The Day-to-Day Management of Chronic Illness: How Family Members Help and (Sometimes) Hinder

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26th Annual Colloquium - Institute on Aging
University of Wisconsin, Madison, WI
Badger for a day… 😊
“Chronic diseases, such as heart disease, stroke, cancer, chronic respiratory diseases and diabetes, are by far the leading cause of mortality in the world, representing 60% of all deaths.”
Rates of Chronic Illness are Rising

Prevalence of Chronic Disease in the U.S.

- 1995: 118
- 2000: 125
- 2005: 133
- 2010: 141
- 2015: 149
- 2020: 157
- 2025: 164
- 2030: 171

An Example: Increase in Percentage of U.S. Adults with Diagnosed Diabetes: 1994-2008

Chronic Illness is also a Concern in Europe

EU countries change health strategies to tackle ageing population

Though Europeans’ life expectancies are increasing, a growing number of elderly people is also experiencing more years living with a chronic disease, which is a big challenge for future societies.
Chronic Illness is Not Only a Problem in High-Income Countries

- Rates of chronic illness are rising in low- and middle-income countries, adding to the burden of infectious disease.

<table>
<thead>
<tr>
<th>Deaths (all ages)</th>
<th>2005</th>
<th>2015</th>
<th>2030</th>
</tr>
</thead>
<tbody>
<tr>
<td>CVD and diabetes</td>
<td>12.4 (33%)</td>
<td>14.3 (35%)</td>
<td>17.3 (36%)</td>
</tr>
<tr>
<td>Cancers</td>
<td>4.5 (12%)</td>
<td>5.6 (14%)</td>
<td>7.5 (15%)</td>
</tr>
<tr>
<td>Chronic respiratory</td>
<td>3.1 (8%)</td>
<td>4.1 (10%)</td>
<td>5.9 (12%)</td>
</tr>
<tr>
<td>All chronic diseases</td>
<td>23.1 (61%)</td>
<td>27.2 (66%)</td>
<td>34.3 (71%)</td>
</tr>
</tbody>
</table>

For 23 selected low- and middle-income countries, millions of projected deaths and percentage of all deaths attributable to chronic disease.

Abegunde et al. (2007).
Chronic Conditions are More Common in Later Life

Percent of Adults with Chronic Conditions in the U.S. by Age Group

But Rates of Chronic Illness are also Rising among Children

- Due to an increase in childhood obesity
- Example: Type 1 and type 2 diabetes increased by 21% and 31%, respectively, among U.S. youth from 2001-2009.¹

Chronic illness is a concern for many millions of people worldwide.

¹Dabelea et al. (2014).
The Day-to-Day Management of Chronic Illness can be Demanding

Patients frequently must:

• Initiate and sustain changes in multiple health behaviors, often indefinitely
• Follow a complex medication schedule
• Monitor bodily condition and functions
• Cope with emotional distress associated with the illness

Treatment adherence is often difficult, and lapses are common.
Management of a Chronic Illness Often Occurs in a Social Context

• Others can *observe, monitor, and seek to play a role* in the patient’s illness management.

• Family members, especially spouses, are most often involved (e.g., Ell, 1996; Fisher et al., 2000).

• Spouses are in a unique position to observe *nonadherence* and to try to intervene (Trief et al., 2003).

Family members’ involvement is often *helpful* but can be *unhelpful*. 
Questions Addressed Today

- In what different ways do family members tend to become involved in a loved one’s chronic illness management?
- What is helpful? Unhelpful? Or, possibly, both?
- Are family members themselves affected by their involvement in a loved one’s chronic illness management?
- What practical suggestions can be drawn from existing research?
Q1: In what different ways do family members become involved in a loved one’s chronic illness management?
Have You had Experiences Like These?

• A family member offered to help when you were trying to improve one of your health behaviors.

• A family member criticized your health behavior and said it should change.

• A family member’s actions made it harder for you to improve one of your health behaviors.

