



SILVER CHAIN

EVERY MINUTE. EVERY HOUR. EVERY DAY. WE CARE.

Ageing intensifies the care needs of adults living with Parkinson's Disease and their carers

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- Neurodegenerative Disorders Project, 2006 - 2008 was funded by Lotterywest, the official state lottery for Western Australia.
- Margaret's attendance at IFA Conference, Melbourne, is funded by Edith Cowan University

Overview of the project



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Four disorders – ALS/MND, MS, PD and HD

Project component	n (with PD)	Used in this presentation
Client and carer surveys	391 of 1,080	*
Client and carer interviews (targeted)	13 of 49	
Client and carer case studies (targeted)	1 of 4	
Health and allied health professionals and care workers interviews	6 of 9 groups	
Clients and members data and data linkage	n.a.	
Projections to 2021 (PD and NDD populations in WA)	7,144 of 9,591	

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391 respondents with PD:

- Average age 72.4 years
- 58 % male
- 24.6 % live alone, most without a carer
- 75.4% live with others but only 3 in 4 have carers
- 86.8 % members of PWA

219 respondents with PD have carers:

- Average age of those with carers 73.7 years
- Average age of carers 70.2 years

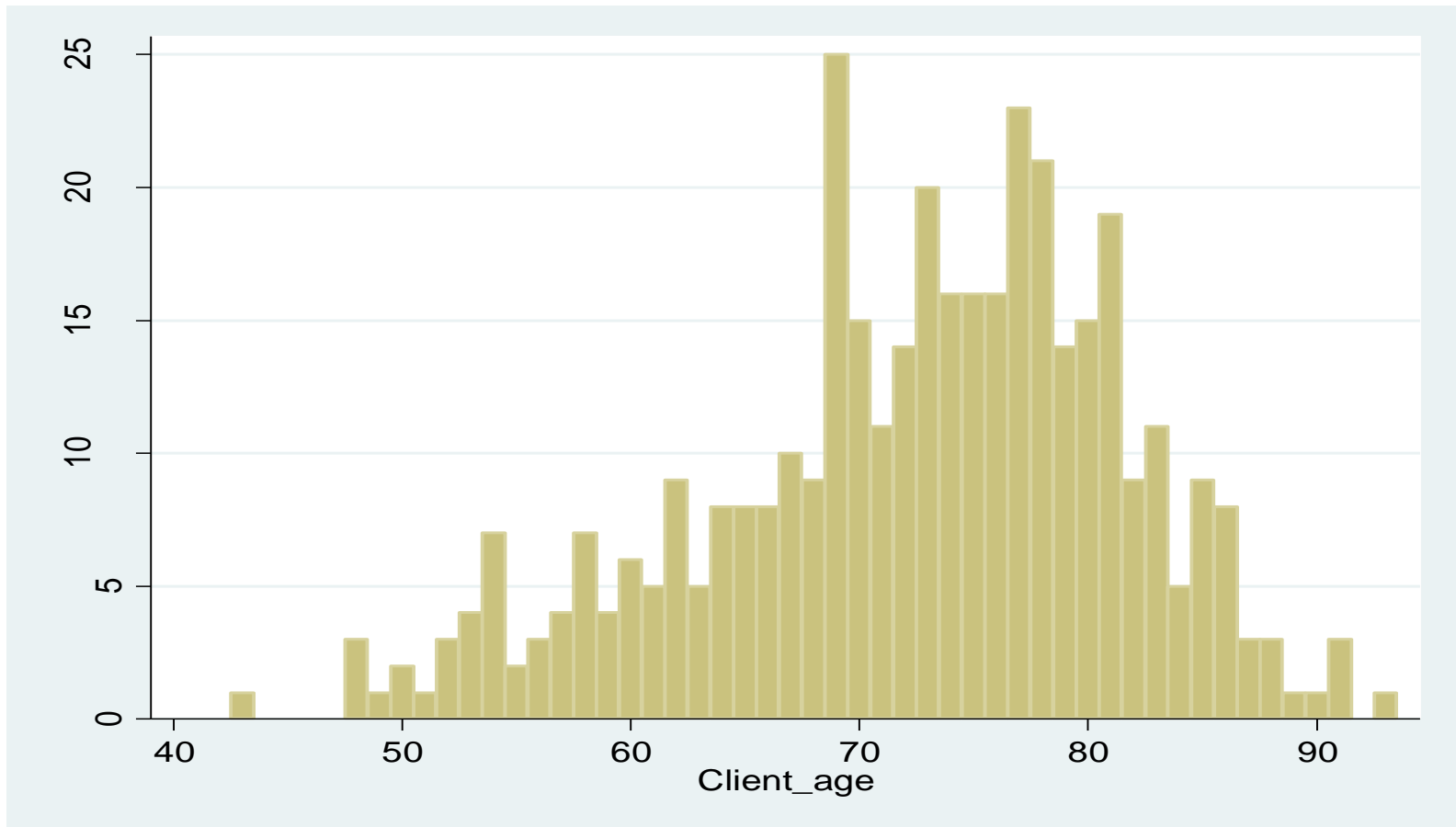
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Age distribution of PLWPD



