Thirteenth Family Research Network (FRN) Forum

"Familial Caregivers and their Impact on the Resilience of Family Function"

Monday, 27 April 2015
Auditorium, Level 1, Civil Service College

family research network

MSF

Lee Kuan Yew School of Public Policy
National University of Singapore

IPS Institute of Policy Studies

THIRTEENTH FAMILY RESEARCH NETWORK (FRN) FORUM:
“FAMILIAL CAREGIVERS AND THEIR IMPACT ON THE RESILIENCE OF FAMILY FUNCTION”
27 APRIL 2015

PRESENTATION I

Family Caregivers as Partners in Health Care Provision: The Case of Mental Health

Dr Stella Quah
Adjunct Professor
Health Services & Systems Research Program
Duke-NUS Graduate Medical School Singapore

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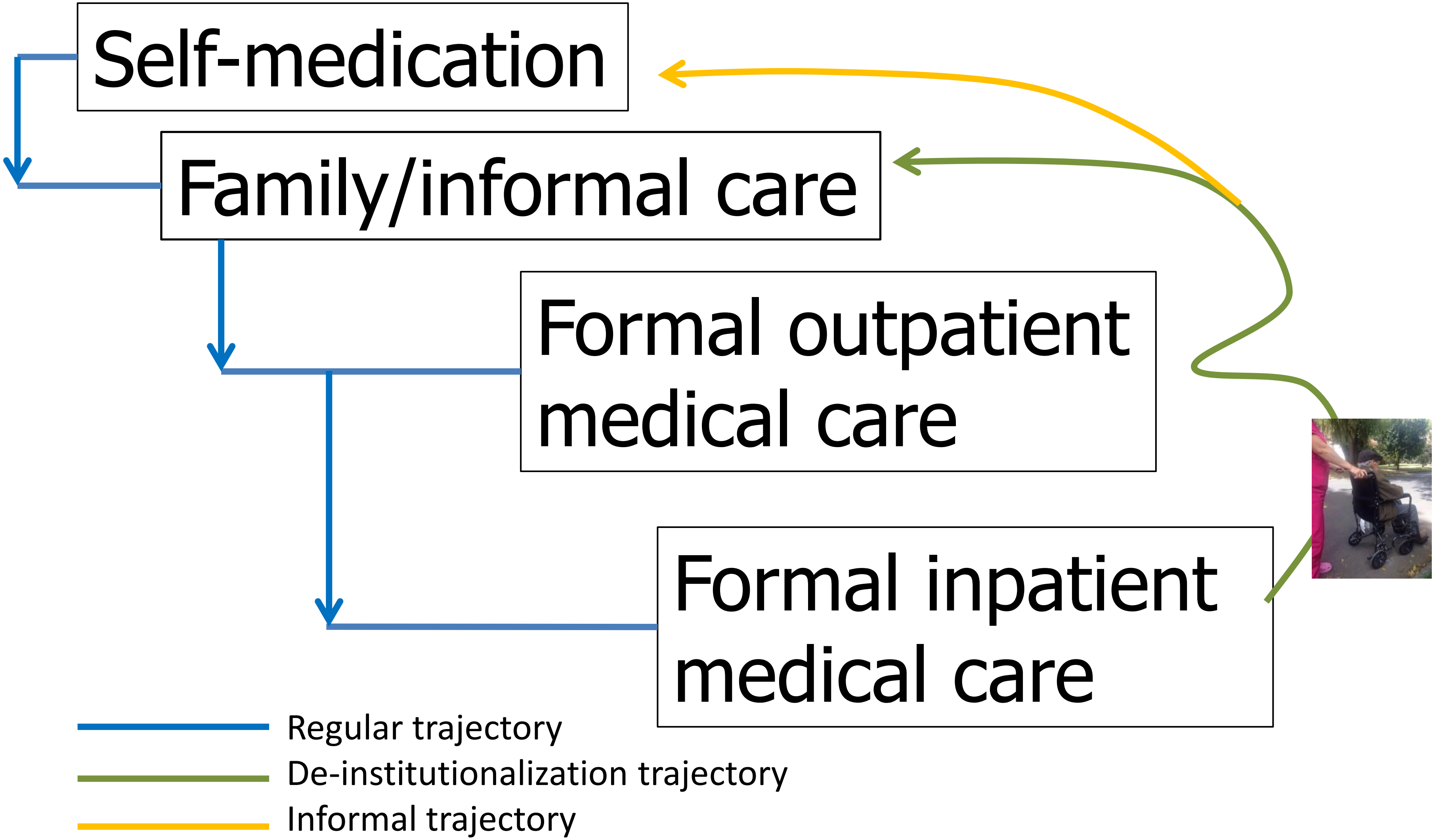
DUKE NUS
GRADUATE MEDICAL SCHOOL SINGAPORE

Families as partners in health care provision:
the case of mental illness

13th Family Research Network Forum
"Building Resilient Families Living With Disability".
27th April 2015, 2.00 - 5.30pm, Civil Service College Auditorium

Stella R. **Quah** (PhD)
Adjunct Professor
Health Services & Systems Research
Duke-NUS Graduate Medical School
http://www.stellarquah.com/; http://www.duke-nus.edu.sg .

Typical care trajectory



- Regular trajectory
- De-institutionalization trajectory
- Informal trajectory

1. Who is the family caregiver?

☐ Immediate family member of the patient;
☐ Supports the patient financially either alone or in cooperation with others;
☐ Is the most frequent collaborator in the patient’s treatment; and
☐ Serves as the main contact for medical staff in case of emergency.

The family caregiver takes on the additional duty because of his/her commitment and cultural norms.

