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“Can I do that?” How advice impacts on reengagement for patients with heart failure

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Joyce's words

Anne (researcher); “How do you know what you can do, how much you can do?”

- “It’s trial and error and you pay for it if you do too much, feeling tired, fatigued, you just know. I was told I needed to take it easy so you do. Everyone knows not to rush or lift heavy things to not put a strain on my heart”.

Anne (researcher); “So you have had to try things out for yourself, and you got advice?”

- “No I did it really, well and Jeff [husband] he was very clear what I should stop doing, he took over. They can’t be clear really I asked but they say just pace yourself and take it easy so I did- but really you have to try things out. Your mind stops you though; you’re scared to push yourself too much. You can’t see your heart so you have to guess and go on how you feel. Pushing you just a little at a time. No one really gives clear answers.”

Information Gathering	Processing	Output
<p>Medical Messages</p> <ul style="list-style-type: none"> • General Advice “Pace yourself” “Don’t lift heavy weights” “Look after your heart • CHD Prevention “The GP said that healthy eating and regular exercise such as walking would be good and I stick to that”. • Specific advice “This is serious” “You could die” “This will get worse”. • Inappropriate Advice/no advice. “No-one explained”. “I cannot die and leave the kids so it would be good to have some clear guidance on what I should do <p>Symptoms/experience</p> <ul style="list-style-type: none"> • Breathlessness • Fatigue • palpitations 	<p>Beliefs. “This will get worse” “Pace yourself” “Don’t exert your heart”</p> <p>Take exercise “I always walk each day to build my heart up”.</p> <p>“I do more now and have stopped smoking and eat better”</p> <p>Eat a healthy diet “I eat better”</p> <p>Don’t drink “ I can’t drink now so I don’t go out with my mate so much”</p> <p>Take the tablets “I just take the tablets and do as I told”</p> <p>Lack of information/understanding “No one was clear and said what I could do” “you would like to be reassured that you are doing something safe”</p> <p>Psychological state Fear “I don’t feel safe doing”</p> <p>Anxiety “I could die”</p> <p>Isolation “no-one else like me” “I’m too young”</p>	<p>IDCM work “I pace myself” “take the tablets”</p> <p>Reduced occupational performance “I won’t run if I can help it though-it’s hard when the kids are playing, - it’s like I’m scared of putting too much pressure on my heart.” “I also make myself sit down-it’s not me I was always doing something all the time”.</p> <p>Reduced social engagement “tried going to the pub with my mates, not drinking cos of the tablets, but I just felt panicky”</p> <p>Seeking information “My sister had read something in Bella and she asked her (GP) if this was what I had. This woman had died. But she said it wasn’t.” “Can I do this?” “Is it serious?”</p> <p>Carer Pressure “The family are different with me too; stop me doing things I don’t bother now cos it causes to much upset”.</p>

These influences can be summarised as the main influences on occupational performance and are identified below:

- Anxiety or fear of causing damage to the heart.
- Carer or family pressure to stop or modify activities which they view will damage the heart.
- General advice given by clinical team, and from publications aimed at this group of patients, and also those with heart disease and heart failure.
- The beliefs held by the individual about IDCM and what they need to do in order to “Guard their Heart”.
- The avoidance of what the participant views as symptoms which are often “fatigue” and “breathlessness on exertion”.

Constructed Grounded Theory





This core category “Guarding the Heart

The main factors which describe the occupational performance of people with IDCM can be viewed as the following four concepts;

- **Seeking information**, the challenges that arise in the seeking and processing information about IDCM, This information is then processed and interpreted and impacts on occupational performance and increasing adherence to IDCM work.
- **Reduced occupational performance/participation**, reduced in the presence or **absence of symptoms in everyday life**.

Adopting IDCM work; these are activities required for the medical management of the condition, ie, complying with medication, adopting a healthy lifestyle and pacing/avoiding activities.

Symptoms; which are provoked by activities and exercise and are viewed as damaging or ‘bad’ for the heart. Normal breathlessness and tiredness are interpreted as deterioration in the medical condition.

Influences on Occupational Performance.

