

Health My Way: A person/family centred rethink of effective self-care Results of a Qualitative Research Study

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... a rethink of effective self care

- People make decisions that affect their health - self care is the reality
 - *'The question is not whether patients with chronic conditions manage their illness, but how they manage.'*
- Paradigm shifts; 'compliance', 'adherence', 'patient self care'... what would a truly person centred approach be like?
- A 'citizen' research project – through their eyes, their world
- **Implications – five claims:**
 1. Increase the number of people with effective self care by leveraging impact at critical change points
 2. Improve the impact of self care on health outcomes by supporting balanced, relevant, whole person learning - 'to live well with disease'
 3. Extend the influence of self care through mobilising family/whanau resources to support complex behavioural/life style changes
 4. Increase the resiliency of self care, maintenance of good practices over long enough durations to have cumulative effects, reduction of crisis events
 5. Reduce inequalities in self care, with support that works for the vulnerable and disadvantaged

The research approach

- Commissioned by the Ministry of Health as part of Key Directions for the Primary Health Information Environment
- Literature review
- Primary health team focus groups
- Patient life journey mapping
- Recruitment via 3 primary health practices
 - South Auckland, West Auckland, Rotorua.
- 9 focus groups across 3 stages of chronic disease progression
- Stratified by NZ European, Maori and Pacific
- 12 in-depth interviews: people with diverse range of conditions



Luisa's story...

"What happened? I call him the boy whose pants fell down. He lost 6 kgs in a week...he had a seizure on the way to school, he was semi conscious and cold, 32degrees. We went immediately to Starship. They were amazing..."

It dawned on me at Starship, the enormity of what had happened, and now at home, I've got the responsibility. I am it. I manage my son. I lost a lot of weight. I had to rewrite our family's relationship with food..."

I didn't cry. I didn't feel grief...but I tried to find out why. I desperately wanted to know why. And no one could tell me. So you can't blame anyone, you cant get angry. You can drive yourself nuts about why you've got it.

Our life fundamentally changed. It is enormous, but manageable...we can only manage it. We talk about it..."

He's had angry times. He woke up yesterday and said I don't want to do it today. I just walked out and left him alone for a bit and gave him an alternative time later..."

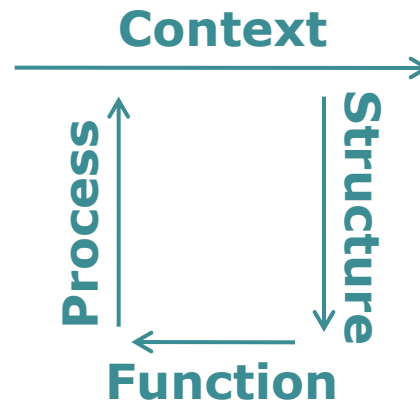
There's no holiday from it. There are no Sundays. There is no downtime. The regime doesn't allow it."

Female, European, Mother of 8 year old Type 1
Diabetes

Making sense of self care

Ever changing context of self care
within long term conditions

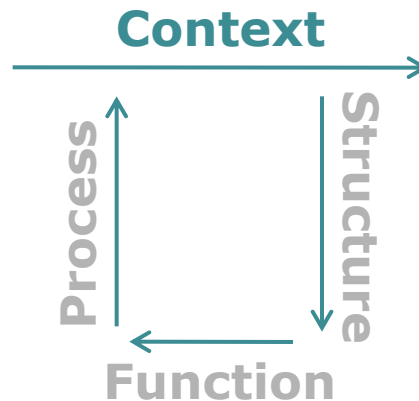
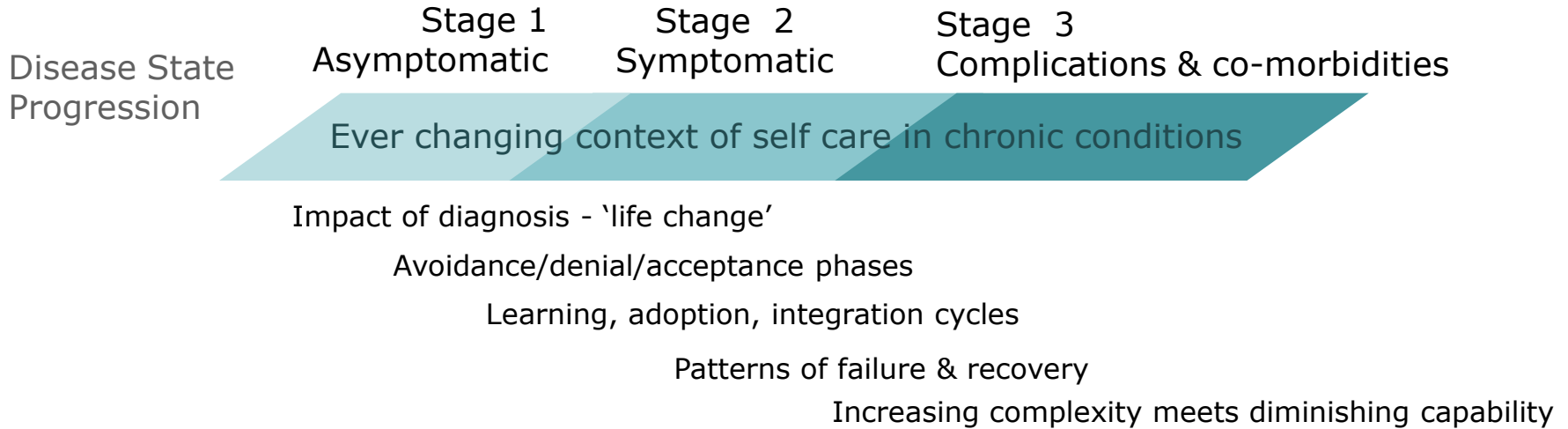
How does it work,
what are the
processes of self
care?