2. Shifting burden of care from medical team to family caregiver

The health system’s ‘de-institutionalization movement’ is based on two main premises:

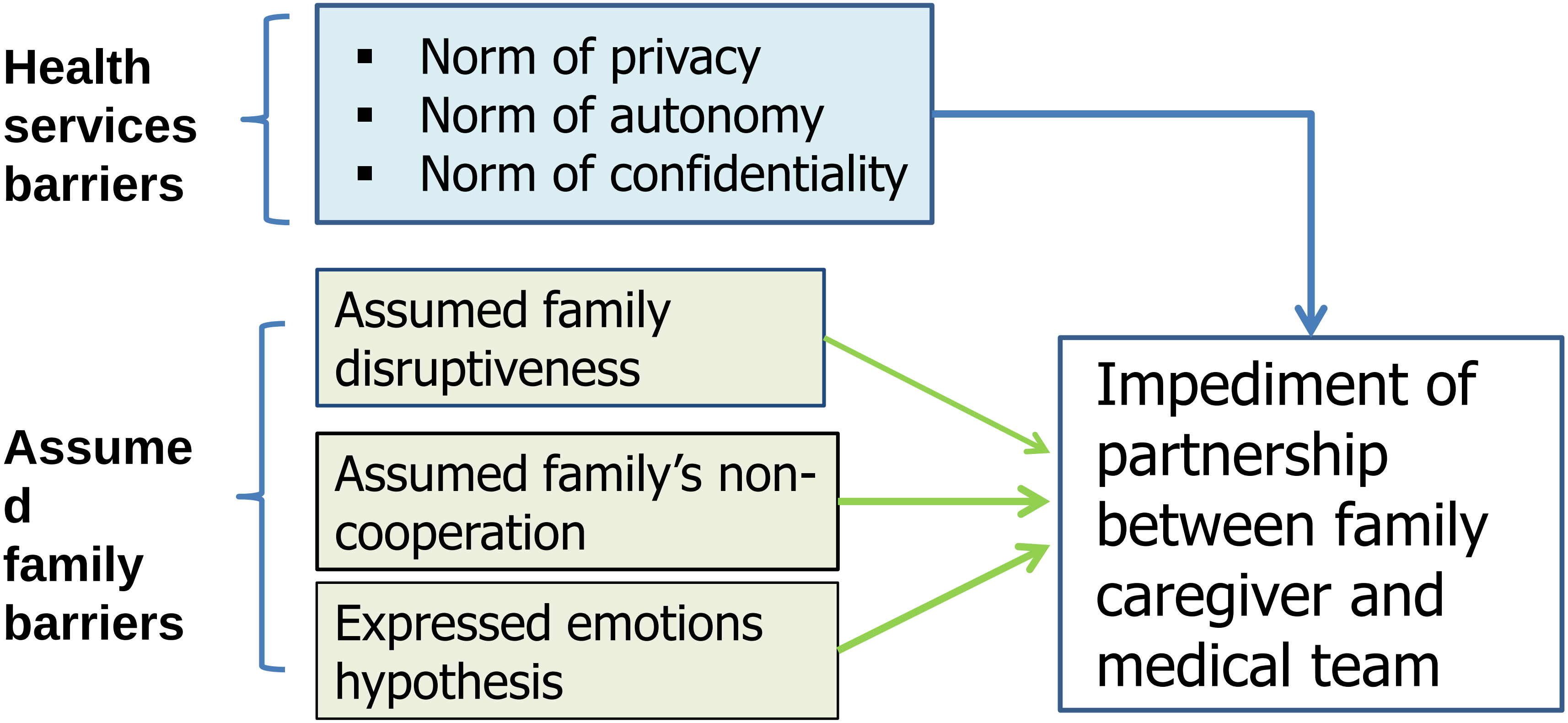
- Better management of limited health care resources [personnel, equipment, budget]; and
- Hope of improvement in patient’s health condition when returned to the community (to his/her family).

BUT a key element is missing: The effective cooperation between the medical team and the family caregiver.

- ✓ The family caregiver as a medic by proxy, is responsible for the well-being of the patient at home; however,
- ✓ The design of medical services excludes the family caregiver from the medical treatment team.

3. Research hypotheses

Two types of barriers impede effective partnership between family caregiver and medical team



Health services barriers

- Norm of privacy
- Norm of autonomy
- Norm of confidentiality

Assumed family barriers

Assumed family disruptiveness

Assumed family's non-cooperation

Expressed emotions hypothesis

Impediment of partnership between family caregiver and medical team

4. Types of care burden faced by the family caregiver

a. Burden varies with nature/type of illness
b. Provision of care is daily and continuous
c. Practical direct care provided at home involves:
   - **Clinical** tasks (i.e., dispensing medications, monitoring illness signs and behaviour including personal hygiene, recording medical appointments, requesting ambulance services)
   - **Housekeeping** tasks (i.e., cleaning, preparation and dispensing of meals, laundry)
   - **Financial** support and budgeting

d. Affective care
   - Love, companionship
   - Moral support, advice, encouragement

5. Study details

- A purposive sample of 47 family caregivers
- Snowballing technique
- Informed consent
- Subjects were asked to choose their interview venue, date and time, as well as the language of the interview. Venues included workplaces, public places such as libraries and coffee shops, private homes and organizations' meeting rooms
- Personal in-depth interviews using both qualitative and quantitative measurement of predictors, care burden, and contact between family caregiver and medical team.

Quah, S.R. (2014) "Caring for persons with schizophrenia at home: Examining the link between family caregivers' role distress and quality of life," ***Sociology of Health & Illness*, 36, 4: 596-612.**

6. FINDINGS from the larger study on family barriers and the need for effective cooperation between family caregiver and medical team

6.1 Dealing with the patient at home increases significantly the family caregiver's stress level (Table 1) and lower their quality of life (Table 2).

