

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

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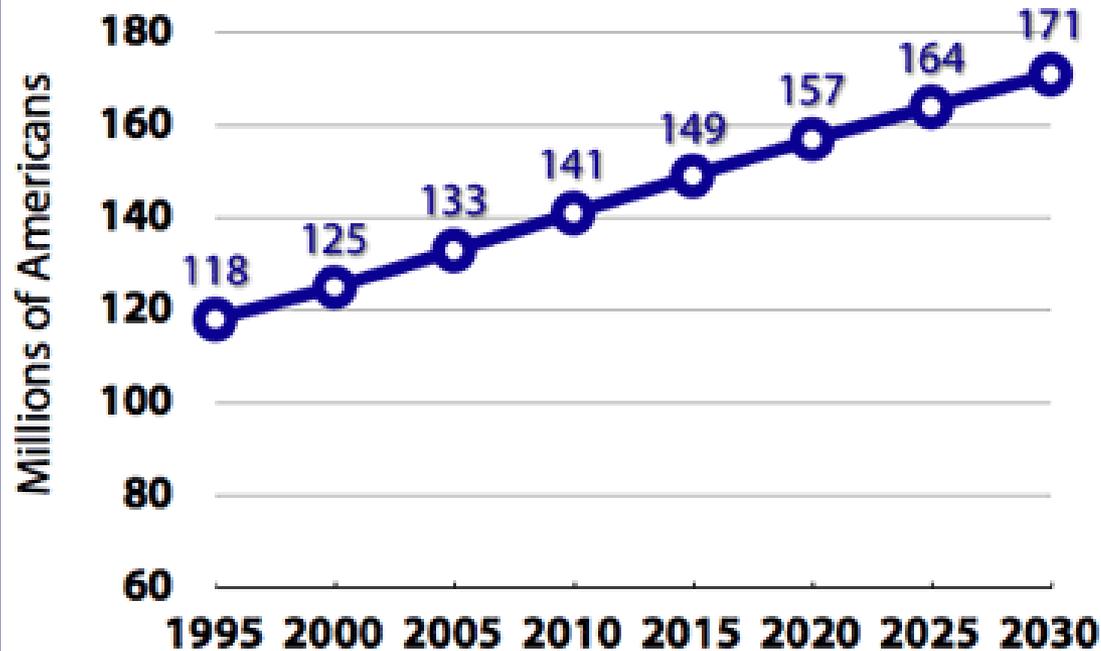


Badger for a day... 😊

“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.”