Structures of self
within self care – who
is doing it?

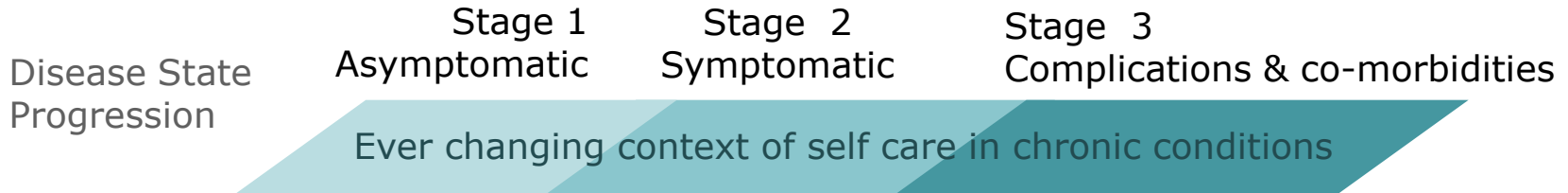
Functions, what does
self care do?

Making sense of self care





Making sense of self care



Impact of diagnosis - 'life change'

Avoidance/denial/acceptance phases

Learning, adoption, integration cycles

But... of failure & recovery

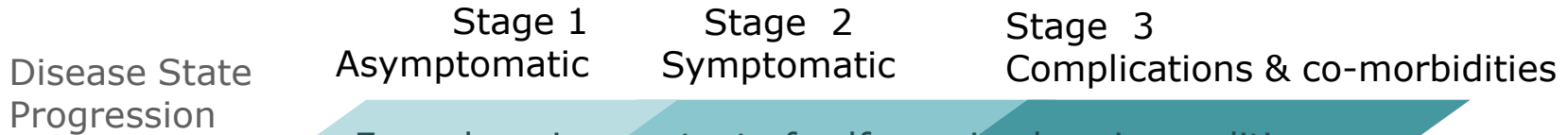
Complexity meets diminishing capability

"That's ok but hey doc will it kill me? Will it kill me this disease that you say I have? And what will happen next? Am I going to be in bed for the rest of my life? All these questions, the things that are never ever asked, and then he says 'pills'. How long am I going to be on those pills for? All this coming on. Scary. I think that was another thing too was the biggest thing was fear. You know am I going to drop dead tomorrow or whatever?"

Maori Female 45+years Stage 2 Diabetes



Making sense of self care



Impact of diagnosis - 'life change'

Avoidance of self care

"I think to be honest – success is being able to get through day positively. I think just learning to deal with everything that crops up – like if you don't have good nights sleep and you're tired – then coping with that day. I suffer from depression, and you know you can have good days and bad days, but it's just actually coping with all those things and actually enjoying life.

Some days can be pretty hairy but you learn to cope with it and you say 'well ok I could be a lot worse off' you know. And start looking around – like we've got some lovely trees out with the Kowhais and the Tui's come and it's just so nice. You can sit on the deck in the sun and you kind of look at all these things and think how blessed we are. And that's really cool."