6.2 The family caregivers most affected are parents of the patient (Chart 1).

6.3 The majority (94%) of family caregivers express the need for information and guidance from the medical team to do a good job at home caring for their loved ones sick (Table 3).

6.4 The expressed emotions hypothesis was not supported by the data: Relapses are significantly associated with a discontinuation of medication by the patient against the best efforts of the family caregiver to persuade the patient to take the medication as prescribed (Charts 2, 3).

Table 1. Family caregivers’ personal distress		% who felt this “occasionally” or “frequently”
1	Do you ever get depressed by the situation?	91.5
2	Do you ever feel that you need a break?	89.4
3	Do you ever feel frustrated at times with your loved one?	85.1
4	Do you ever get crossed or angry with your loved one?	83.0
5	Has your health suffered at all?	80.9
6	Feeling that there is no end to the problem?	78.7
7	Worrying about accidents happening to your loved one?	76.6
8	Do you ever feel you can no longer cope?	74.5

Table 2- Spearman correlation of Role Distress Seriousness and Quality of Life among family caregivers with and without Role Overload[1]

Quality of Life Domains[2]	Role distress seriousness[3]	Role overload (Hours of Care)[4]	
		No (6 hours or less)	Yes (More than 6 hours)
Domain 1 “Physical functioning”	-.500 (.0001)	-.191 (.400)	-.686 (.0001)
Domain 2 “Mental health”	-.515 (.0001)	-.304 (.180)	-.490 (.011)
Domain 3 “Social support network”	-.340 (.020)	-.304 (.180)	-.522 (.006)
Domain 4 “Living conditions”	-.470 (.001)	-.070 (.763)	-.674 (.0001)

1. Spearman coefficients and level of significance (in brackets).
2. The four domains are identified by WHO (WHO, 2004) as described in Table 1.
3. Correlation between total role distress seriousness score and each of the four domains of Quality of Life.
4. Correlation between distress seriousness and each quality of life domain calculated independently for each one of two groups of family caregivers: those with no role overload and those in a situation of role overload. Role overload is ascertained by the estimated hours of care per day: role overload is absent when the hours of care are below the mean, that is, less than 6 hours per day. Role overload is present when the hours of care are “High”, that is, above the mean, or briefly, 6 hours or longer. The mean number of daily hours of care for all subjects is 6.79 (SD = 3.189).

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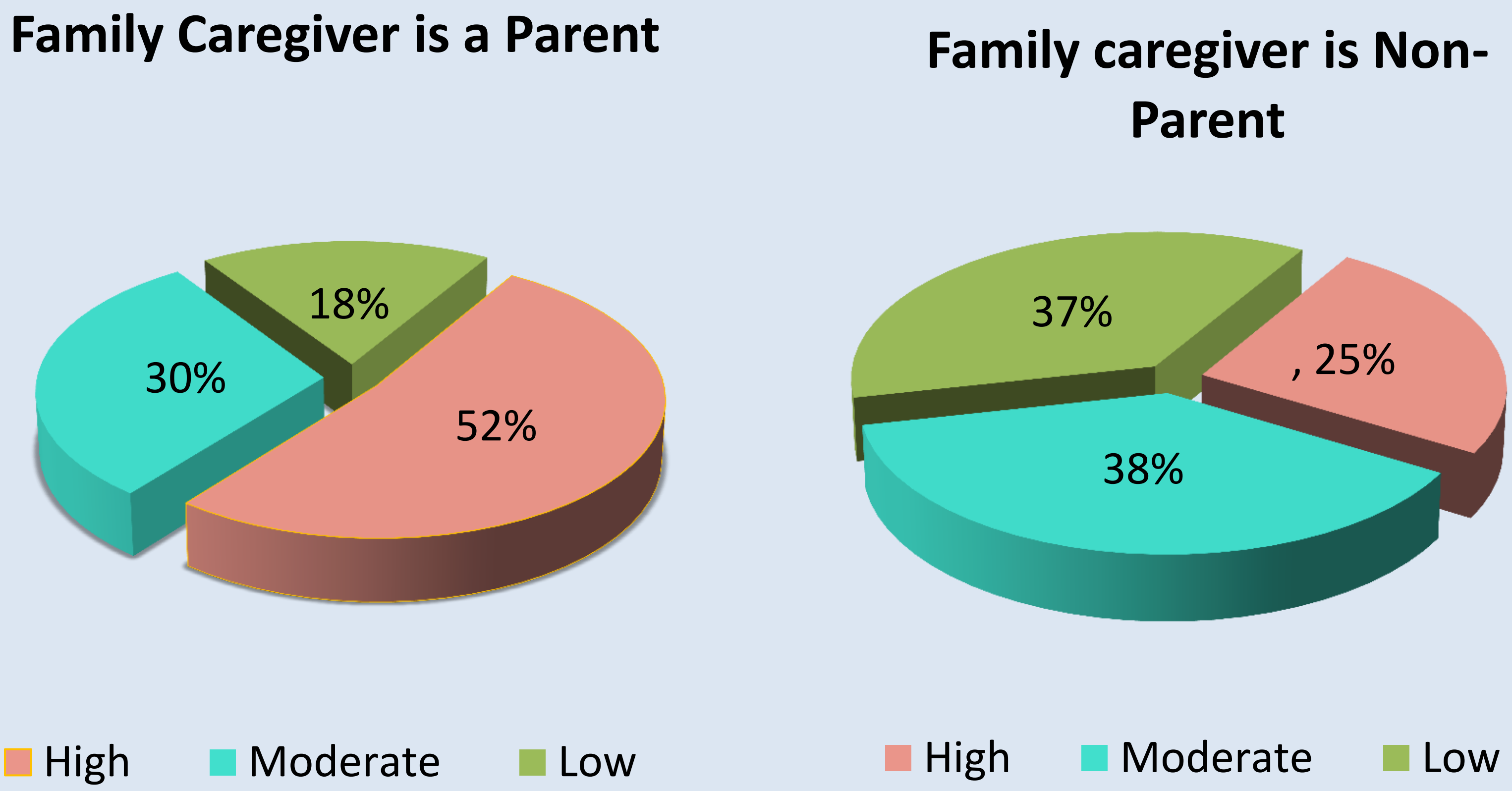
Chart 1. Role distress scores of family caregivers who are parents and non-parents of patient