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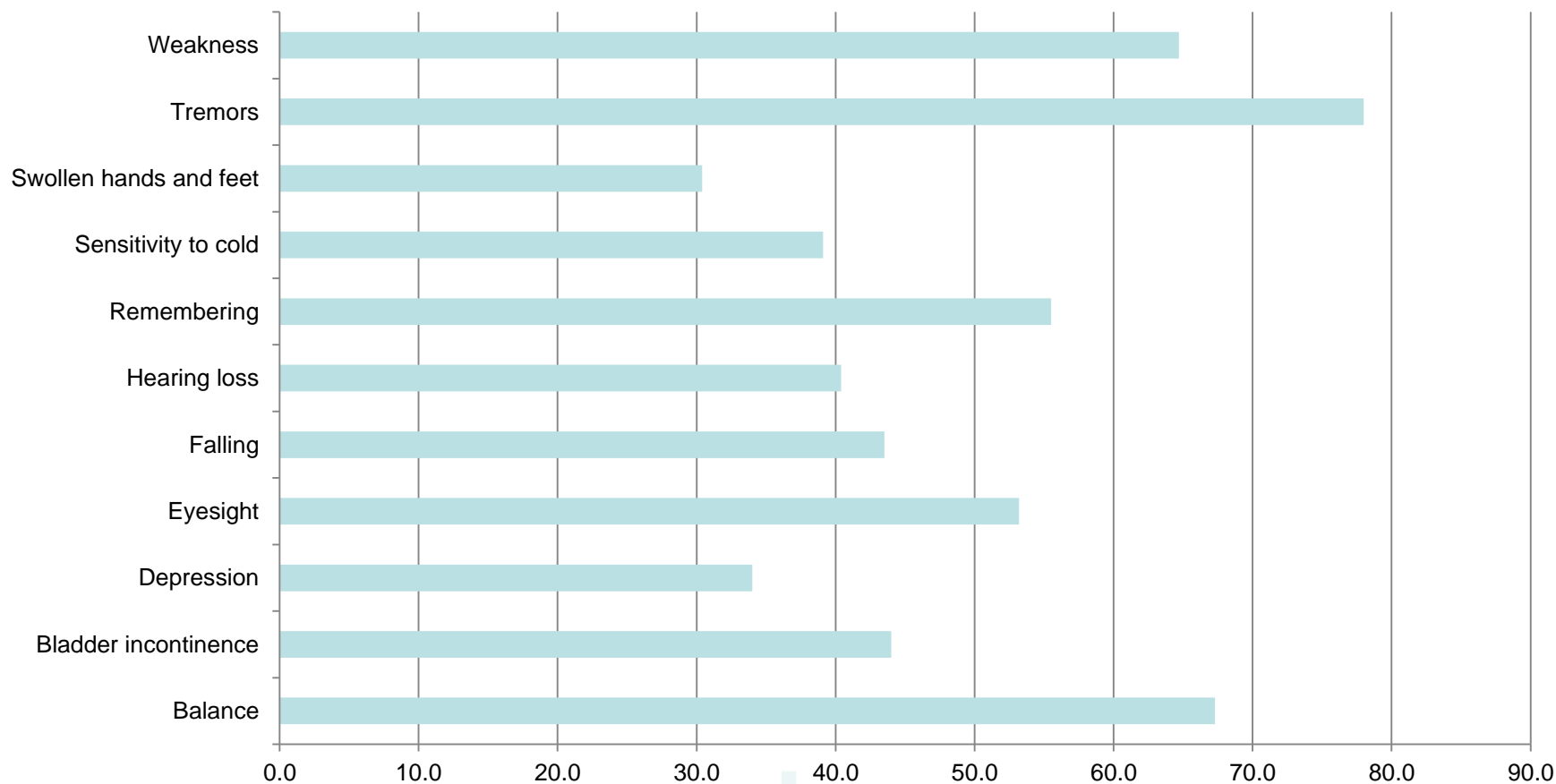
Difficulties due to PD