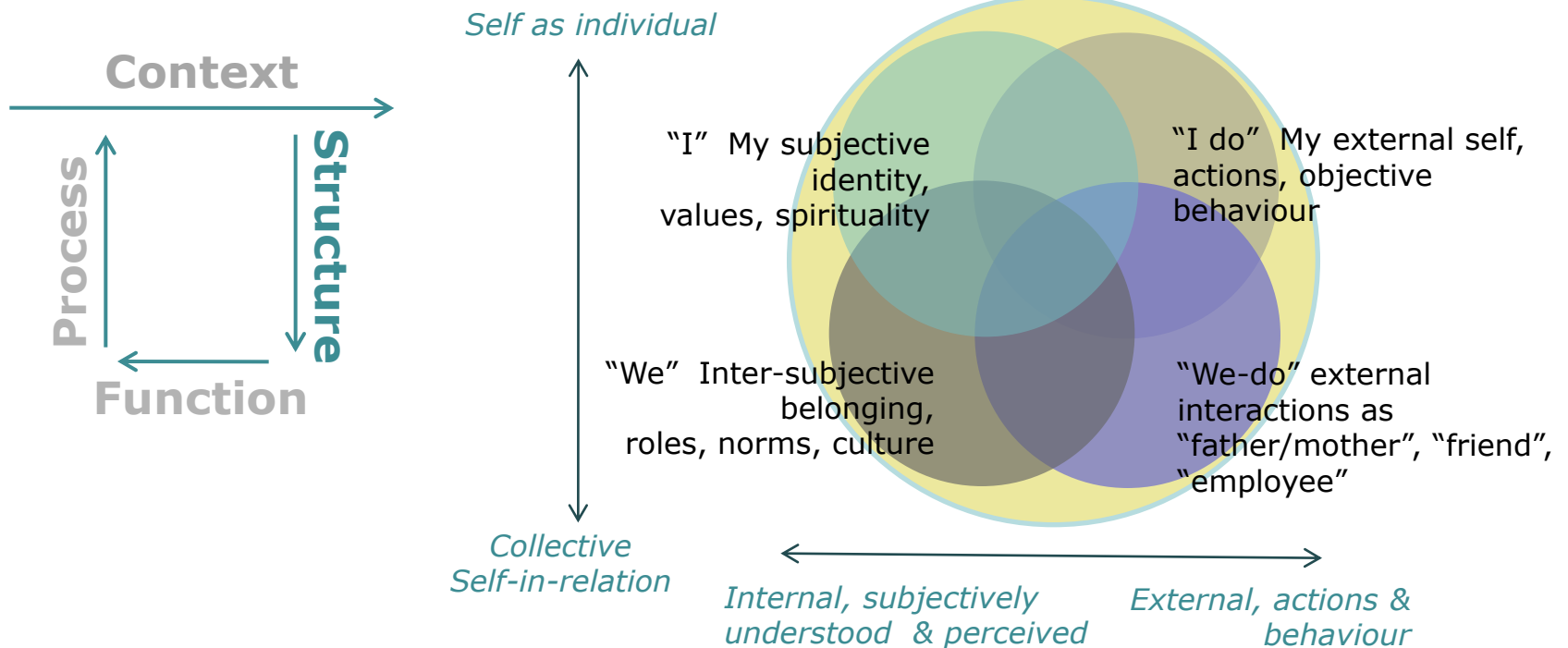
European Female 70 years, Stage 3, Multiple Conditions

Making sense of self care

Stage 1 Asymptomatic Stage 2 Symptomatic Stage 3 Complications & co-morbidities



Structures of 'self'





“When I was first told oh I wasn’t listening. I was like oh he must be talking to somebody else. And he says you are not listening. He said I am trying to tell you and I says no but when he told me I had to take all these pills, oh I am not taking any pills because I don’t take pills... he just kept saying you could have a stroke, you could lose your legs and you know just telling me all the yucky things that could happen.

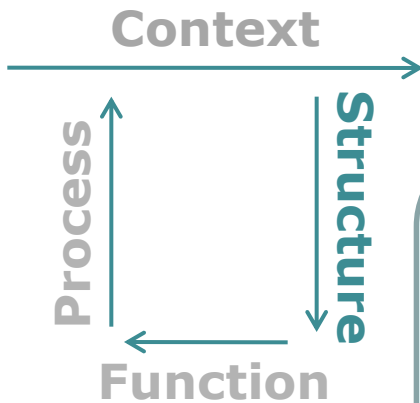
But I was still like ‘whatever’. I am going to eat whatever I want to eat. What’s the bloody point if you are not going to eat and live your life.”

