

## Reaching Family Caregivers in your Community

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## Disclaimer

- One research grant on family caregiving from Pfizer Canada Foundation: unrestricted...no involvement in study goals, design, operationalization, or data interpretation (MY)

## TODAY'S TALK

- Introduction
- The medical world
- Research on family caregivers and physicians
- History of attempts to link physicians and social service agencies
- Suggested goals and means for recruiting physicians to disseminate caregiver support services

## Introduction

- 4 phases of healthcare and social welfare movements:
  - 1) Study problem
  - 2) Design and study interventions
  - 3) Disseminate findings
  - 4) Change systems of care
- Every movement eventually turns its attention to primary care as portal and point of intervention

## Introduction (cont.)

- Example: Domestic Abuse
- Portal: Screening questions, refer
- Intervention: basic counseling
- Family caregiving movement has turned to primary care in past with mixed results
- Introduction of multidisciplinary "patient-centered medical home" offers new possibilities for making primary care effective portal and point of intervention for family caregivers

## What do medical students learn about family caregivers?

- Mail survey (2) of Canadian Associate Deans, Undergraduate Medical Education (16): 10/16 responded
- Does the topic of "Family Caregiving" receive a dedicated time slot in your 3 or 4 year curriculum? Yes: 3/10
- Time allotted: 0.5hr-2hr.
- Written learning objectives for "Family Caregiving"? Yes: 3/10
- In hospital or ambulatory teaching settings, are there means to ensure that clinical teachers role model concern and interface with caregivers? Yes: 3/10

Yaffe 2004, Unpublished

## What do licensed doctors learn about family caregiving?

- Mail caregiver questionnaire survey of 200 Montreal family doctors : 75% had not attended a CPD activity in previous 3 years that had any discussion about caregivers.

Yaffe & Klvana, Isr. Med Assoc J. 2002

- In UK study only 10% of GPs had received any training about CG health.

Simon & Kendrick, 2001, Br J Gen Practice

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## Factors Affecting Encounters with Caregivers in Primary Care (1)

- Shortage of primary care doctors
- Chronic care is time-consuming
- US Preventive Services Task Force estimates 7.4 hrs/day needed for doctors to address 70+ CPGs. Where is the time for acute pt.care, or CG support?

Yarnall et al, Am. J. Public Health 2003

- "Family doctors have so many problems in so many disciplines to be familiar with...we have difficulty remembering who to approach for what kind of help....or who to refer people to..."

Sussman, McCusker, Yaffe et al, in submission

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## Factors Affecting Encounters with Caregivers in Primary Care (2)

- Family doctors are aware of (only) 25% of their patients good or bad life events.
- Fewer than ¼ of U.K. GPs record in chart if someone was a caregiver.
- Multidisciplinary, interdisciplinary, managed care, collaborative models (nurse practitioners, physician assistants...) for chronic care advocated, but not enough research or "on-site" data to show that they make a great difference across a range of medical or economic outcome variables .....Impact on caregivers not well-researched.

Yaffe & Stewart, Medical Care 1983

Simon & Kendrick, 2001, Br J Gen Practice

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## Family Doctors' perspectives on elderly patient-family caregiver-doctor encounters (1)

- Mail survey, 200 Montreal fam docs (72% RR) :
- 94% felt they were meeting CG needs.
- Stat. signif. number indicated lack of knowledge about community resources.

Yaffe & Klvana, Isr. Med Assoc.J. 2002

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## Use of educational / community resource materials.

- Only 16.9% of Montreal fam. docs. maintained office lists of community resources for caregivers.
- Focus groups in 4 regions of Province of Quebec with purposeful sample of family doctors doing frequent elder care (dementia): "Not my job to keep resource lists ....difficult to maintain up to date lists"
- Only 7% of U.K. GPs actively gave educational or written information; more did so on request; just under half kept info in waiting rooms.
- GPs in France strongly favor use of materials on community resources.....but favor distribution by others.
- AMA guidelines for dementia care recommend a designated office staff member with expertise on community resources.....Does that occur?

Yaffe & Klvana, Isr. Med Assoc.J. 2002

Yaffe et al. Canadian Family Physician 2008.

Simon & Kendrick, 2001, Br J Gen Practice

Fantino et al. Sante publique, 2007.