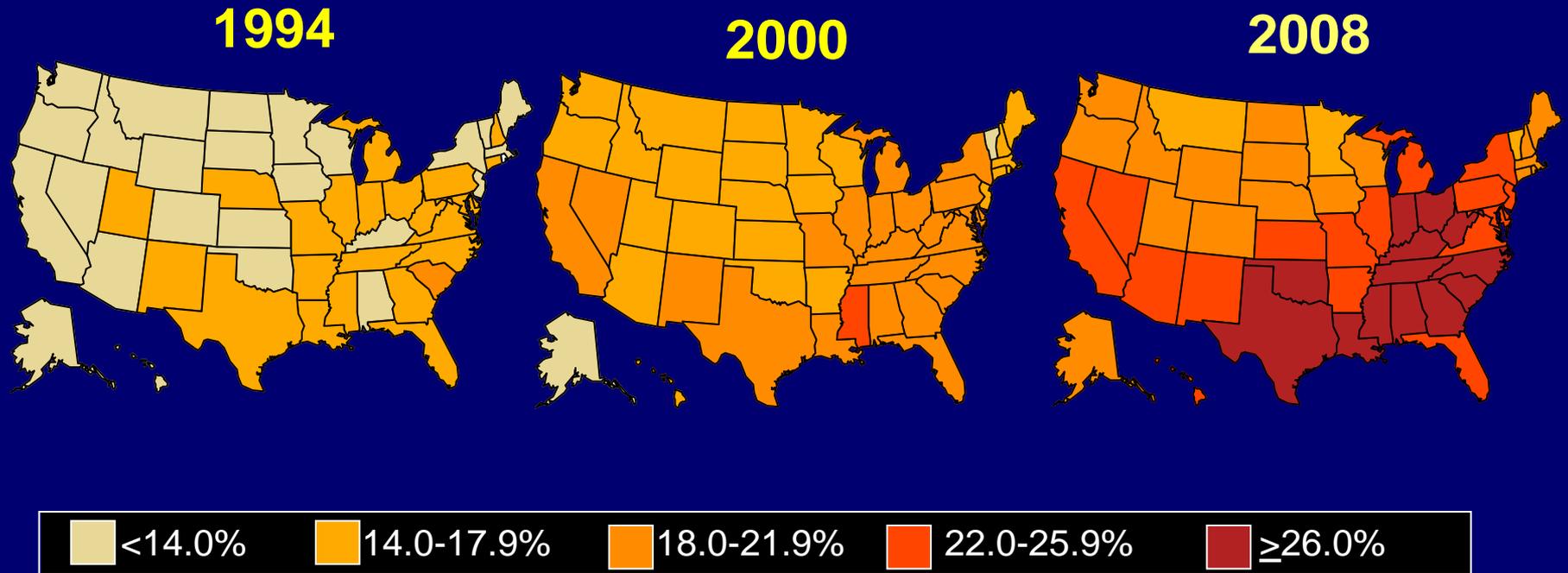
Rates of Chronic Illness are Rising

Prevalence of Chronic Disease in the U.S.

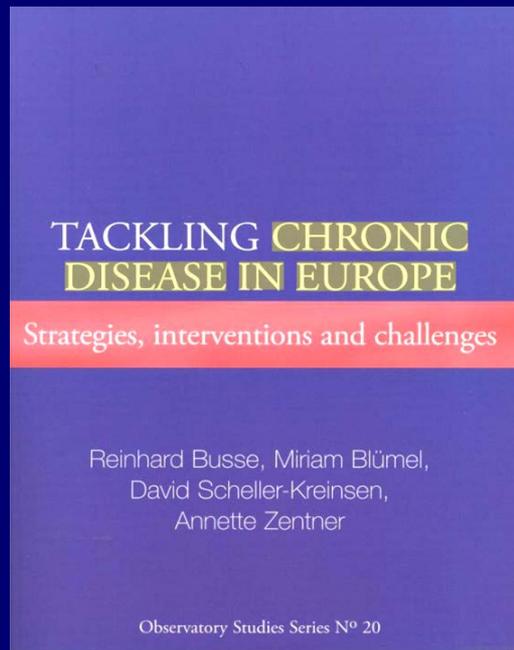


Source: Wu, Shin-Yi *et al.* 2000. Projection of Chronic Illness Prevalence and Cost Inflation. RAND Corporation.

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



Chronic Illness is also a Concern in Europe



EurActiv EU News & Policy Debates **SPECIAL REPORT | 7 - 11 April 2014** With the support of **SANOFI**  

TACKLING CHRONIC DISEASES IN THE EU

<http://www.euractiv.com/sections/tackling-chronic-diseases-eu>

 1 > 7  8 > 14  15 > 21  22 > 30  31 > 37

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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.



Photo: Ammentorp Photography/Shutterstock

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.

