

Supporting Carers in the super-aged Japanese society: Marginalized agenda in the long-term care system

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1. Introduction

- Population aging in Japan

The elderly persons aged 65 or older:

26.8%(2015)  30.3%(2025)

The elderly persons aged 75 or older:

13.6%(2015)  18.1%(2025)

- Facing the dilemma of maintaining sustainable caring society
- supporting carers has been a “forgotten, invisible” agenda (Yamaguchi et.al 2012)
- Creating the integrated community care system
- Increasing the burden of informal carers
- The marginalization of the agenda of supporting carers

2. Purpose

- To explore the factors for the marginalization of the agenda of supporting carers
- To argue our challenges in mainstreaming the issue of supporting carers in the super-aged Japanese society.



3. Factors for the marginalization of the agenda of supporting carers

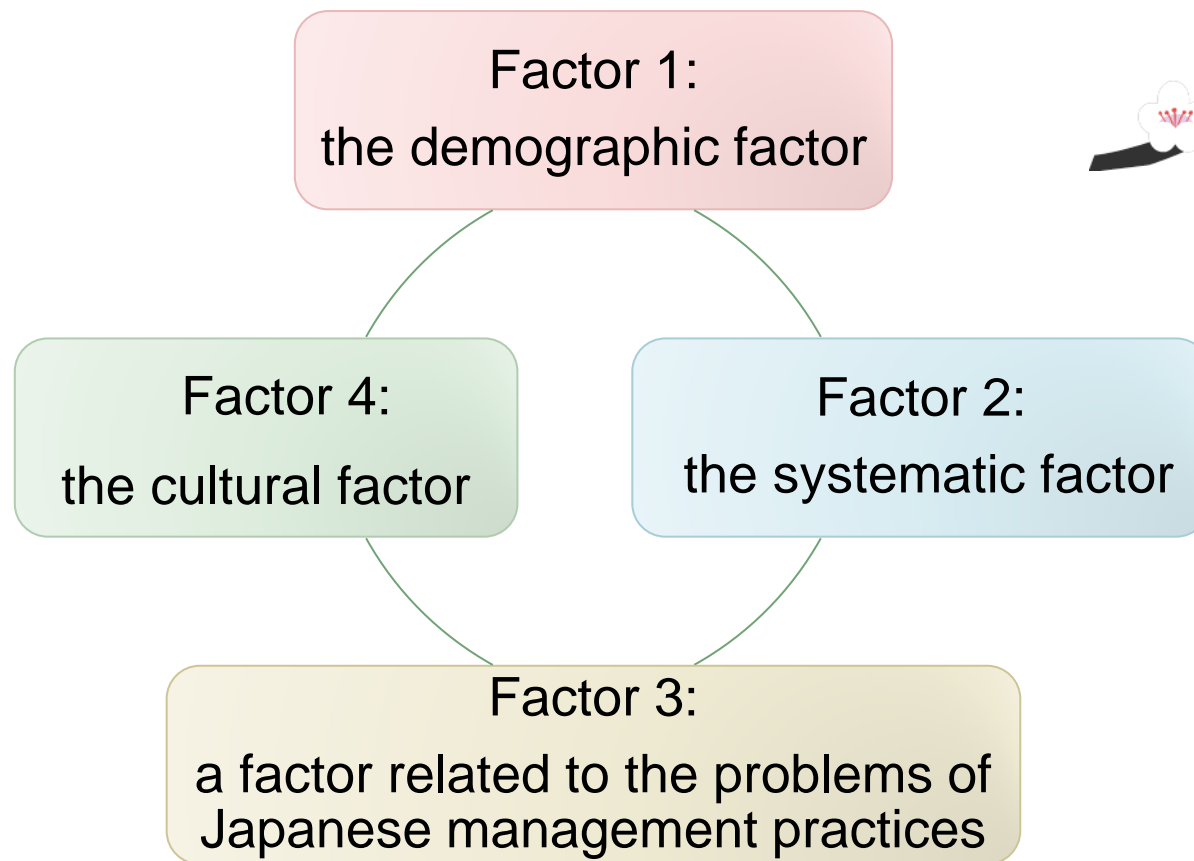
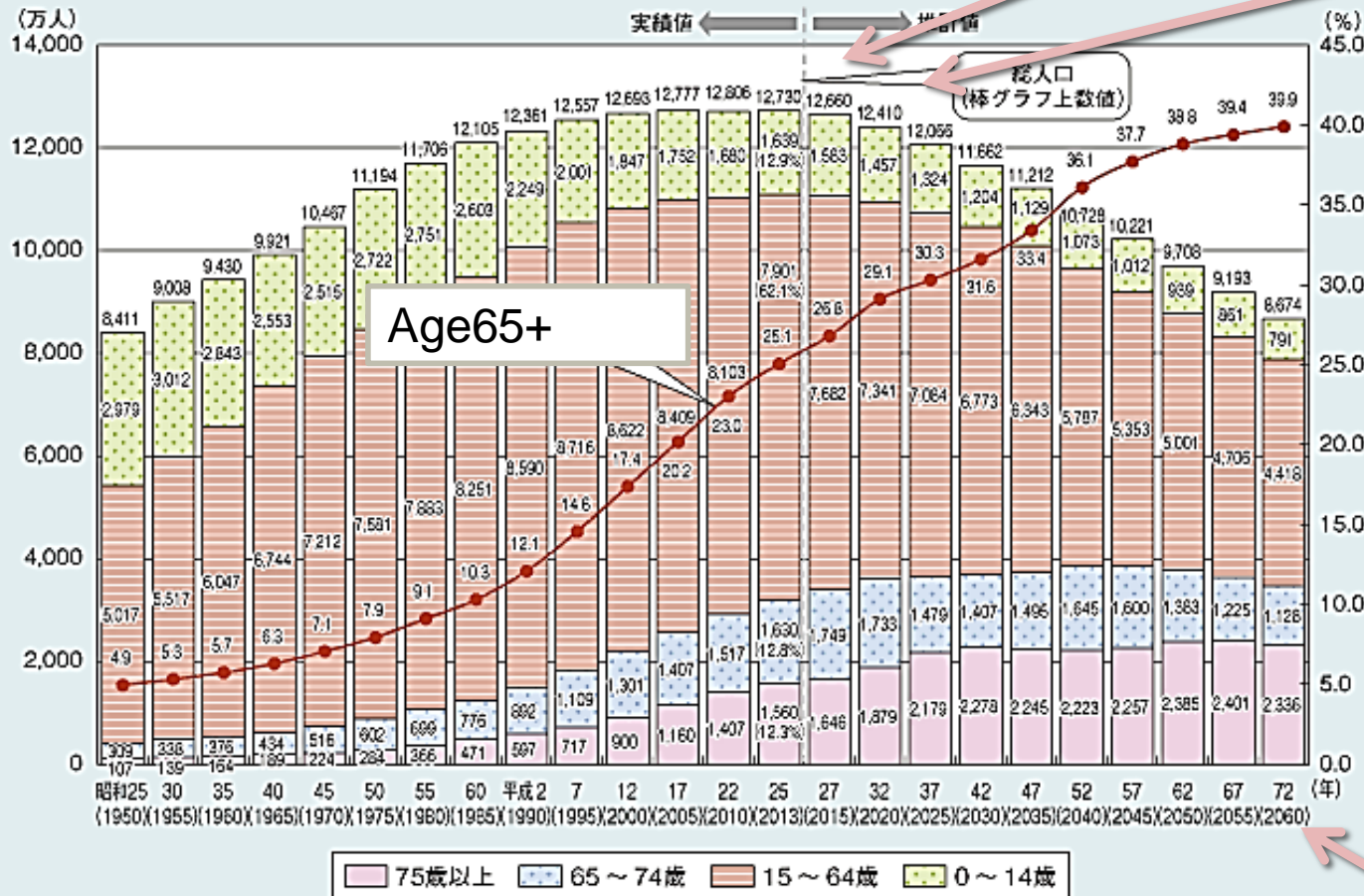


