AUT CENTRE FOR
PERSON CENTRED RESEARCH

AUT

Whose Behaviour Matters? Valuing *who we are* and *how we work* as critical to outcome following mTBI

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Brainstorm, November 2019

AUT CENTRE FOR PERSON CENTRED RESEARCH

AUT

Three inter-related purposes guide our work:

1. Rethinking rehabilitation
2. Embedding person-centredness
3. Making a difference

Our **core research themes** include:

- Co-creating health and engagement
- Vocational rehabilitation
- Disability, diversity and accessibility

Always in conversation . Engaging with diversity . Connecting as people . Pushing the boundaries

Setting the context

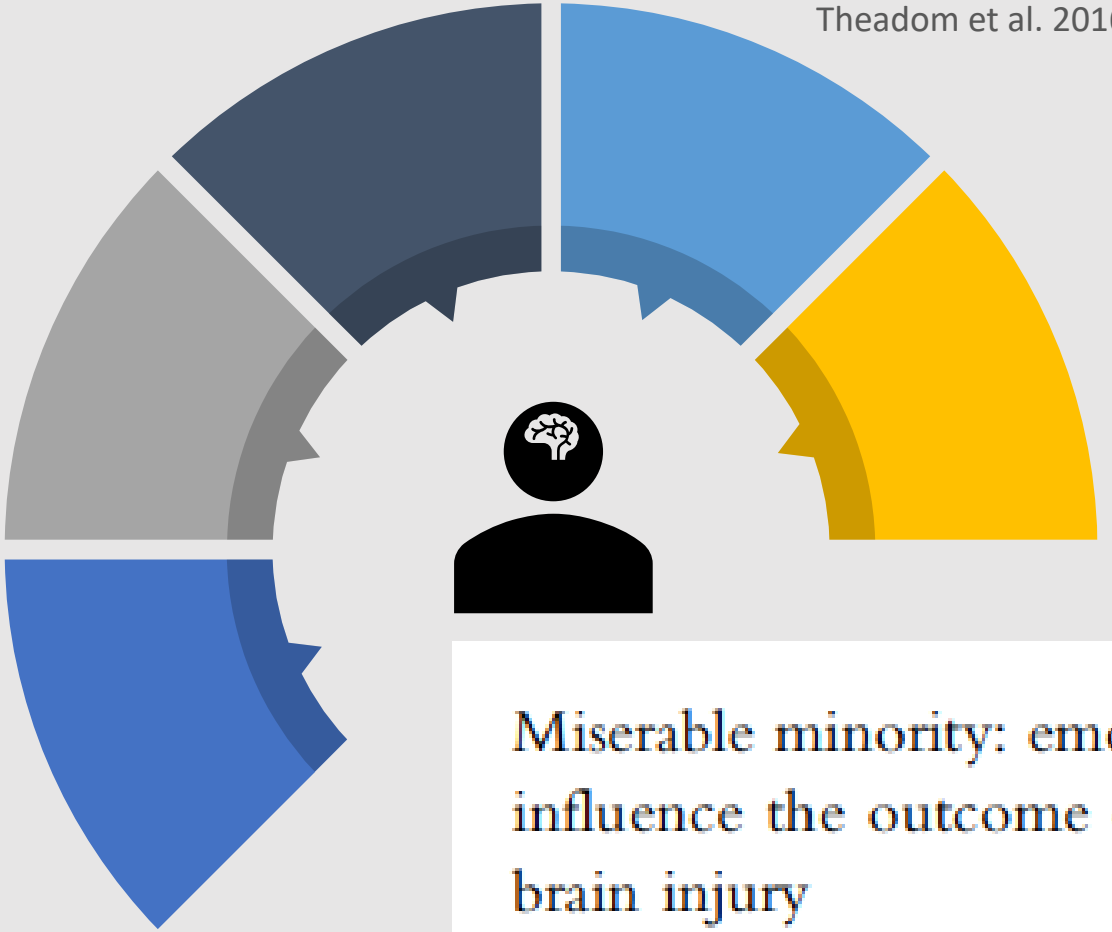
- We spend considerable resource on interventions focused on:
  - reducing impairment and improve function
  - developing compensatory strategies
  - changing patient beliefs and behaviour
- We seek to understand patient characteristics which predict rehabilitation outcomes and help us understand behaviour
- When things are not going well, we label them as unmotivated, not ready, non-compliant or difficult

Post-traumatic stress

Lange et al. 2013: McCauley et al. 2010

History of brain injury

Theadom et al. 2016



Co-morbid depression and anxiety

Lange et al. 2013; Hou et al. 2012; McCauley et al. 2010; Dischinger et al. 2009

Illness perceptions

Hou et al. 2012; Snell et all. 2011; Whittaker et al. 2007

Pre-injury psychological difficulties

Ruff et al. 2019; Kashluba et al. 2008.

Miserable minority: emotional risk factors that influence the outcome of a mild traumatic brain injury

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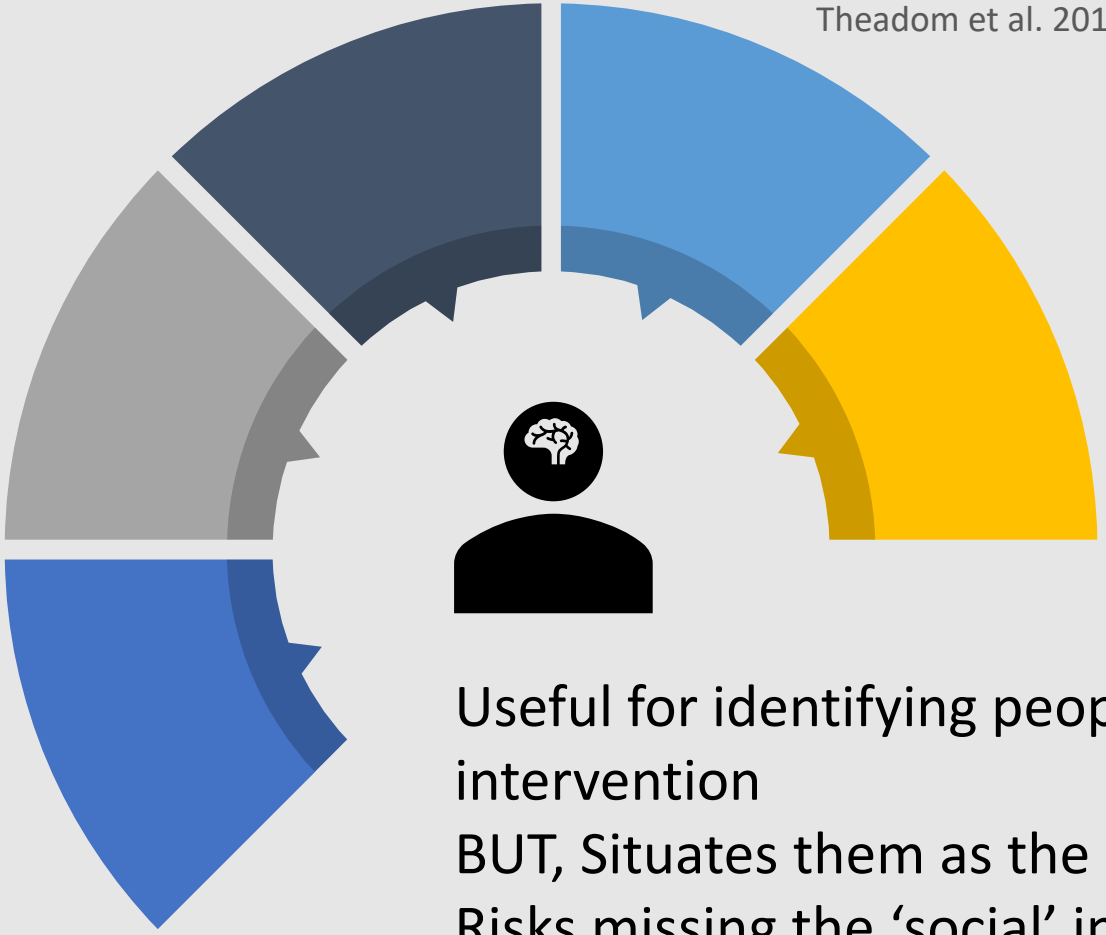

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Pre-injury psychological difficulties

