Responsibilization of caregivers in depression: the harmful potential of policy-based evidence

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<table>
<thead>
<tr>
<th>Guideline/policy</th>
<th>Year</th>
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<tbody>
<tr>
<td>NICE depression guideline</td>
<td>2004</td>
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<tr>
<td>NICE depression guideline revised</td>
<td>2009</td>
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<tr>
<td>NICE service user experience guideline</td>
<td>2011</td>
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<tr>
<td>The Care Act 2014</td>
<td>2014</td>
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<tr>
<td>NICE depression guideline draft update</td>
<td>2017</td>
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- All refer to informing and involving carers
- Most detailed is NICE 2011 guideline – details involvement in a range of setting
- Discourse reflects responsibilization
- Example: NICE 2009:

  “Carers should also be advised to be “vigilant for mood changes, negativity and hopelessness, and suicidal ideation, and to contact their practitioner if concerned”

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Evidence for recommending carer involvement

• Too generic (to mental health)
• Too specific (e.g. schizophrenia studies)
• Unsystematic, patchy
• Individual testimony (e.g. NICE lay committee members)
• Cost-focused
• Rebrands old policy as evidence (e.g. NICE 2011)
• Outcome studies treated as unrelated (couples therapy in NICE reviews)

Recommendations follow reponsibilization agenda rather than evidence
Missing evidence on family involvement in depression

• NICE 2009 service user experience chapter: no systematic review of primary qualitative research; adhoc data (e.g. 7 accounts, 1 review, 1 re-analysis); not linked to treatment recommendations; not updated 2017

• Evidence side-lined:
  • Perspectives of family caregivers: 2 metasyntheses
    • Hansen & Buus, 2011
    • Priestley & McPherson, 2016
  • Perspectives of depressed people: 9 studies

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Perspectives of family caregivers
Metasyntheses based on 15 primary qualitative studies (to 2015), representing 263 participants

Making sense of depression: recognition and impact

Moving forward: changing sense of self, adapting to depression, looking to the future

Changes in family dynamics: role reformation, coping strategies

Overcoming challenges: healthcare professionals, community support


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Perspectives of depressed individuals
Review (by McPherson & Oute, currently unpublished) found 9 primary qualitative studies (2009-2018), representing 316+ participants
• Depression impacts negatively on relationships and vice versa (vicious cycle)
• Practical and emotional support at home is pivotal
• Family members can trigger depression, impede recovery
• Involving family can cause tensions
• Improving family relationships is a key goal for recovery
• Stigma within family can prevent help-seeking
• Family lifestyles can model poor or positive lifestyle changes

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Conclusions

• Involvement policies have ‘responsibilization’ agenda
• Evidence informing policy is skewed and ignores subjective experience research with carers and depressed people
• Qualitative research reveals complexity
• Depression impacts on relationships and vice versa
• Family dynamics are a crucial part of recovery, either impeding or facilitating recovery
• Family involvement should be about seeing depression as social and relational and less about ‘responsibilization’ of citizens
• Responsibilization may even be counterproductive, impede recovery and lead to more conflict and potential relationship breakdown

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We aim to…

• Further synthesise studies on perspectives of depressed people
• Update syntheses of studies on caregiver perspectives
• Feed into ongoing stakeholder discussions with NICE about guideline methodology on:
  • Use of qualitative research
  • Disease vs social model of depression
  • Using service user experience research to inform treatment recommendations
See also


A paper based on this presentation is currently under review in the journal *Social Theory and Health*