Maori, Female, Stage 2

s & co-morbidities

‘self’

Self as individual



“I” My subjective identity

“Me” My external self, actions, objective behaviour

“The first picture is a sad face, how I was before. The other one is now happy. When I found out I hate myself. I didn’t expect it. I played lots of sports and rugby and didn’t expect it. But I am a heavy drinker. I didn’t like myself at that time. So I kept drinking and ended up in hospital. So I gave up drinking and smoking. I was feeling the needles in my toes and my fingers and I was sad. I didn’t know what was going on. Now I am proud of myself because I am doing something for myself”

Pacific Islander, Male, 28 yrs, Stage 2

subjectively understood & perceived

actions & behaviour

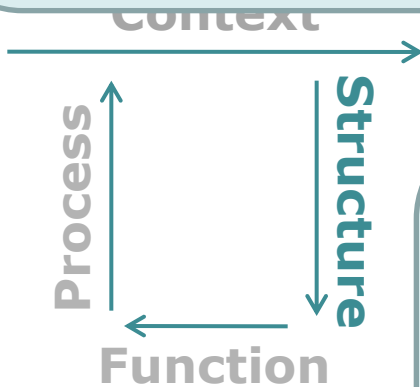


It's a lot easier to get over something when it's, when you don't focus on yourself. When you focus on like your children or your mum, you husband. It's a lot easier to do something because of them, not because of yourself, because you've, you are not thinking about yourself and when you think about yourself that's when it makes it all hard because you are only looking at yourself you are not looking at the bigger picture like a family and those who are around you all the time..

European, Female, Stage 2

s & co-morbidities

'self'



"I" My subjective identity

"Me" My external self, actions, objective behaviour

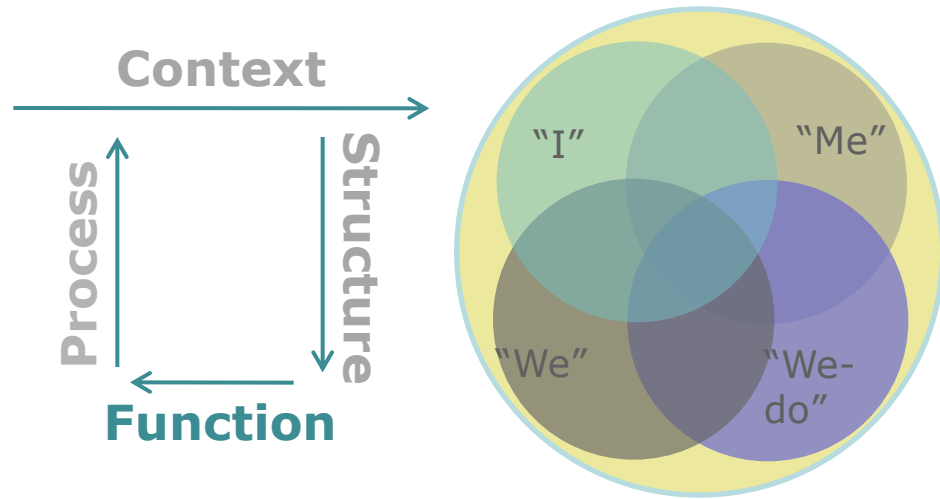
Well responsible to my mokopuna. I've brought up 12 mokopuna. I have 25 mokopuna, thank god I am not dead but I've brought them up in my house and they've gone out to work. My oldest one is about 26 or 27. He's in Levin but my responsibilities make sure that I am healthy when they come back. I will always be there for them. I never have a down day. It is just in my nature not to be down. I am not down with the dog. I think my responsibility is to my whanau, to my wife as well. If I am ill I am just a burden."

Maori, Male, Stage 2

understood & perceived

behaviour

Making sense of self care



The 'work' of self care

- ← 'I' work – self identity, self responsibility, motivation
- ← 'We' work – family, roles, social/cultural identity
- ← 'Illness' work – personal behaviours & skills
- ← 'Life-style' work – adapting social behaviours



Making sense of self care

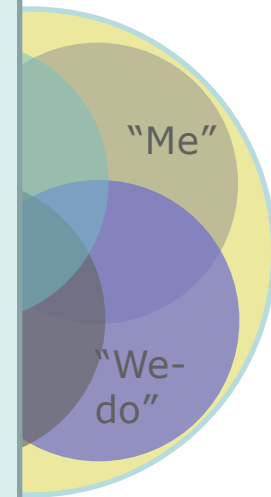
"There's just lots of things – all of the time. You know those little things like – we get the phone call every – he has blood test – not the Diabetes ones – but for the thickness of his blood for the bowel thing – and we get a phone call generally once every 7-10 days from the anti-coag clinic – which basically says your I&R is this. This is your dosage for the next 10 days – go and test again, so there's always that message.

