Exploring the Stigma of Pernicious Anaemia

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What is Health Psychology?

The study of people’s thoughts and actions in relation to health issues

Explores the link between physical health and the psychological and social environment

Interdisciplinary field concerned with the application of psychological knowledge and techniques to health, illness and healthcare

(Marks, Murray, Evans & Estacio, 2015)
Biopsychosocial Model of Health

**Biological**
genetics, sex, physical health, drug effects,

**Psychological**
coping skills, self-esteem, mental health

**Social**
peers, family, work environment, society, SES
Stigma

A mark or sign of disgrace or discredit
Health Related Stigma

Those living with chronic conditions often fear that their health status will lead them to be devalued by wider society or discriminated against (Brown, 2015).

Populations with high levels of health related stigma have

- Increased psychological distress
- Decline in physical health
- Poor mental health
- Lower acceptance of illness

(Quinn & Chaudior. 2009)
Exploring PA Patients Perceptions of Stigma (Seage, 2018)

Variable | N | % | M (SD)
--- | --- | --- | ---
Sample Size | 217 | 100.0 | 
Age | 53.74 (11.46) | 100.0 | 
Age at diagnosis | 42.75 (14.31) | 100.0 | 
Gender | | | 
Female | 83.9 | 39.3 | 
Male | 16.1 | 60.7 | 
Treatment Type | | | 
12 weekly* | 53.6 | 27.3 | 
8-10 weeks* | 21.0 | 31.0 | 
>8 weeks* | 7.3 | 10.2 | 
Daily* | 5 | 2.3 | 
Other | 3.1 | 1.4 | 

*intermuscular injections of hydroxobalmin 100ug
<table>
<thead>
<tr>
<th>What is the likelihood that you would encounter these stigmatizing experiences in the future</th>
<th>Mean (SD) Rating</th>
<th>Likely or very likely</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>(Because of your chronic disease)</strong></td>
<td>1-5</td>
<td>(%)(n)</td>
</tr>
<tr>
<td><strong>Friends or family</strong></td>
<td>2.13 (1.12)</td>
<td></td>
</tr>
<tr>
<td>A friend or family member will think that your illness is your fault</td>
<td>2.16(1.26)</td>
<td>16.1</td>
</tr>
<tr>
<td>A friend or family member will not think as highly of you</td>
<td>2.12(1.18)</td>
<td>13.3</td>
</tr>
<tr>
<td>A friend or family member will blame you for not getting better</td>
<td>2.12(1.23)</td>
<td>15.8</td>
</tr>
<tr>
<td>A friend or family member will be angry with you</td>
<td>2.14(1.22)</td>
<td>16.7</td>
</tr>
<tr>
<td><strong>Work Colleagues</strong></td>
<td>2.67(1.29)</td>
<td></td>
</tr>
<tr>
<td>Someone at work will think that you cannot fulfil your work responsibilities</td>
<td>2.59(1.36)</td>
<td>26.5</td>
</tr>
<tr>
<td>Your employer will assign a challenging project to someone else</td>
<td>2.61(1.34)</td>
<td>26.8</td>
</tr>
<tr>
<td>Someone at work will discriminate against you</td>
<td>2.68(1.39)</td>
<td>30.3</td>
</tr>
<tr>
<td>Your employer will not promote you</td>
<td>2.83(1.39)</td>
<td>33.1</td>
</tr>
<tr>
<td><strong>Healthcare Professionals</strong></td>
<td>2.84(1.24)</td>
<td></td>
</tr>
<tr>
<td>A healthcare worker will blame you for not getting better</td>
<td>2.94(1.38)</td>
<td>36.6</td>
</tr>
<tr>
<td>A healthcare worker will be frustrated with you</td>
<td>2.99(1.38)</td>
<td>38.2</td>
</tr>
<tr>
<td>A healthcare worker will give you poor care</td>
<td>2.58(1.28)</td>
<td>25.9</td>
</tr>
<tr>
<td>A healthcare worker will think you are a bad patient</td>
<td>2.83(1.37)</td>
<td>32.8</td>
</tr>
</tbody>
</table>
The Impact on Well-being

The chronic disease stigma index for this sample indicates moderate levels of stigma [M=30.31(12.35)]

Anticipated stigma was significantly higher for healthcare professionals & workplace [p<0.05]

Higher levels of anticipated stigma were associated with increased symptoms of anxiety and depression [p<0.05]

Results indicate that higher rates of perceived stigma were associated with lower acceptance of illness [r (165) =0.30 p=0.00]
Receiving a Diagnosis of Pernicious Anaemia: Exploring Experiences of Relationships with Health Professionals (Glover, Mercer & Seage, under review)

Eligible participants were aged 18 - 75 years, English speaking with a formal diagnosis of PA (N=11)

