

WHAT ARE CAREGIVING
BURDENS AND HEALTH RISKS
FOR CAREGIVING TO PATIENTS
WITH DEMENTIA?

DEPARTMENT OF HEALTHCARE ADMINISTRATION,
NAGOYA UNIVERSITY GRADUATE SCHOOL OF MEDICINE
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SELF-INTRODUCTION

- Doctor of Medicine (M.D.): 1990/4-1996/3
 - ✓ Showa University School of Medicine, Tokyo, Japan
- Doctor of Philosophy (Ph.D.): 2003/4-2006/3
 - ✓ Department of Preventive Medicine, Nagoya University Graduate School of Medicine, Nagoya, Japan
- Master of public health (M.P.H.): 2007/8-2009/1
 - ✓ Division of Epidemiology and Biostatistics of Public Health at University of Illinois at Chicago
- Lecturer (part-time) :2024/4-Present
 - ✓ Department of Healthcare Administration, Nagoya University Graduate School of Medicine

PROFESSIONAL SUMMARY

- Gastroenterologist with more than 20 years of experience.
- At the medical affairs at Takeda pharmaceutical company, did epidemiological studies using electrical database like JMDC, MDV.
- Joined the project of Ministry of Health, Labour and Welfare regarding the regional medical care vision with Deloitte

I am not a specialist of dementia!!

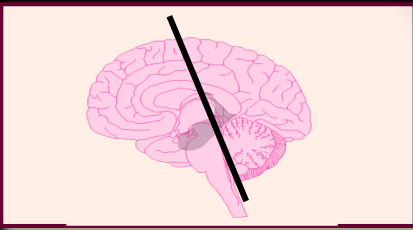
TODAY`S TOPICS

- **What is Dementia? (3 slides)**
- Epidemiology of Dementia
- Integrated care systems and long-term care insurance
- Caregiving burden
- Health problem
- Coping with the burden
- Intervention
- Our research

CAUSES OF DEMENTIA

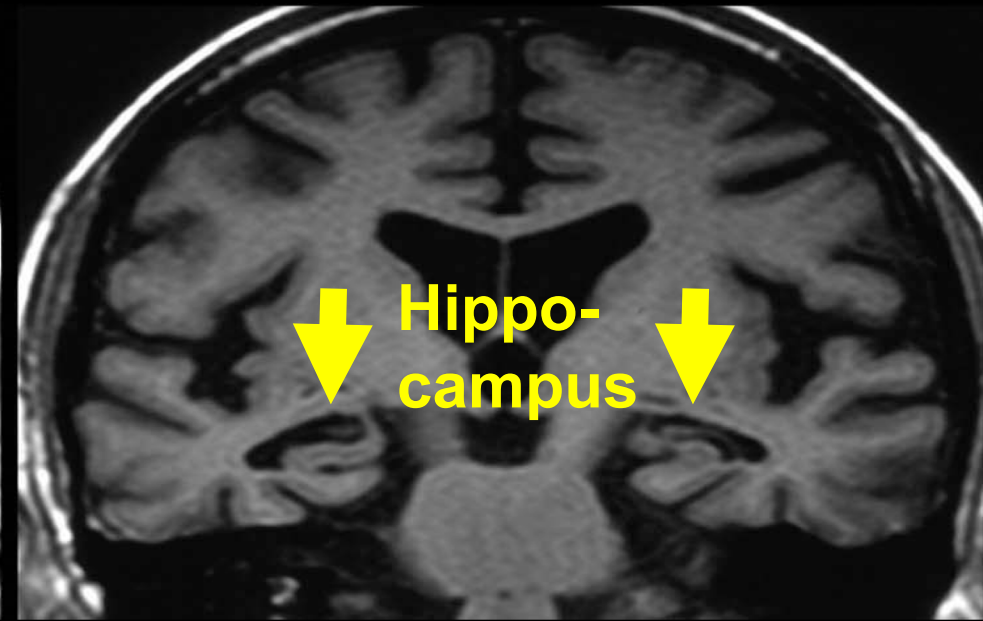
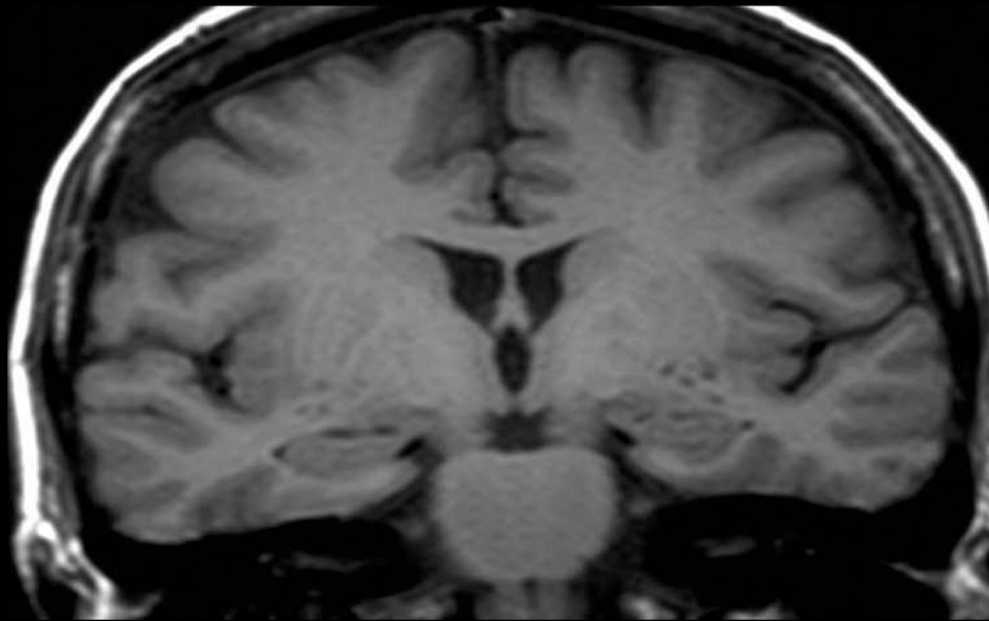
- Alzheimer's disease: 68%
- Cerebrovascular disease: 15%
- Lewy body disease: 9%
- Frontotemporal lobar degeneration: 8%