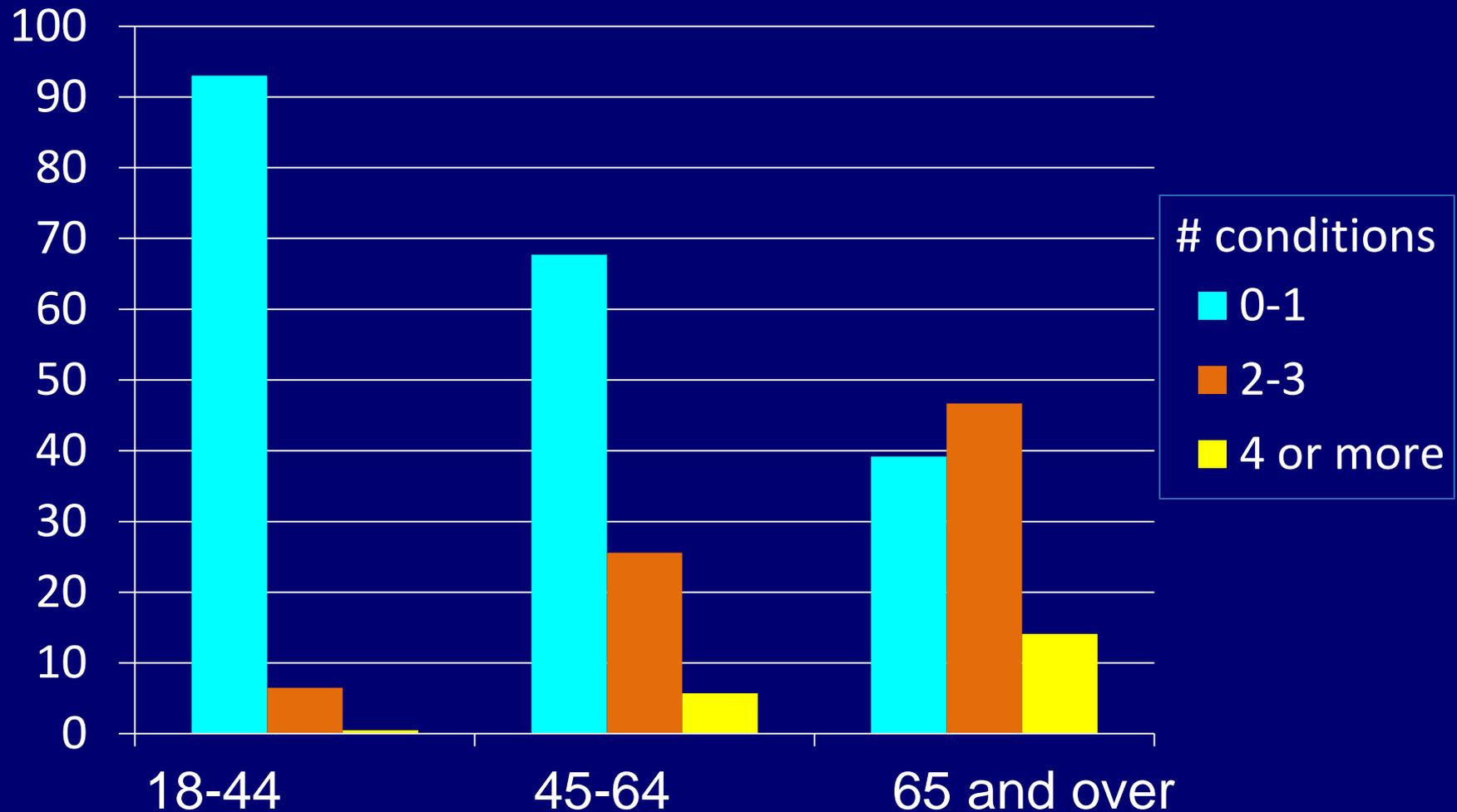


	2005	2015	2030
Deaths (all ages)			
CVD and diabetes	12.4 (33%)	14.3 (35%)	17.3 (36%)
Cancers	4.5 (12%)	5.6 (14%)	7.5 (15%)
Chronic respiratory	3.1 (8%)	4.1 (10%)	5.9 (12%)
All chronic diseases	23.1 (61%)	27.2 (66%)	34.3 (71%)

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

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?
-



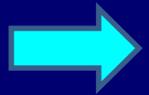
An Exercise for Audience Members

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.

❖ 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*

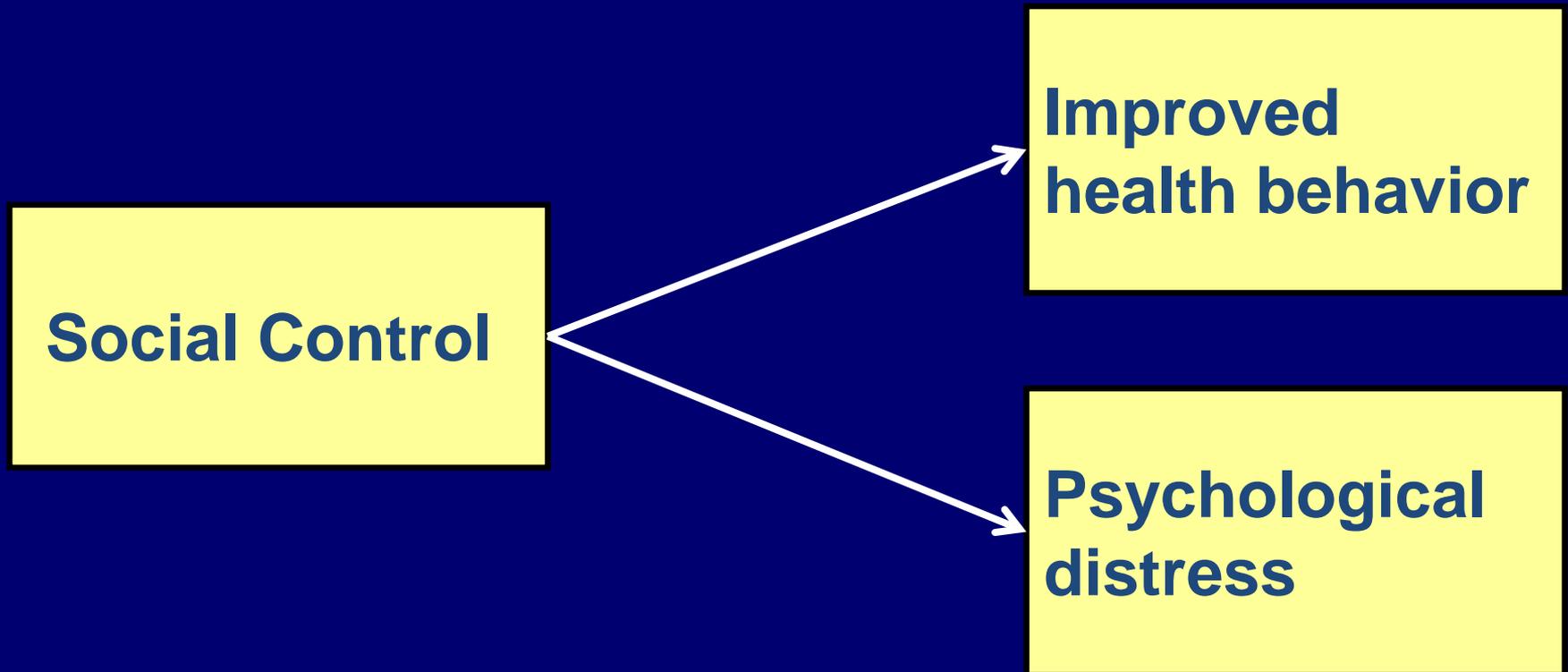
Compared to social support, social control is more likely:

- 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)



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



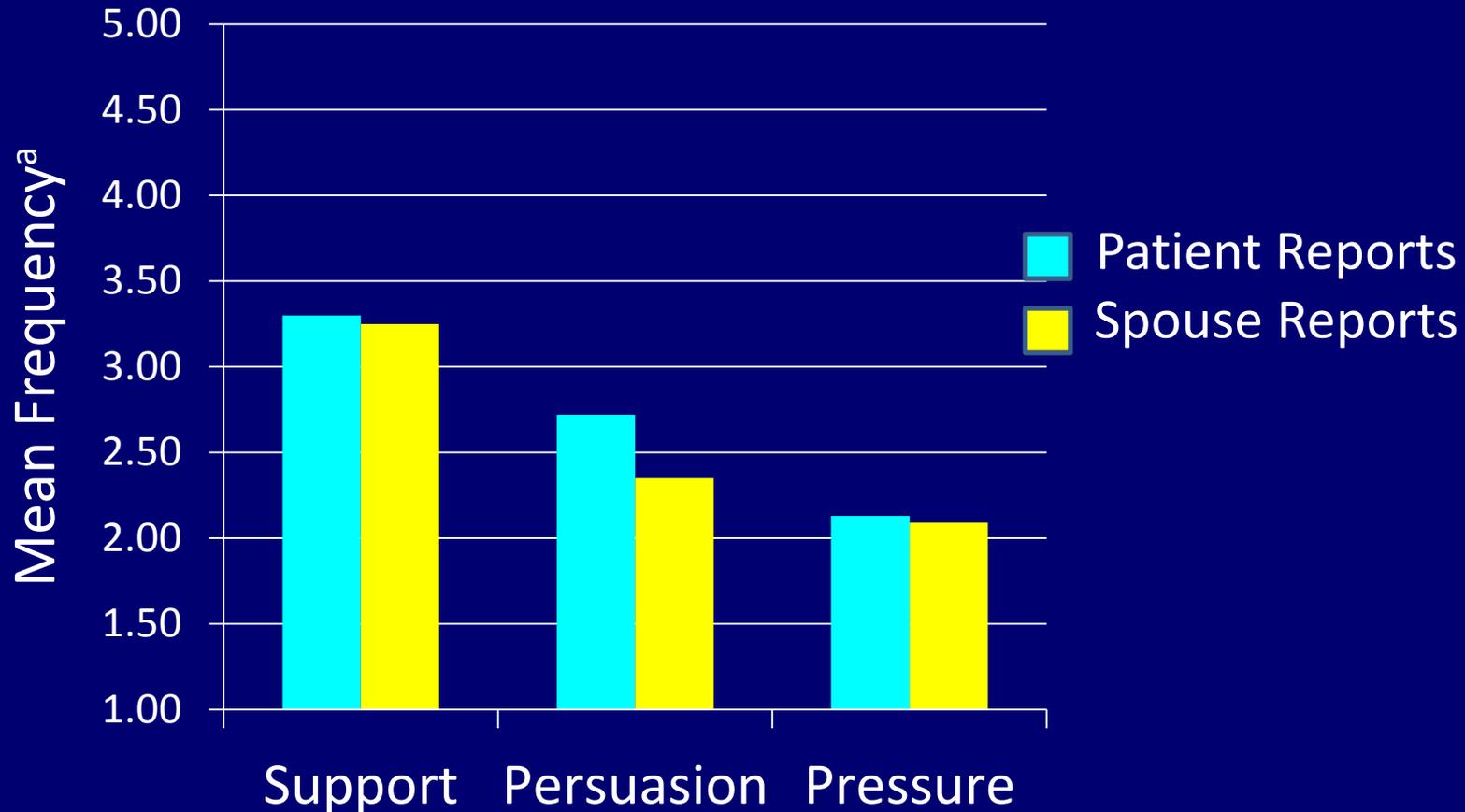
Less forceful vs. more forceful forms of social control are often distinguished (sometimes referred to as *persuasion* vs. *pressure*).