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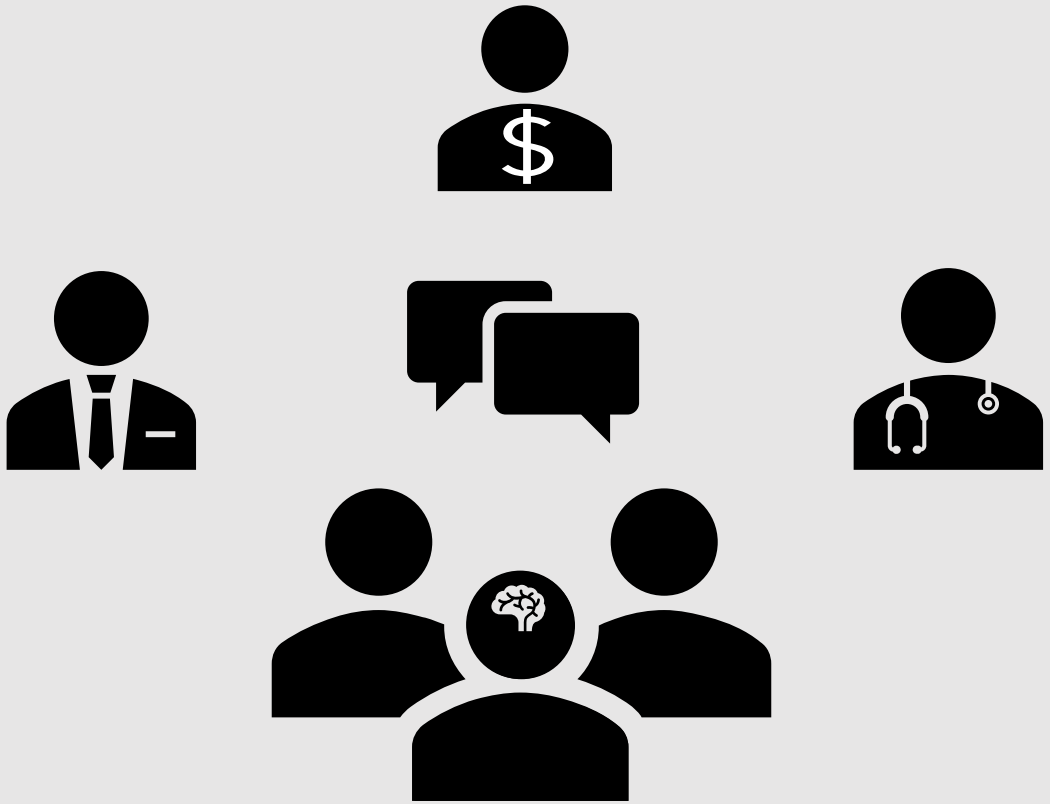
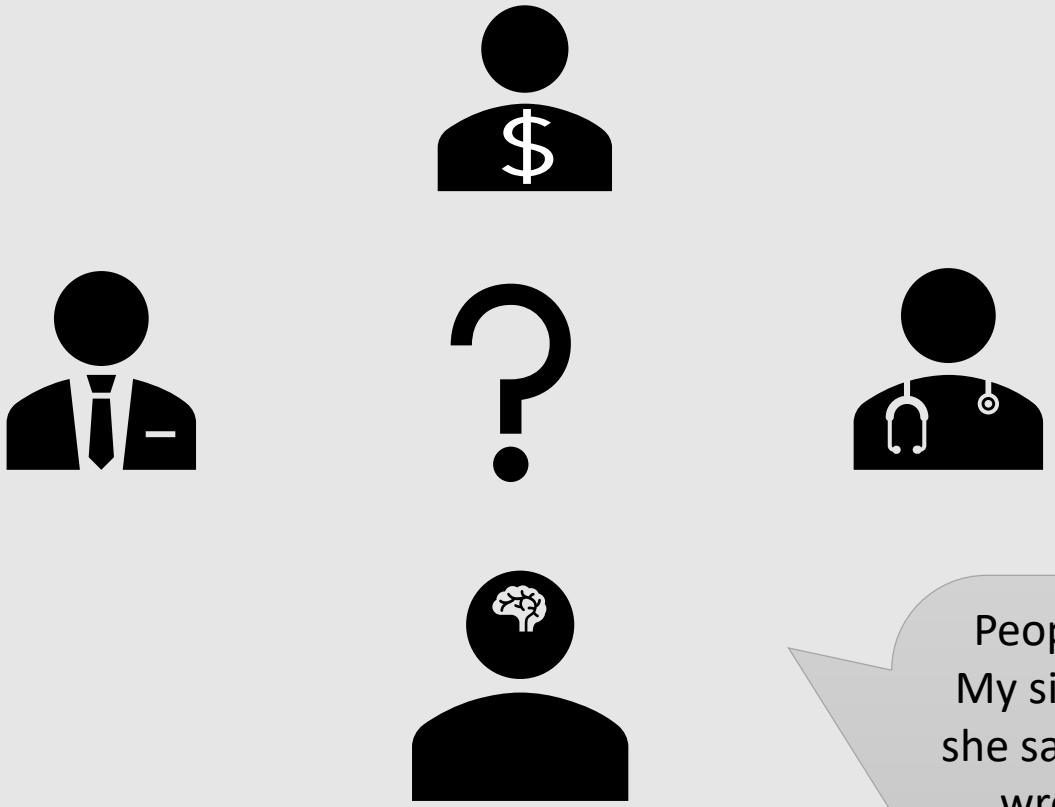
Useful for identifying people at risk for targeted intervention

BUT, Situates them as the exception to the rule

Risks missing the ‘social’ in psycho**social**

Attributes the ‘problem’ to the individual, w/o critical reflection on the broader context





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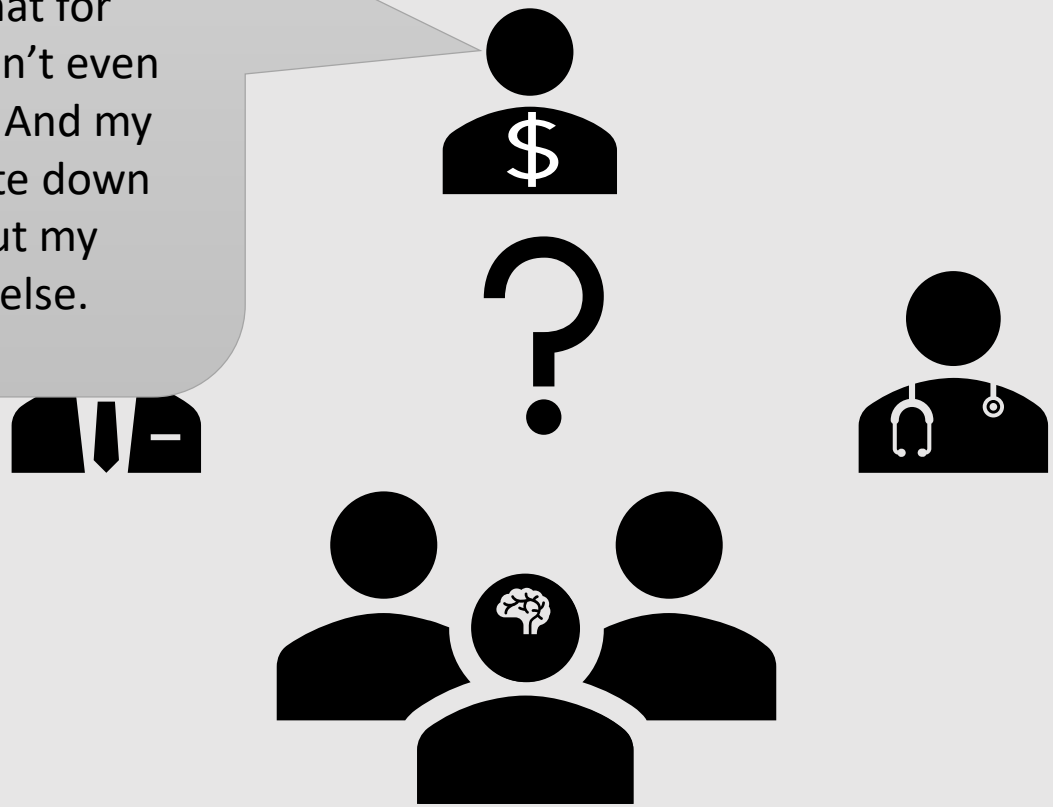
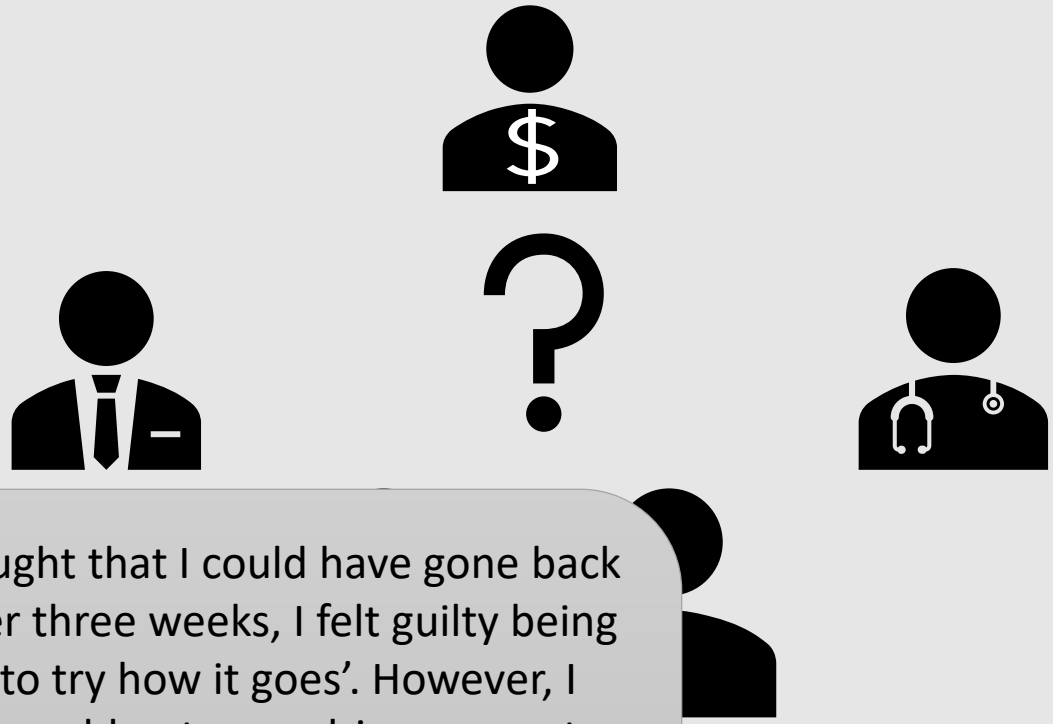
(McPherson et al., 2018)

I don’t think doctors and just everybody [usually] understand how you feel and what kind of things you’ve gone through with head injuries. It really messes with you and just changes everything [. . .] they don’t believe you when you tell them that, they think they know better, … you can tell they just don’t really think what you’re saying is right. (McPherson et al., 2018)

My wife went through hell too because like I was in no condition to keep track of every damn thing and I had to do that for Workers' Comp . . .My head wasn't even working that good at that time. And my wife, she was just having to write down every date and plus parcel out my medications and everything else.
(Mansfield et al., 2015)