We go to the chemist to pick up the prescription – even though it's 4 monthly it's this huge, huge, huge packet that looks like this, you know. He goes to the podiatrist every 6 weeks to get his toenails cut and feet checked.

There's lots and lots of little moments all of the time.

And then we have the big moments – so when he goes to visit the specialist – he see the heart doctor every 3 months, he sees the Renal doctor something – he sees a doctor for I dunno – it's about once every 6 weeks we go to the hospital for some ongoing regular check-up. Normally there's an eye doctor in there because he's had cataracts in his 40's so we've got to watch his eyes all the time, and at the moment – his teeth – he's bleeding quite a lot 'cos he bites his lip – so we go for that but not a normal dentist 'cos he's on the anti-coag."

& co-morbidities



'Life-style' work – adapting social behaviours



(Husband) "Me and my wife and the 2 kids have a walk in the park and feel good...Exercise is hard work. I get home from work and I feel tired..."

(Wife responds) "Now we are flying with the wind. I love to do exercise...Before, my husband and I, we were in a cage. Now I know I can help him to control his sugars because we exercise together"

Male and Female PI - Hypertension and Diabetes

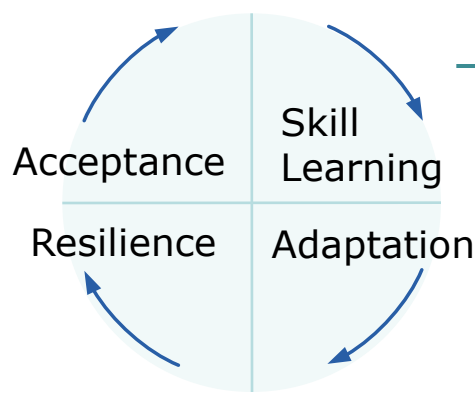
"It's hard, especially telling my brothers and sisters what I have got. My brother knows that I have got diabetes, the other 3 (brother and sisters) don't know anything about it, what is happening to me...."

Interviewer: When you go out with workmates...How do you manage around that?

When they say, especially Friday happy hour, and I just say I have got something else to do at home, I am trying to escape from them. It is hard to walk away from your mates. Yeah, I had to lie and said I had some other things to do, only truth is I do want to drink..."

Male 28 years PI Stage 2 Diabetes

Making sense of self care

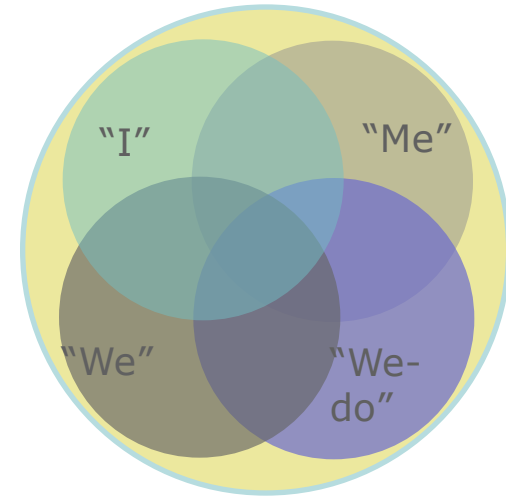


Context

Process

Structure

Function



The 'work' of self care

'I' work – self identity, self responsibility, motivation

'We' work – family, roles, social/cultural identity

'Illness' work – personal behaviours & skills

'Life-style' work – adapting social behaviours

Cycles of learning over time

Making sense of self

Stage 2
Asymptomatic



"Kiora. I'm a diabetic sitting at the River Nile. Been sitting there for a while. It's like; 'No, I will eat what I want to eat and I will do what I want to do', and then..."

Interviewer: Are you happy?

Yes and the doctor says 'well you are going to have to go onto insulin'.