Figure 1: Factors for the marginalization of the agenda of supporting carers

Factor 1: The demographic factor

図1-1-4 高齢化の推移と将来推計



2015
Total 126.6m
26.8%

2025
Total 120.7m
30.3%

2060
Total 86.7m
39.9%

資料：2010年までは総務省「国勢調査」、2013年は総務省「人口推計」（平成25年10月1日現在）、2015年以降は国立社会保障・人口問題研究所「日本の将来推計人口(平成24年1月推計)」の出生中位・死亡中位仮定による推計結果
(注) 1950年～2010年の総数は年齢不詳を含む。高齢化率の算出には分母から年齢不詳を除いている。

Figure 2 Aging population Source: MHLW(2015)Aging Society White Paper(2015)

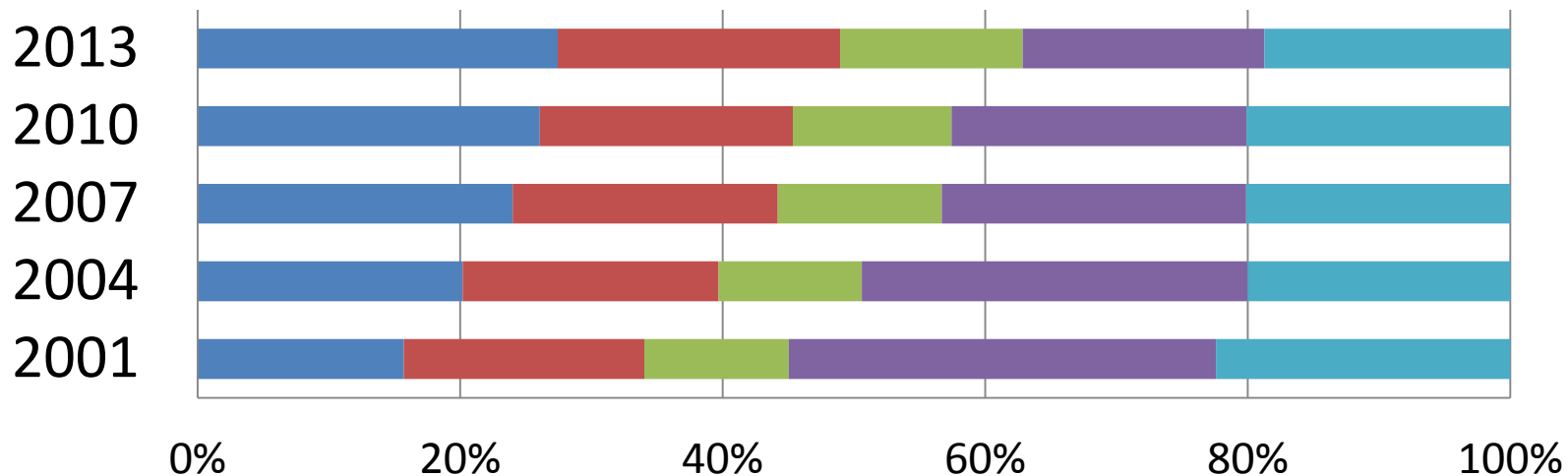
Population aging in Japan

	% Age65+	% Age75+	Total population	Age65+ population	Age75+ population	Dementia population
2014	26.0%	12.5%	127.1M	33.0M	15.9M	4.6M 1 in 7
2015	26.8%	13.6%	126.6M	34.0M	17.5M	
2025	30.3%	18.1%	120.7M	36.6M	21.8M	7M 1 in 5
2035	33.4%	20.0%	112.1M	37.4M	22.5M	
2060	39.9%	27.0%	86.7M	34.6M	23.4M	