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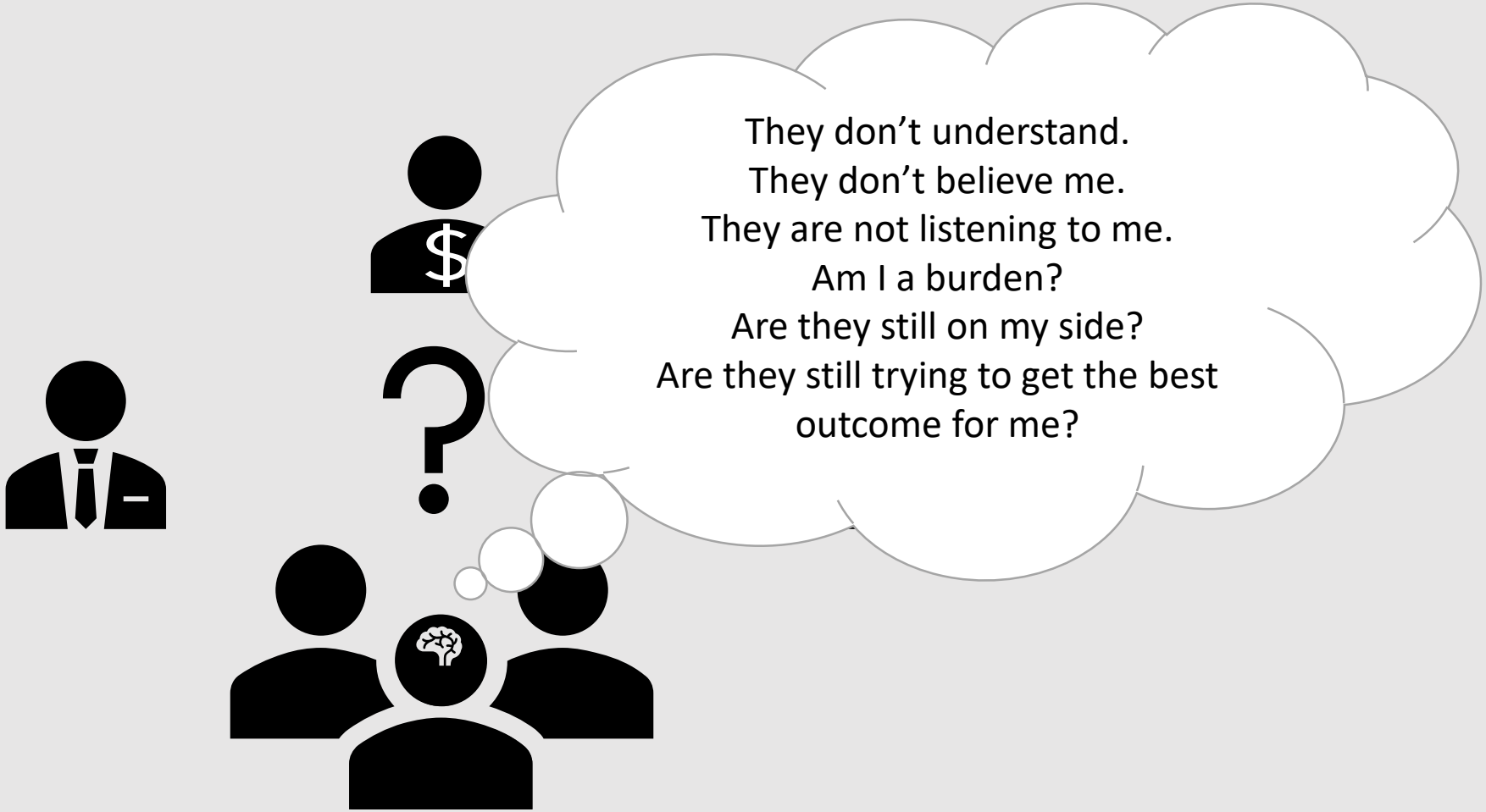
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Are they still on my side?
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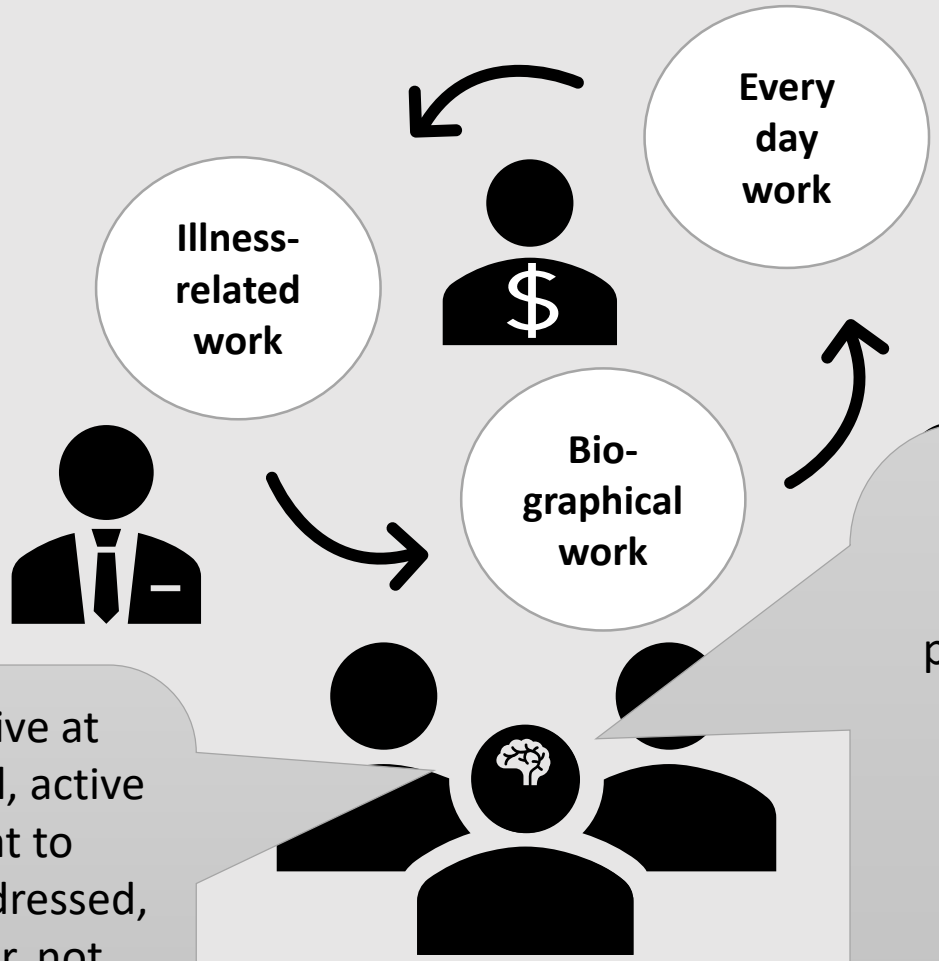

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To ‘keep many balls in the air simultaneously’ is a problem. This reflects [not only] on my study performance but also on how I organise everyday life with all that is going on. Remembering things for my children, remembering appointments, remembering what they have to do at school and during leisure time. To organise everyday life, that is not my favourite activity these days.
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Corbin & Strauss, 1985

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Illness-related work

Every day work

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Bio-graphical work

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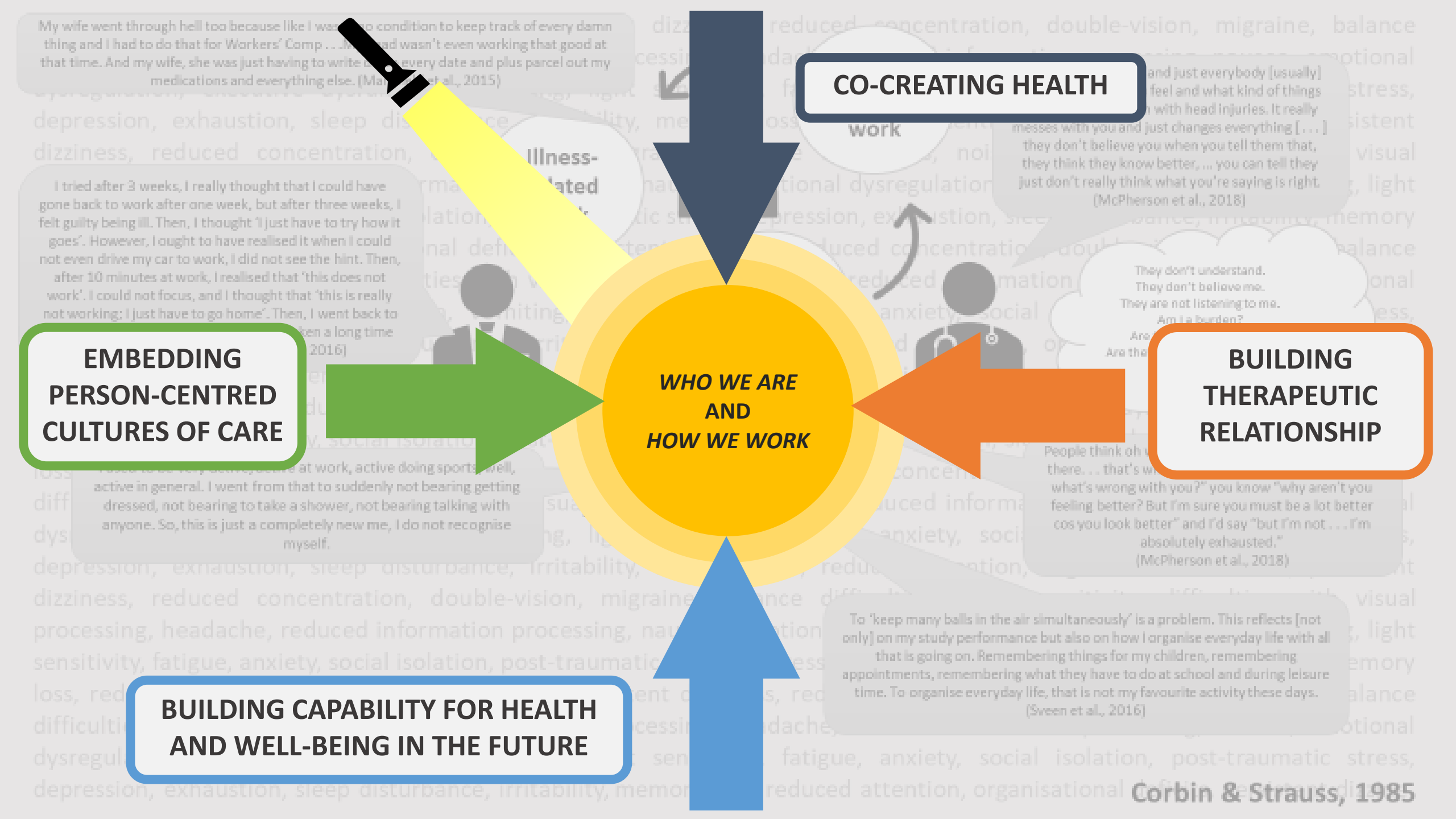
CO-CREATING HEALTH
EMBEDDING PERSON-CENTRED CULTURES OF CARE
BUILDING THERAPEUTIC RELATIONSHIP
BUILDING CAPABILITY FOR HEALTH AND WELL-BEING IN THE FUTURE
WHO WE ARE
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CO-CREATING HEALTH

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informa healthcare

REVIEW

A conceptual review of engagement in healthcare and rehabilitation

Felicity A. S. Bright[1], Nicola M. Kayes[1], Linda Worrall[2], and Kathryn M. McPherson[1]

[1]*Person Centred Research Centre, School of Rehabilitation and Occupation Studies, AUT University, Auckland, New Zealand and* [2]*Communication Disability Centre, CCRE-Aphasia and School of Health and Rehabilitation Sciences, The University of Queensland, Brisbane, Australia*

Abstract

Purpose: This review sought to develop an understanding of how engagement in healthcare has been conceptualized in the literature in order to inform future clinical practice and research in rehabilitation. A secondary purpose was to propose a working definition of engagement. *Methods*: EBSCO and SCOPUS databases and reference lists were searched for papers that sought to understand or describe the concept of engagement in healthcare or reported the development of a measure of engagement in healthcare. We drew on a Pragmatic Utility approach to concept analysis. *Results*: Thirty-one articles met the criteria and were included in the review. Engagement appeared to be conceptualized in two inter-connected ways: as a gradual process of connection between the healthcare provider and patient; and as an internal state, which may be accompanied by observable behaviors indicating engagement. *Conclusion*: Our review suggests engagement to be multi-dimensional, comprising both a co-constructed process and a patient state. While engagement is commonly considered a patient behavior, the review findings suggest clinicians play a pivotal role in patient engagement. This review challenges some understandings of engagement and how we work with patients and highlights conceptual limitations of some measures.