Hippocampal atrophy Due to Alzheimer's disease



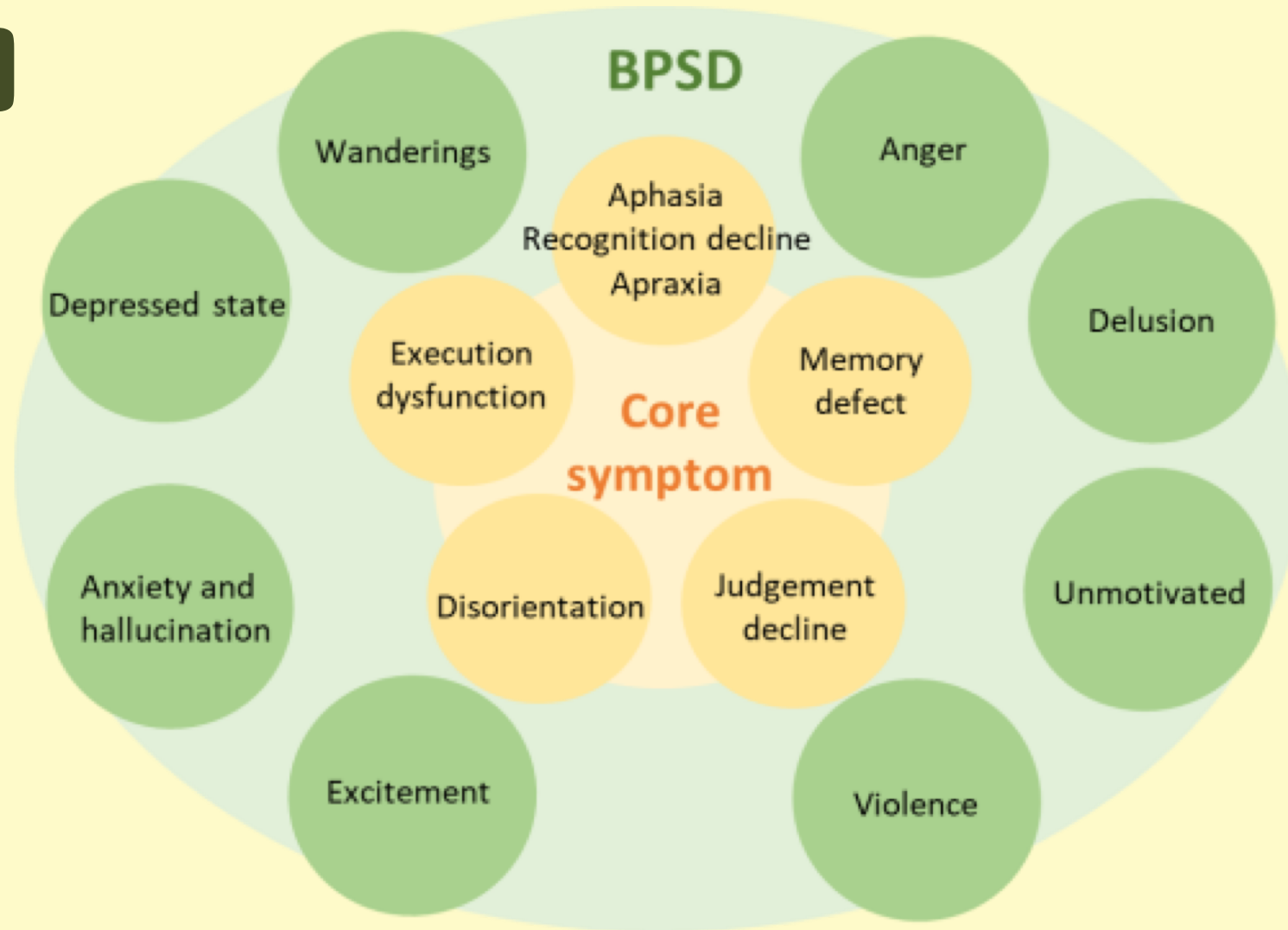
Normal

Alzheimer's disease



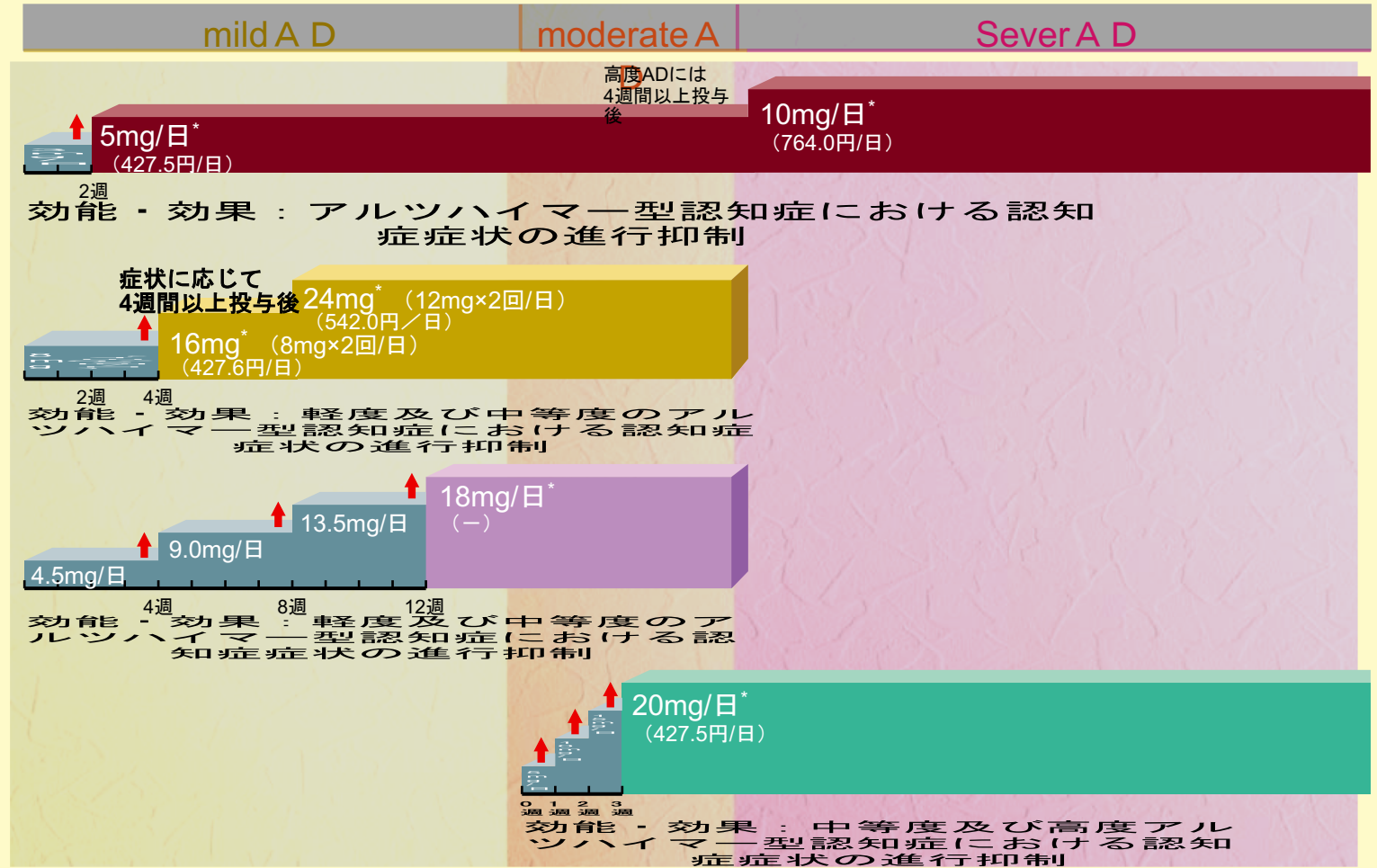
〈原図〉 東京医科大学病院 老年病科 羽生 春夫

CORE SYMPTOMS AND BEHAVIORAL AND PSYCHOLOGICAL SYMPTOM OF DEMENTIA (BPSD)



FOUR DRUGS FOR DEMENTIA

- Donepezil
- Rivastigmine
- Galantamine
- Memantine



1) アリセプトインタビューフォーム 2011年1月改訂 (改訂第22版) より作図
 2) 平成22年12月24日付 薬事・食品衛生審議会分科会 報道発表用資料より作図
 3) 平成23年3月25日付 薬事・食品衛生審議会分科会 報道発表用資料より作図
 4) 平成23年3月11日付 官報より作図

SUMMARY 1

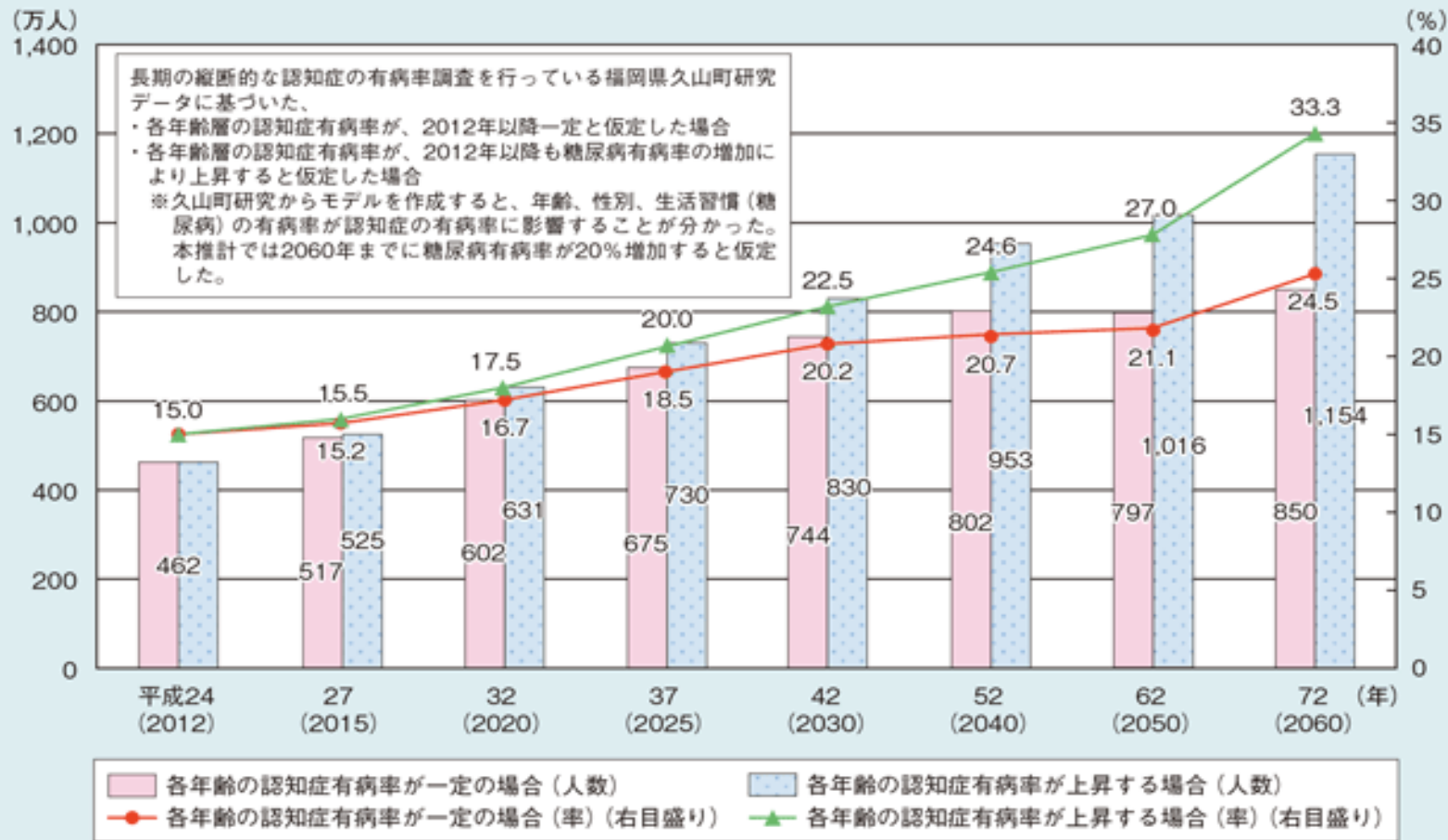
- Dementia is caused by mainly four diseases
- The number of the drugs effective against core symptoms is just 4.