How did you feel? What did you do?

These examples illustrate the forms of family members’ involvement studied by researchers.
Most Common Forms of Family Members’ Involvement in the Management of a Chronic Illness

Social support: Actions directed toward facilitating/reinforcing sound health behavior. Examples:

-- offering to help (e.g., joining in dietary changes)
-- praising a person for sound health behavior

Social control: Actions directed toward prompting improved health behavior. Examples:

-- nudging a person to engage in better health behavior
-- questioning or criticizing a person’s unsound health behavior
Less Common Form of Family Members’ Involvement in the Management of a Chronic Illness

**Undermining:** Actions (intentional or unintentional) that interfere with a person’s efforts to initiate or maintain sound health behavior. *Examples:*

-- offering unhealthy food to a person on a restricted diet
-- interfering with a person’s plans to exercise
-- showing indifference toward the person’s illness-management efforts
A Brief Note on Terminology

• The term “social control” originated with the French sociologist Emile Durkheim:

  Emphasized that social relationships are a key source of meaning and support but also of constraint → which can deter people from health-damaging behavior.

• Social control refers to actions by others meant to protect a person’s health, not attempts to dominate the person or achieve personal gains.

Durkheim (1897). *Suicide: A study in sociology.*
Q2: Of these different forms of family members’ involvement, what is helpful? unhelpful? or both?

Wait! What does she mean by “or both”?

A little background to the rescue...
Recall that Health-Related Social Control Involves *Constraint*

Compared to social support, **social control** is more likely:

- to occur when a person frequently exhibits poor health behavior
- to be experienced by the person as unwelcome or critical
- to convey to the person that (s)he is exhibiting poor self-control

Even if social control fosters improved health behavior, it may have a psychological cost.
Dual Effects Model of Social Control (Posits Both Helpful *and* Unhelpful Effects)

Social Control

- Improved health behavior
- Psychological distress

Hughes & Gove (1981); Rook, Thuras, & Lewis (1990); Umberson (1987)
An Intriguing Paradox…Good Intentions Gone Awry?

• Maybe audience members have experienced it personally?

• This “dual effects” model has seldom been studied in patient populations.

• Does it apply to chronic illness?
How have Social Support and Social Control Typically been Assessed?

**Social support**: encouraging, praising, or assisting an individual to maintain sound health behavior

**Social control**: prompting, persuading, nagging, or criticizing an individual to engage in improved health behavior

Less forceful vs. more forceful forms of social control are often distinguished (sometimes referred to as *persuasion vs. pressure*).
Examples: Less Forceful vs. More Forceful Forms of Social Control (or Persuasion vs. Pressure)

<table>
<thead>
<tr>
<th>Persuasion</th>
<th>Pressure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Explaining/reasoning</td>
<td>Criticizing</td>
</tr>
<tr>
<td>Hinting/suggesting</td>
<td>Inducing guilt or fear</td>
</tr>
<tr>
<td>Reminding</td>
<td>Nagging</td>
</tr>
<tr>
<td>Bargaining</td>
<td>Threatening/withdrawing</td>
</tr>
<tr>
<td>Pointing out positive role models</td>
<td>Drawing comparisons with negative role models</td>
</tr>
</tbody>
</table>

Badr (2014), Lewis & Butterfield (2007), Lewis & Rook (1999); Stephens et al. (2013)
People Understand the Questions and Report Both Support and Control in the Context of Chronic Illness

Older adults with type 2 diabetes (N=129)

<table>
<thead>
<tr>
<th>Mean Frequency$^a$</th>
<th>Support</th>
<th>Persuasion</th>
<th>Pressure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Reports</td>
<td><img src="image1.png" alt="Graph" /></td>
<td><img src="image2.png" alt="Graph" /></td>
<td><img src="image3.png" alt="Graph" /></td>
</tr>
<tr>
<td>Spouse Reports</td>
<td><img src="image4.png" alt="Graph" /></td>
<td><img src="image5.png" alt="Graph" /></td>
<td><img src="image6.png" alt="Graph" /></td>
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</tbody>
</table>

$^a$ In the past month…(1 = not at all, 5 = every day)

How do Health-Related Social Support and Social Control Provided by Family Members Affect Patients?