Keywords

Adherence, clinical practice, compliance, engagement, healthcare, participation

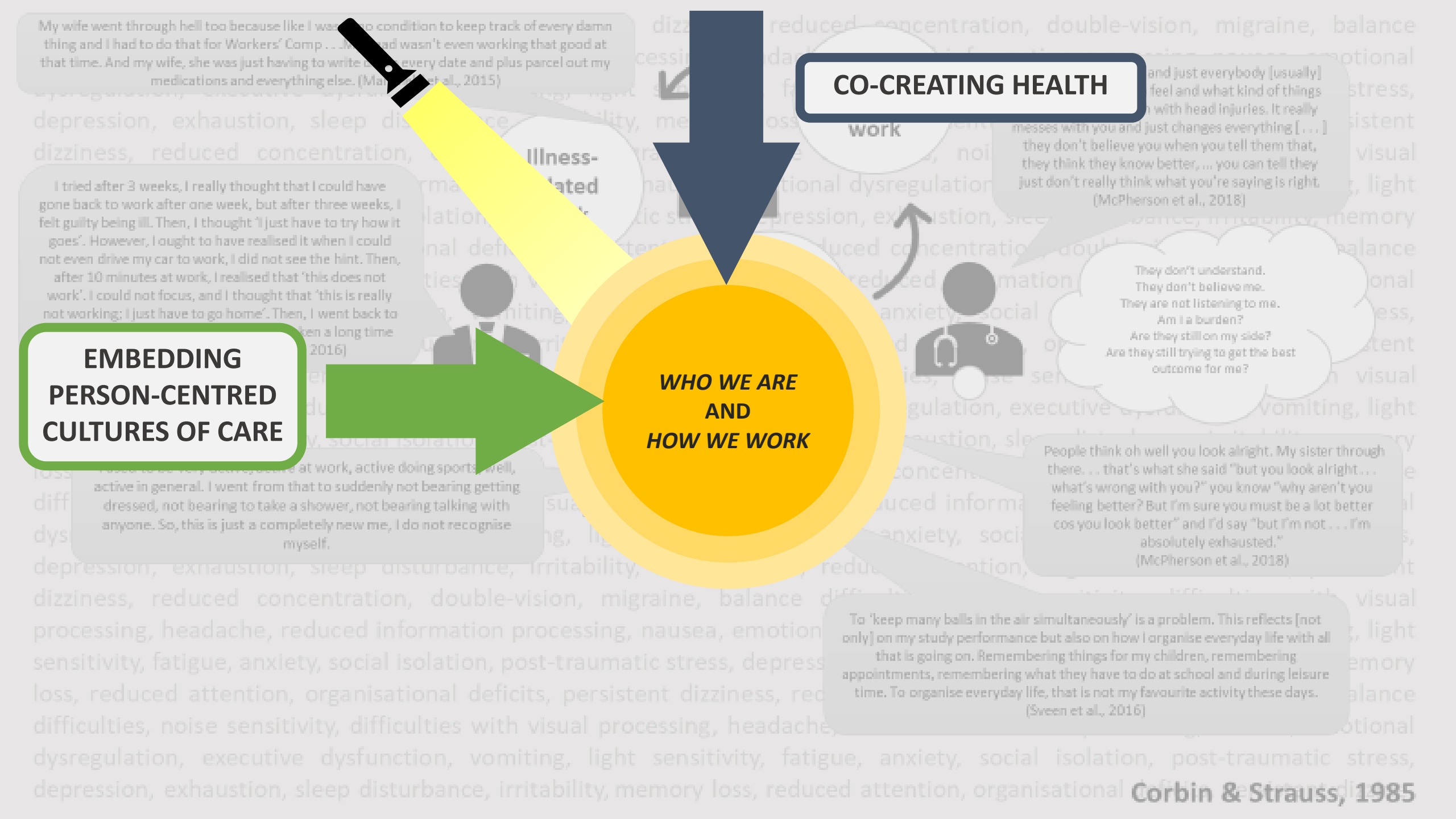
History

Received 14 November 2013
Revised 3 June 2014
Accepted 09 June 2014
Published online 27 June 2014

Engagement is a co-constructed process and state. It incorporates a process of gradually connecting with a person and/or therapeutic programme which enables the individual to reach and maintain a state of being an active, committed, invested collaborator in rehabilitation.

(Bright et al., 2014)

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 […] so I think it’s, the therapists’ attitude and skills that helped me through and persist.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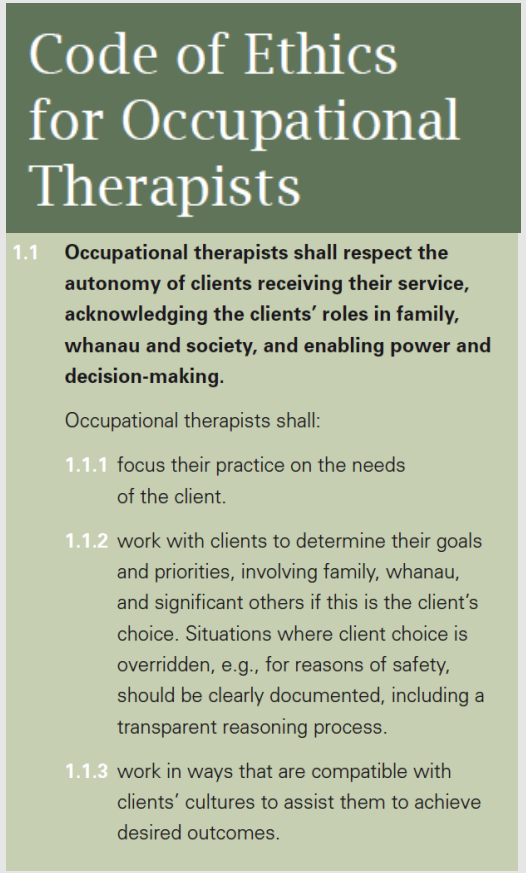
EMBEDDING PERSON-CENTRED CULTURES OF CARE

- Strong rhetoric of person-centredness in rehabilitation models of service delivery
- Extensive and growing body of research
- Professional commitment to person-centred models of practice



Code of Ethics for Occupational Therapists

1.1 **Occupational therapists shall respect the autonomy of clients receiving their service, acknowledging the clients' roles in family, whanau and society, and enabling power and decision-making.**

Occupational therapists shall:

1.1.1 focus their practice on the needs of the client.

1.1.2 work with clients to determine their goals and priorities, involving family, whanau, and significant others if this is the client's choice. Situations where client choice is overridden, e.g., for reasons of safety, should be clearly documented, including a transparent reasoning process.

1.1.3 work in ways that are compatible with clients' cultures to assist them to achieve desired outcomes.

But, where on the continuum of ‘patient-centred’ care are we?

LACK OF DEFINITIONAL AND OPERATIONAL CLARITY

UNDERESTIMATE THE COMPLEXITY

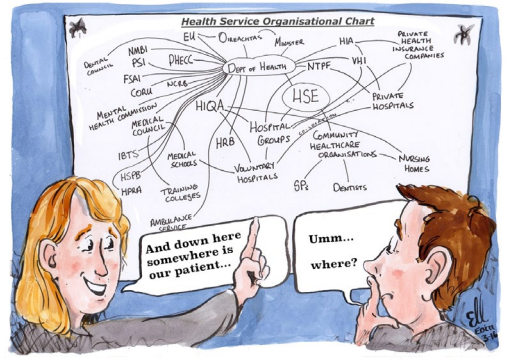
“It is enabled by cultures of empowerment that foster continuous approaches to practice development” (McCormack & McCance, 2017)

RHETORIC

≠

REALITY?

BIOMEDICAL MODEL PREVAILS



SYSTEMS AND PROCESSES INHERENTLY UNSUPPORTIVE

We are person-centred but….

IT IS IMPORTANT PEOPLE ARE REALISTIC
"She did have a lot of goals around her mobility which were really difficult though, for the physio to manage, because there weren't realistic things that she wanted to be doing."
(Occupational therapist)

WE WANT TO AVOID OPENING A CAN OF WORMS
"I was a bit concerned about how my client would actually respond for the simple reason that he had a lot of social things going on in his life, and I just wondered whether it un-earthed stuff…"
(Physiotherapist)

WE HAVE A JOB TO DO
"Some of the questions are very sensitive, so at times you are like 'I don't know if this is actually the right time for me to ask this?' But, that's… you know, how we do our first visit."
(Speech and Language therapist)

WE MAKE ASSUMPTIONS
"He has got a lot going on in his head sort of brain injury wise […] he's not going to want a bar of this." (Physiotherapist)

But, it’s complex!

- What person-centredness looks like as a way of working can vary from person to person
- A need to move away from fixed assumptions about what person-centred practice is

“[The ‘right’ client is] basically someone who is cognitively intact, has very good judgement, probably already has some pretty good insight into how they’re functioning within their environment. I guess along with that is some-one who has pretty good problem-solving skills already.”

Wilkins et al. (2001), p.77

But, it’s complex!

- What person-centredness looks like as a way of working can vary from person to person
- A need to move away from fixed assumptions about what person-centred practice is
- To
  - a more reflexive, nuanced way of working informed by the question *how do they need me to work?* (Bright, 2015)
  - flexible, responsive services that can *meet people where they are at?*

How do the voices of our participants inform us about person-centred care?