Family Caregiver is a Parent

Family caregiver is Non-Parent

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Table 3. Predictors of Family Caregivers' contact with Mental Health Medical Team – Odds Ratio Estimates (N = 47)[a]

Predictors		Probability of contact	(95% CI)[b]
Age	Below 53	.487	(.244 - .972)
	53 and older	*1.855	(1.036 - 3.323)
Social network	Satisfactory	.291	(.103 - .822)
	Unsatisfactory	***2.560	(1.444 - 4.540
Work status	Employed	.391	(.186 - .823)
	Not working	**2.217	(1,198 – 4.104)
Kin relation	Parent	**2.036	(1.100 – 3.769)
	Non-parent	.447	(.224 - .893)

a. Family caregivers' (CGs) contact refers to their inclination to seek biomedical health services (as opposed to other forms of help including traditional healing) for the diagnosis of symptoms, treatment, and help during the loved one's crises. The odds ratio (OR) coefficient is a standardized measure of association and risk estimate or ratio of the proportion of subjects exposed to different levels of the predictor or explanatory variable.

b. The associated standard error is presented as 95% confidence intervals (CI). The statistical significant level p is denoted as follows: (*) p = .020 to .050; (**) p = .002 to .019; (***) p = .001 or lower.

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Chart 2. Frequency of hospitalization due to relapse