Findings from several studies →
Evidence that Social Control has Dual *(Helpful and Unhelpful)* Effects

Older osteoarthritis patients (*N*=70), assessed pre- and post-knee replacement surgery

**Spouses’ social control (pressure, persuasion)**

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**Adherence tasks included:**
- Daily physical therapy sessions
- Increasing physical activity at home
- Elevating the affected leg
- Icing the wound
- Taking pain medications

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Adjusted regression coefficients are shown.  

*Stephens, Fekete, Franks, Rook, Druley, & Greene (2009)*
Partial Evidence that Social Control has Dual (*Helpful and Unhelpful*) Effects

Adolescents with type 1 diabetes (*N*=180); 14-day daily diary study

- **Mothers’ social control (persuasion)**
  - $b = -5.00^*$ (better)

- **Patients’ blood glucose levels**
  - $b = -0.04^*$ (worse)
  (among adolescents with high self-efficacy)

- **Patients’ confidence in their illness management**

Fixed effects from multilevel analyses are shown.

Berg, Butner, Butler, King, Hughes & Wiebe (2013)
Evidence that Social Control is Only *Unhelpful* and that Social Support is *Helpful*

Older couples (N=129) in which one spouse has type 2 diabetes; 24-day daily diary study

- **Spouses’ support**
  - Support: $b = .14^{***}$ (better)

- **Spouses’ control (pressure, persuasion)**
  - Pressure, persuasion: $bs = -.04^+, -.05^+ $ (worse)
  - Pressure, $b = .06^*$ (worse)
  - Persuasion (no effect)

- **Dietary adherence**
  - Positive effect

- **Diabetes distress**
  - Negative effect

Fixed effects from multilevel analyses are shown.

Findings from these and Other Studies of the Management of Chronic Illness Suggest:

- Social support is typically helpful.
- Evidence for social control is mixed:
  - Linked to better adherence in some studies, but to worse adherence in other studies.
  - Often linked to psychological distress.

Fekete, Geagan, & Druley, 2009; Franks et al., 2006; Grzyswacz et al., 2013; Helgeson et al., 2004; Khan et al., 2013; Martire et al., 2013
Mixed Evidence Regarding the Effects of Social Control has Prompted a Search for Moderators

Moderators are factors that tell us *when* particular effects are likely to occur.
Moderators: Some Examples

- Patients’ preferences/expectations for family members’ involvement
- Patients’ and family members’ relative commitment to disease management
- Relationship satisfaction
Patients’ Preferences for Spousal Involvement Vary

Older couples ($N=129$) in which one spouse has type 2 diabetes

**Open-ended question:**

*Are there things you wish your spouse would do or stop doing in relation to your diabetic diet?*

Strikingly different responses
Desire for *less* spousal social control

• “Yes, stop monitoring me.”
• “Yes, she nags me if I eat the wrong things and it’s hard to hide things from her…It gets on my nerves.”

Desire for *more (or continued)* spousal social control

• “Yes, he should remind me to eat better more often.”
• “No, she keeps me on the ball.”
Patients’ Expectations for Spousal Involvement
Influence Reactions to Social Control

Older couples ($N=191$) in which one spouse has type 2 diabetes

What is behavioral resistance?

- *Doing the opposite* of what the spouse urged
- *Hiding* unsound health behavior from the spouse
- *Ignoring* the spouse’s suggestions

It is not very common in our studies, but is reported by some patients.

Moderators: Examples – cont’d

• Patients’ preferences/expectations for family members’ involvement

• Patients’ and family members’ commitment to disease management

• Relationship satisfaction
Patients’ and Family Members’ Relative Commitment to Managing the Chronic Illness

Family members are sometimes more committed than the patient to managing the patient’s chronic illness.