- Eligible projects explored perspectives and experiences of ways of working in rehabilitation
- 12 projects met criteria => 3 projects purposefully selected
- Data included:
  - 40 interviews and 3 focus groups with clients, carers, or family members
  - 2 interviews and 6 focus groups with practitioners

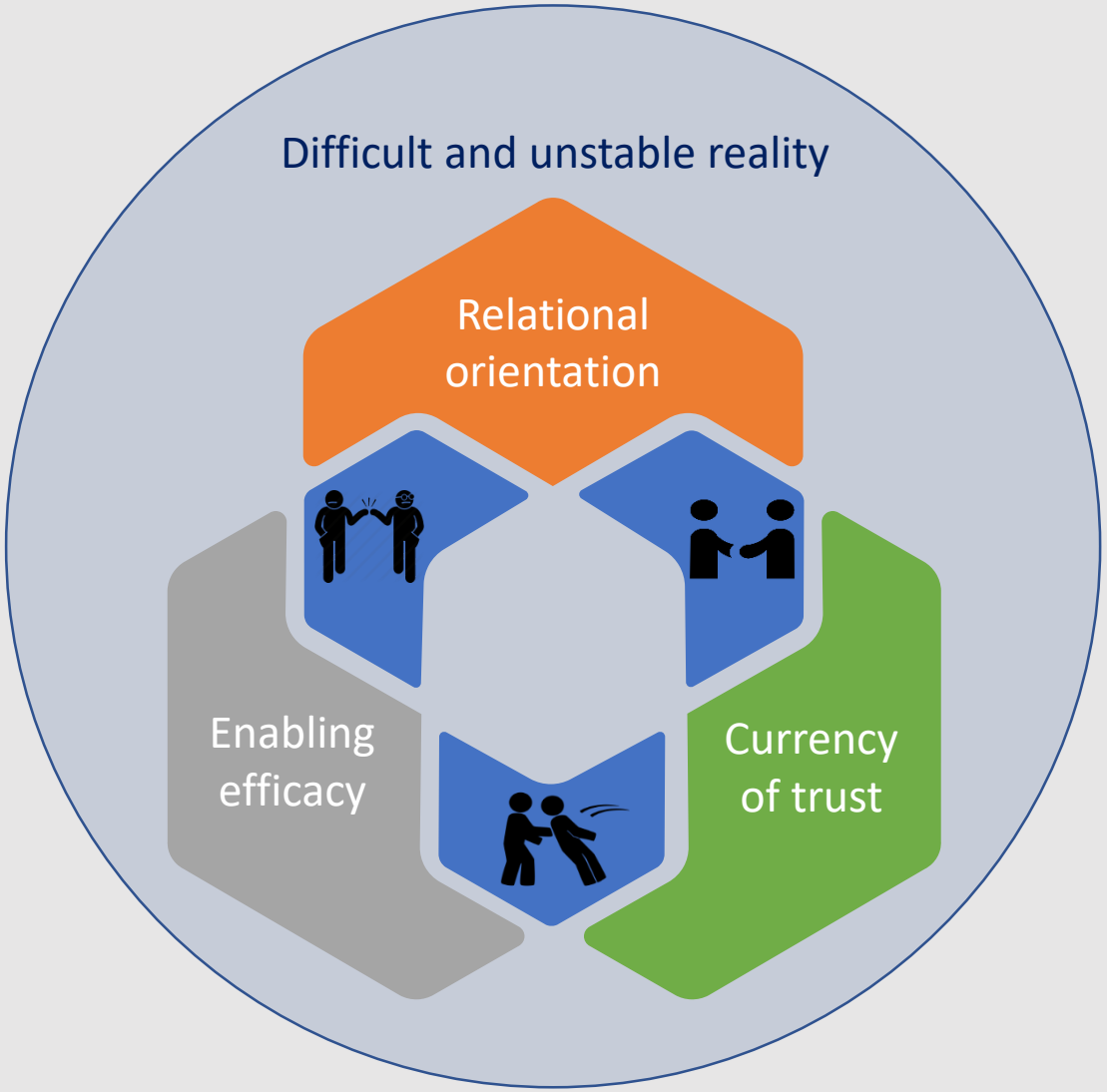
Person centered care in neurorehabilitation: a secondary analysis

Gareth Terry and Nicola Kayes

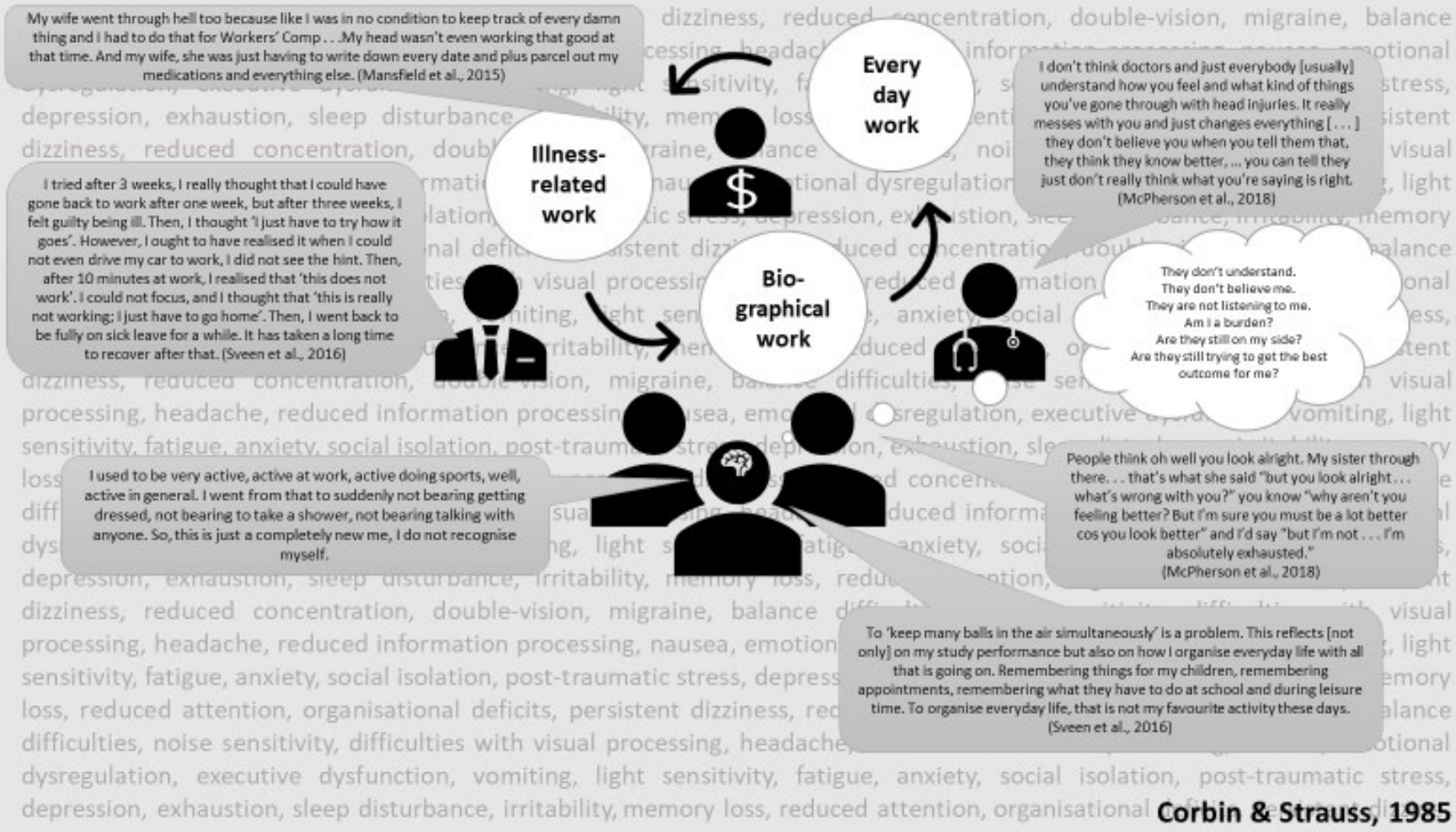
Centre for Person Centred Research, Auckland University of Technology, Auckland, New Zealand

ABSTRACT

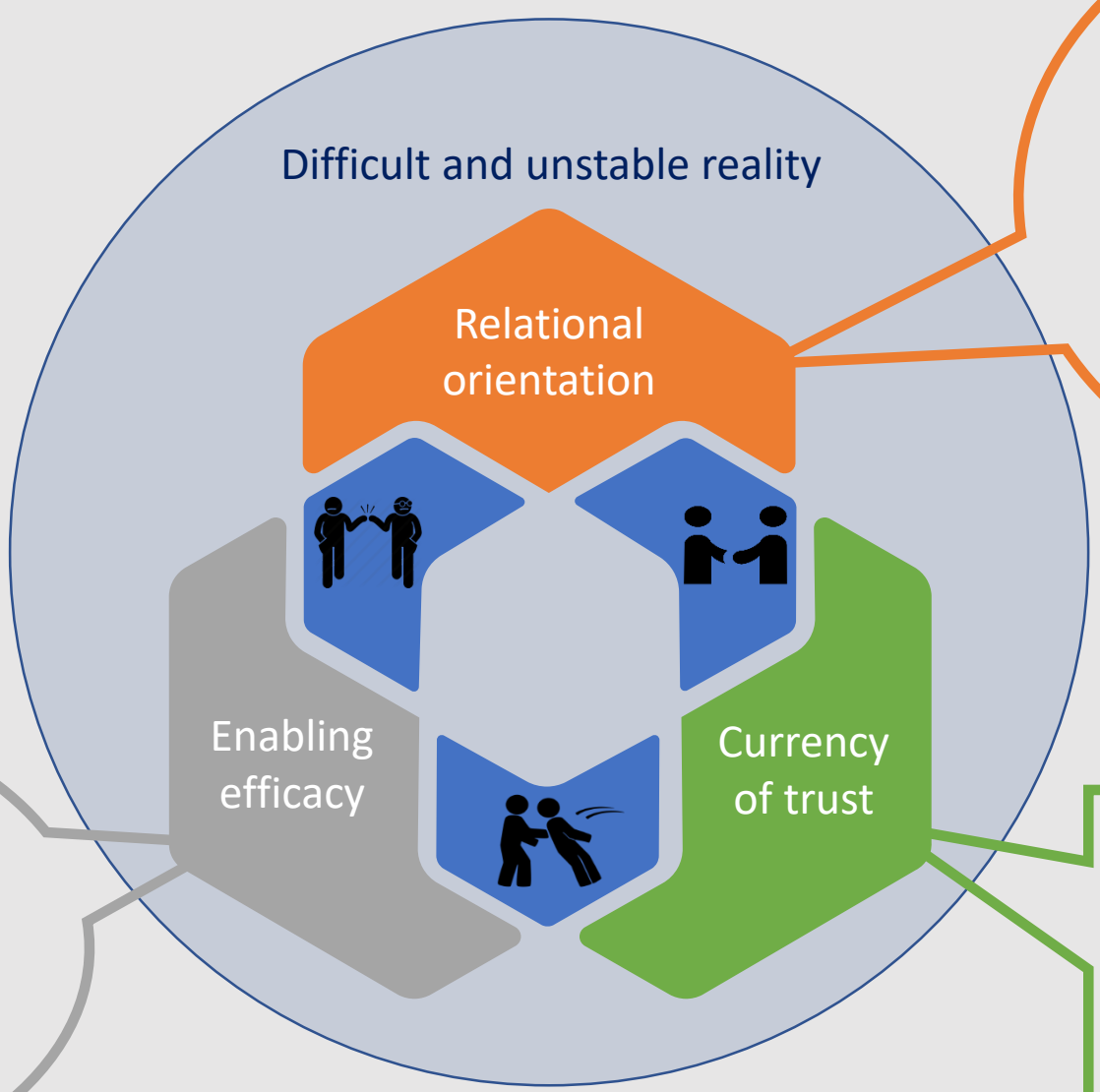
Person centered care has been described as being in its ascendency, despite some of the complexities of embedding it within healthcare systems. The emphasis of research now seems to be moving toward the promotion of cultures of care that support the efforts of practitioners. Informed by some of the principles 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.