Figure 3 Aging population Source: MHLW(2015)Aging Society White Paper(2015)

Household type for the aged who need care

The elderly who need care lives alone: 27.4%(2013)



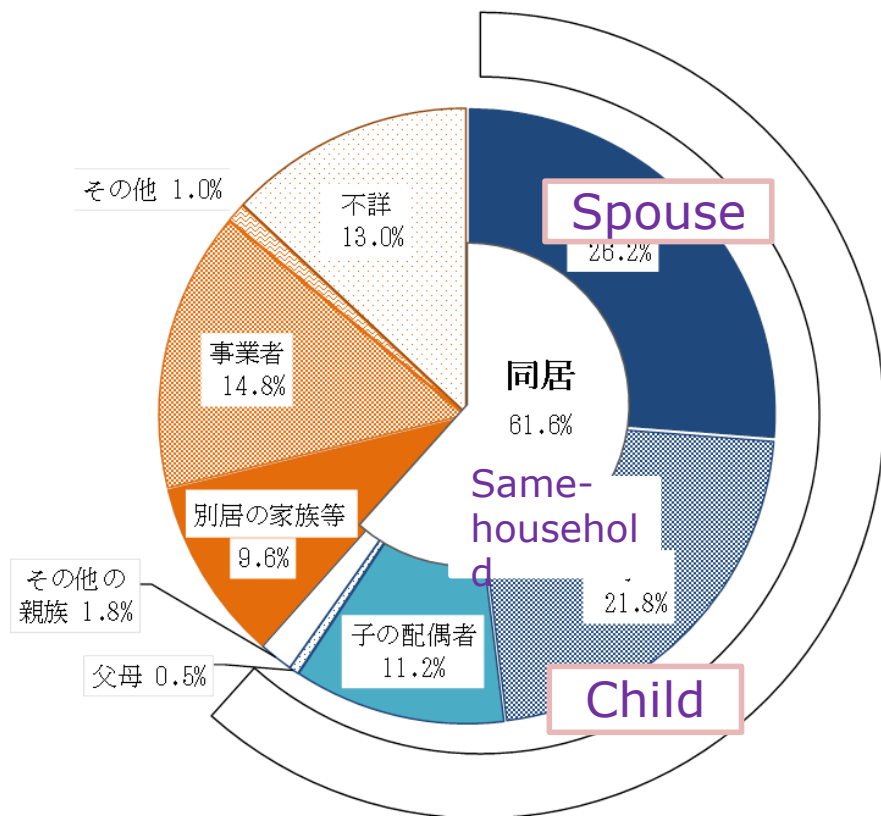
	2001	2004	2007	2010	2013
living alone	15,7	20,2	24,0	26,1	27,4
couple	18,3	19,5	20,2	19,3	21,5
with any child	11,0	10,9	12,5	12,1	13,9
3 generation	32,5	29,4	23,2	22,5	18,4
other	22,4	20,0	20,1	20,1	18,7

Figure 4 Household type for the aged who need care

Source: MHLW, National life basic survey (2013)

Main carer: Same-household family 61.6%

(Spouse 26.2%, Child 21.8%, Child's spouse 11.2%)



Same-household	61.6%	Spouse	26.2%
		Child	21.8%
		Child's spouse	11.2%
		Father/Mother	0.5%
		Other relatives	1.8%
Family not same-household	9.6%	Service provider	14.8%
		Other	1.0%
		NA	13.0%

Figure 5 Carers characteristics: MHLW, Aging Society White Paper(2015)

Main carers in the same-household : Male 28.5% Female 71.5% (2013)

	Husband	Son	Other (Male)	Wife	Daughter	Daughter-in-law	Other (Female)
2000	14.3%	12.0%	1.0%	36.8%	15.6%	17.2%	3.3%
2013 (H25)	16.1%	11.4%	0.9%	38.2%	19.3%	9.6%	4.3%