TODAY`S TOPICS

- What is Dementia?
- **Epidemiology of Dementia (3slides)**
- Integrated care systems and long-term care insurance
- Caregiving burden
- Health problem
- Coping with the burden
- Intervention
- Our research

PREVALENCE OF DEMENTIA

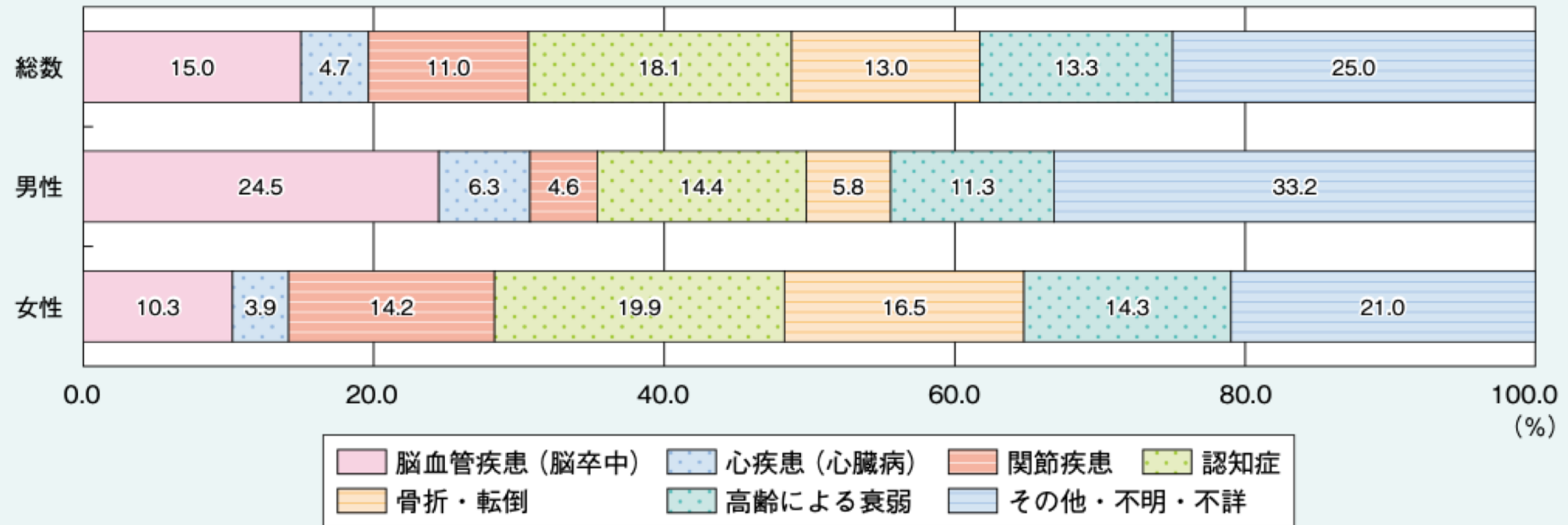
図1-2-11 65歳以上の認知症患者の推定者と推定有病率



資料：「日本における認知症の高齢者人口の将来推計に関する研究」(平成26年度厚生労働科学研究費補助金特別研究事業 九州大学二宮教授より内閣府作成)

DEMENTIA IS MOST FREQUENTLY CARED

図1-2-2-7 65歳以上の要介護者等の性別に見た介護が必要となった主な原因



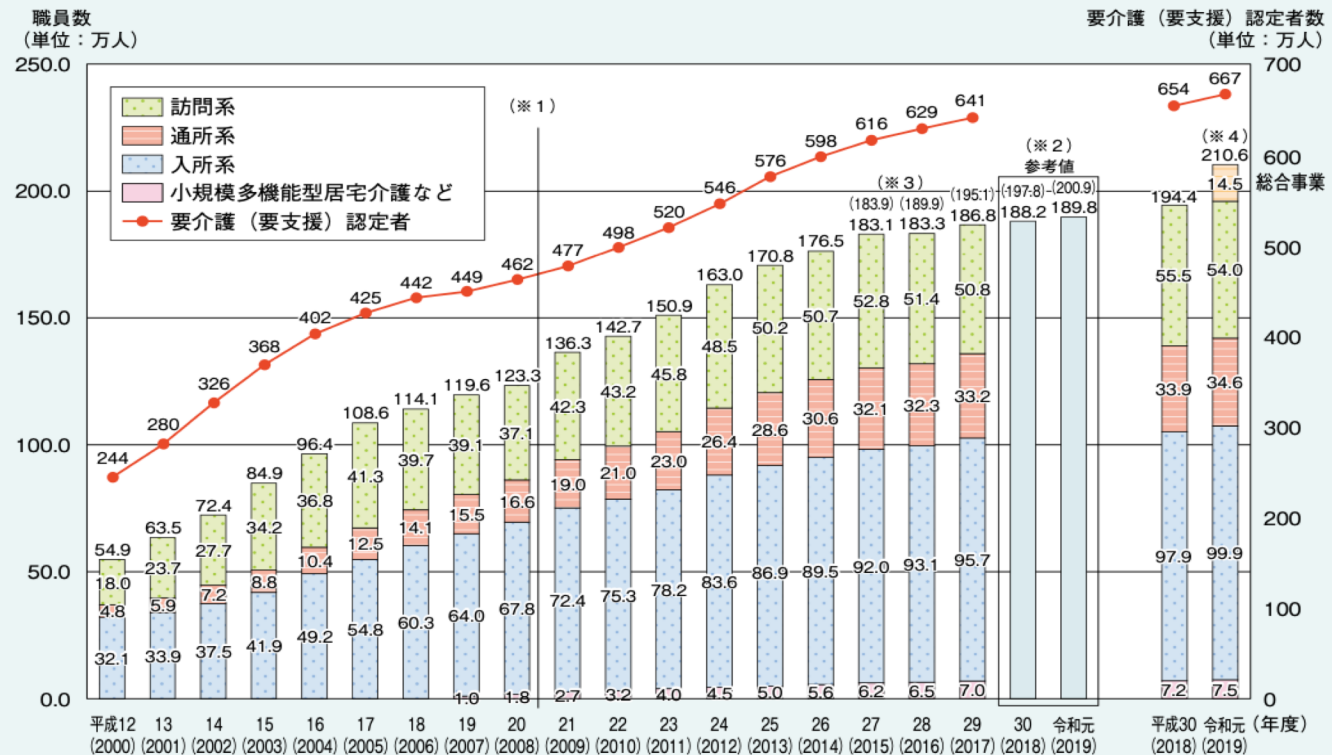
資料：厚生労働省「国民生活基礎調査」（令和元年）

（注）四捨五入の関係で、足し合わせても100.0%にならない場合がある。

THE NUMBER OF FORMAL CAREGIVERS

図1-2-2-12 介護職員数の推移

○本表における介護職員数は、介護保険給付の対象となる介護サービス事業所、介護保険施設に従事する職員数。



SUMMARY2

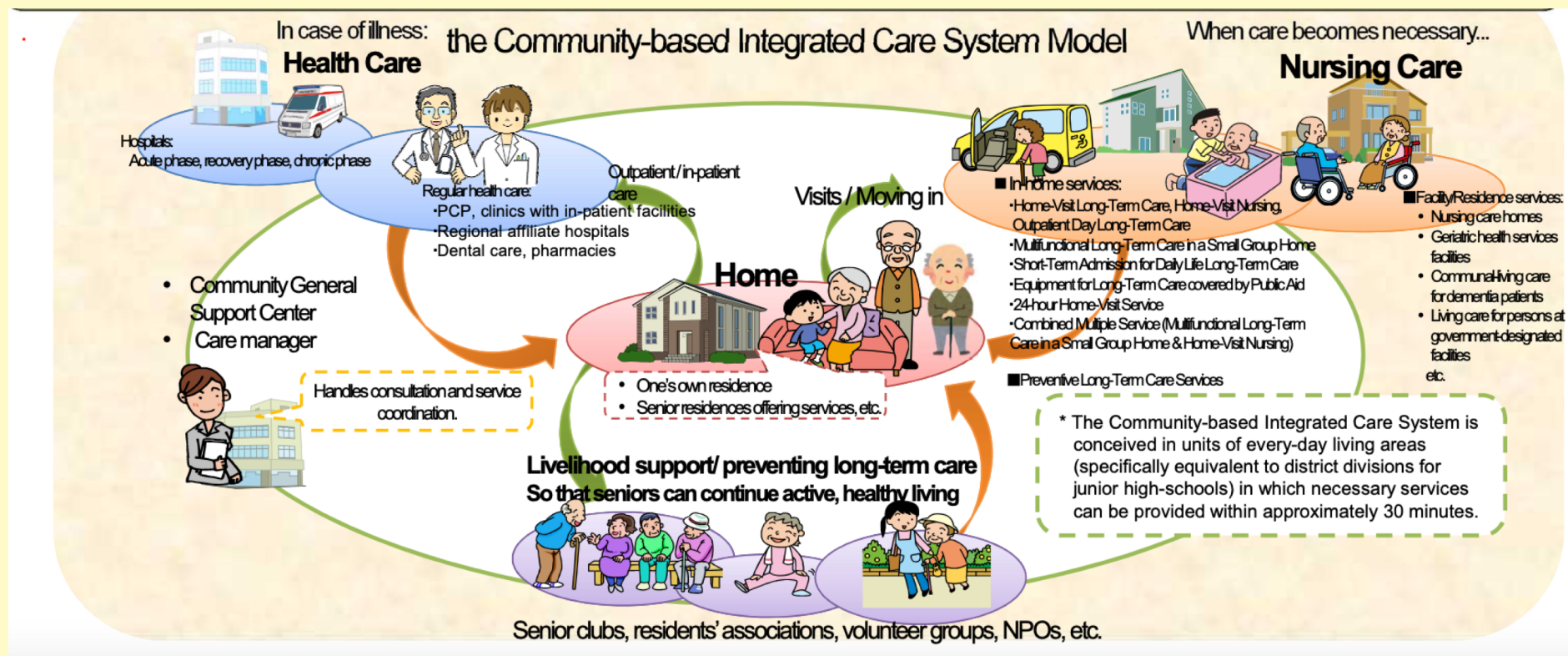
- The number of patients with dementia is increasing with population aging
- The number of formal caregivers is increasing after the long term care insurance was implemented but is not enough for the demand.