Difficult and unstable reality
Relational orientation
Enabling efficacy
Currency of trust

A difficult and unstable reality



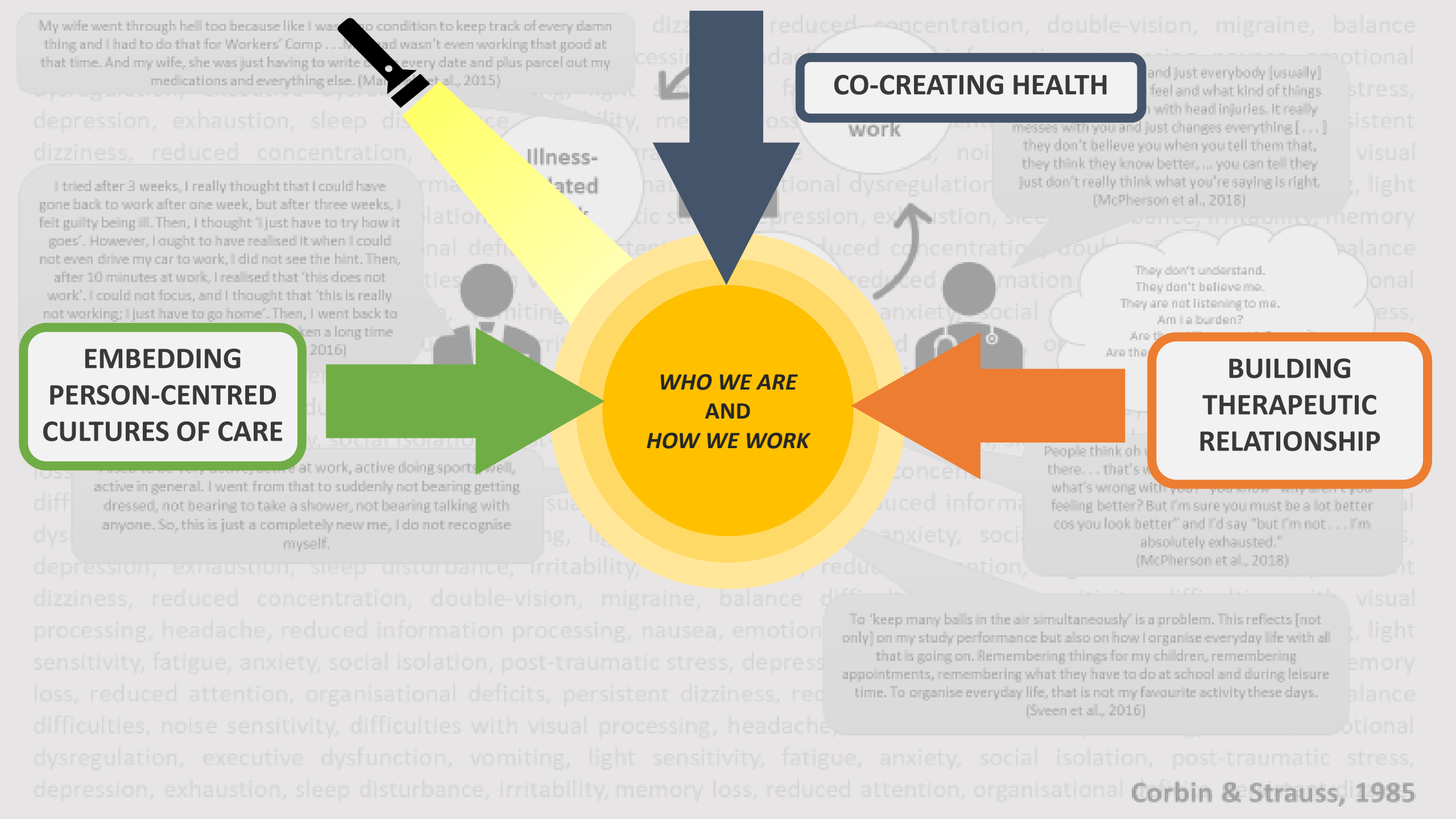
Corbin & Strauss, 1985



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

You get the feeling you can do the things she teaches you, and she tends to make you believe in yourself a lot more than you normally would.

I think you've got to trust that they know what they're doing, that they care about what they are doing, that they are going to do it to the best of their ability, and that they've got your best interests at heart.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feeling better? But I'm sure you must be a lot better cos you look better" and I'd say "but I'm not . . . I'm absolutely exhausted."
(McPherson et al., 2018)
To 'keep many balls in the air simultaneously' is a problem. This reflects [not only] on my study performance but also on how I organise everyday life with all that is going on. Remembering things for my children, remembering appointments, remembering what they have to do at school and during leisure time. To organise everyday life, that is not my favourite activity these days. (Sveen et al., 2016)
Corbin & Strauss, 1985

Not just a nice to have…

PERSPECTIVES IN REHABILITATION

A scoping review of the working alliance in acquired brain inju

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ABSTRACT

Purpose: The aim was to review the empirical literature to determine the nature and breadth of
into the working alliance in acquired brain injury (ABI) rehabilitation.

Methods: A scoping review was conducted, beginning with a systematic search of relevant da
using key search terms. Studies with a focus on the role of the working alliance in shaping rehab
outcomes, and factors influencing perceptions of the working alliance were included and key info
extracted.

Results: A total of 10 quantitative studies met inclusion criteria. In most studies, ratings of the
alliance were compared with other process variables or outcome measures. The working allia
linked to positive activity and participation outcomes, including return to work, school, and drivin
related factors such as age, level of education and approach to rehabilitation tasks were associat
client and therapist perceptions of the working alliance.

Conclusions: The working alliance emerged as a complex process that interacts with many fact
processes at play in the rehabilitation environment. Notwithstanding the limitations of the resear
findings indicate that enhancement of the working alliance may indeed influence rehabilitation ou
Allowing time for the development of the working alliance, and consideration of factors such as t
skill, may support therapists to strengthen their alliances in ABI rehabilitation.

The Influence of the Therapist-Patient Relationship on Treatment Outcome in Physical Rehabilitation: A Systematic Review

Amanda M. Hall, Paulo H. Ferreira, Christopher G. Maher, Jane Latimer, Manuela L. Ferreira

Background. The working alliance, or collaborative bond, between client and psychotherapist has been found to be related to outcome in psychotherapy.

Purpose. The purpose of this study was to investigate whether the working alliance is related to outcome in physical rehabilitation settings.

Data Sources. A sensitive search of 6 databases identified a total of 1,600 titles.

Study Selection. Prospective studies of patients undergoing physical rehabilitation were selected for this systematic review.

Data Extraction. For each included study, descriptive data regarding participants, interventions, and measures of alliance and outcome—as well as correlation data for alliance and outcomes—were extracted.

Data Synthesis. Thirteen studies including patients with brain injury, musculoskeletal conditions, cardiac conditions, or multiple pathologies were retrieved. Various outcomes were measured, including pain, disability, quality of life, depression, adherence, and satisfaction with treatment. The alliance was most commonly measured with the Working Alliance Inventory, which was rated by both patient and therapist during the third or fourth treatment session. The results indicate that the alliance is positively associated with: (1) treatment adherence in patients with brain injury and patients with multiple pathologies seeking physical therapy, (2) depressive symptoms in patients with cardiac conditions and those with brain injury, (3) treatment satisfaction in patients with musculoskeletal conditions, and (4) physical function in geriatric patients and those with chronic low back pain.

Limitations. Among homogenous studies, there were insufficient reported data to allow pooling of results.

Conclusions. From this review, the alliance between therapist and patient appears to have a positive effect on treatment outcome in physical rehabilitation settings; however, more research is needed to determine the strength of this association.