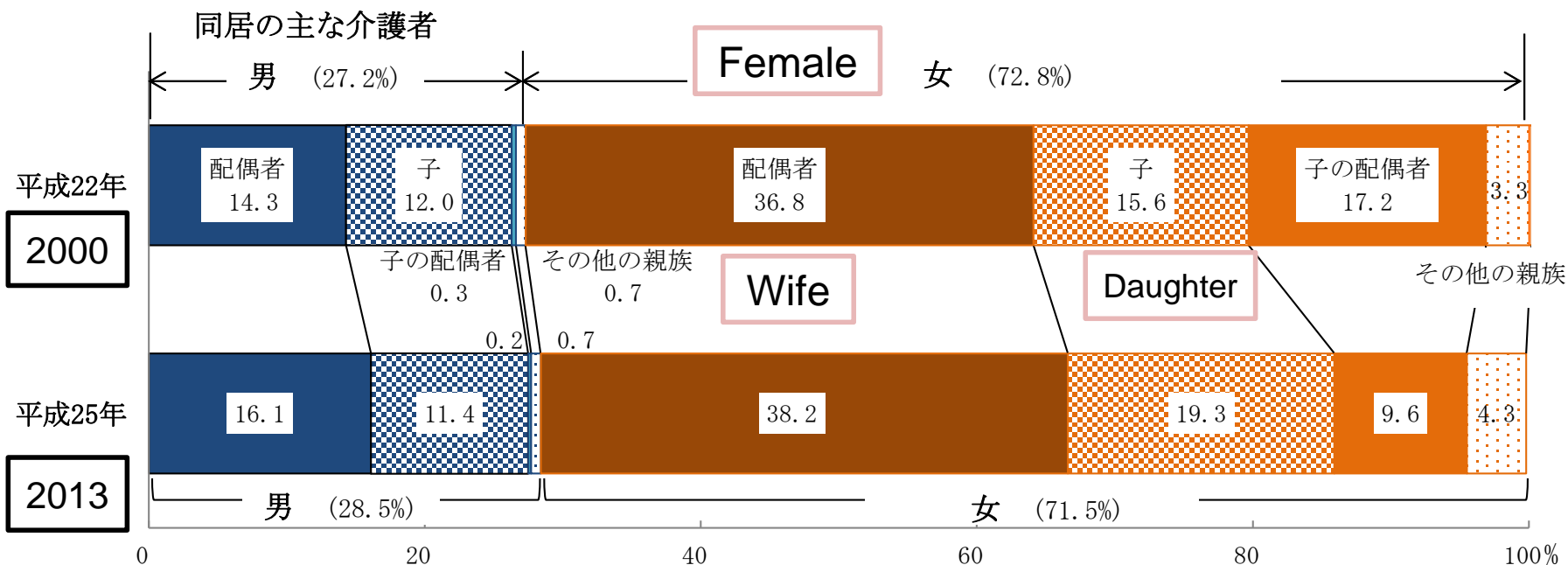
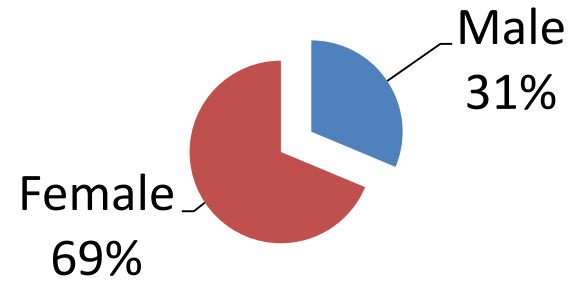
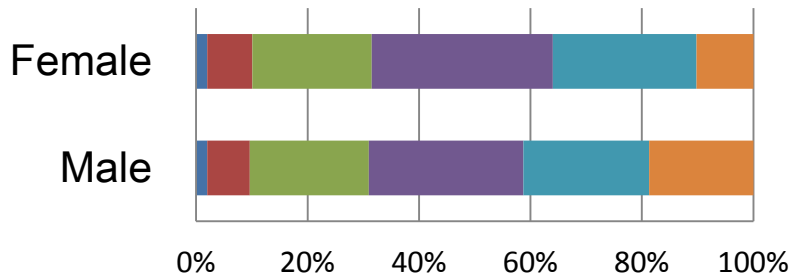


Figure 6 Main Carers in the same-household Source:MHLW(2015) Aging Society White Paper

Caring relations: Both Age65+ 51.2%, Both Age 75+ 29.0%

main carers' age by sex



	Male	Female
Under Age 40	2,0	2,0
40 ~ 49	7,6	8,1
50 ~ 59	21,4	21,4
60 ~ 69	27,7	32,5
70 ~ 79	22,6	25,8
Age 80+	18,7	10,2