**Study:** Older couples ($N=129$) coping with type 2 diabetes

**Assessed:** Patients’ and spouses’ commitment to managing the patient’s diabetes.

**Found:** Less committed patients reacted more negatively to spousal control (more resentment and resistance). 

Rook et al. (in progress)
Moderators: Examples – cont’d

• Patients’ preferences/expectations for family members’ involvement

• Patients’ and family members’ commitment to disease management

• Relationship satisfaction
Relationship Satisfaction Influences Reactions to Social Control

Married/cohabitating prostate-cancer patients ($N=109$) following radical prostatectomy

**Assessed:** Patients’ adherence to pelvic floor exercises, negative affect, spouse/partner social control, relationship satisfaction

**Found:** Among patients who reported greater relationship satisfaction, social control was related to:

- greater adherence
- no increase in negative affect

Knoll, Burkert, Scholz, Roigas, & Gralla (2011).
In some contexts, therefore, social control does not elicit negative reactions and may foster greater adherence.

Social control may help patients get back on track after a lapse in adherence.

A peek at some ongoing work
Getting Back on Track after a Lapse in Adherence

Older adults with type 2 diabetes ($N=129$). Collected daily diary data about dietary adherence for 24 days.

- Patients find following a restricted diet every day to be especially difficult, and lapses are common.
- Many patients in our study experienced lapses during the 24-day assessment:
  - 87.6% → one or more lapses
  - 48.1% → two or more lapses
  - 17.1% → three or more lapses

Rook et al., in progress
• Diary days were coded to detect lapses in adherence and recovery and maintenance of adherent behavior (each sequence defined as 2+ consecutive days).

Example: 1 Patient, 1st 11 days
Did the spouse’s support or control help to prevent lapses or to facilitate getting back on track after a lapse? Yes

<table>
<thead>
<tr>
<th></th>
<th>Onset of a Lapse</th>
<th>Recovery of Adherence</th>
<th>Maintenance of Adherence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse support</td>
<td>Helped prevent</td>
<td></td>
<td>Helped facilitate</td>
</tr>
<tr>
<td>Spouse control (persuasion)</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Spouse control (pressure)</td>
<td>--</td>
<td>Helped facilitate</td>
<td>--</td>
</tr>
</tbody>
</table>

Note: Preliminary findings from lagged multilevel models, 24-day diary study
Studies that examine day-to-day shifts (process studies) help to address a key ambiguity:

Social control $\rightarrow$ Poor health behavior? Distress? 

or

Poor health behavior $\rightarrow$ Social control? Distress?

Other analyses revealed some evidence for the latter idea.

Lapses $\rightarrow$ elicit social control and, by themselves, contribute to decreased self-efficacy (*patients react to their own behavior*).

We should be careful not to attribute poor health behavior and low self-efficacy/distress only to social control.
Summing up so far:

• Family members engage in *both support and control* in the context of chronic illness.

• *Support often has positive effects* on patients’ illness management.

• *Control* can have either *positive or negative effects*, depending on *moderating conditions*.

• *Patients do not always resent social control*; some tolerate, appreciate, or welcome it.

Family members may be seen as allies in a tough campaign, even when they apply pressure.
But…

Family members sometimes do not behave like allies → A quick look at undermining.
Undermining

• Indifference – expressing disinterest in or disregard for the patient’s illness management

• Tempting – e.g., offering unhealthy food or eating unhealthy food in the person’s presence

**Examples**: Patients’ comments about the spouse’s role in their type 2 diabetes management

“He just centers on himself.”

“I wish she would listen…be more involved.”

“He eats cookies & ice cream every night. It would be helpful if he didn't.”