TODAY`S TOPICS

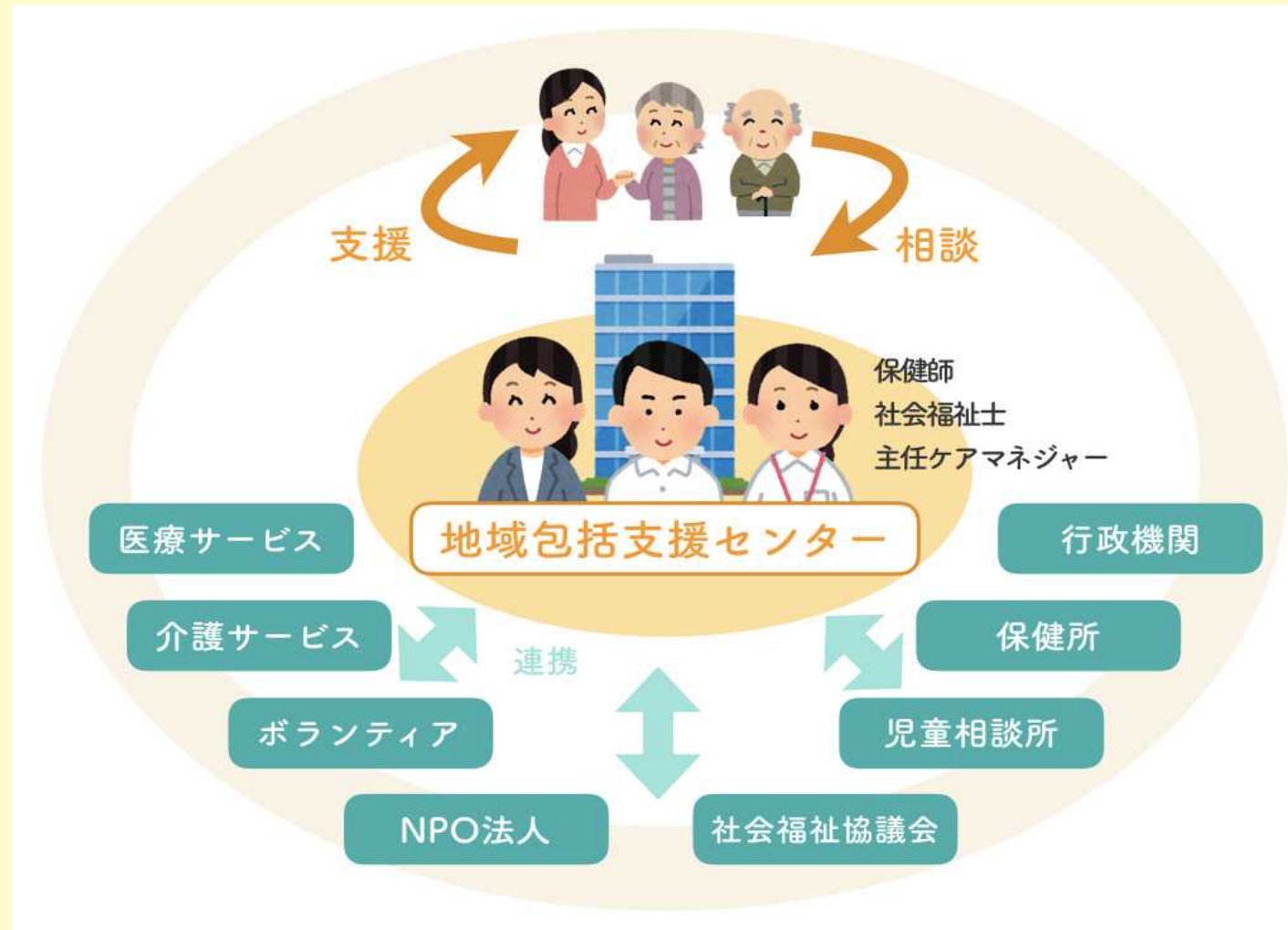
- What is Dementia?
- Epidemiology of Dementia
- **Integrated care systems and long-term care insurance (6 slides)**
- Caregiving burden
- Health problem
- Coping with the burden
- Intervention
- Our research

CAREGIVING SUPPORT

- Community based integrated care systems, where a care package of housing, health care, long-term care, preventive care and support for living can be provided.



WHAT IF YOUR PARENTS SUFFER FROM DEMENTIA?



LONG-TERM INSURANCE SYSTEM (LTIS)

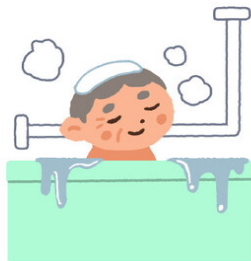
- Support levels 1 and 2
- Care need levels 1 (least disabled) to 5 (most disabled).

【要支援と要介護の違い】

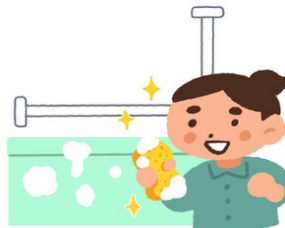
要支援

日常生活は自分で行えるが、
多少の支援が必要な状態

入浴は
ひとりで可能



浴槽掃除は
支援が必要



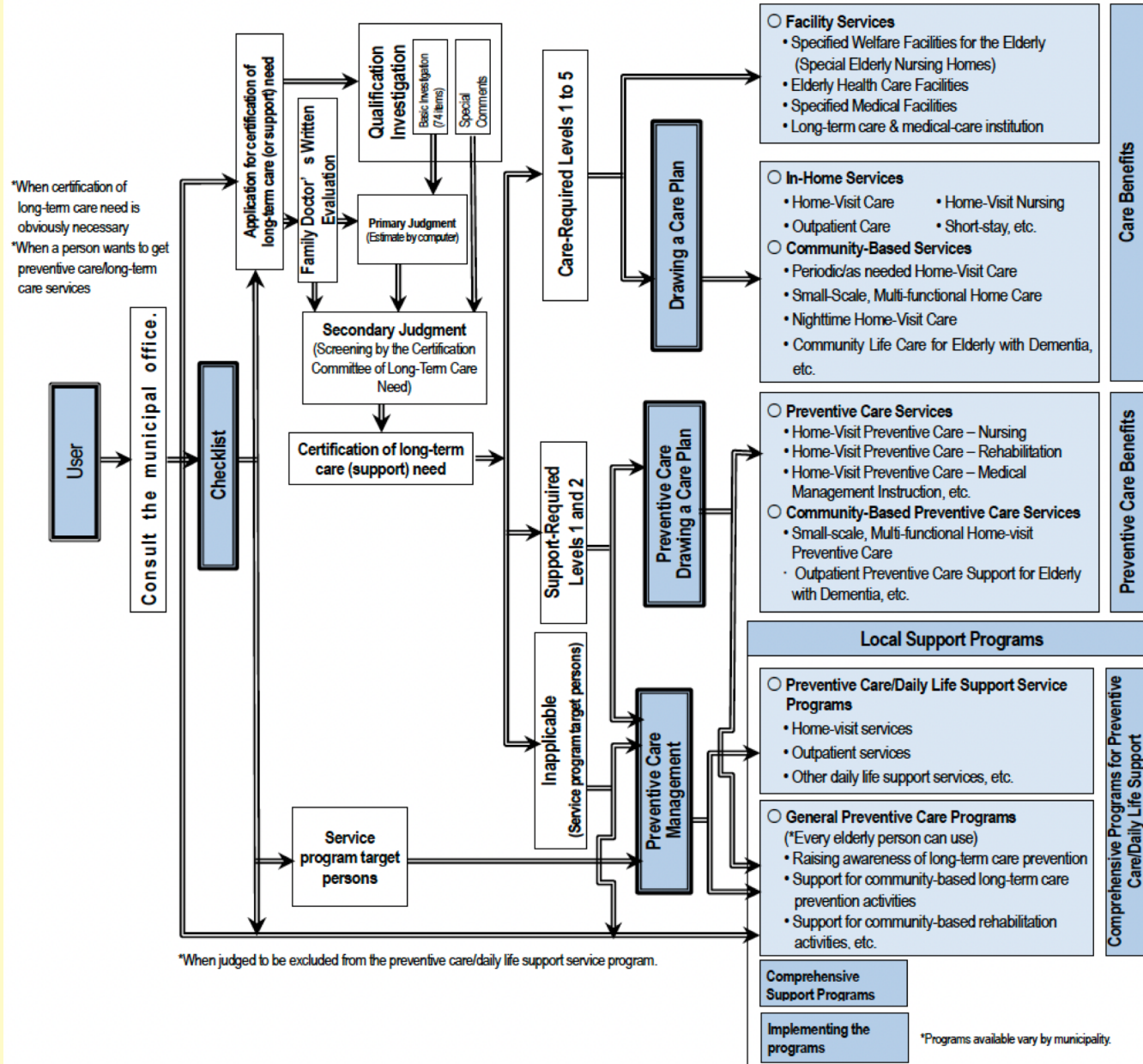
要介護

自分一人で日常生活を送ることが
難しく、誰かの介護が必定な状態

入浴介助が必要



(3) Procedure to use Long-term Care Services



THE FAMILY CARE SUPPORT PROJECTS IN JAPAN

Local Support Programs

○ Preventive Care/Daily Life Support Service Programs

- Home-visit services
- Outpatient services
- Other daily life support services, etc.

○ General Preventive Care Programs

- (*Every elderly person can use)
- Raising awareness of long-term care prevention
 - Support for community-based long-term care prevention activities
 - Support for community-based rehabilitation activities, etc.

Comprehensive Support Programs

Implementing the programs

Comprehensive Programs for Preventive Care/Daily Life Support

*Programs available vary by municipality.