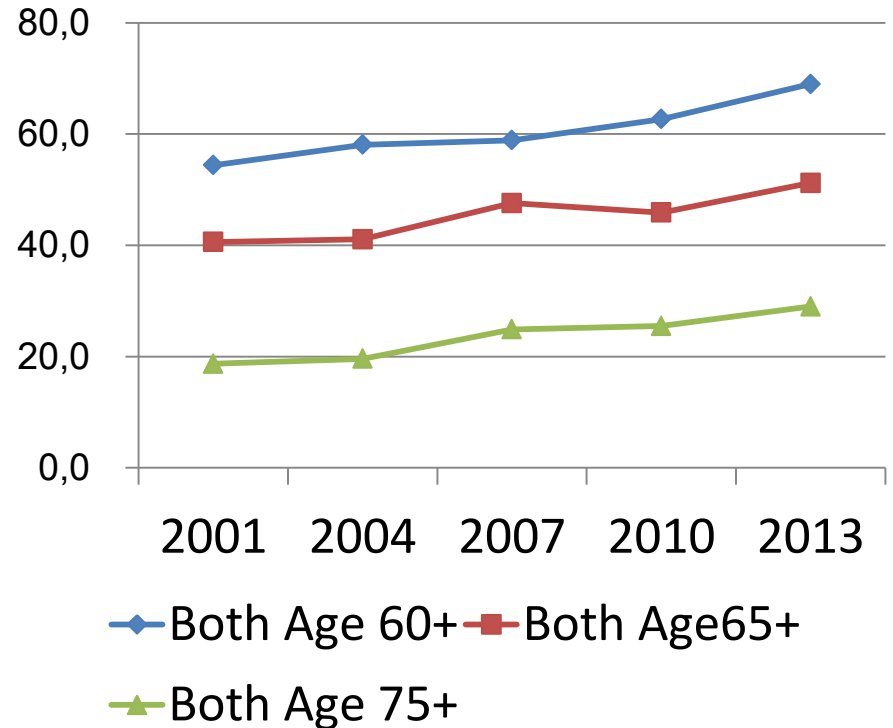
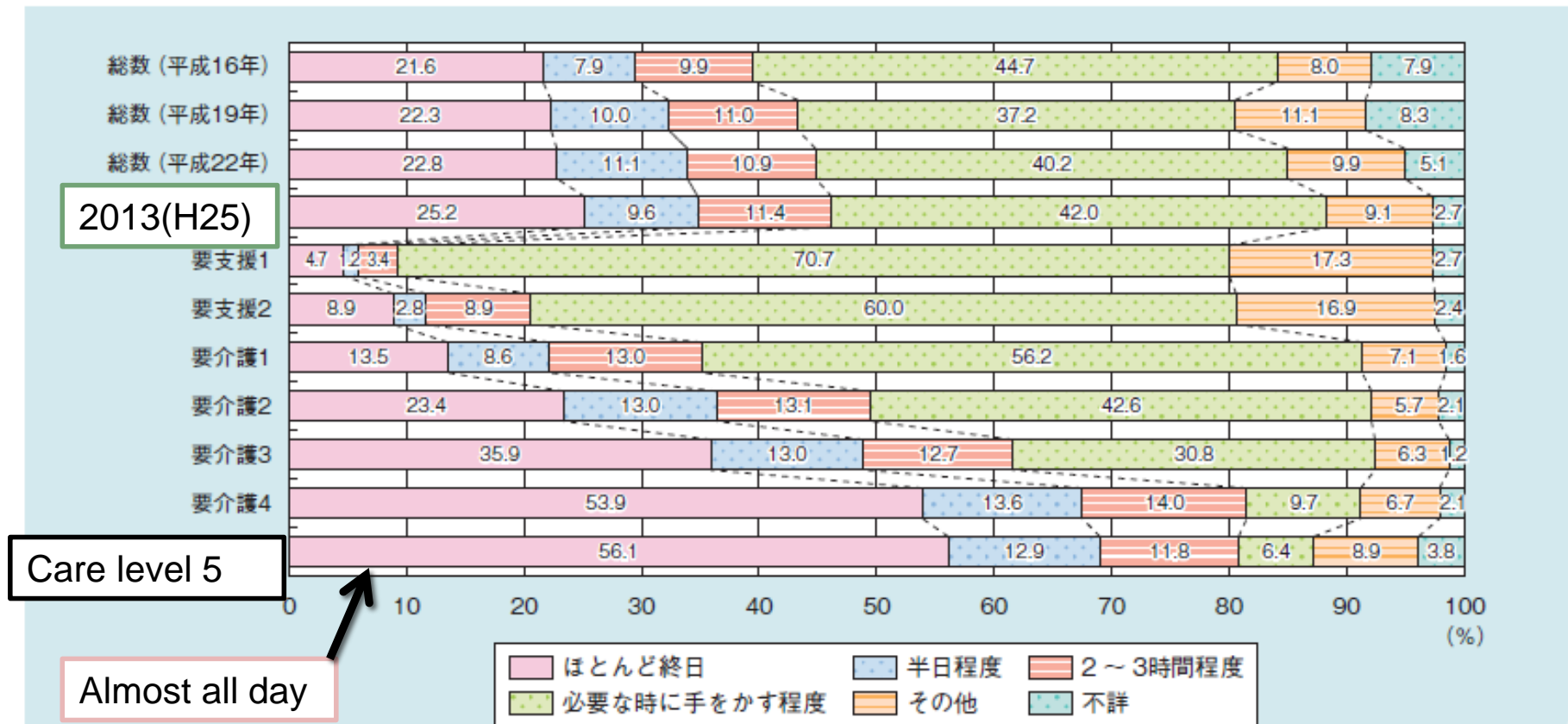


Figure 7 Main carers by age & sex Source :MHLW (2015) Aging Society White Paper

Caring hours of the main carers (cohabitation)

All most all day: Care level 4(53.9%) Care level 5 (56.1%)

図1-2-3-17 同居している主な介護者の介護時間（要介護者等の要介護度別）



資料：厚生労働省「国民生活基礎調査」(平成25年)
 (注)「総数」には要介護度不詳を含む。

Figure 8 Caring hours Source :MHLW (2015) Aging Society White Paper

Factor 2: the systematic factor

Fragmentation of the system: Facing the dilemma of maintaining sustainable caring society

- Policy for Elderly Care Policy

 - Long Term Care Insurance (LTCI) Policy**

 - National Dementia Strategy**

- Policy for the person with disability

- Policy for Child Care

- Policy for Work Life Balance

 - Childcare and Family Leave Act**

No Carers Law. No direct policy for Carers.

Missing agenda: Young carers

Long Term Care Insurance (LTCI) System in Japan

(1) The Long-Term Care Insurance (LTCI) System (2000-)

- A Universal system
- 10% co-payment
- Care level classification (6 level)1 Support + 5 Care level
- Market mechanisms for service providers within insurance

(2) Restructuring of the LTCI System

- 2005 Reform
- 2012 Reform
- 2015 Reform

(2014: The amendatory law to the related acts for securing Comprehensive Medical and Long-term care in the community)

Financial difficulties and Regional disparities (Yamaguchi et. Al 2012)

Carers support: Option for local government. Not main LTCI benefit
As Community-based program

Restructuring of the LTCI System

<p>2005 Reform</p>	<p>Shift to a prevention-oriented system Creation of a comprehensive support center in a local community Change in Care level classification (6 ⇒7 level, 2 support & 5 Care level) Creation of a community-based service</p>
<p>2012 Reform</p>	<p>Promotion of Comprehensive community care (the community-based integrated care system) Comprehensive, Continuous and Seamless care Multi-purpose facilities & Services Health Care, Personal Care, Prevention, Social Support & Housing Care for the older person with dementia</p>
<p>2015 Reform</p>	<p>Strict eligibility for Nursing Home (Care level 3+) Review of Co-payment for Service Users Above Certain Income Levels Increasing Copayment (20% co-payment for some users) Razing the Maximum copayments/copayment limits Creating the integrated community care system Revision of Preventive Long-term Care and Expansion of Community Support Projects Change of Daycare & home-help service for Support-level users</p>