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% PLWPD with difficulties



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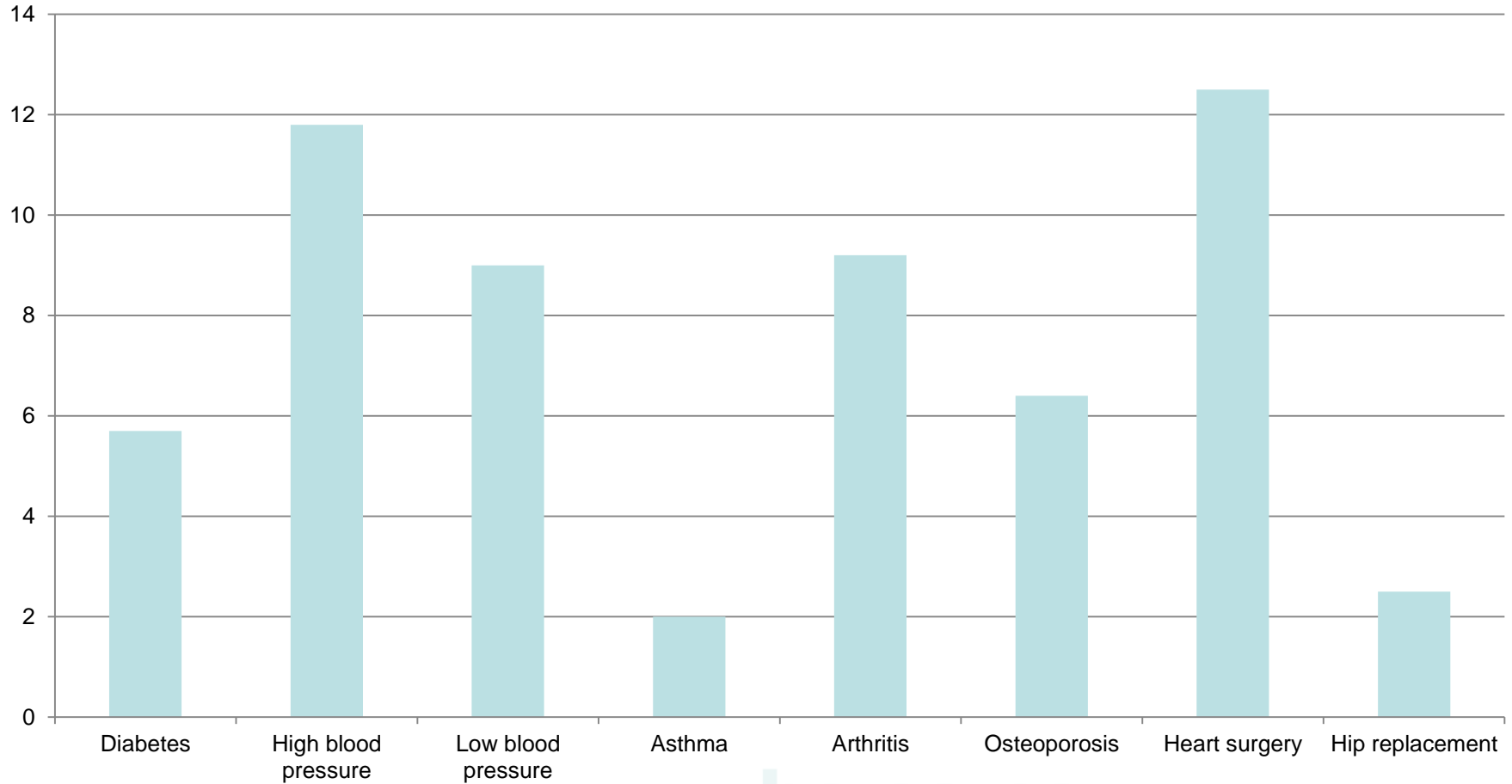
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Co-morbidities