Examples: Less Forceful vs. More Forceful Forms of Social Control (or Persuasion vs. Pressure)

Persuasion	Pressure
Explaining/reasoning	Criticizing
Hinting/suggesting	Inducing guilt or fear
Reminding	Nagging
Bargaining	Threatening/withdrawing
Pointing out positive role models	Drawing comparisons with negative role models

People Understand the Questions and Report Both Support and Control in the Context of Chronic Illness

Older adults with type 2 diabetes ($N=129$)



^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)**

Adherence tasks included:

- Daily physical therapy sessions
- Increasing physical activity at home
- Elevating the affected leg
- Icing the wound
- Taking pain medications



here and elsewhere

Stephens, Fekete, Franks,
Rook, Druley, & Greene (2009)

Adjusted regression coefficients are shown.

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

$b = -.04^*$ (worse)
(among adolescents with high self-efficacy)

Patients' confidence in their illness management

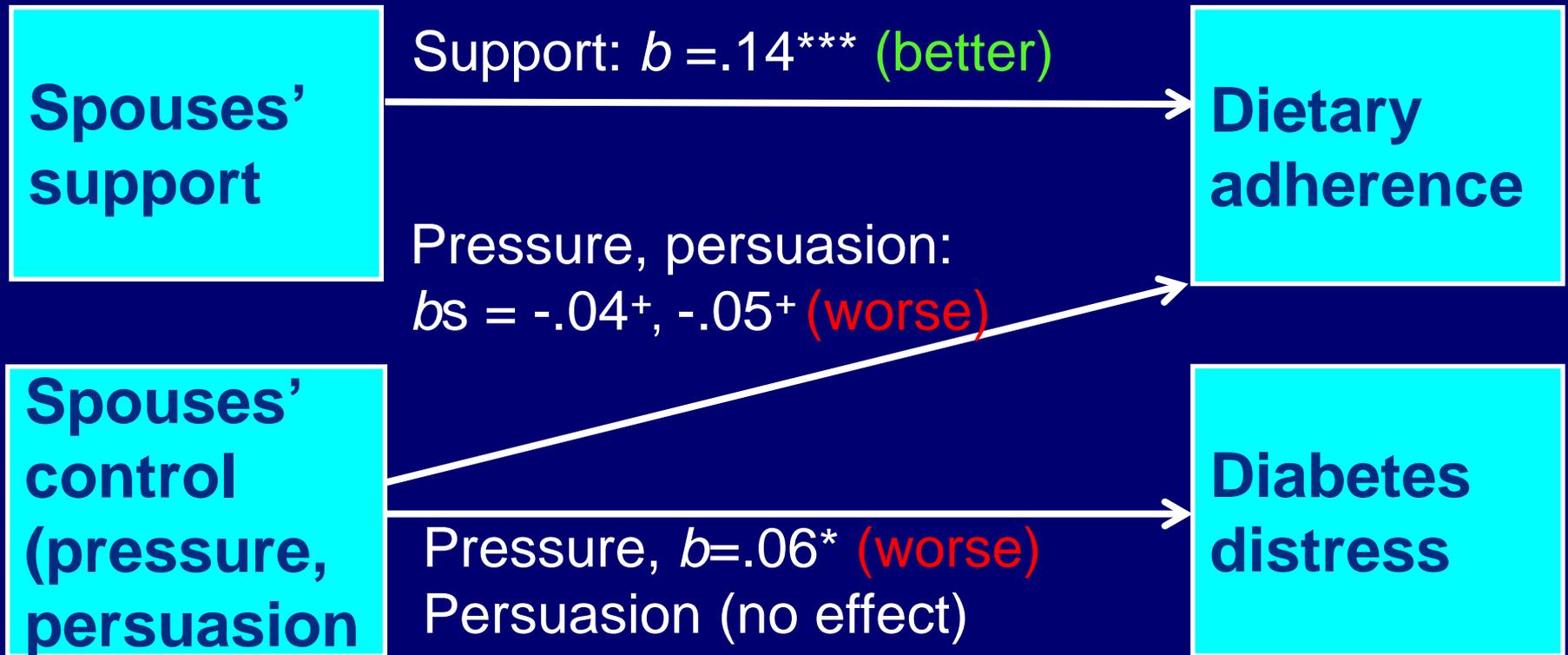


Berg, Butner, Butler, King, Hughes & Wiebe (2013)

Fixed effects from multilevel analyses are shown.

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



Stephens, Franks, Rook, Iida, Hempill, & Salem (2013).

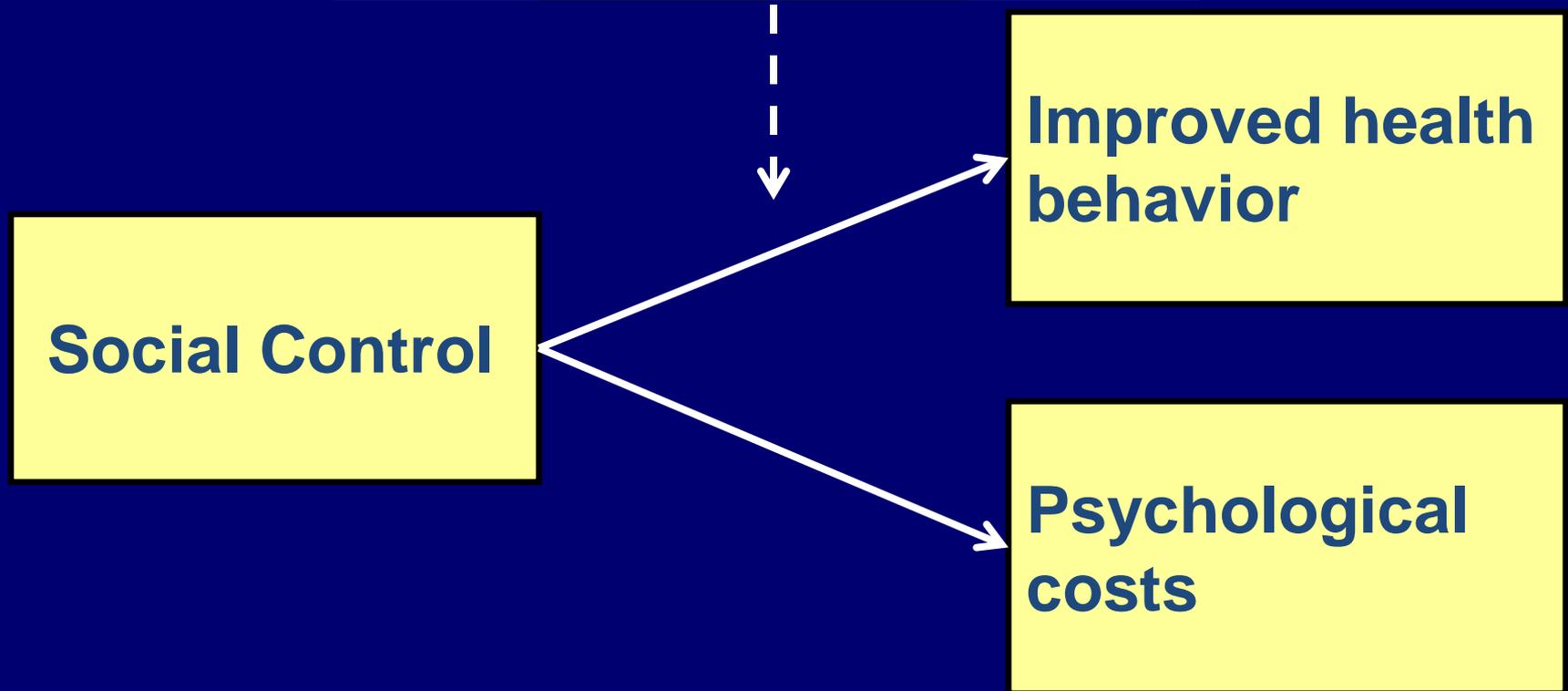
Fixed effects from multilevel analyses are shown.