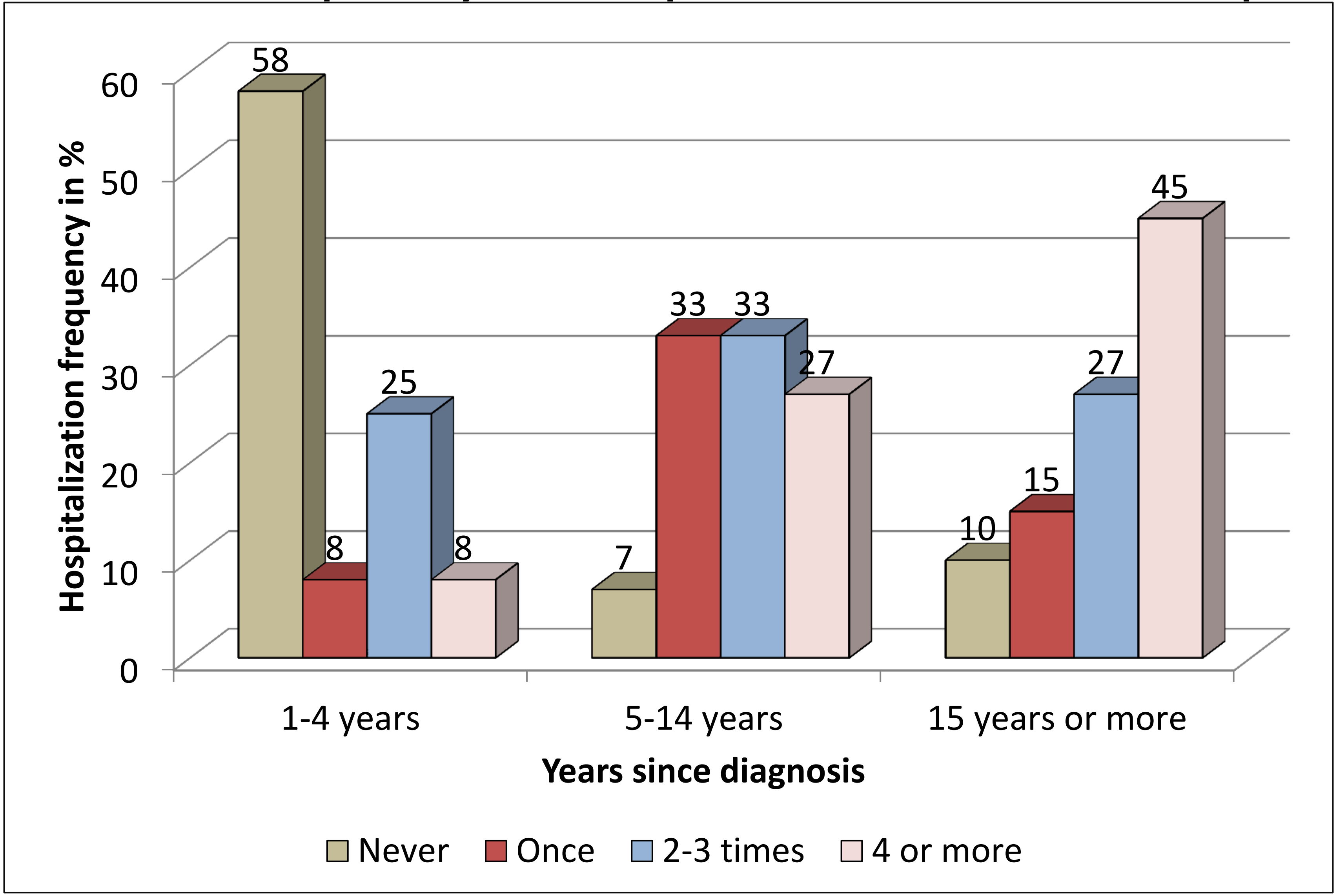
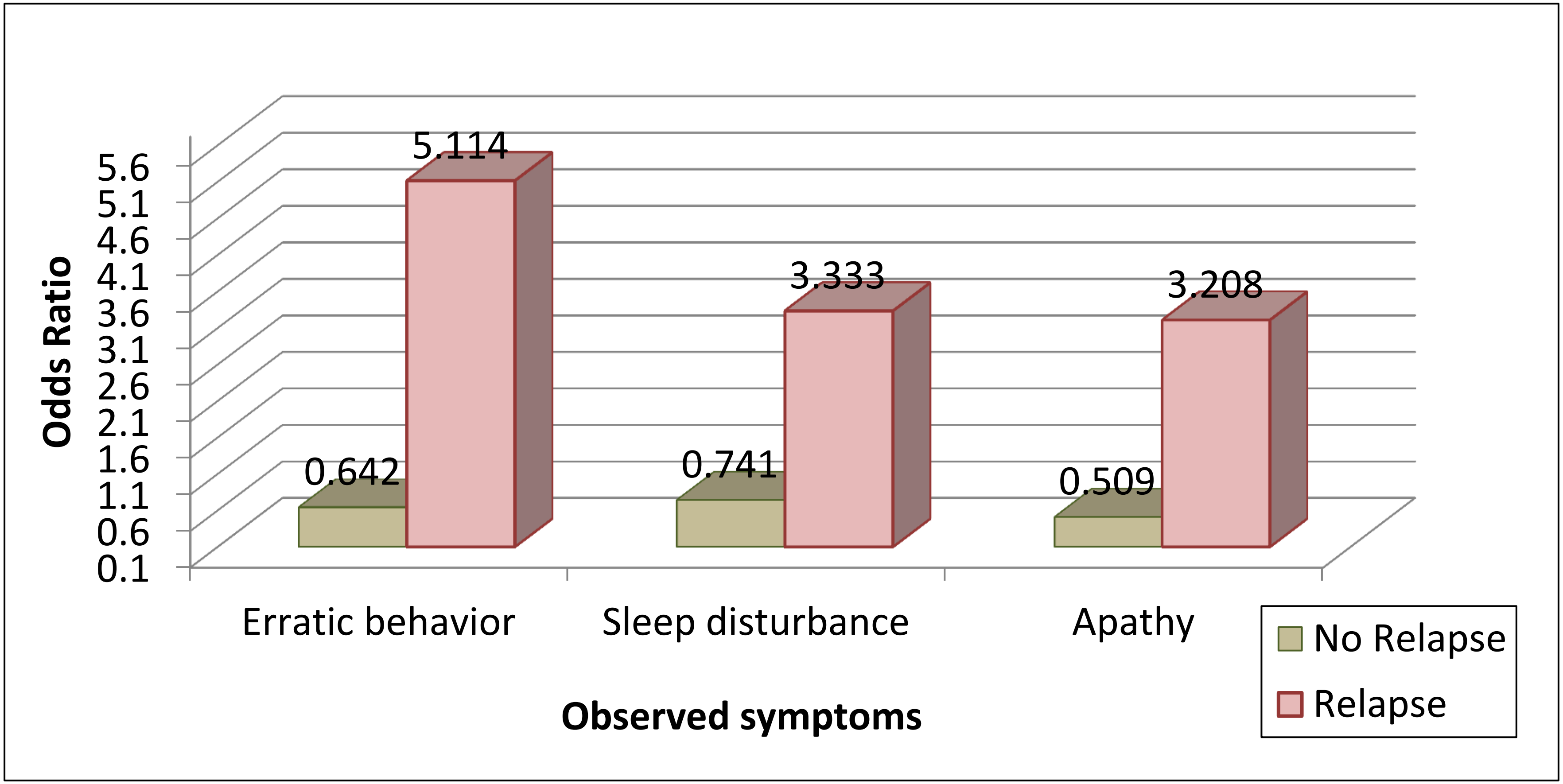