From 社会保障審議会介護保険部会「地域支援事業の推進」(参考資料)
倉田あゆ子 日本家政学会誌 2022

①介護教室の開催

②認知症高齢者見守り事業

認知症に関する広報・啓発活動

徘徊高齢者を早期に発見できる仕組みの構築運用

認知症高齢者に関する知識のあるボランティア等による見守りのための訪問

③家族介護継続支援事業

ア. 健康相談・疾病予防事業

イ. 介護者交流会の開催

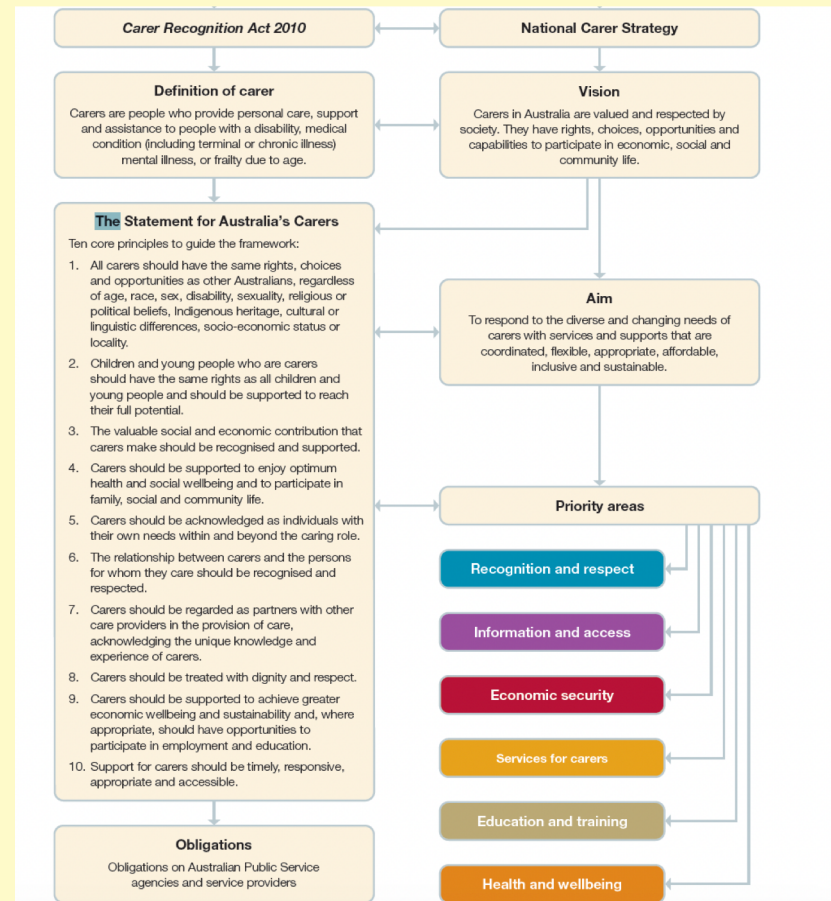
ウ. 介護自立支援事業 慰労金等の贈呈

エ. 介護自立支援事業 介護用品の支給



THE NATIONAL STRATEGY IN AUSTRALIA

The Carer Recognition Act 2010 has been enacted to support caregivers.



From National Carer Strategy 2011

SUMMARY 3

- The purpose of the community integrated care system under long term care insurance is to shift the patients from institution to home.
- Family caregiver support program in Japan seems to be for the stable operation of long-term care business, not for caregiver.

TODAY`S TOPICS

- What is Dementia?
- Epidemiology of Dementia
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- **Caregiving burden (7 slides)**
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- Coping with the burden
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CAREGIVER BURDEN BECOMES CONCERNED

Before and after the start of the long-term care insurance system in Japan, caregiver burden felt by informal caregivers has widely surfaced since the system promoted an overall trend of shifting patients with dementia from institutional care to domiciliary care .

WHAT IS CAREGIVING BURDEN ?

- Caregiving often includes assistance with one or more activities of daily living (ADLs), including bathing and dressing, as well as multiple instrumental activities of daily living
- **The term caregiver burden** is most often used to describe the situation, where much of the caregiving responsibility fall on caregivers.



THREE OF THE MAIN REASONS

- Three of the main reasons caregivers provide assistance to a person with Alzheimer's or another dementia
 - (1) The desire to keep a family member or friend at home (65%)
 - (2) Proximity to the person with dementia (48%)
 - (3) The caregiver's perceived obligation to the person with dementia (38%).

WHO ARE THE CAREGIVERS?

- **Approximately two-thirds** of Alzheimer's and dementia caregivers are **women**
- About 30% of caregivers are age 65 or older
- Approximately 10% of caregivers provide help to a spouse with Alzheimer's disease or another dementia
- **Over one-third of dementia caregivers** are **daughters** caring for a parent



From 2022 Alzheimer's disease facts and figures

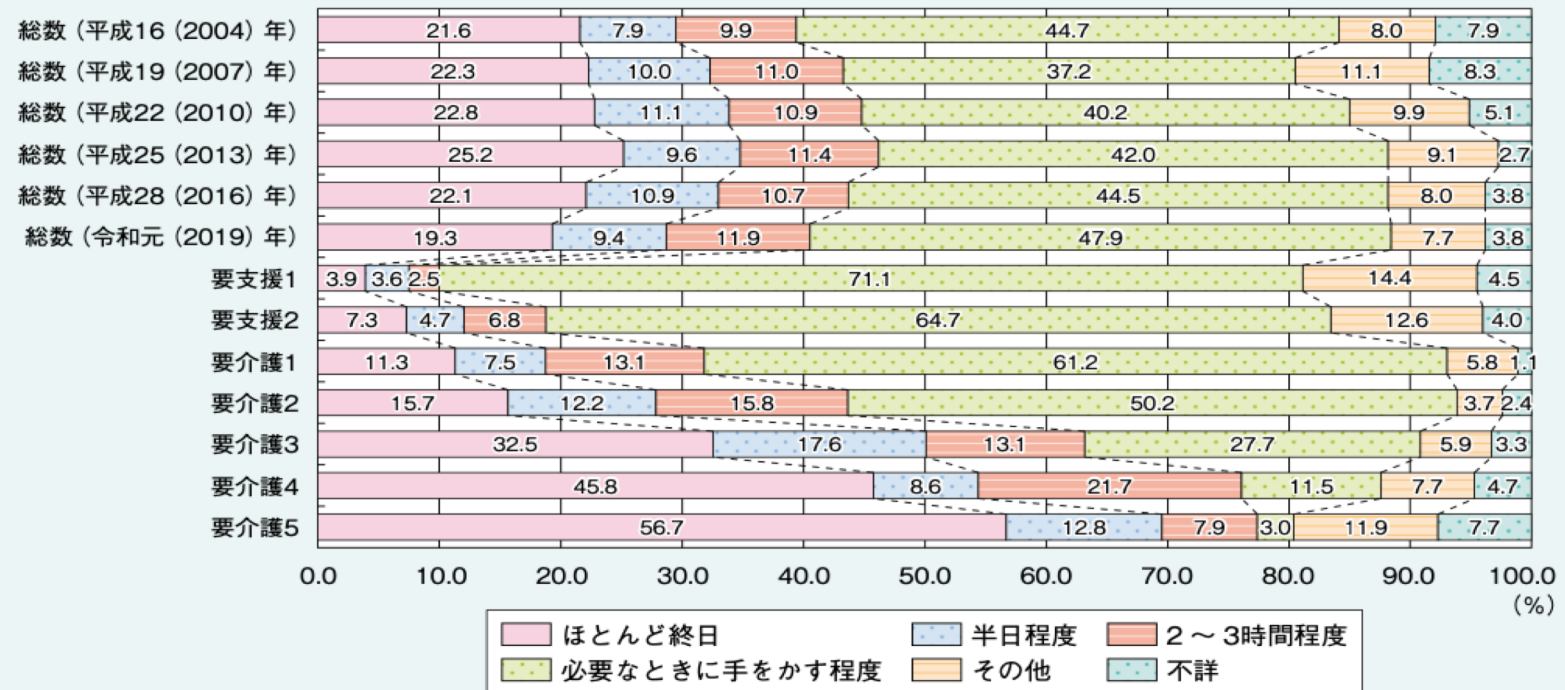
THE FREQUENCY OF WOMEN CAREGIVER IN THE WORLD

- The United States: 61.5%
- Japan: 51.9%
- France, Germany, the United Kingdom, Italy and Spain: 56.3%