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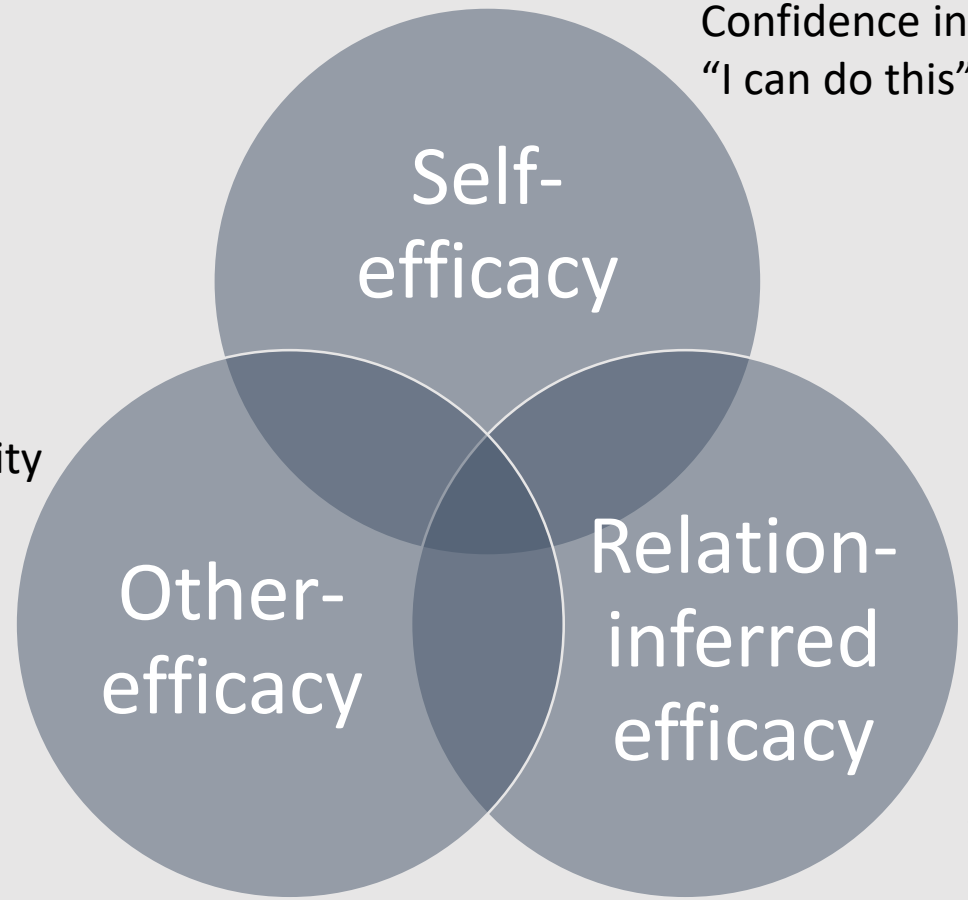
[Hall AM, Ferreira PH, Maher CG, et al. The influence of the therapist-patient relationship on treatment outcome in physical rehabilitation: a systematic review. *Phys Ther.* 2010;90:1099–1110.]

You get the feeling you can do the things she teaches you, and she tends to make you believe in yourself a lot more than you normally would

Kayes, Cummins, Theadom, McPherson

A tripartite efficacy perspective?

Confidence in ones own ability
"I can do this"



Confidence in therapists ability
"I have a great therapist"

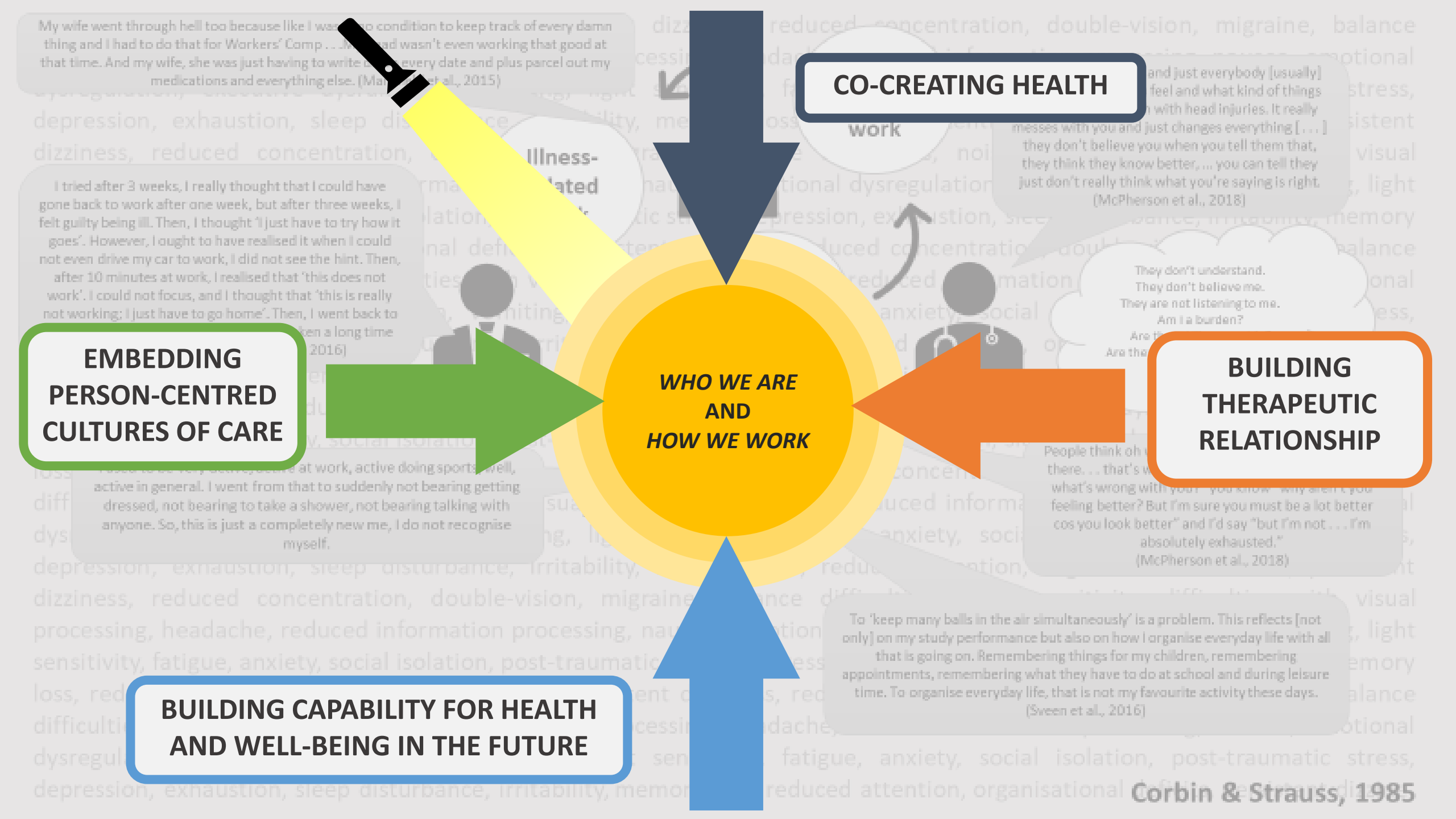
Appraisal re: how confident the therapist is in their ability
"I think my therapist really believes in me"

Lent & Lopez (2002); Jackson et al. (2012)

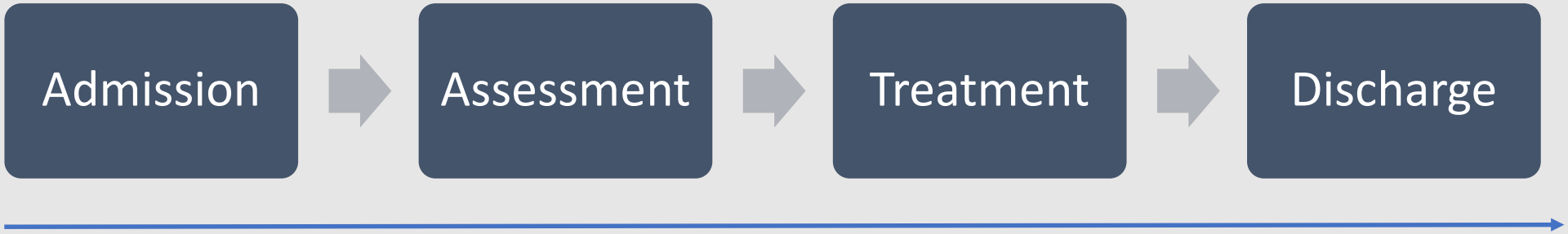
For whānau Māori, whānau is fundamental. You can't push that away […]. Whānau, or whakapapa, is really fundamental. We're groupies, historically we work as groupies… whereas from a te ao pakeha… they are quite individual in their approach to things. But we are groupies, we work together, we work collectively […]. When I look at you, I don't just see you […] because you don't walk alone […] When I go in to whānau , I am looking at you and I'm looking at your whakapapa. So, the best way to start a conversation with Māori is… let's talk about your whānau […] Ko wai au? Who am I? How do I identify me? Identify me through the lens of culture and language… whakapapa.

[…] fundamentally… it's the wairua, the connection.

Wilson, Kayes, Cummins, Bright, Elder


CO-CREATING HEALTH
EMBEDDING PERSON-CENTRED CULTURES OF CARE
BUILDING THERAPEUTIC RELATIONSHIP
BUILDING CAPABILITY FOR HEALTH AND WELL-BEING IN THE FUTURE
WHO WE ARE
AND
HOW WE WORK
Corbin & Strauss, 1985

Where we focus our energy…



Impairment
Function

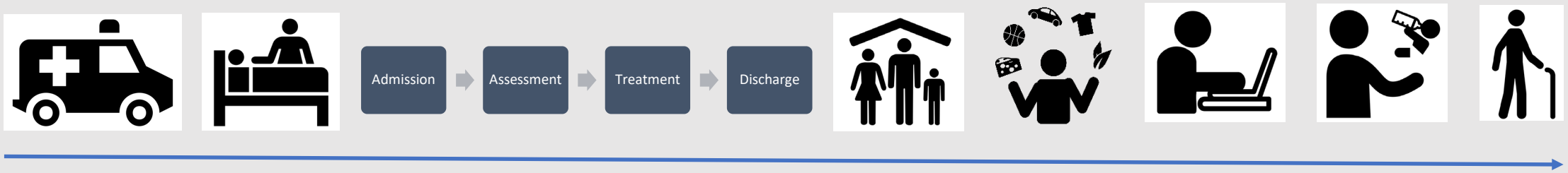
Primary outcome of interest:
Return to work

KPIs:
Days off work
Weekly compensation

Leads to….

