Psychological Aspects of Vasculitis
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## Demands of a Chronic Illness

### Rolland’s Model

Psychosocial demands of a chronic illness on patients and their families

<table>
<thead>
<tr>
<th>Type of disease</th>
<th>Acute</th>
<th>Gradual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Expected disease course</td>
<td>Progressive</td>
<td>Constant</td>
</tr>
<tr>
<td>Outcome</td>
<td>Fatal</td>
<td>Shortened lifespan</td>
</tr>
<tr>
<td>Associated Disability</td>
<td>None</td>
<td>Mild</td>
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### Vasculitis

**Rolland’s Model**

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<table>
<thead>
<tr>
<th>Expected disease course</th>
<th>Progressive</th>
<th>Constant</th>
<th>Relapsing/episodic</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Fatal</th>
<th>Shortened lifespan</th>
<th>Non-fatal</th>
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</thead>
</table>

<table>
<thead>
<tr>
<th>Associated Disability</th>
<th>None</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
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Vasculitis tends to be acute in onset and the expected course of the illness is unpredictable. It is usually relapsing/episodic in nature and the level of disability varies but can be severe affecting both physical and social functioning.
Vasculitis

Patients and their families need to be adaptive and flexible

Families can go from providing intense care-giving during episodes of disease activity to that of less care-giving at periods of remission.

Can be difficult coping with uncertainty and anxiety about the future for both patients and their families.
Adjustment to diagnosis - A Grieving Process?

- **SHOCK** - detached, numb, unable to ask questions

- **ANGER** – towards others and self, frustration, “why me”, questioning, bargaining, “this isn’t fair”

- **DENIAL** - deny existence of problem

- **ANXIETY** – about procedures, the future, what it means

- **DEPRESSION** – feeling sad, facing the losses

- **ACCEPTANCE** - recognising that life has changed and adapting to this.
The Physical Changes

Related to the disease
Changes to organs - kidneys, lungs
Altered physical appearance

Due to treatment
Weight gain
Moon face
Hair loss
Acne

These can negatively effect emotional and social quality of life.

Ask yourself
What do I do to help cope with the physical effects of vasculitis and the vasculitis treatments prescribed?
Quality of Life in Vasculitis

Social Quality of Life

Partner

Negative effects
- Stress from adapting to primary caregiver role
- Feeling depressed

Positive effects
- Feeling closer
- More equal distribution of household labour
- Making relationship a priority

Ask yourself

Has vasculitis affected the relationship with my partner in a positive or a negative way?
Coping

Coping Strategies

“Active” coping strategies are associated with better psychological adjustment and “avoidant” strategies with worse adjustment.

Wish-fulfilling fantasy - “I wish this hadn’t happened to me” –not helpful

Information-seeking –related to higher levels of well-being- more helpful

Learning to accept and tolerate the condition, its treatment and the associated side effects of treatment whilst trying to have a satisfactory quality of life throughout is the challenge.

Ask yourself

*How do I cope with vasculitis? What strategies do I use?*
# Quality of Life in Vasculitis

## Social Quality of Life

### Frienships

<table>
<thead>
<tr>
<th>Positive changes</th>
<th>Social support</th>
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<tbody>
<tr>
<td></td>
<td>Understanding friends</td>
</tr>
<tr>
<td></td>
<td>Feeling closer</td>
</tr>
<tr>
<td></td>
<td>Gaining new friends</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Negative changes</th>
<th>Fewer social activities</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Losing a friend</td>
</tr>
<tr>
<td></td>
<td>Not understanding</td>
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**due to**

<table>
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<tr>
<th></th>
<th>Fatigue</th>
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<tbody>
<tr>
<td></td>
<td>Physical/lifestyle changes</td>
</tr>
<tr>
<td></td>
<td>Patient withdrawal</td>
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</table>

*Ask yourself*

*How has vasculitis affected my friendships?*
Quality of Life in Vasculitis

Fatigue
More than 75% of patients report fatigue

Ask yourself
Has vasculitis affected my energy levels?

Managing Fatigue
Energy management techniques
Pace
Prioritise activities
Delegate tasks
Exercise
Medication
Quality of Life in Vasculitis

Depression
People with long term conditions are up to 3 times more likely to experience depression.
Studies show that between 23% - 60% of patients report experiencing depression related to vasculitis

Ask yourself
Has vasculitis affected my mood?

Coping with depression
Try not to become isolated
Reach out to family and friends
Participate in activities you enjoy
Discuss with Doctor if feeling low in mood
Seek help from psychologist/therapist/counsellor
Cognitive Behavioural Therapy Model

Therapy is mainly based on CBT principles and approaches. How we think and feel influences how we interact and behave in the world around us.
Unhelpful Thinking Styles

All or nothing thinking – “If I am not perfect I have failed”

Over- generalising - “nothing good ever happens to me”

Mental Filter- Noticing failures but not successes

Jumping to conclusions- Mind Reading- imagining we know what others think
Fortune Telling- predicting the future

Disqualifying the Positive – That doesn’t count

Catastrophising – blowing things out of proportion

Emotional Reasoning – “I feel embarrassed so I must be an idiot”

Labelling – “I’m a loser”, “I’m completely useless”

Critical Words – “should”, “must”, “ought”

Personalisation – Blaming yourself for something that wasn’t your fault
Thank you
Any Questions
References