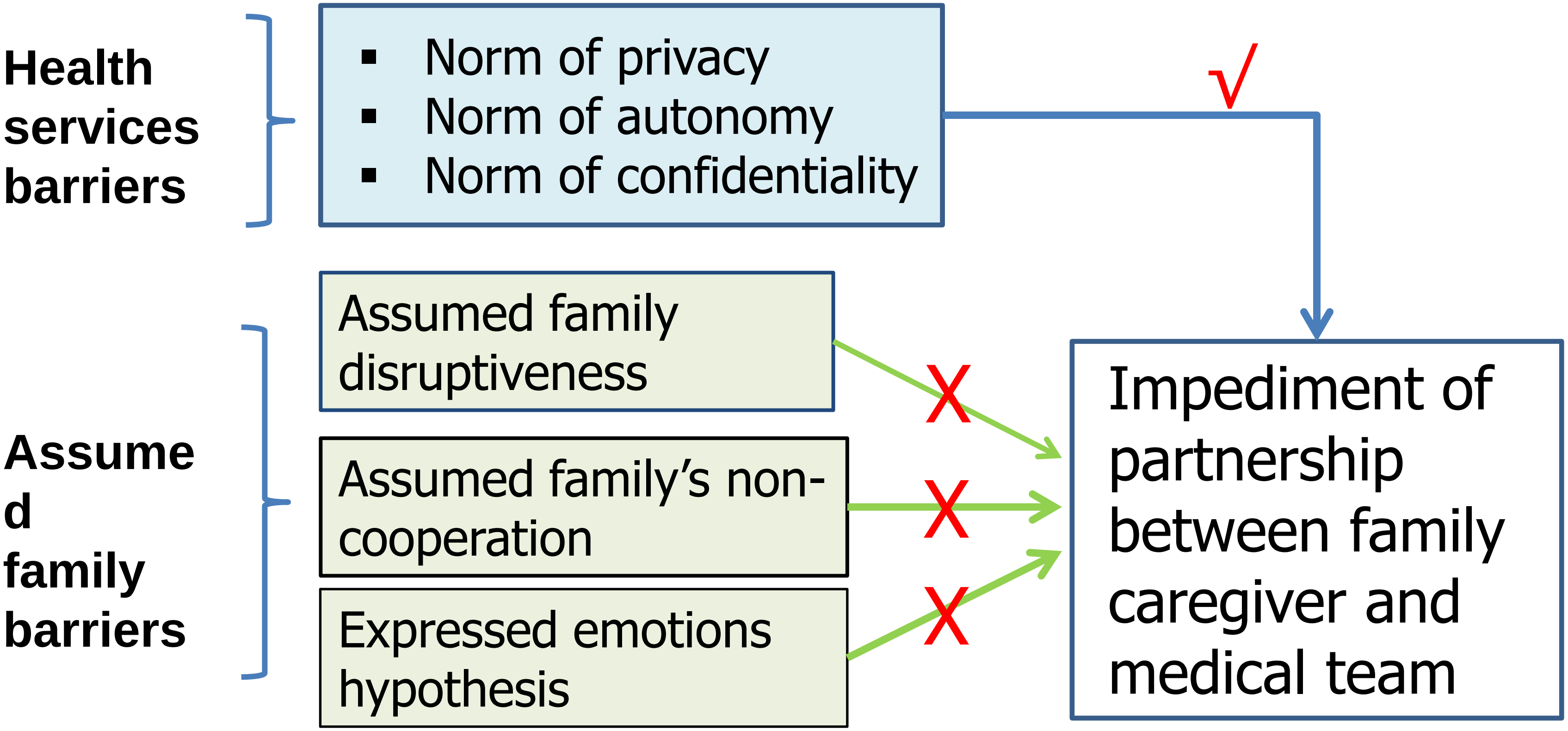
Chart 3. Risk of relapse by symptoms observed at Home[1]



1. The associated standard error for the risk of relapse (odds ratio coefficients) is presented as 95% confidence intervals (CI) as follows: apathy (.889 – 11.581, p < .02); erratic behaviour (1.235 – 21.177; p < .008); and sleep disturbance (.807-13.775; p < .06). Number of FCGs = 47.

IN SUM:

Findings on barriers to effective partnership between family caregivers and medical team



Health services barriers

- Norm of privacy
- Norm of autonomy
- Norm of confidentiality

√

Assumed family barriers

Assumed family disruptiveness

Assumed family's non-cooperation

Expressed emotions hypothesis

X

X

X

Impediment of partnership between family caregiver and medical team

7. **Multi-pronged approach needed to remove health care system barriers**

a. Modification of the medical team design to include the family caregiver in cases where the illness renders the patient unable to make rational decisions about his/her care.

b. Correction of the negative perception of family caregivers by the medical team.

c. Systematic training of the medical professionals and family caregivers to work together as a team for the well-being of the patient.

8. We need more multidisciplinary research on health care services provision and its link with the family caregiver

- Research interest on mental illness has increased considerably over the past two decades
- Dementia is the predominant topic
- Most of the research takes place in North America and Europe
- Most published research comes from the medical sciences