from the 2018 National Health and Wellness survey

TIME NEEDED TO CARE BY THE SEVEN LEVELS

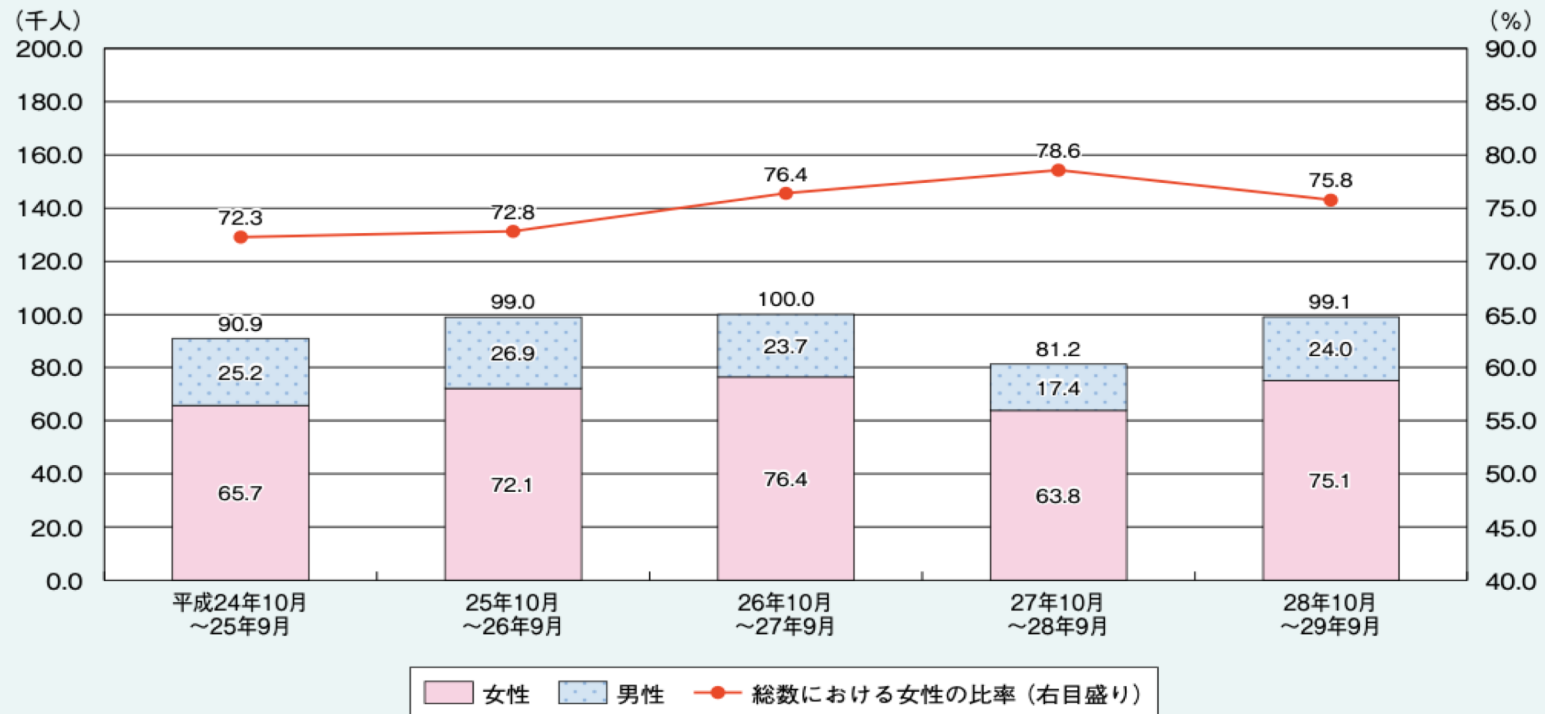
図1-2-2-9 同居している主な介護者の介護時間（要介護者の要介護度別）



資料：厚生労働省「国民生活基礎調査」（令和元年）
 (注1) 「総数」には要介護度不詳を含む。
 (注2) 平成28年の数値は、熊本県を除いたものである。
 (注3) 四捨五入の関係で、足し合わせても100.0%にならない場合がある。

THE NUMBER OF THOSE WHO HAVE TO STOP WORK DUE TO CAREGIVING

図1-2-2-10 介護・看護により離職した人数



資料：総務省「就業構造基本調査」

SUMMARY 4

- Caregiver responsibility fall on women like daughter, who love dementia parents.
- They have to quit job to continue to give a dementia person their care.
- The system that supports caregivers is necessary so that they can keep job.

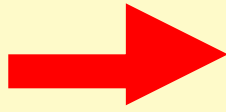
TODAY`S TOPICS

- What is Dementia?
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- **Health problem (3slides)**
- Coping with the burden
- Intervention
- Our research

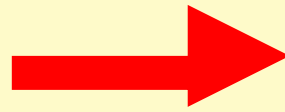
WHY HEALTH PROBLEM?



Dementia symptoms worsen



Increased emotional stress and depression.
Insufficient sleep.



Delayed or did not do things they should to maintain their own health



Developed

- high levels of stress hormones,
- impaired immune function,
- slow wound healing
- coronary heart disease
- depressive symptoms

TABLE 10 Percentage of Dementia Caregivers Who Report Having a Chronic Health Condition Compared with Caregivers of People without Dementia or Non-Caregivers

Condition	Dementia Caregivers	Non-Dementia Caregivers	Non-Caregivers
Stroke	5.2	3.4	3.2
Coronary heart disease	8.3	7.2	6.6
Cardiovascular disease*	11.8	9.5	8.6
Diabetes	12.8	11.1	11.3
Cancer	14.3	13.3	11.5
Obesity	32.7	34.6	29.5

From 2022 Alzheimer's disease facts and figures

WHAT IS PROBLEM IF CAREGIVER IS UNHEALTHY?

- Distress on family caregivers is associated with increased odds of institutionalization of the patients with dementia.



SUMMARY 5

- Caregiving burden leads to insufficient sleep
- The stress of providing dementia care increases caregivers' susceptibility to disease and health complications
- These result in difficulty keeping care dementia patients at home;
It is very hard to maintain the community based integrated care systems

TODAY`S TOPICS

- What is Dementia?
- Epidemiology of Dementia
- Integrated care systems and long-term care insurance
- Caregiving burden
- Health problem
- **Coping with the burden (2slides)**
- Intervention
- Our research

COPING WITH BURDEN

Coping strategies are defined as specific behavioral and psychological efforts to mitigate stress that caregivers feel when they try to handle external and internal demand that exceeds the resources of them.

THREE DOMAINS OF COPING STRATEGIES

- 1) **Emotion-focused** (i.e. to ameliorate depression symptoms, anxiety, stress and burden by using thoughts and indirect actions)
- 2) **Problem-focused** (i.e. to alter or control them in an active and constructive way)
- 3) **Dysfunctional** (i.e. to relive them by confrontation, escape and avoidance)

SUMMARY 6

- The emotion-focused strategies like wishful thinking might tend not to look for help from others, in which case such caregivers were more likely to suffer from depression.
- The problem-focused strategy is widely adopted and is effective when dealing with specific problems .
- The combination of emotion focused and problem focuses strategies has been reported to be better.

TODAY`S TOPICS

- What is Dementia?
- Epidemiology of Dementia
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- Caregiving burden
- Health problem
- Coping with the burden
- **Intervention (2 slides)**
- Our research

NON-PHARMACOLOGICAL INTERVENTIONS FOR CAREGIVERS

- (a) Those aimed at reducing the objective amount of care provided by caregivers (i.e., respite)

- (b) Those aimed at improving the caregiver's well-being and coping skills (e.g. psychosocial and/or psychoeducational interventions).

INTERVENTION TOOLS

- The tools should prevent “familism”, which means less delegation of caregiving responsibilities to outsourced caregivers.
- Of them, online communication tool could facilitate the interaction regardless of geographic distance



SUMMARY 7

- The intervention based on the adequate coping strategies is necessary to mitigate caregiver burden so that they continue to give cares.
- The online communication fits the intervention like psychoeducation.

SUMMARY SO FAR

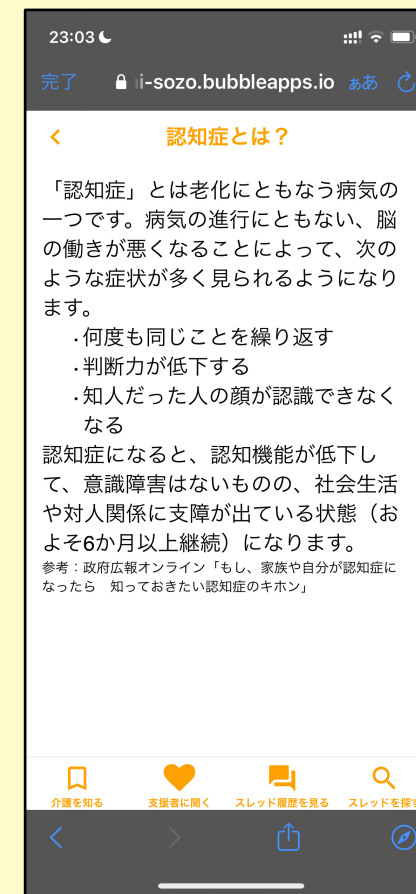
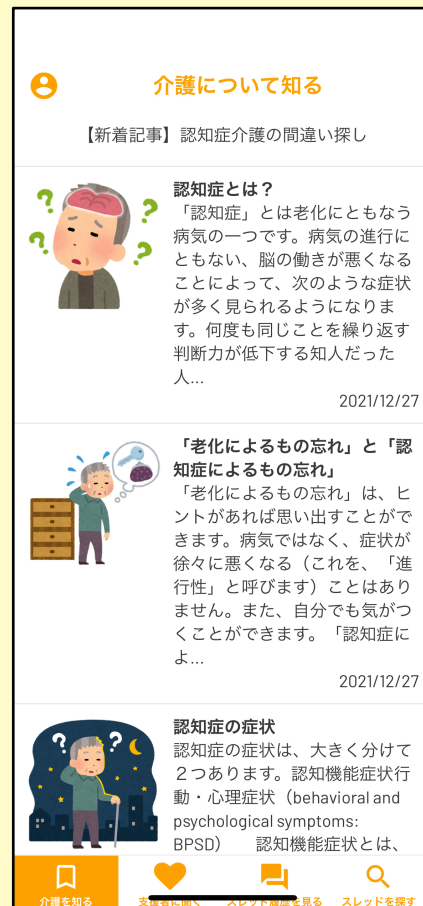
- In Japan, after the implementation of long term care insurance, the dementia patients are cared at home by family caregivers
- The shift from institution to home causes caregiver burden problem.
- In the current health system, nobody care about informal caregivers. Especially, the systems which provide financial support with caregivers are necessary.
- The online intervention would be good to mitigate caregivers distress, resulting in maintaining the community based integrated care systems

TODAY`S TOPICS

- What is Dementia?
- Epidemiology of Dementia
- Integrated care systems and long-term care insurance
- Caregiving burden
- Health problem
- Coping with the burden
- Intervention
- **Our research (15 slides)**

COLUMN OF DEMENTIA

You can select your favorite topics and learn them



Two sections for their conversation

With care managers

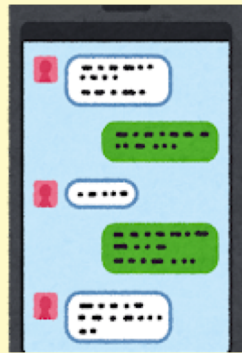


With other peers



INFORMATION AND COMMUNICATION TECHNOLOGIES (ICT) FOR INTERVENTION

- Online communication is a candidate interventional tool for facilitating the interaction between healthcare professionals and/or other caregivers regardless of geographic distance.