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## Factors Affecting Encounters with Caregivers in Primary Care (3)

- CG and patients have different agendas 63%
- Pts. reluctant to use suggested resources 62%
- CG and elderly have different /conflicting responses to doctors' suggestions 51%
- CG reluctant to use community resources 42%
- CG intrudes into care of elderly patient 31%

Yaffe & Klvana, Isr. Med Assoc.J. 2002

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## Doctor as “Expert” may clash with caregiver “Receptivity”

- **Systematic, on-line review: 3525 abstracts reviewed for possible relevance; 47 papers and 1 book reviewed in entirety.**

(Yaffe, 2008, unpublished)

- **Fragmented, disparate literature.....little aimed at MDs.**
- **Degree of confidence, trust, credibility established in the doctor-patient-caregiver encounter impacts on receptivity**
- **Doctors need to evaluate readiness of patient/family to consider new options of care.**

(Wilkinson et al 2004)

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## Factors Affecting Encounters with Caregivers in Primary Care (4)

- **Australian GPs appear to try to help caregivers, but are at a loss when it comes to responding to emotional needs.**

Bulsara & Flynn, BMC Family Practice 2006

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## What would help doctors help CGs of those with dementia?

- ***Recognition that physicians are NOT the answer to most caregivers' needs — support resources are!***

Yaffe et al. Canadian Family Physician 2008

- This may be the starting point when AAAs and social service workers consider what they can expect of doctors.

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## Paradoxical Behaviors of MDs

- **Low use of printed material for caregivers.**
- **Quebec doctors don't use support services like Alzheimer Societies.**
- **U.S. doctors in the mid-west also report limited use of Alzheimer Societies-- interpreted as doctor difficulty shifting from "curing to caring".**

Yaffe et al. Canadian Family Physician 2008.

Jogerst et al.

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## What might be taught to Primary Care Physicians about Caregiving? (1)

- **Medical /societal changes that have promoted the rise in family CG.**
- **The chronic disease model**
- **Issues of CG. across the lifespan**
- **Impact that health belief models and family attitudes to seeking and /or accepting help play in problem-solving.**
- **Family systems theory (including issues such as enmeshment and communication patterns).**

Yaffe & Jacobs. Canadian Family Physician, 2008

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## What might be taught to Primary Care Physicians about Caregiving? (2)

- **Patient and family experience with illness**
- **Gender differences in CG.**
- **Physical, mental, financial, family, & vocational consequences of CG.**
- **Somatic symptoms-- possible reflection of CG distress.**
- **Techniques, inventories to evaluate CG burden/ roles, interactions.**

Yaffe & Jacobs. Canadian Family Physician, 2008

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## What might be taught to Primary Care Physicians about Caregiving? (3)

- Strengths, weaknesses of health care team members working with CGs.
- Barriers in patient-caregiver-doctor triad & conflict resolution skills.
- Ethical Issues (patient needs vs. CG needs)
- Caregiving career or trajectory
- Caregiver "readiness"  
Yaffe & Jacobs. Canadian Family Physician, 2008
- Sentinel events as predictors of caregiver distress: Eg. Pt. Visit to E.R.  
Sewitch, Yaffe, et al BMC Family Practice 2006

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## Does doctor education about caregiving make a difference?

- 2 yr. U.K. partnership (Princess Royal Trust for Caregivers and RCGP) to improve MD knowledge & understanding of CGs. (2006):
- Training about caregiving was positively associated with flagging charts as to who was a caregiver, and with increased CG follow-up.

(Carers at the Heart of 21<sup>st</sup>-Century Families & Communities)

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## Educating Doctors about Caregiving

- 2008: UK project to establish a national registry of CGs to send to MDs a list of CGs in their practices.
- 2008: A U.K. partnership\* (Dept. of Health and RCGP) to develop, pilot, & evaluate training programs for GPs about CG across the lifespan. This will extend to annual health care checks on CGs.

(Carers at the Heart of 21<sup>st</sup>-Century Families & Communities)

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## Past efforts to recruit physicians to refer family caregivers to AAAs

- "Making the Link"—3-year (2002-05), AoA-funded initiative by National Association of Area Agencies on Aging, endorsed by major medical organizations
- Consisted of guide for agencies to reach out to physicians (sample letter, labels, etc.) and Physician Resource Kit (local resource materials, assessment tool, educational article)
- Supported by national promotional campaign

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## Making the link (cont.)