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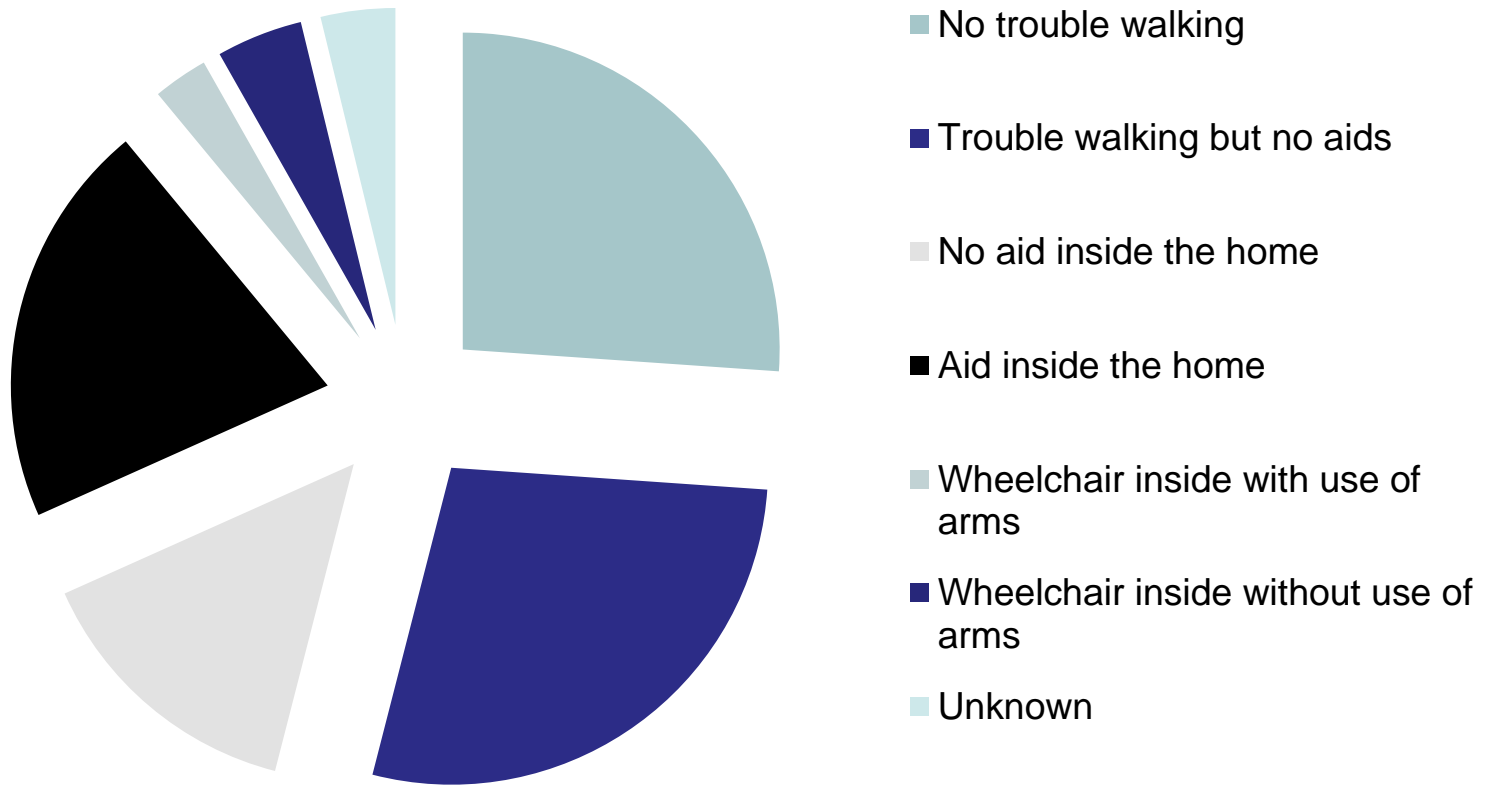
% PLWPD with other health problems



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% of PLWPD



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Activities of daily living (Collin, Wade, Davies, Horne (1988)	Instrumental activities of daily living (Lawton and Brody (1969)
Eating and drinking	Using the telephone
Showering or bathing	Shopping
Dressing and grooming	Preparing food
Getting on and off the toilet	Managing finances
Managing your bladder	Managing medications
Managing your bowels	Managing medical equipment
Moving about the house	Laundry
Transferring (chair to wheelchair, wheelchair to bed)	Housework
	Going out (attending appointments, social activities)