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.

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).

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 reporter *greater relationship satisfaction*, social control was related to:

- *greater adherence*
- *no increase in negative affect*



- ❖ 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

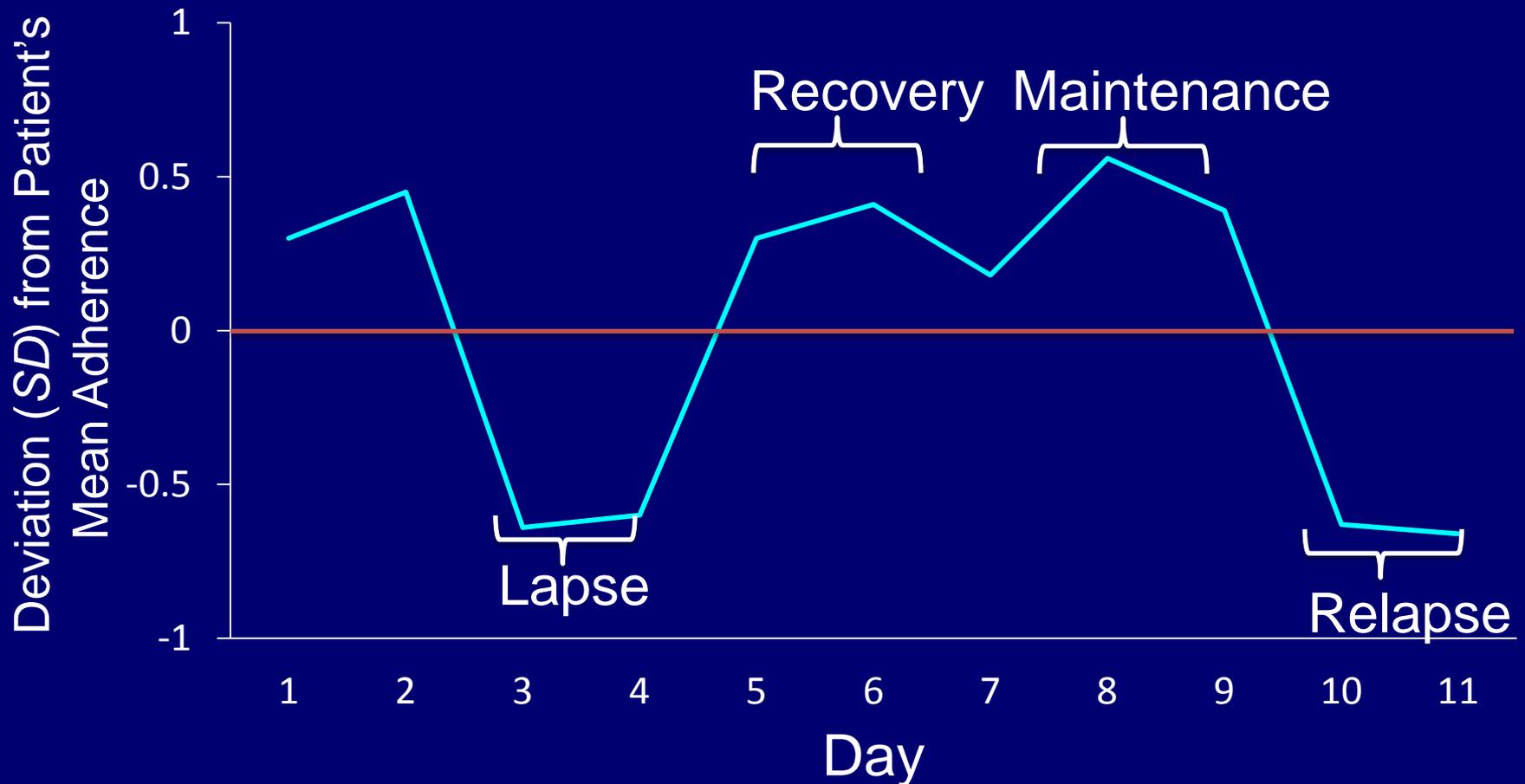
Older adults with type 2 diabetes ($N=129$). Collected daily diary data about dietary adherence for 24 days.