2015 National Dementia Strategy

- 1 Promotion to deepen the understanding about dementia
- 2 Timely provision of the medical and care services considering the change of situation of the person with dementia
- 3 Enforcement the program for Early-onset (presenile) dementia
- 4 **Supporting carers of persons with dementia**
 - Easing the burden of carers of persons with dementia (Early intervention team, Dementia Cafe)
 - Supporting family carers (Promotion of workshop for carers)
 - Easing the burden for carers/Balancing work & care (Support for the development of Care Robots etc. Establishing working environments to take caring role for workers)
- 5 Creating friendly community for the elderly including those with dementia
- 6 Development of preventive measures and treatment
- 7 Emphasis on the point of view of people with dementia **and their family**

Childcare and Family Leave Act

1991 Childcare Leave Act (for all workers)

1995 Revision (Childcare and Family Leave Act)

Employer recommended

1999 Revision: Employer obliged

93 days/year (unpaid)

2011 Revision of Childcare and Family Leave Act

Care holiday (Paid day-off, 5days/ year)

Employer over 100 employees obliged

2014 Application to Employer (under 100 employees)

Care holiday (5days/ year)

Percentages of users of care leave:3.2% (2014)

Percentages of users of care holidays: 2.3% (2014)

Factor 3: Factor related to the problems of Japanese management practices

◆ Long working hours

60 hours +/-week (2012) Male 15.8% Female 5.3%

◆ Gender inequality

Japan ranked 104 out of 142 countries

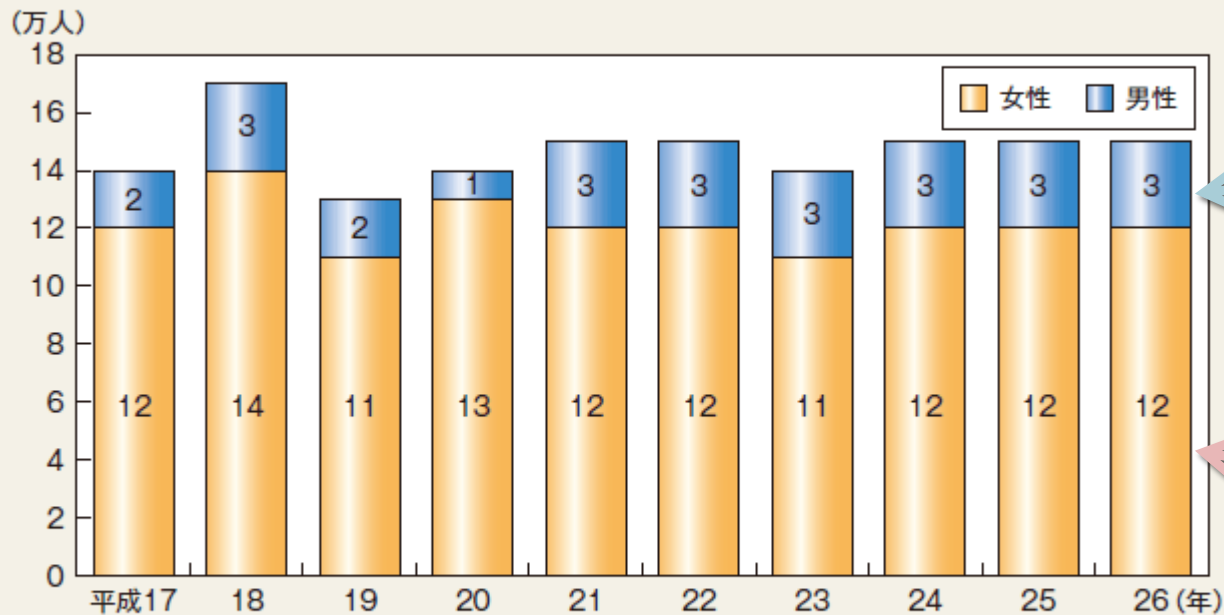
(Global Gender Gap Index, 2014 World Economic Forum)

- ✓ Labor force participation : Male 68.8% Female 48.2%(2012)
- ✓ Among all carers (5.6m), working carers are 2.9m (2012)
- ✓ During recent 5 years, 0.5 m. workers quitted their job, about 80% of those are female.

Numbers of Working carers who quitted job due to care role

More than 100 thousands every year, most of them are female

I-5-6図 非就業者のうち介護・看護を理由とした離職者数の推移（男女別）



Male
30 thus.

Female
120 thus.

2014

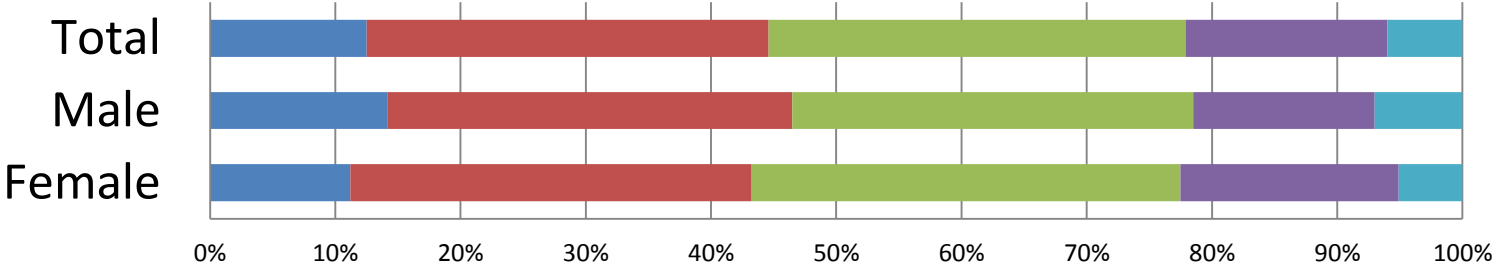
(備考) 1. 総務省「労働力調査（詳細集計）」より作成。
 2. 前職が非農林業雇用者で過去3年間の離職者のうち、現在、就業している者を除く。
 3. 平成23年の数値は、岩手県、宮城県及び福島県を除く。