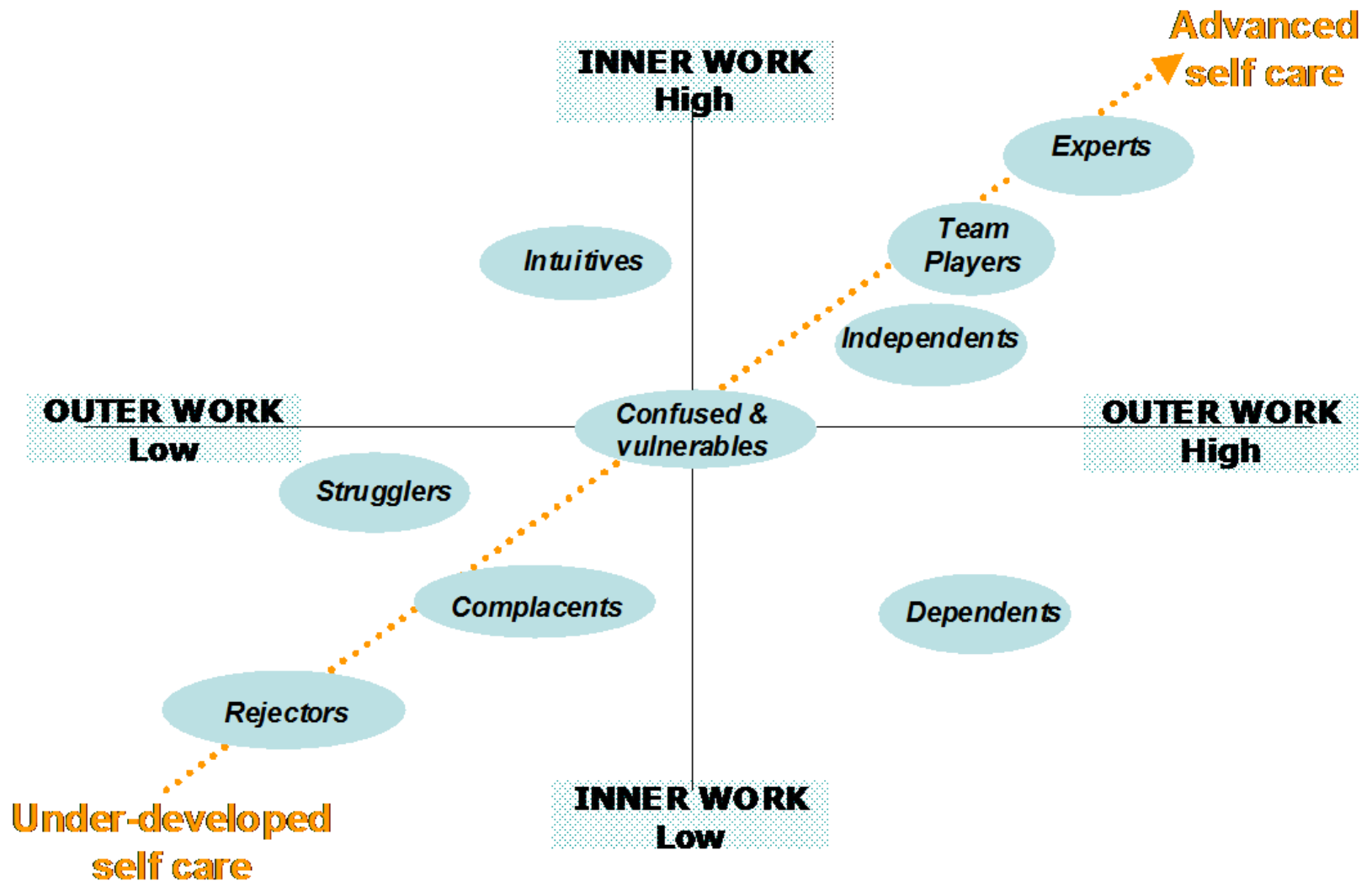
And I don't think so because at the end of the day it's my body and I chose.

Still in denial. My mother's got diabetes and my two brothers have got diabetes and a sister that's got diabetes, the other two are still diabetes free but they are only small too.