Use application

**Facilitate the conversations
among other participants**

**Mitigate the burden and
BPSD symptoms**

OUR RESEARCH PLAN

- **Criteria of inclusion**

- Family caregivers of the patients who diagnosed as dementia by DSM-V and visit Nagoya University Hospital.
- Care managers and helper

- **Required number of subjects**

- Informal caregiver 15、demented patients 15

- **Methods**

Subjects		
Informal caregivers	Zarit score	Measuring caregiver burden
Demented patients	Abe's BPSD score	Assessment of BPSD

ZARIT SCORE

- Currently use revised version contains 22 items evolved from 29-item version published in 1980.
- Each item on the interview is a statement which the caregiver is asked to endorse using a 5-point scale.
 - ✓ Interpretation of Score:
 - 0 - 21 little or no burden
 - 21 - 40 mild to moderate burden
 - 41 - 60 moderate to severe burden
 - 61 - 88 severe burden
- The two-factor measured: 1) personal strain and 2) role strain.

BPSD (BEHAVIORAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA)SCORE

- Use Abe's BPSD score with 10 BPSD items for assessment of BPSD

ABS score sheet.

Inquiry	Seldom	Occasionally	Sometimes	Often
1) Wandering in/outside home	0	3	6	9
2) Eating or toilet problem	0	3	6	9
3) Delusion or hallucination	0	2	4	6
4) Offensive & abusive words	0	2	4	6
5) Day-night reversal	0	2	4	6
6) Excitation & agitation	0	1	2	3
7) Apathy & indifference	0	0	1	2
8) Depressive & gloomy mood	0	0	0	1
9) Violent force	0	0	0	1
10) High irritability	0	0	0	1

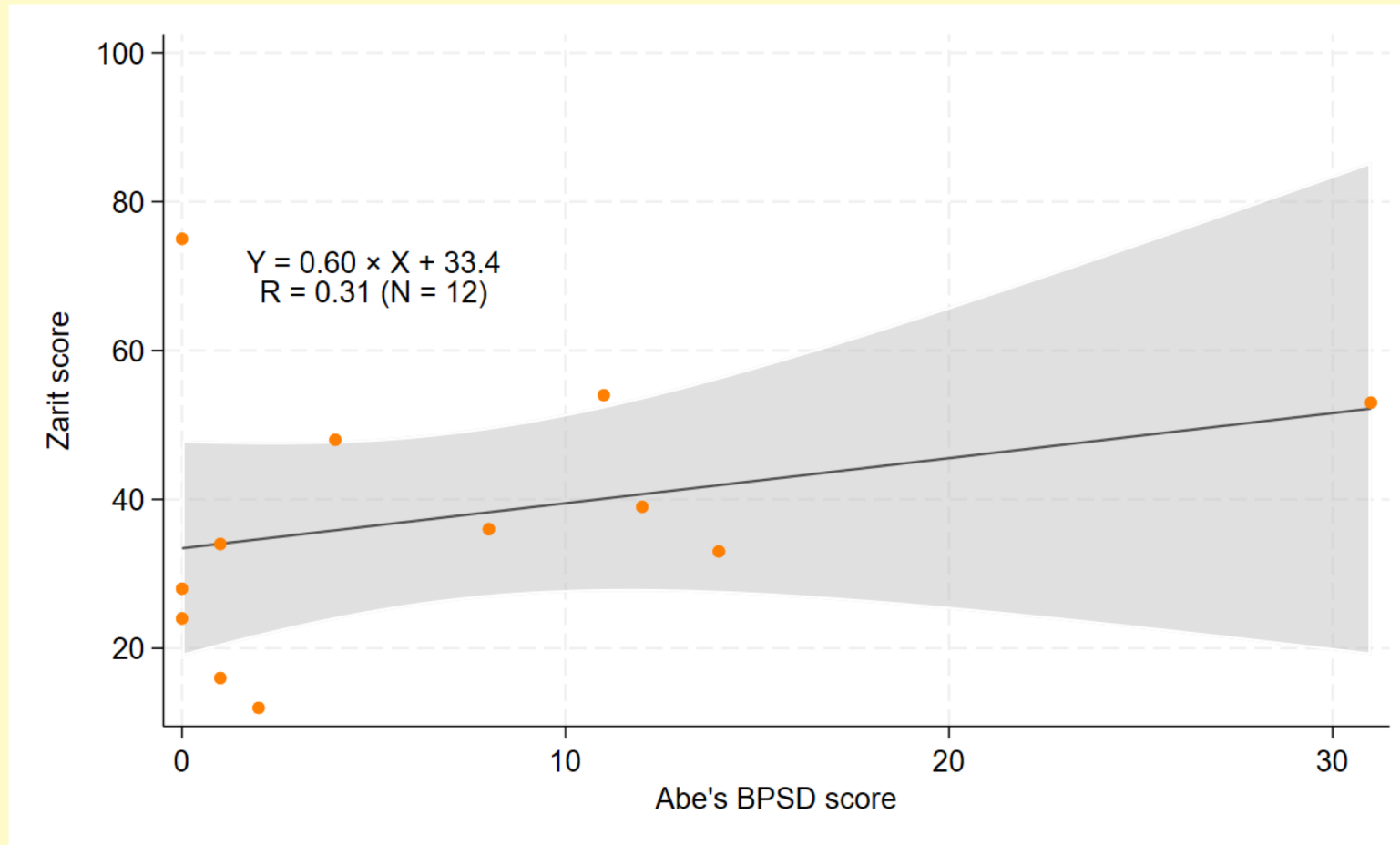
Total score 44.

Table 1

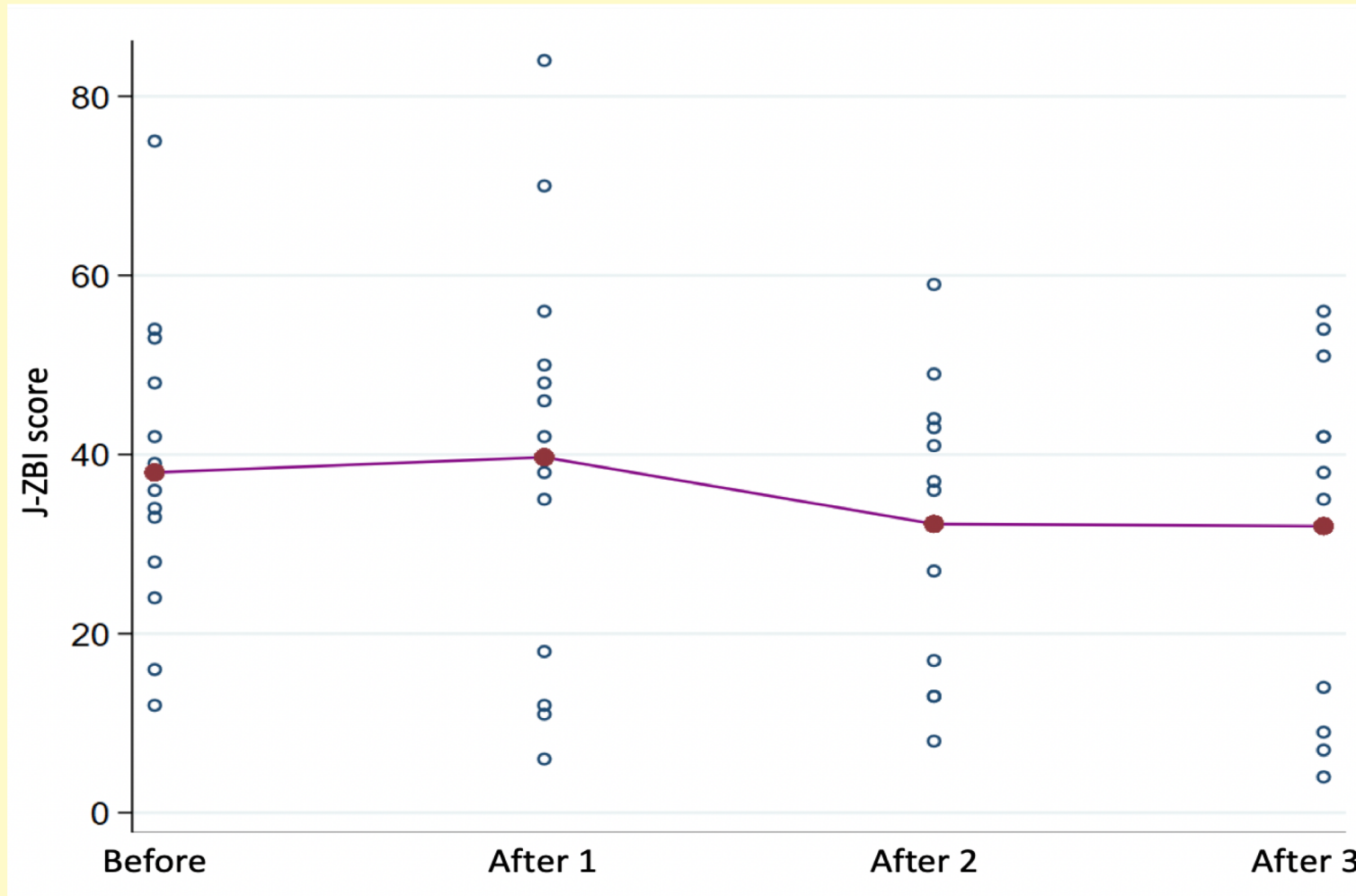
+ The demographic and clinical characteristics of caregivers and patients (n=13)