Semi-structured interviews

Analysed using IPA

<table>
<thead>
<tr>
<th>Participant</th>
<th>Sex</th>
<th>Age (years)</th>
<th>Approximate years since PA diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daphne</td>
<td>F</td>
<td>65</td>
<td>20</td>
</tr>
<tr>
<td>Gwen</td>
<td>F</td>
<td>58</td>
<td>5</td>
</tr>
<tr>
<td>Madison</td>
<td>F</td>
<td>50</td>
<td>4</td>
</tr>
<tr>
<td>Anna</td>
<td>F</td>
<td>41</td>
<td>8</td>
</tr>
<tr>
<td>Grace</td>
<td>F</td>
<td>32</td>
<td>2</td>
</tr>
<tr>
<td>Susie</td>
<td>F</td>
<td>55</td>
<td>7</td>
</tr>
<tr>
<td>Emma</td>
<td>F</td>
<td>38</td>
<td>13</td>
</tr>
<tr>
<td>Rebecca</td>
<td>F</td>
<td>44</td>
<td>1.5</td>
</tr>
<tr>
<td>Samantha</td>
<td>F</td>
<td>55</td>
<td>8</td>
</tr>
<tr>
<td>Florence</td>
<td>F</td>
<td>47</td>
<td>6</td>
</tr>
<tr>
<td>Matthew</td>
<td>M</td>
<td>58</td>
<td>2</td>
</tr>
</tbody>
</table>

F = female; M = male; PA = pernicious anaemia
Themes

- Struggle to achieve diagnosis
- Seeking sufficient treatment
- The significance of diagnosis
The Struggle to Achieve Diagnosis

- All participants had experienced a lengthy diagnostic process
- Symptoms initially labelled as depression or viewed as consequence of lifestyle
- Suggestion that symptoms were purely psychological “all in your head”
- Symptoms were trivialised

‘I kept saying to my consultant that I was exhausted, and I couldn’t speak, and that I was really forgetful and that-, he just told me to basically “have a coffee... once you find you’re doing exercise, once you eat better then you’ll be fine”. But I was actually really physically fit at the time... I think it probably took me three goes at telling this to him... at the last one, I was crying.’
The Significance of Diagnosis

"It made me feel justified in myself as to why I was feeling that way...it makes me feel like I'm not going insane because I was feeling really upsetting me because I was thinking "no" I was 30 years old and I was feeling like this. All my friends thought I was boring. So, now it makes me feel better. I don't think it makes anybody understand it though....

- All valued received their diagnosis
- Diagnosis prompted adaptation, “moving on” with their health
- Legitimised their illness to themselves and others
- Decreased reliance on health professionals
Each participant reported that they consider their current PA treatment to be insufficient.

A need for replacement B12 was evident through a ‘lull’ towards the end of their treatment cycle where symptoms would return.

Request for more frequent treatments often denied

Treatment rigidity rather than symptom-led

‘... before I have an injection I’m really tired. I have a really dry mouth... bad pain, awful pain in my legs and my um, shoulders...I’m less inclined to do anything, because I’m just so tired, but when I have the injection, it feels like I’ve got a boost of energy. For about- for about a week or so but then I can feel it going again. And then after about 2 weeks my mouth goes dry, and I’ll think “oh here we go”. And then it is a vicious circle.’

[Florence]
Seeking Sufficient Treatment

‘... I made a mistake because the nurse said to me
“I bet you really need this jab, you’re looking
forward to it” and I said “no actually I’m okay, I
feel okay because I had one four weeks ago” and
she then refused to uh, to treat me, and got really
upset because I was self-injecting and I was um, I
was doing something wrong...”

• Self-injections, common but hidden
  behaviour
• Patients report feeling forced into the
  behaviour after attempts to
  collaboratively manage treatment are
  refused.
• Lack of understanding and trust in the
  patient-health professional relationship
  led to reduction of help seeking and
  expectation of negative
  treatment/stigma.
‘... I was given a telephone appointment, um, and he [general practitioner] rang me and I said “oh I- I wanted more B\textsubscript{12} injections”, you know, and- and he just said... “the NHS is not here to help you feel better”. And I said “no it doesn’t make me feel...... I’m saying that I’ve been really ill and I’ve started to feel better and I’m frightened of that slipping backwards again, and I’m asking for more B\textsubscript{12} injections” and he said “no, that is not what the NHS is here for”.’ [Susie]
Implications for Practice

Reduce likelihood of professional-patient relationship breakdown

Mismatch in perceptions of PA’s Impact is at the root of stigma.

Patient led treatment

Increased social and psychological support
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Any Questions?

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References


Seage, C. H (2018) Living with Pernicious Anaemia: Exploring the link between anticipated