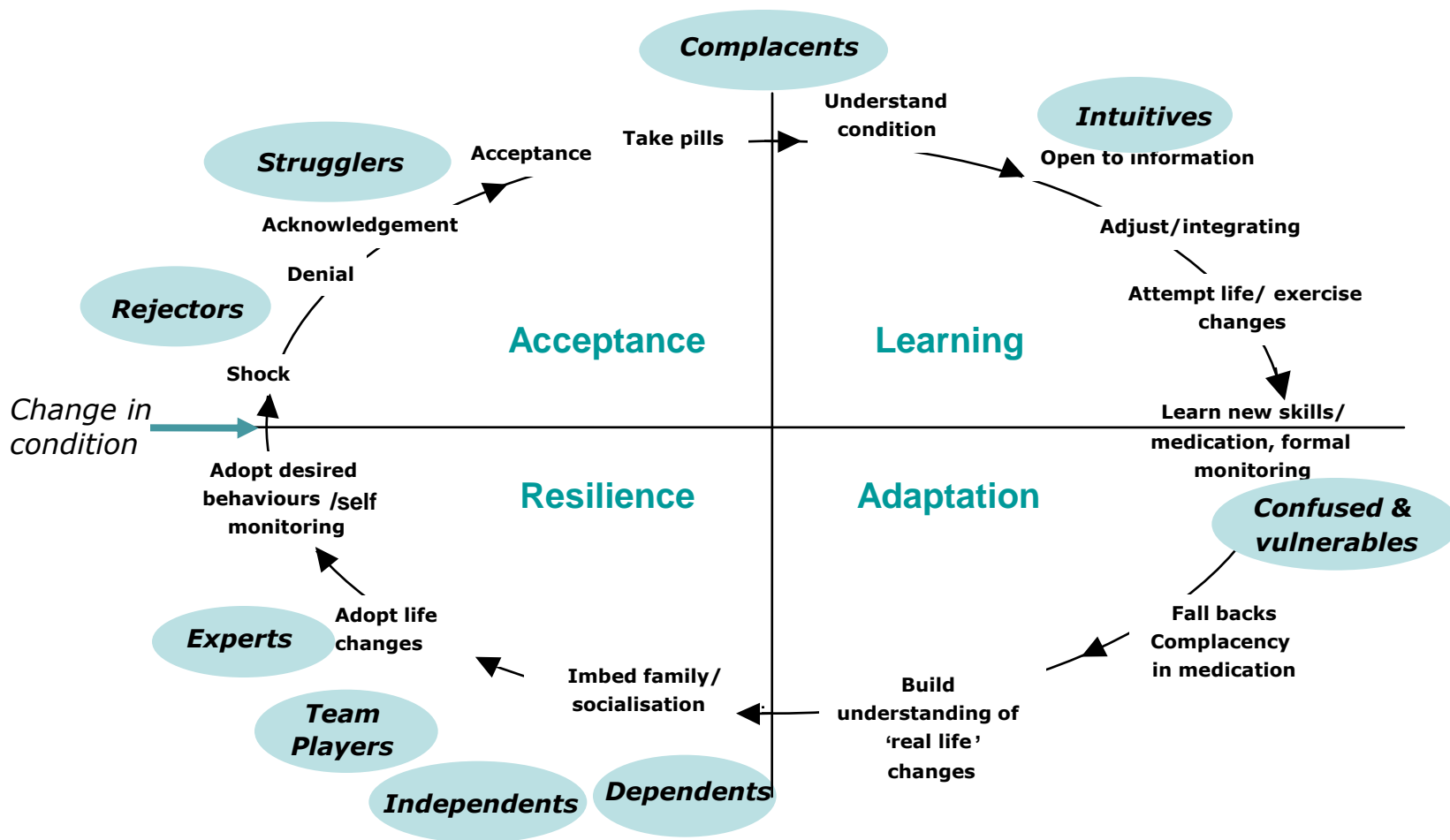
Mary has been trying hard to get me to conform and do the right thing, take my pills. I don't like taking pills. My doctor knows that so the more he gives me the more I rebel. I came here to try and get some more help and stop being at the river. I need to take control and I haven't"