- Time-limited goals and outcomes
  - Often disciplinary-specific and service-centred
- Dominant focus on specific impairment and function
  - Lack of value ascribed to developing skills and capability for the future
- Limited opportunity to address complexity
- Conditional person-centredness

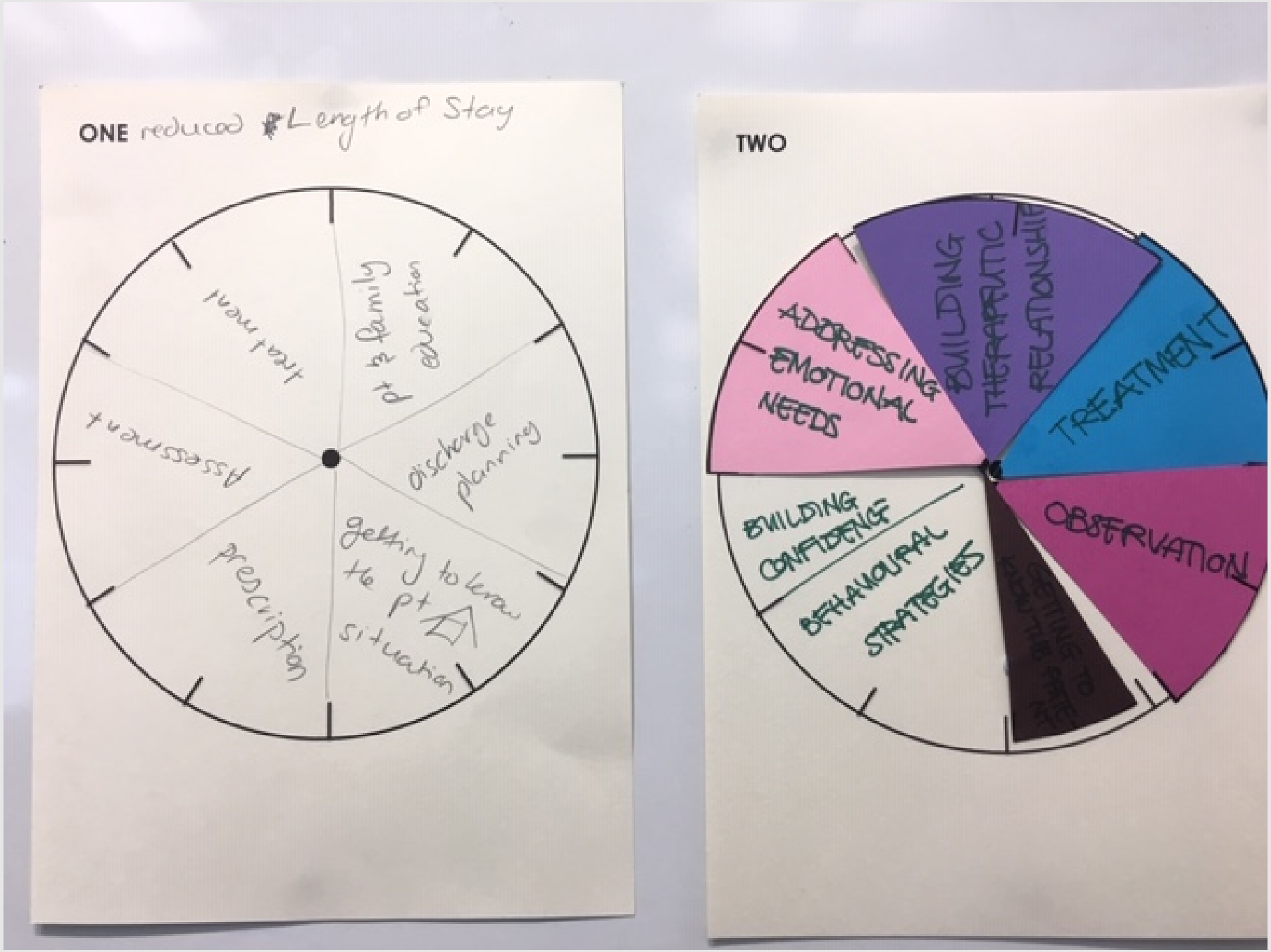
For the individual…



?

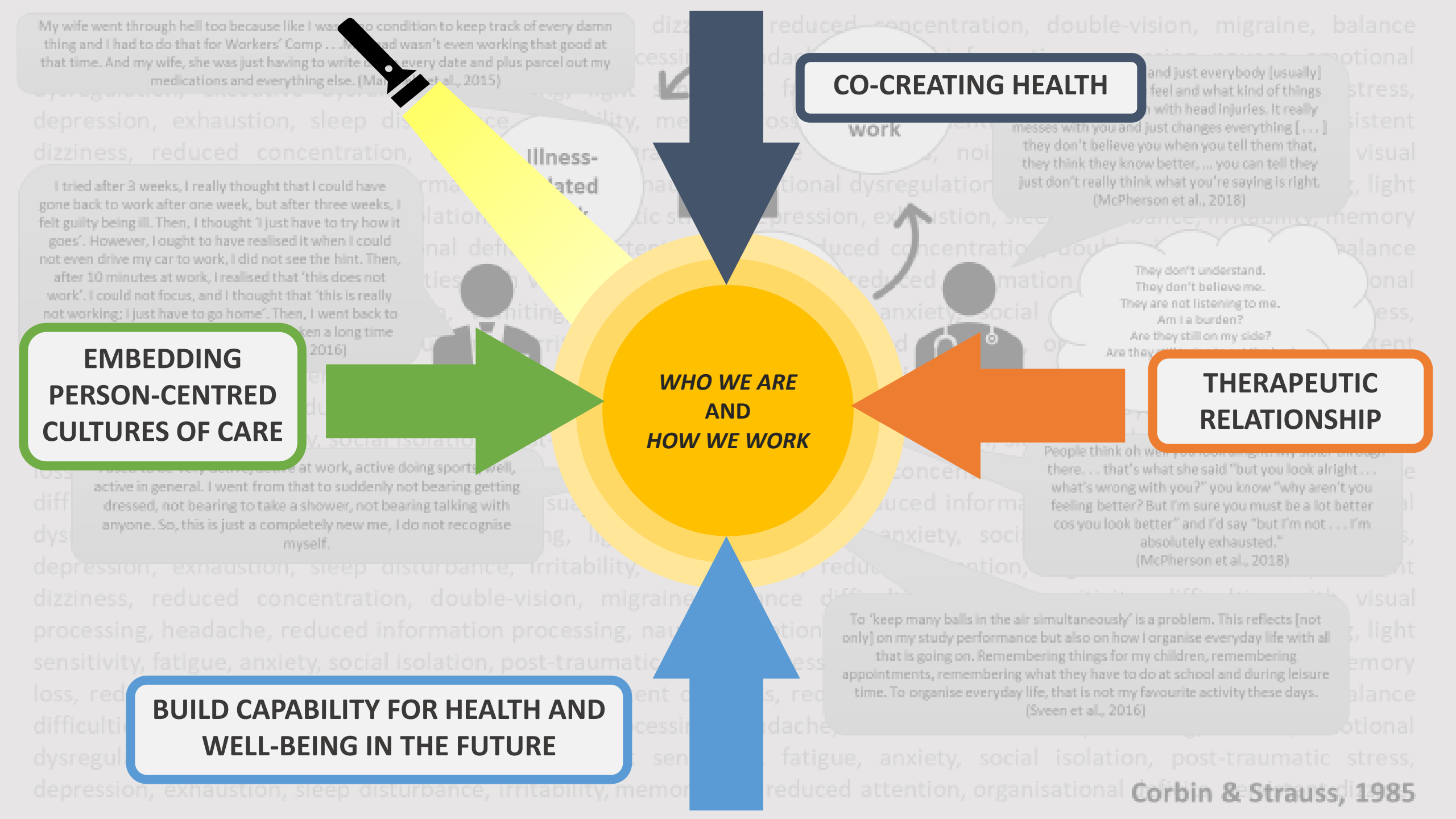
Primary outcome of interest:
Long term health and well-being

KPIs:
Living a healthful and meaningful life


ONE reduced Length of Stay
pt & family education
discharge planning
getting to know the pt situation
treatment
assessment
prescription
TWO
ADDRESSING EMOTIONAL NEEDS
BUILDING THERAPEUTIC RELATIONSHIP
TREATMENT
OBSERVATION
BUILDING CONFIDENCE
BEHAVIOURAL STRATEGIES

Again, it’s complex!

- A more fundamental shift in service delivery may be necessary to support long term health and well-being:
  - Shift focus from *managing the condition well* to *managing well with the condition*
  - Optimise what happens at the point of care to build skills and capability to manage health and well-being into the future


CO-CREATING HEALTH
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WHO WE ARE
AND
HOW WE WORK
Corbin & Strauss, 1985

While *what* we do is important, aspects of *who* we are, and *how* we work with our clients may be crucial

PERSPECTIVES IN REHABILTATION

Human technologies in rehabilitation: 'Who' and 'How' we are with our clients

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Purpose: It is often observed that different rehabilitation practitioners carrying out the same intervention can have a quite different impact on outcome. The relationship or connection between the practitioner and patient, referred to here as the therapeutic alliance (TA), is receiving growing attention as potentially contributing to the disparate response to treatment observed. In this paper, we discuss what we currently know about the TA in rehabilitation and its impact on engagement (and what do we not know) and consider the ramifications of not knowing. *Key Messages*: The TA is increasingly identified as an important determinant of engagement in, and health outcome following, rehabilitation. However, research identifying its core components is limited, with very little exploring *how* practitioners might develop a more positive TA with patients. Further, what we do know/understand is limited by inadequate measurement tools. Research aiming to better understand the key ingredients of the TA that contribute to outcome and its role in rehabilitation is urgently required. *Conclusions*: Arguably, if we fail to advance knowledge in this field and seek answers to some of the questions we have raised, we may fail to tap into the true potential of the TA as a covariate of rehabilitation outcome.

Keywords: Connection, collaboration, partnership, therapeutic relationship, therapeutic alliance

Introduction

All too often, what is found to be efficacious in research fails to translate to an effective strategy in real world rehabilitation practice [1–3]. It has also been observed that different practitioners carrying out the *same* intervention can have a quite *different* impact on patient perceptions of the quality of care [4,5], and indeed outcomes [6,7]. These findings highlight that while *what* we do is important, aspects of *who* we are, and *how* we work with our clients may be crucial.

Implications for Rehabilitation

- While *what* we do is important, aspects of *who* we are, and *how* we work with our clients may be crucial.
- Aspects of the therapeutic alliance (TA) have been linked to perceptions of quality care, treatment adherence, patient satisfaction, and improvements in a range of outcomes.
- Further research developing a sound conceptual framework of TA specific to rehabilitation, a robust measure of TA in rehabilitation, and further exploration of the role of TA in rehabilitation is urgently required.

The therapeutic alliance (TA) has long been considered a key contributor to treatment effect in psychotherapy and other related fields such as counselling. In his paper in 1979, Bordin proposed "*that the working alliance between the person who seeks change and the one who offers to be a change agent is one of the keys, if not the key, to the change process*" (p. 252 [8]). Research in these fields has consistently found the TA to be related to outcome [9–12]. In their 2001 review of more than 100 papers, Lambert and Barley found that factors associated with the therapist-client relationship accounted for a greater proportion of variance in outcome than any other therapy factors (such as the therapeutic technique itself and client expectancy effects [12]).

The notion that *who* we are and *how* we work with clients may be an active ingredient in the rehabilitation context is not a novel idea. In 1994, Stenmar and Nordholm explored physiotherapist perceptions of factors associated with treatment success and found that the majority perceived the therapeutic relationship and patient resources to be more important than the treatment itself [13]. Dahlgreen et al. [14] interviewed a group of physiotherapists regarding their

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