Figure 9 Numbers of Working carers who quitted job due to care role
 Source: Cabinet office (2015) White paper on Gender Equality

Factor 4: the cultural factor

Stereotype perception of the gender norm (2014, N=3037)

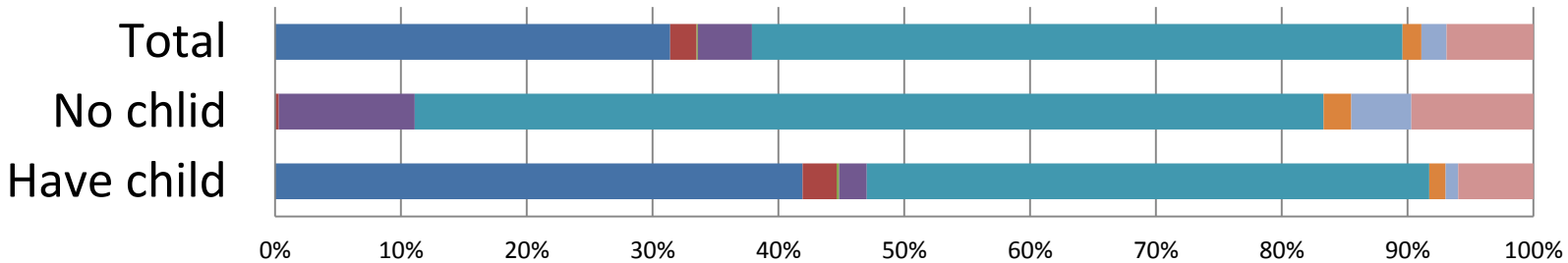
“Husband is expected to work outside the home, while wife is expected to take on domestic duties”



	Female	Male	Total
■ Agree	11,2	14,2	12,5
■ Rather agree	32	32,3	32,1
■ Rather disagree	34,2	32	33,3
■ disagree	17,4	14,5	16,1
■ Don't know	5,1	7	6

Figure 10 Stereotype perception of Gender norm
 Source: Cabinet office (2015) White paper on Gender Equality

To whom do you want to rely on when you become frail and need personal care? (2014 Survey for the elderly living alone N=1480)



	Have child	No child	Total
Child	42	0	31,4
Child's spouse	2,7	0,3	2,1
Grandchild	0,2	0	0,1
Brothers/Sisters	2,2	10,8	4,3
Careworkers	44,8	72,3	51,7
Friends	1,3	2,2	1,5
Other	1	4,8	2
Don't know	6	9,7	6,9

Figure 11 To whom do you want to rely on? (Living-alone elderly survey)
 Source: MHLW (2015) Aging Society White Paper

Social concerns in Aging Japan

Increase of the elderly, especially those with dementia

“老老介護(rou-rou kaigo)” Older couple caring

“認認介護(nin-nin kaigo)” Dementia-dementia caring

Number of the missing elderly: 10,783(2014)

Missing Elderly with dementia: 359 (died), 219 (missing) in 2012

Taro's story (Lost in 2012, Found after TV broadcast in 2014)

(Mainichi newspaper press group 2015)

Care-related Homicides or murder-suicides (Age 60+)

About 40 cases per year (Yuhara 2015)

Elder abuse (15,731, among them, 21 died in 2013)

by sons (41%), husbands (19%), daughters (16%) and wives (2013, MHLW).

3. Our challenges in mainstreaming this issue in Japan

- A) To raise public awareness that carers should be recognized as citizens who have their own lives

- B) To expand the grass-roots activities in Carers movement



Carers support movement in Japan

- 1963 Act on Social Welfare for the Elderly
- 1972 “Koukotsu no hito (the twilight years)” by Sawako Ariyoshi
- 1973 <Free medical coverage for the elderly & pension benefit up >
- 1970s- < Family caregiver support program (mainly provided by Local government & Council of Social Welfare)>
- 1980 Establishment of Alzheimer’s Association Japan (AAJ)
- 2000 <Establishment of LTCI system>
<Family caregiver support program within LTCI scheme>
- 2001 Establishment of NPO Carer’s Support Network Centre Alajin
- 2009 Establishment of Male Carers Network
- 2010 Set up of Carers Japan, National Carers Survey 2010
- 2011 Establishment of Carers Japan as General Incorporated Association
- 2014 Formation of National Federation of Carer’s support organization (Zenkoku Kaigoshu Shindantai Rengoukai)
12 organizations

Our mission

- ◆ To support carers
- ◆ To realize a society where both people who need care and support and their carers can live their own lives.

Our activities

1. Advocacy
2. Research and study
3. Policy recommendations
4. Enlightenment
5. Provision of information and advice to carers

2010 National Carers Survey (Carers N=2075)

Having to get up for toilet help three times every night, I suffer from lack of sleep and heavy head.

I sometimes hate myself for wondering what my life would have been like without this caring responsibilities.



一般社団法人

日本ケアラー連盟

Carer Survey Report

March 2011 (published by the Ministry of Health, Labour and Welfare)



Edited and published by Carers Japan

I sometimes hate myself for wondering what my life would have been like without this caring responsibility.

I have never rested well since my child was born with a disability.

Having to get up for toilet help three times every night, I suffer from lack of sleep and heavy head.

I wish I could work just for a few hours a day as a break from the caring role.

"We Need to Support Carers."

I need someone who understands me, I am crying out "Help!" in my mind.

I miss time for myself. I wish I could join some activities in the community.

I have been caring for my demented mother for 3 years and for my brother who suffers from higher brain dysfunctions for 30 years. My own health is deteriorating.

I'm interested in doing some volunteer activities where my caring experiences would be useful.

I have been caring for my husband who has had cancer for 2 years. I need to work doing newspaper routes to make both ends meet. I'm tired and can't smile anymore.