Maori, Female, 40+ years, Stage 2

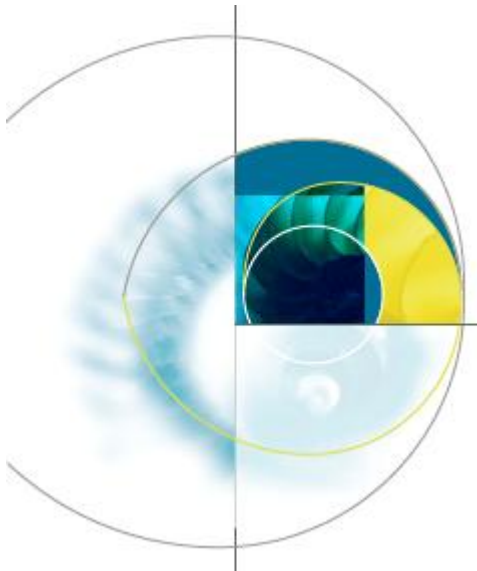
'Function' - Patterns of response

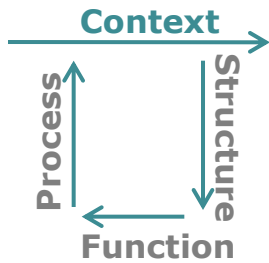


'Process' - Patterns of response



Conclusions & implications for policy, programme & service design

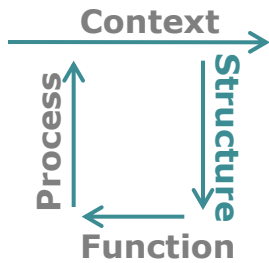




Implications - context of self care

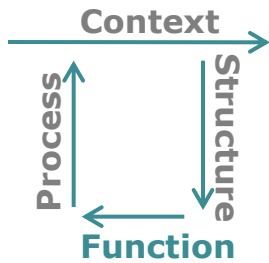
Across the continuum:

- Self care of chronic conditions is dynamic, ever changing and never fully mastered
 - Plan for changes, respond to phase shifts, ramp up support as complexity grows
 - Impermanence of seeming stability & confidence
 - Design in low cost assurance and recovery support
- Critical life change events; diagnosis/hospitalisation, should be used as leverage points to develop self care
 - Opportunity to engage and activate – the 'equip' concept
 - We have undervalued diagnosis & tended to weight self care support towards the complex end (e.g. CarePlus)
 - Challenge of earlier recognition, asymptomatic lack feedback



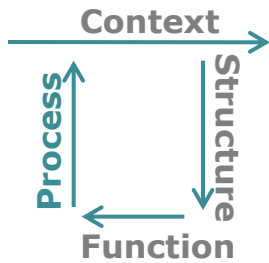
Implications – structure of self in self care

- 'Patient self management'; a health fiction & does not exist in reality
- Self care belongs to the whole person; physical, emotional, social belonging, spiritual, cultural identity
 - Trans-cultural but culture specific expression and meaning
 - Understanding the implications of this reality a first (and huge) step
- Whanau-ora self care closest we have to whole person ideal
 - Increase mainstream support for whanau-ora
 - More broadly; an explicit recognition of role of family in shaping/creating strong resilient responses
- 'Health My Way' – means self authorship of wellbeing with family, whanau, friends
 - A new life story of living well with a chronic condition
 - Requires respectful encouraging, informing, guiding, supporting
 - 'Strengths based practice'; well developed in social work & mental health - strong implications for self care support work force



Implications – functions of self care

- Health My Way composed of distinct streams of 'self care work'
 - I / We / Illness / Life-style
 - Intrinsic purpose, function and challenges within each stream with interdependencies and tensions between them
 - Centrality of interwoven individual/family processes
- Requires a partnership of different support roles;
 - Doctor, nurse specialist and family centric self care support guides
 - Complementary roles and contributions from dieticians, activity & lifestyle coaches, medical specialists
 - Peer support networks – practical living expertise
- Could we create a 'Health My Way Story', a cross stream narrative rather than an 'illness work' care plan?
 - 'Maternity Notes' closest to the ideal



Implications of the processes of self care

- Stages of acceptance, skill learning, adaptation, resiliency development
- A necessary starting point – ‘I work’; identity, life-story, acceptance
 - Supports but demands reframing of approaches like motivational interviewing
 - Needs a specialist self care support role (out of comfort zone for most GPs!)
- An experiential learning orientation (*learn from adult learning sector!*)
 - Strengths based self care learning processes – “Health My Way”
 - Integration of education and self care learning support
 - Sharing medical results for progress feedback & reflective learning
 - Peer learning support for family for harder lifestyle issues
- Segmentation from patterns of response
 - Suggestive of why standardised programmes may fail
 - Potential to differentiate support to suit common patterns of response
 - Tune the ‘people/process/information’ environment to improve individual and population outcomes

... a rethink of effective self care

- 'Health my way'
 - Whole person/family
 - Balanced
 - Learning based
 - Supported by professional guides and learning support
- **Implications – five claims:**
 1. Increase the number of people with effective self care by leveraging impact at critical change points – especially diagnosis
 2. Improve the impact of self care on health outcomes by supporting balanced, relevant, whole person learning - 'to live well with disease'
 3. Extend the influence of self care through mobilising family/whanau resources to support complex behavioural/life style changes
 4. Increase the resiliency of self care, maintenance of good practices over long enough durations to have cumulative effects, reduction of crisis events
 5. Reduce inequalities in self care, with support that works for the vulnerable and disadvantaged

With thanks

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- *Dr Lannes Johnson Healthwest PHO and the Westview Clinic*
- *Rotorua PHO*
- *Thanks to the participants who gave so freely of their views and experiences*