Caregivers		n	
Gender	Male	2	
	Female	11	
Age	40-49	1	
	50-59	4	
	60-69	4	
	70-79	3	
	≥80	1	
Duration of care (years)	less than 1	3	
	1- 2	2	
	2-3	4	
	3-4	1	
	4-5	2	
	more than 10	1	
Patients with dementia			
Gender	Male	6	
	Female	7	
Age	60-69	1	
	70-79	5	
	≥80	7	
Type of dementia^a	Alzheimer's disease	9	
	Cerebrovascular disease	1	
	Frontotemporal lobar degeneration	1	
	MCI	2	
Long-term care service^b	Commuting rehabilitation service	3	
	Commuting for care	4	
	Home-visit nursing care	1	
Long-term care/support need^c	Independence	3	
	Requiring support level 1	2	
	Requiring support level 2	1	
	Requiring long-term 1	3	
	Requiring long-term 2	2	
	Requiring long-term 3	1	

THE CORRELATION BETWEEN THE ZARIT SCORES AND ABE'S BPSD SCORES



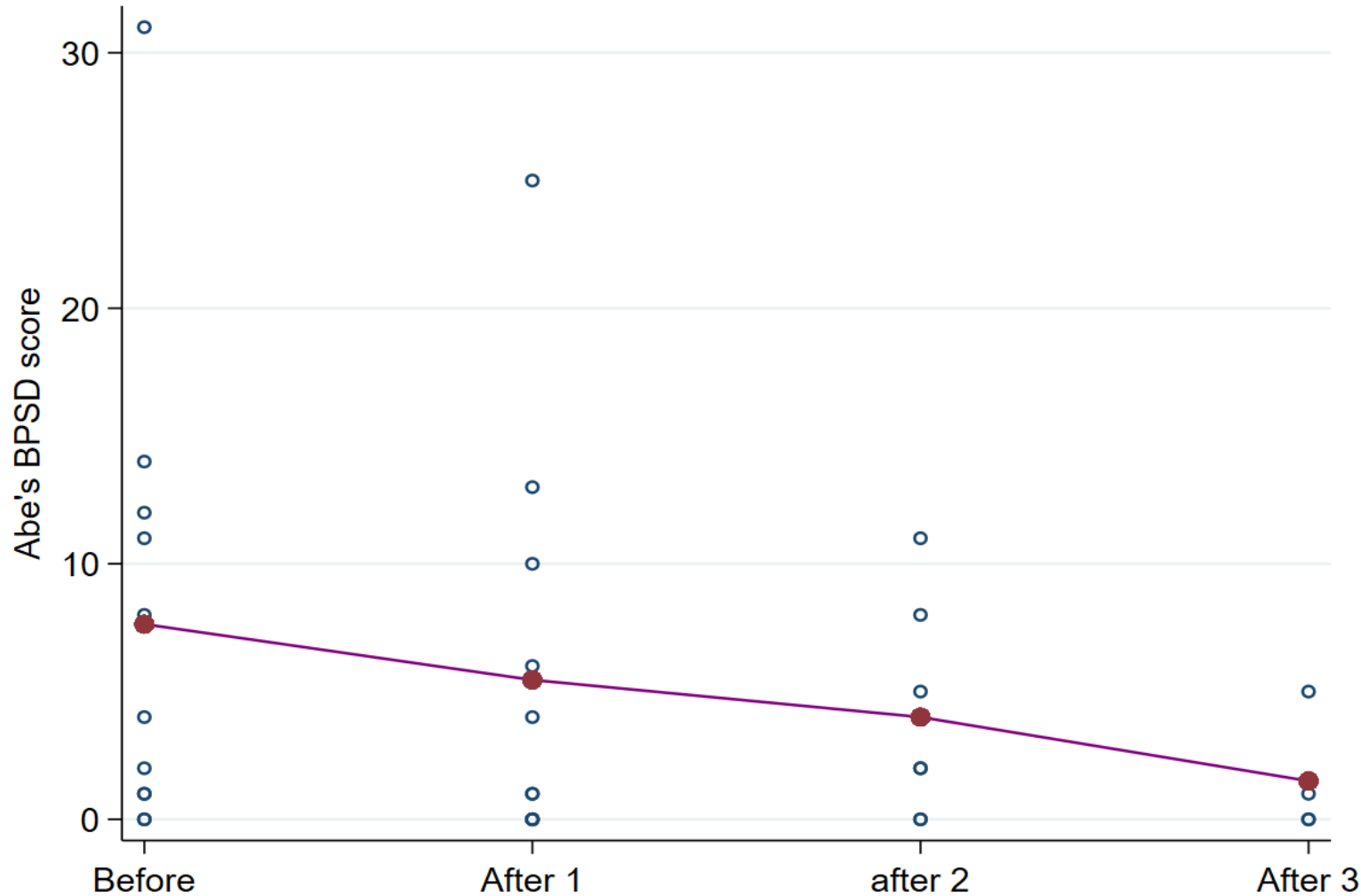
EFFECT OF WEB APPLICATION ON CAREGIVER BURDEN



$p=0.013$

From Nagoya J Med Sci. 86 2024.

EFFECT OF WEB APPLICATION ON BPSD



From Nagoya J Med Sci. 86 2024.

DISCUSSION

Our findings indicated that exchanging information in the virtual community could alleviate caregiver burden, although not the BPSD of their patients with dementia.

Therefore, whether or not the reduction of caregiver burden alleviates BPSD remains unclear.

NARRATIVE META ANALYSIS

Internal Medicine

The Japanese Society of Internal Medicine

doi: 10.2169/internalmedicine.0911-22

Intern Med Advance Publication

<http://internmed.jp>

[REVIEW ARTICLE]

Caregiver Burdens, Health Risks, Coping and Interventions among Caregivers of Dementia Patients: A Review of the Literature

Yasuyuki Goto¹, Kohei Morita², Mina Suematsu³, Takahiro Imaizumi⁴ and Yusuke Suzuki⁵

NEWS!

2022年(令和4年)4月8日(金曜日) 市民版 14

認知症介護者の悩み アプリで語ろう

名大など開発 孤立感、負担軽減へ

認知症の家族の世話をする介護者同士がメッセージをやりとりして相談もできるスマートフォンアプリ「私の介護」を、名古屋大などが開発した。パッチャル版の認知症カフェを目指す。介護者が徘徊や暴力など多様な症状への悩みや対処法を語り合い、介護の負担感を軽くするのが狙い。効果を見るための研究も始まっている。参加者たちが認知症の家族への接し方を変えることで、患者の症状を和らげられるかも調べる。

アプリには、複数の介護者が投稿し合えるチャット機能があり、「認知症の家族に」車の運転をやめさせるには「なぐ、共通の悩みを語れるスレッドを作ることができる。介護者も支援者も匿名のため、個人は特定されない。

支援者としてアマネシャウも参加しており、専門職に質問ができるほか、認知症の知識を学べるコラムも掲載されている。

認知症による徘徊や暴力などの症状は、介護者の対応や働き掛けにより、良くなったり、悪くなったりする。ただ、介護者の中には、認知症の知識を持たないまま急に介護に直面し、誰にも相談できずに孤立感を覚めている人も少なくない。

アプリを開発した名古屋大の後藤康幸委員研究員(医療行政学)は「診療では主に患者の状態を見るが、それだけでは問題解決にはな

ない」と話す。介護者がアプリを通して必要な情報を得て、他の介護者らと悩みやノウハウを話し合えることで、負担を減らなげることができる。効果を調べる研究に参加する三重県四日市の四十代女性は、認知症の八十代の父母とともに介護する。父から突然、暴言を浴びることがあり、今後の症状の進行が不安になることも。「認知症のことを周りの人には聞かずに、認知症カフェへ近くに行き、そんな時に、アプリで相談し、いろいろなことを聞いて不安が軽くなった」と話す。

研究では、参加する介護者を千人まで増やし、介護の負担感が軽減するかどうかや患者への影響などを今秋まで調べる予定で、参加者を募集している。名古屋大医療行政学教室(070-69085)099

2022年03月02日(水) test003 支援者75-30

私たちが「本人の気持ち」を一番大事にしたいと思っています。経験上、住み慣れた自宅に帰りたいた方が多いと考えられておりましたが、自宅に帰りたくない理由はなんだろうか。と、ふと気づいてしまいました。

TK001 患者: 家族22-08

私も家族も父が自宅に戻りたくない理由を知りたいのですが、本人の話をしたくないのか黙ってしまいました。

2022年03月03日(木) test003 支援者15-06

本人の気持ちを知るというよりは簡単なようで、実は難しいものなのではないか。話さないのか、何を話したらよいか。わからぬのか。認知症である

アプリで行われた介護と支援者とのやり取り(名古屋大医療行政学教室提供)

研究で参加する女性の大半は、三重県四日市市にある名古屋大医療行政学教室で



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2022年（令和）

東海 NEWS WEB

名古屋大が認知症介護者向けの支援アプリを開発

06月07日 11時02分



認知症の人を介護する人たちの心の負担を減らそうと、名古屋大学などの研究グループが悩みなどを匿名でやりとりできるアプリを開発しました。

アプリを開発したのは、名古屋大学医学部の後藤康幸客員研究者らのグループです。

「私の介護」と名付けられたアプリは認知症の介護を行う人が登録すると、ほかの介護者やケアマネージャーなどの支援者と匿名でメッセージをやりとりすることができます。

TO BE CONTINUED NEXT WEEK!