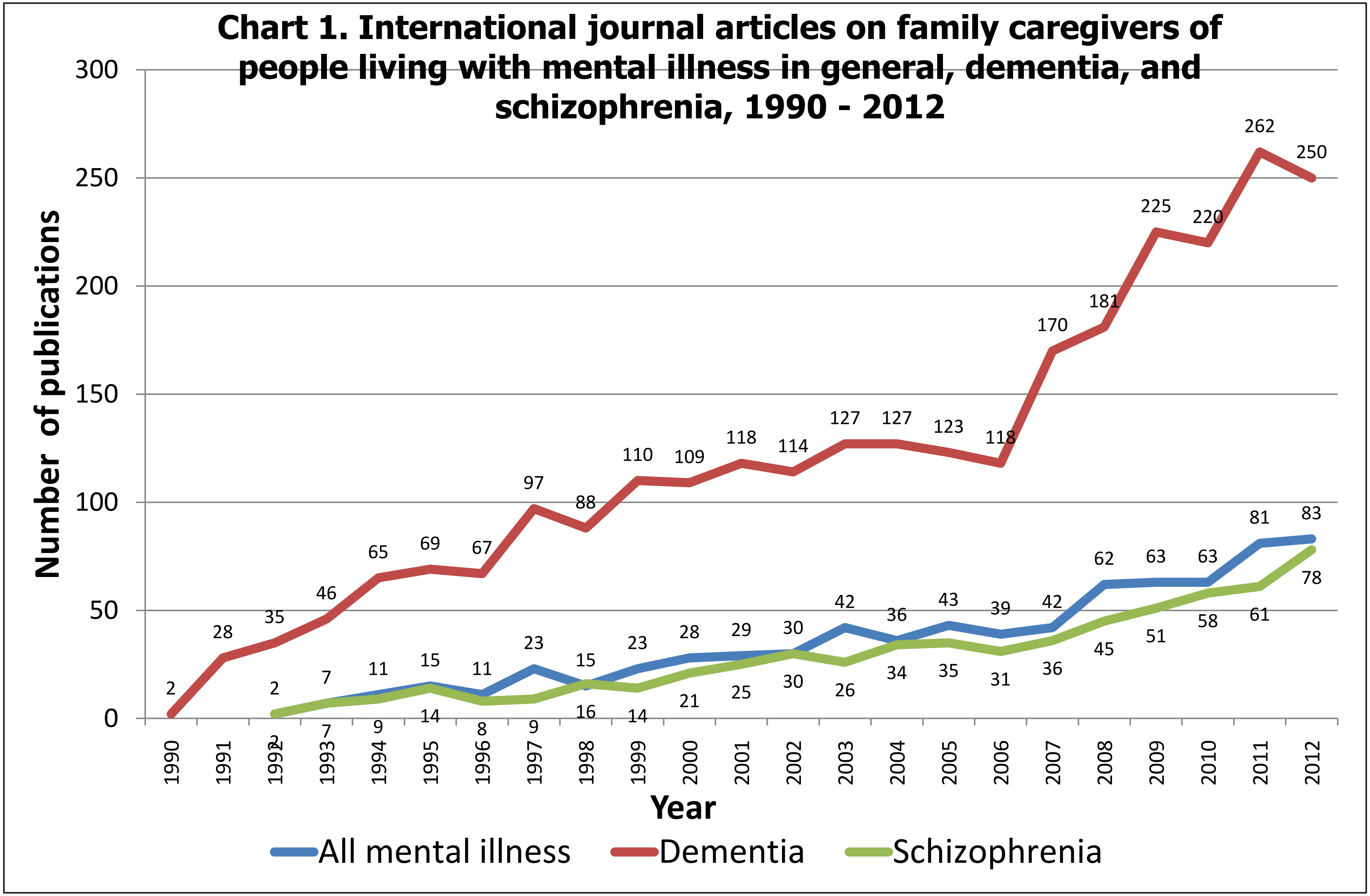
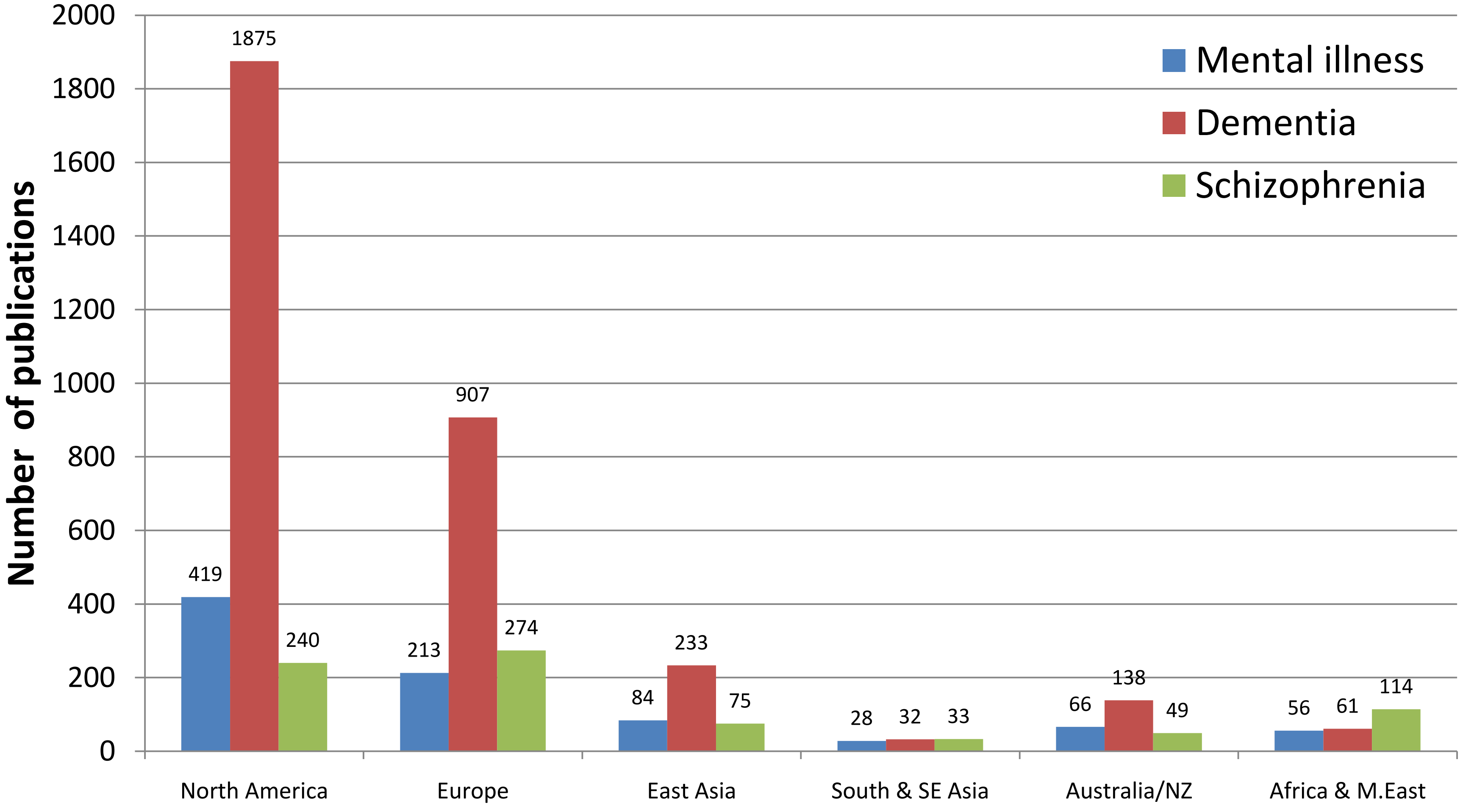