- Outcomes: over 200 AAAs signed up; increased referrals from physicians' offices; increased physician awareness of caregiver issues
- BUT didn't lead to many sustainable partnerships between MDs-AAAs
- Family caregiving still receives scant attention in medical journals, practice
- Too far ahead of the curve? Right infrastructure not in place?

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## Northern California Chronic Care Network for Dementia

- Partnership of managed care, community-based care, consumer education, advocacy, funded by California Healthcare Foundation (1998-2004)
- Among initiatives, system of faxed referrals of names of patients and caregivers to local Alzheimers Association from physicians
- Greatly increased utilization of support services by families and in more timely fashion—within 6 months rather than 2 years

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## NYUCI in Primary Care

- RCI-funded initiative to disseminate highly touted NYUCI through several rural Vermont primary care practices (Fletcher-Allen); on site services a la patient-centered medical home
- As per Anita Royer (NYUCI supervisor on site), 1<sup>st</sup> year outcomes included decreased caregiver depression, increased caregiver self-appraisal of health, increased AAA referrals, high physician satisfaction

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## How to foster AAA-MD partnerships

- Goals: Increased referrals of caregivers from MDs to AAAs
- Easy access for MDs to reach AAAs:
  - "Case support is more helpful than printed materials or handouts... We want information that is just in time".
- Rapid response with feedback loops to reassure MDs that referral has triggered action
- Need to overcome confidentiality barriers

Sussman, McCusker, Yaffe et al, in submission

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## Systems issues

- Identify "physician relations" point person—routine in domestic abuse
- Identify health system/practice contacts (in PCMH model, probably not a physician)
- Create means of identifying family caregivers in physicians' practices—e.g., question on registration form, flag in charts

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## Systems issues (cont.)

- Create dependable mechanisms for rapid referral, response, feedback—e.g., templated forms for local health system's EMR (akin to "e-prescribing"), dedicated fax/email systems—phone not ideal for many MDs.
- Try to customize to doctor's identified preference..... Remember: Electronics is not a panacea.....no studies to date showing they make a positive impact on care outcomes
- Lobby your state association of AAAs to join efforts with chronic care collaboratives

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## Possible Roles for AAAs (1)

- Promote local physician "champions" of caregiver care to give talks.
- If no local champion or speaker, consider "outside firemen" (often more influential).
- Annual award or recognition of champions.
- Co-sponsor (with local medical societies) CME (continuing medical education) programs on family caregiving.....Go to the doctors, they will rarely come to you.

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## Possible Roles for AAAs (2)

- Discuss Guidelines for doctors: American College of Physicians & 10 other professional societies: Guidance to MDs for developing mutually supportive patient-physician-caregiver relationships.  
Mitnick S et al, J Gen Intern Med. 2010
- Content of article well-researched and credible (not new or revolutionary.....but stated by medical organizations.
- Journal excellent, high impact, but not read by average clinician....Takes time for message to filter down.

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### Possible Roles for AAAs (3)

- Disseminate 2009 American College of Physicians MD-caregiver guidelines:

[www.springerlink.com/openurl.asp?genre=article&id=doi:10.1007/s11606-009-1206-3](http://www.springerlink.com/openurl.asp?genre=article&id=doi:10.1007/s11606-009-1206-3)

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### Possible Roles for AAAs (4)

- Promotion campaign to doctors to clearly flag in charts who is family caregiver.
  - e.g. supply caregiver identification decals for charts; include contact number for AAA on them

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### Supporting Primary Care Doctors

- In outreach to doctors go with your strengths....where you think you have credibility & competency.
- Content may be reflective of local issues, or draw it from theme areas suggested.
- Doctors will have varying openness, and needs for information.
- Development a hierarchy of shared info: what is essential—important—worthwhile.

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### What can AAAs expect from doctors?

- Variability, overall
- May or may not know who is a caregiver
- Attentiveness to physical health
- A range of responses to mental health and social issues
- BUT if you make their lives easier by rapid response and on-going simple feedback (flag your charts to give regular reports) most MDs will gradually embrace you as partners in care

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