Undermining – cont’d

• Relatively rare…but linked to poor health outcomes

Older adults with type 2 diabetes (N=129)\(^1\)

- worse adherence\(^1,2\)
- worse blood glucose control\(^1,2\)

\(^1\)Henry et al. (2013)
\(^2\)Mayberry & Osborn (2012)
Undermining may often be unintentional but nonetheless has negative consequences.
Q3: Are family members themselves affected by their involvement in a loved one’s chronic illness management?

She says:

“This is a better choice than pizza, dear.”

And she thinks:

It’s so much work to get him to eat right.
Are spouses of chronically ill partners burdened by exerting health-related social control?

Kristin J. August¹, Karen S. Rook¹, Mary Ann Parris Stephens², Melissa M. Franks³

Spouses’ Involvement in Their Partners’ Diabetes Management: Associations With Spouse Stress and Perceived Marital Quality

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Key Results: Studies of Effects on Family Members

• Spouses who engage in more social control experience:
  – more stress
  – more tense marital interactions

• This is especially true when their partners resist or resent their involvement

• No evidence of negative effects of engaging in health-related social support.
• It can be frustrating for family members to have intervene when a loved one repeatedly fails to follow a treatment regimen.

Over time, family members may:

→ shift to more frequent or more caustic social control
→ disengage

As reflected in comments from *spouses* of older adults coping with type 2 diabetes…
Open-ended question: Has your involvement in your husband’s [wife’s] illness management changed over time? If so, how?

**Indications of frustration and withdrawal:**

“I don’t monitor his snacks as much - it's hopeless.”

“I have become less involved because he resents my advice and attempts to keep him on his diet.”

“I used to be extremely involved, but he was not doing anything, so I stopped talking.”

“My frustration has gone up. He won’t change.”
Managing Chronic Illness Creates Significant Challenges for Family Members and Patients

It is difficult for...

• patients to maintain steadfast adherence to a demanding treatment regimen.

• family members to observe non-adherence that jeopardizes a loved one’s health.

• family members to balance the desire to be supportive, and to avoid conflict, with the need to urge improved health behavior in a loved one.
Q4: What practical suggestions can be drawn from existing research?

It may be valuable for patients and family members to:

- Discuss their expectations/preferences for their roles in the illness management.
  - Whose illness management task it is? “Mine?” “Ours?”
It may be valuable for patients and family members to...(cont’d):

- *Try to empathize* with their respective challenges -- may help to avoid an impasse.

- **Patients feel misunderstood:** e.g., “You tell me to do [X, Y, Z]. You don’t know how hard it is.”

- **Family members can acknowledge this while also explaining their point of view:** e.g., “You’re right. I don’t know what it’s like to have to do [X, Y, Z]. But you need to do those things to avoid complications, and I have to keep after you because I love you.”
It may be valuable for patients and family members to…(cont’d):

- **Spend time doing something enjoyable together.** Stress interferes with treatment adherence,¹ but companionship helps to reduce everyday stress.²

It may be valuable for **family members** to:

- **Avoid being critical** when they feel the need to use social control.

- **Join the patient**, when feasible, **in making health behavior changes** (e.g., diet, exercise).

- **Avoid undermining** (e.g., avoid eating restricted foods in the patient’s presence).

¹Morris et al. (2011); ²Rook (1987).
Chronic illness is a major, and growing, concern worldwide.

The day-to-day management of a chronic illness often occurs in a social context, with implications for patients and family members.

Helping patients and family members work together to manage a chronic illness is a challenging but worthwhile endeavor.
Acknowledgements

• Collaborators
  • Amber Seidel, MA
  • Kristin August, PhD
  • Melissa Franks, PhD
  • Rachel Hemphill, PhD
  • Shayna Henry, MA
  • Masumi Iida, PhD
  • Cynthia Khan, PhD
  • Megan Lewis, PhD
  • Morris Okun, PhD
  • James Salem, MD
  • Dara Sorkin, PhD
  • Mary Anne Stephens, PhD

• Our Study Participants

• Funding: National Institute on Aging, R01 AG024833

Thank You