was evident in their accounts. In the instances where supported efficacy was present, excitement and momentum were often key features of their accounts. Myrtle for instance noted:

> "I just <u>know</u> that when she turns up we're going to be trying something new and something that I know I'm gonna need when I get home. So I look forward to those things, like even showering and stuff, and she watches to see how I do it, so that if I need any adjustments made at home, she can suggest those like handrails and I know that every time she comes, I'm improving every day and she's going to teach me how to improve every day with every day things" (Myrtle, Study 2, 52, person with head injury).

What was evident in this account is the ways in which even the mundane became exciting – especially in the early stages of her rehabilitation. Engagement in this account was viewed as a product of the supportive relationship Myrtle had with her occupational therapist, enabling her to gain a sense of progress in her outcomes. Clearly the level to which this sort of support is appropriate will depend on the individual patient, and thus needs to be a product of the relationship, and knowing the patient, rather than protocol driven [53].

Supported efficacy was often implicit to the accounts of patient participants. It was a feature of the data that tied closely with a relational orientation to care, and the trusting relationships clinicians build with their clients, but it was distinguished by its emphasis on the tasks of rehabilitation, and the sense that participants felt enabled, enhanced, and wrapped around by clinician care.

Discussion and conclusions

The secondary analysis described in this paper has explored the sense-making of patients from several research projects, with the themes described offering examples of person-centered care in neurorehabilitation practice within the Aotearoa/New Zealand context. The four themes we constructed from the data offer insight into person-centredness, which surpass the original intention of the projects the data were drawn from. However, these data provided a useful avenue to accessing positive accounts of care within existing health systems and frameworks, generated from the experiences of those who had experienced significant injury or illness [54]. As these accounts were drawn from existing cultures of care, they indicate that person-centered care is already occurring (whether acknowledged or not) and understood, implicitly and explicitly, in patterned ways.

Some writers have already expressed concern about the transferability of ideas of person-centered care to the specific realm of rehabilitation – especially when from other domains of healthcare [55]. However, the findings of this paper indicate that, following the principles of positive deviancy [24,56,57], solutions to the 'problem' of increasing person-centredness in rehabilitation can be found within existing systems. Particular, patterned types of care were valued and experienced as meaningful by patients and clinicians alike: (1) an understanding of the patient as located within a difficult new reality; (2) a relational orientation to care; (3) trust understood as an important form of currency; and, (4) efficacy as co-constructed and enabled by the efforts of practitioners. Together these themes served to describe an overall orientation to care, not limited by various context bound understandings of the self and the capabilities of patients [5,58,59], nor reduced to shared decision making or provision of information to make informed choices [12,14,50]. This analysis benefitted from access to a number of diverse projects with rich data from which to select. It was limited by the explicit focus on neurorehabilitation, however, these findings are highly transferable and resonate with other areas of healthcare and rehabilitation research [6,9,40,50].

These findings suggest that valued ways of working, particularly beyond emergency care, began with the recognition of a patients' new reality, and continued to centralize it throughout rehabilitation. In this sense, clinicians acting as guides [46], and as guests [18], in the lives of those experiencing new difficulty appeared to be the most beneficial approach to care. Clinicians who began with sensitivity, recognizing the long-term impact on patients, not only of injury or illness, but also a widescale lack of familiarity with the therapeutic landscape of hospitals and rehabilitation, helped produce this guiding orientation [54]. However, clinicians are often not trained or supported in this area to the same level as they are in biomedical models of care, despite increasing evidence that guiding orientations benefit patients, leading to better work satisfaction, outcomes, and quality of care [5,54]. Building upon solutions found within the system such as this, and bolstering the types of care that are valued by patients, seems to be one avenue to enhance patient experience.

Rather than viewing these expressions of care as additional, or supplementary, these are behaviors that can be embedded into the cultures of healthcare settings – with recognition these are complex systems [5,6].

These are principles that can become embedded in the way we do things, and equipping and training new people to do the same – via curriculum adaptions and orientations, but also professional scopes and competencies. In practice, this may involve teaching using models of reflexive praxis that responsively deal with things like power difference, flexibility, defensiveness, and change. It will also involve shifts in language and orientation. For instance, interdependence rather than independence motifs, recognizing interdependence is a typical and important feature of all human experience, rather than something to be avoided [51]. It would involve movements away from the language of adherence to recognizing engagement as a co-construction [44], especially given research evidence highlighting that return to meaningful life is more important than physical ability for many people experiencing the effects of neurological impairment [60]. Central to this engagement is the accumulation and maintenance of trust. The metaphor of trust as currency relates to its protective mechanisms within care, with depth of trust and quality of relationship strengthening clinician capacity to build patient capabilities, and indeed the capacity to challenge patients when appropriate [61,62].

Certainly, the more generative approach to care described in our findings seems to rely less on exceptionalism, where practitioners enact particular types of care despite the systems they work within, and instead on developing cultures where the positive efforts of individual practitioners are supported and enabled [6,54,63]. Such approaches mean there is less likely to be multiple ideals of care competing within one another, diffusing the value of each. Veneers of person-centered care were easily identified by patients in the datasets analyzed and contrasted with more meaningful engagement with the efforts of practitioners. Further, patients in our data seemed well aware and sympathetic in situations where a practitioner was "trying their best", but were stymied by expectations of practitioners' employers, time pressures, or other systemic problems. Although there are clearly examples where practitioners were not enacting the types of care described in our themes, these examples often seemed to be facilitated by, and equated with, systems that placed greater weight on biomedical understanding and cost saving measures, over and above the experience of patients.

Given claims that person-centredness is now in its ascendency, we are well placed in research on person-centered care to see an emphasis on identifying healthcare cultures where care and compassion are prioritized, and see translation of similar effects into other contexts. Data that drills deeply into positive cultures of healthcare should be prioritized over those identifying problems with care, which now seem well rehearsed. Identifying avenues that promote a greater critical reflection on practice, and the context for care, and the extent to which that constrains or makes possible person-centered care as described by our participants may have much to offer the ongoing improvement of care for patients.

Disclosure statement

The authors report no conflicts of interest.

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