- 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



- 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**

	Onset of a Lapse	Recovery of Adherence	Maintenance of Adherence
Spouse support	Helped prevent	--	Helped facilitate
Spouse control (persuasion)	--	--	--
Spouse control (pressure)	--	Helped facilitate	--

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 → Poor health behavior? Distress?

or

Poor health behavior → Social control? Distress?

- ❖ Other analyses revealed some evidence for the latter idea.

Lapses → 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.”

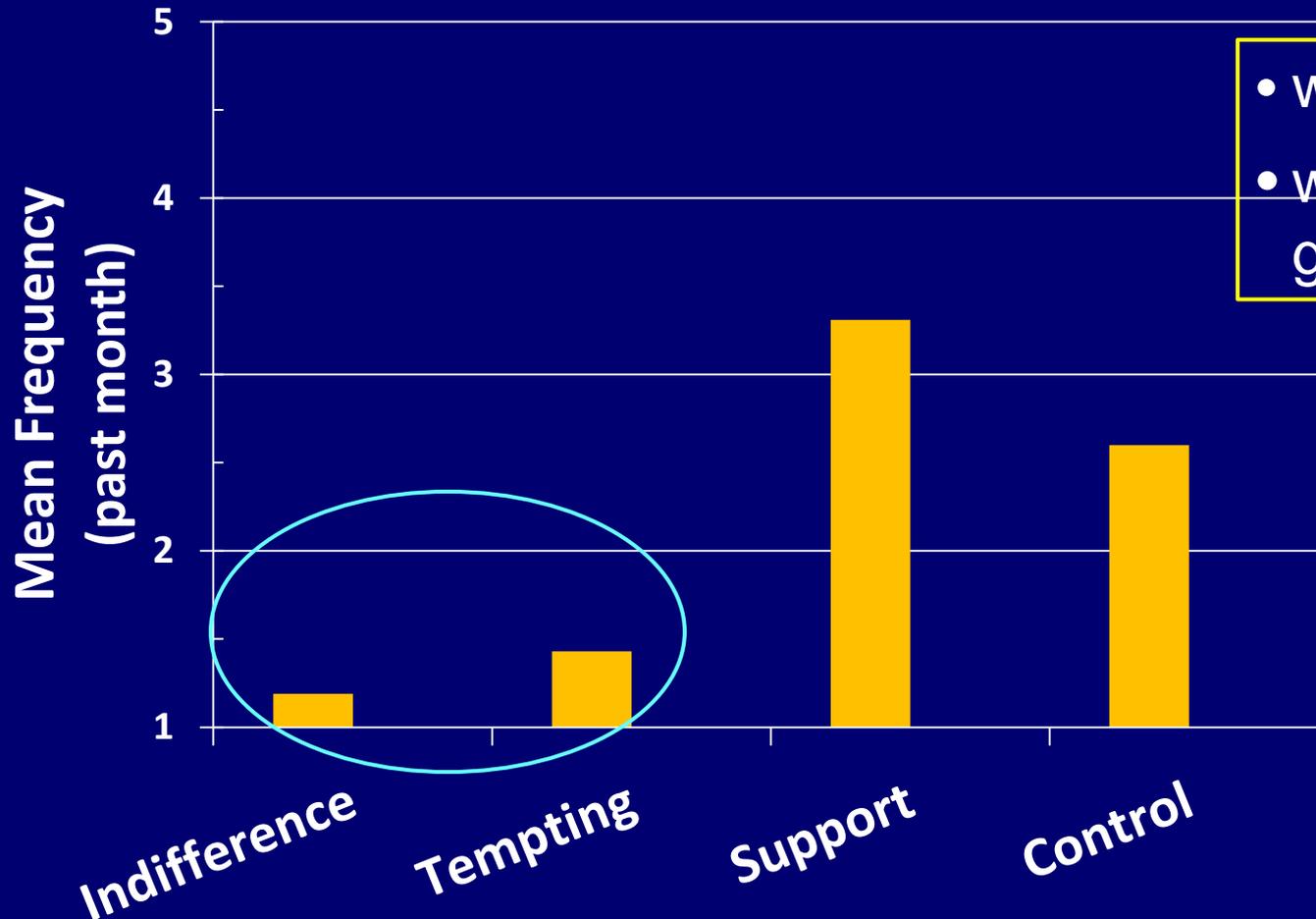
“I wish she would listen...be more involved.”

“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}

¹Henry et al. (2013)

²Mayberry & 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?

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**Key
Results**



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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).

Conclusion

- ❖ 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.

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