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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?”

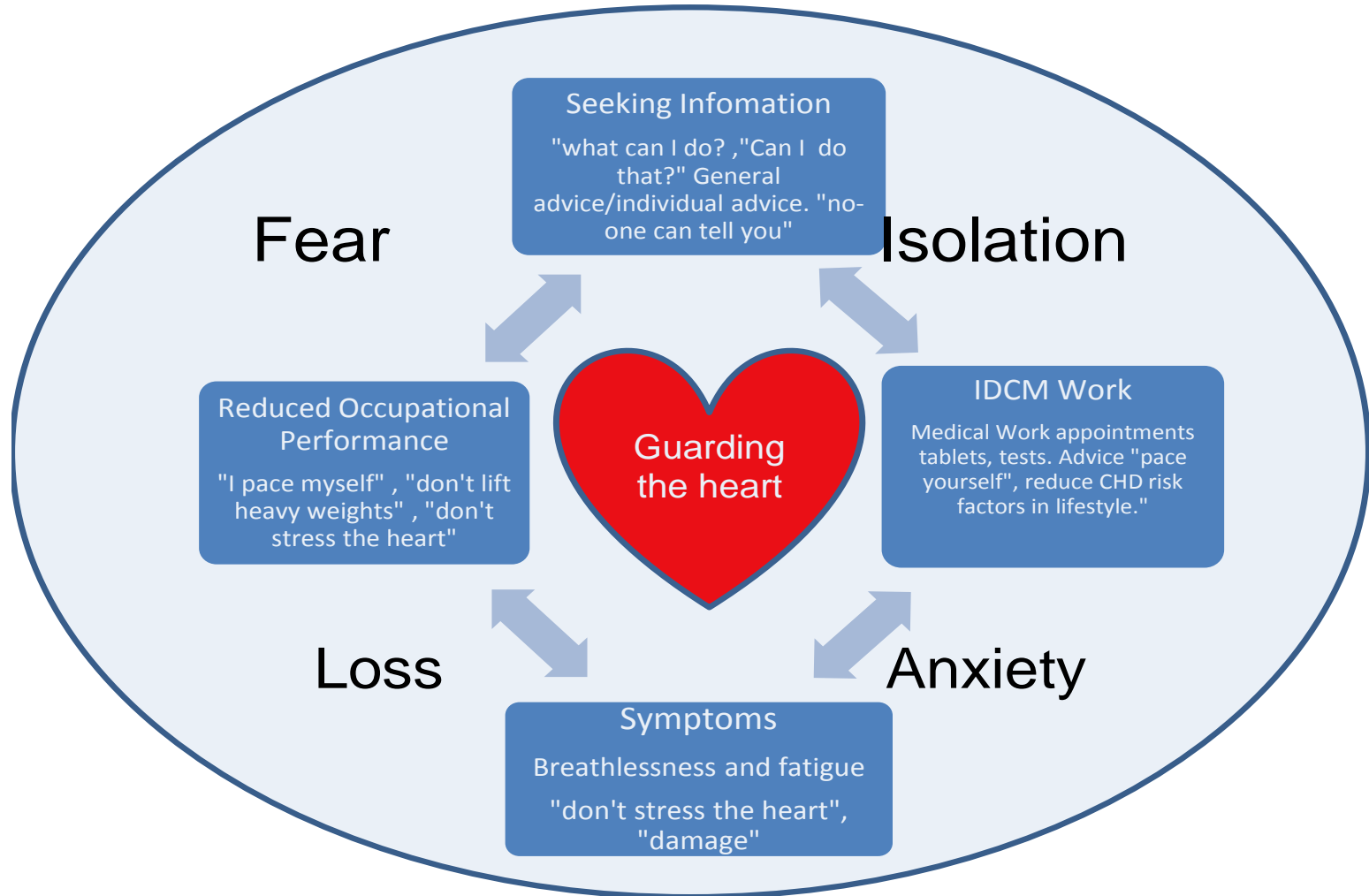
- “No I did it really, well and Jeff [husband] he was very clear what I should stop doing, he took over. They can’t be clear really I asked but they say just pace yourself and take it easy so I did- but really you have to try things out. Your mind stops you though; you’re scared to push yourself too 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><b>Medical Messages</b></p> <ul style="list-style-type: none"> <li>• General Advice “Pace yourself” “Don’t lift heavy weights” “Look after your heart”</li> <li>• CHD Prevention “The GP said that healthy eating and regular exercise such as walking would be good and I stick to that”.</li> <li>• Specific advice “This is serious” “You could die” “This will get worse”.</li> <li>• 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</li> </ul> <p><b>Symptoms/experience</b></p> <ul style="list-style-type: none"> <li>• Breathlessness</li> <li>• Fatigue</li> <li>• palpitations</li> </ul>	<p><b>Beliefs.</b> “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><b>Lack of information/understanding</b> “No one was clear and said what I could do” “you would like to be reassured that you are doing something safe”</p> <p><b>Psychological state</b> 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><b>IDCM work</b> “I pace myself” “take the tablets”</p> <p><b>Reduced occupational performance</b> “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><b>Reduced social engagement</b> “tried going to the pub with my mates, not drinking cos of the tablets, but I just felt panicky”</p> <p><b>Seeking information</b> “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><b>Carer Pressure</b> “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.