Chart 1. International journal articles on family caregivers of people living with mental illness in general, dementia, and schizophrenia, 1990 - 2012

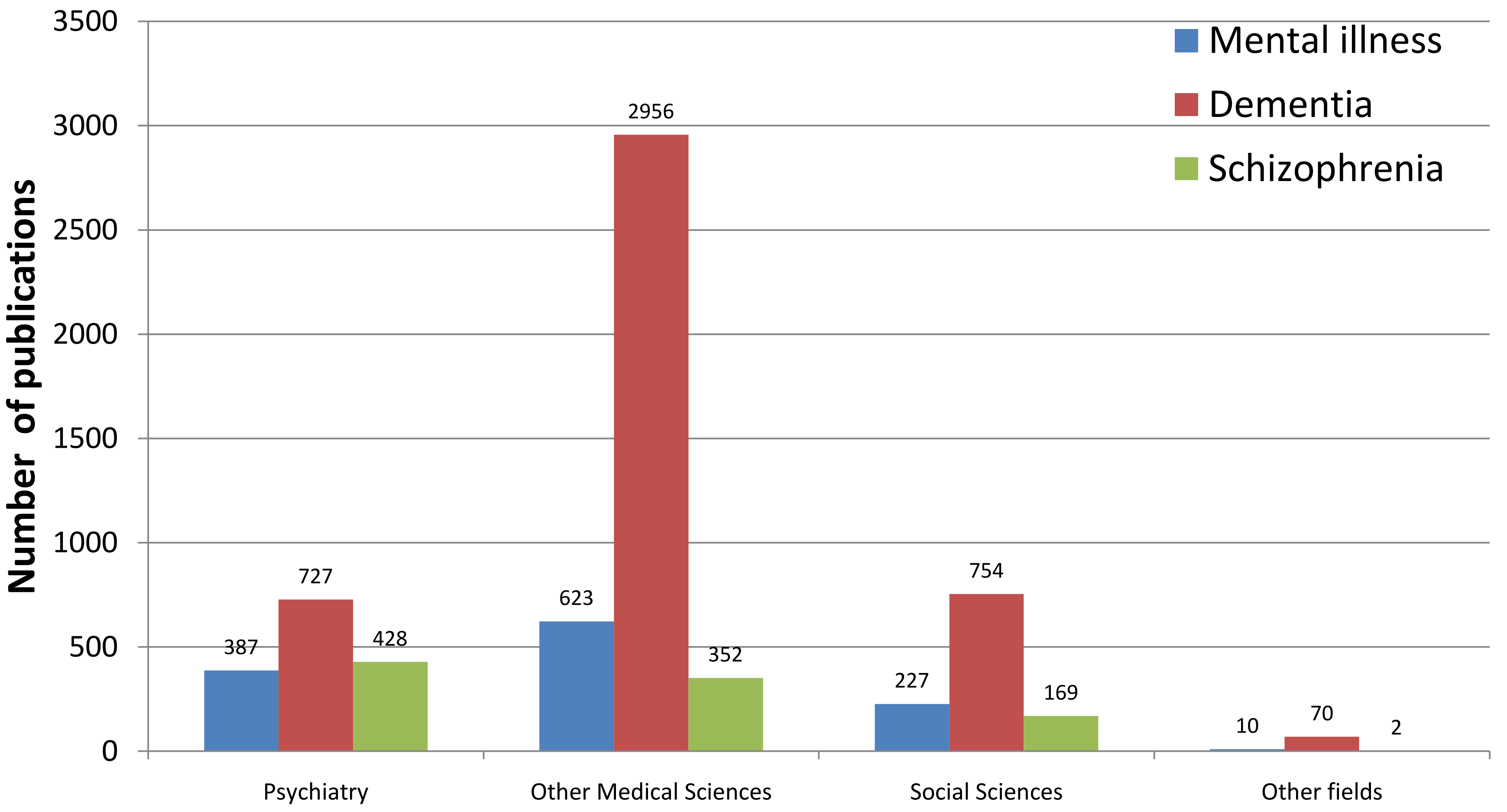
Source: Calculated from Thomson Reuters, Web of Knowledge, 1 January 1990 to 20 July 2013.

Chart 2. International journal articles on family caregivers of people living with mental illness in general, dementia, and schizophrenia, by region 1990 - 2013



Source: Calculated from Thomson Reuters, Web of Knowledge, 1 January 1990 to 20 July 2013.

Chart 3. International journal articles on family caregivers of people living with mental illness in general, dementia, and schizophrenia, by Authors' Area of Expertise 1990 - 2013



Source: Calculated from Thomson Reuters, Web of Knowledge, 1 January 1990 to 20 July 2013.

9. Conclusion: Health care services providers need to team up with the family caregiver

- More research is needed on the link between family caregivers and the medical team.
- Cooperation between the medical team and family caregivers is crucial in mental illnesses where the bioethical norms of doctor-patient confidentiality, patient’s privacy and patient’s autonomy require reassessment for the benefit of the patient.
- Not sufficient attention has been given to the effectiveness and application of these norms in the context of serious mental illnesses such as schizophrenia.

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GRADUATE MEDICAL SCHOOL SINGAPORE

Thank You
for your attention

Stella R. **Quah**, PhD
Adjunct Professor
Health Services & Systems Research
Duke-NUS Graduate Medical School
stella.quah@duke-nus.edu.sg
http://www.stellarquah.com/

Partner in Academic Medicine
SingHealth

www.duke-nus.edu.sg