About the Survey

- The aim of the survey: to provide a clear picture of carers' characteristics and experiences and to discuss its policy implications towards a comprehensive support system for them.
- The target areas:
 - Urban area: Chiyoda Ward, Tokyo
 - Shizuoka City, Shizuoka Pref.
 - Kyoto City, Kyoto Pref.
 - Rural area: Karuyama Town, Ehime Pref.
 - Miyama City, Niigata Pref.
- The methods: questionnaire (August to October 2010) and interview (October to December 2010)
- The first part of the survey: questionnaire
 - Targeted were 4500 households in a roughly same administrative unit of each area.
 - Delivered to 21,861 households in the 6 areas above. Response rate 48.3% with 10,868 valid responses including 2,875 by carers.
 - Who are the 2,875 carers?
 - Two-thirds of them are female, one-third male.
 - One in six carers is regularly employed, one in six is a contractual employee, one in 17 carers is out of work.
 - One in 4 to 5 carers lives separately from the care recipient. One in 7 to 8 of them takes more than 3 hours to get to the person.
 - The conditions of the care recipients (general answer):
 - physical disability 41.0%, dementia 28.7%, mental illness 9.9%, learning disability 7.6%, cancer 7.4%, visual impairment 6.8%, incurable illness 4.9%, substance abuse 1.8%, others 18.2%
- The second part of the survey: interviews of 303 carers



The features of our survey

- We defined carers broadly without limiting our targets by age or care recipient conditions.
- We asked people in the communities such as leaders of resident associations or staff of social care groups to be surveyors both in the questionnaire and interview parts of the survey.
- We observed carers' needs according to their characteristics.

Our recommendations

- We should have more support centers in communities to provide sensitive support to carers.
 - 1. A community life support network center (provisionally named) in each ward/city or every 100-thousand population.
 - 2. A care support center (provisionally named) in every small or every 20-thousand population.
- It should be ensured that both people who need care and support and their carers are able to live healthy lives in dignity without being isolated from the society.
- The government and councils should promote carer support, including legislative measures such as the Carer Support Promotion Act (provisionally named).
- Carers should be involved in the process of policy-making on carer support.

Carers Japan



2010 National Carers Survey

(Carers N=2075)

- ✓ There is a carer for one in 5 households.
- ✓ One in 4 carers are caring for more than one person.
- ✓ One in 12 carers has been caring for more than 20 years.
- ✓ One in 8 carers has nobody to turn to for help.
- ✓ One in 2 carers have a physical health problem.
- ✓ One in 4 carers has a mental health problem.
- ✓ One in 7 carers feels significant burden.
- ✓ One in 5 carers feels isolated.

<2012 Project> Development & Evaluation of tools for supporting carers in the community



Carer's Assessment Sheet



Carer's Handbook
Carer's Emergency card



Carer's Café
(Cafe Alajin)



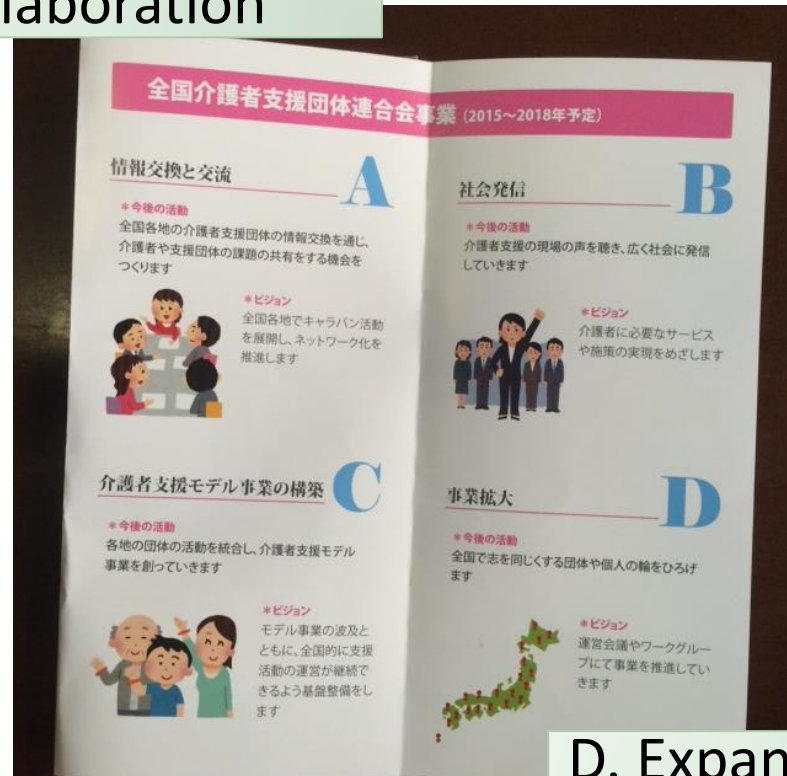
Training program for supporters of carers

National Federation of carer's support organization

Action plan
2015-2018

A. Information
exchange and
collaboration

B. Sending Information
to Society



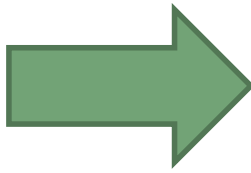
C. Development of Model
of Supporting Carers

D. Expansion of
Support Network
Activities

4. Conclusion

Supporting Carers in the super-aged Japanese society

Marginalized agenda in the long-term care system



Mainstreaming the agenda of Supporting carers

Complicated factors

Factor 1: the demographic factor

Factor 4: the cultural factor

Changeable factors

Factor 2: the systematic factor

Factor 3: a factor related to the problems of Japanese management practices

our biggest challenges

To raise public awareness that carers should be recognized as citizens

To expand the grass-roots activities in Carers movement

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Thank you.(Arigato gozaimashita)