Levels of dependency



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Levels of dependency	ADL	IADL
Independent	No help	No help
Low dependency	No help	Some help
Medium dependency	Help with at least one ADL	No help or help
High dependency	Help always with at least one ADL	No help or help

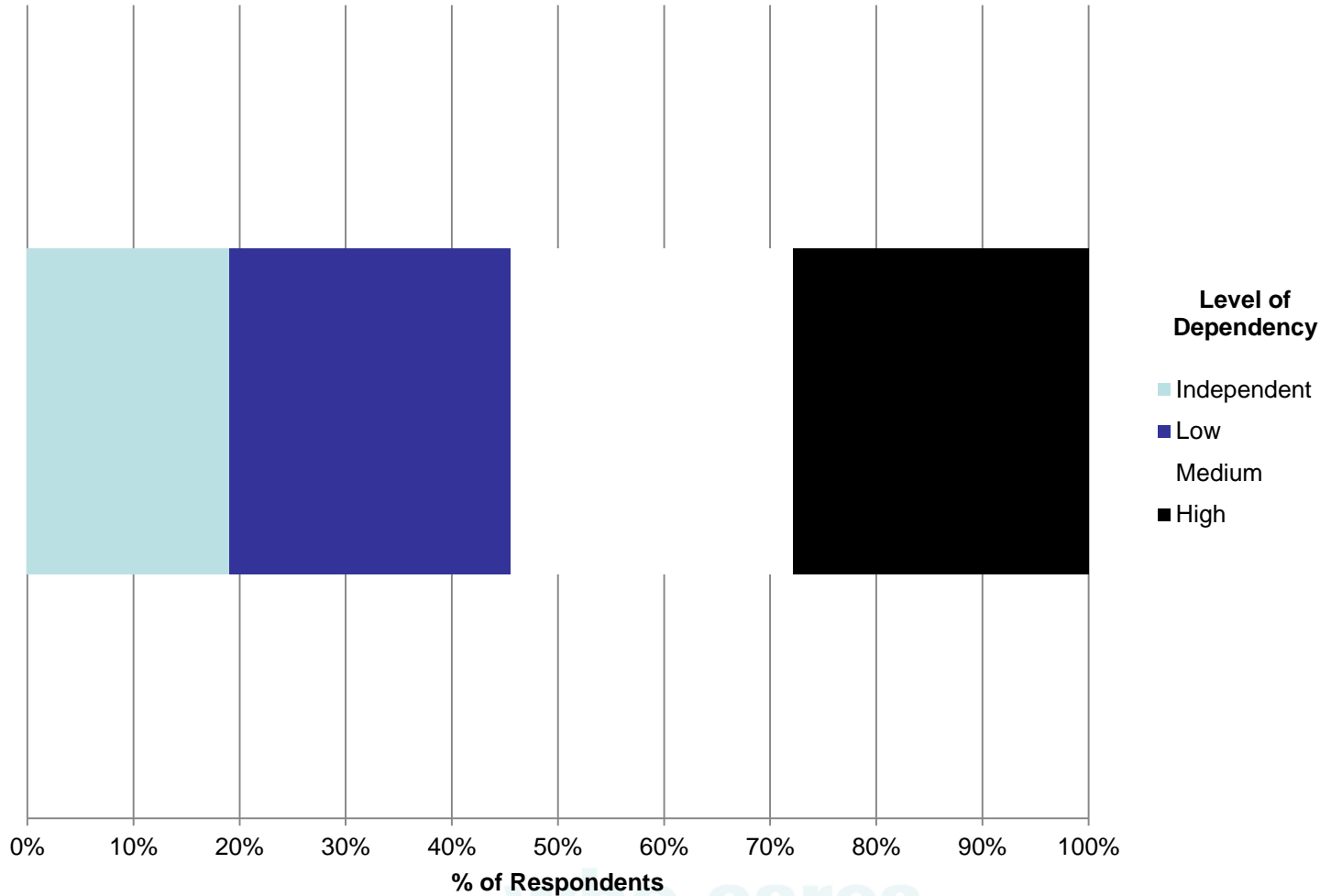
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% of PLWPD by level of dependency



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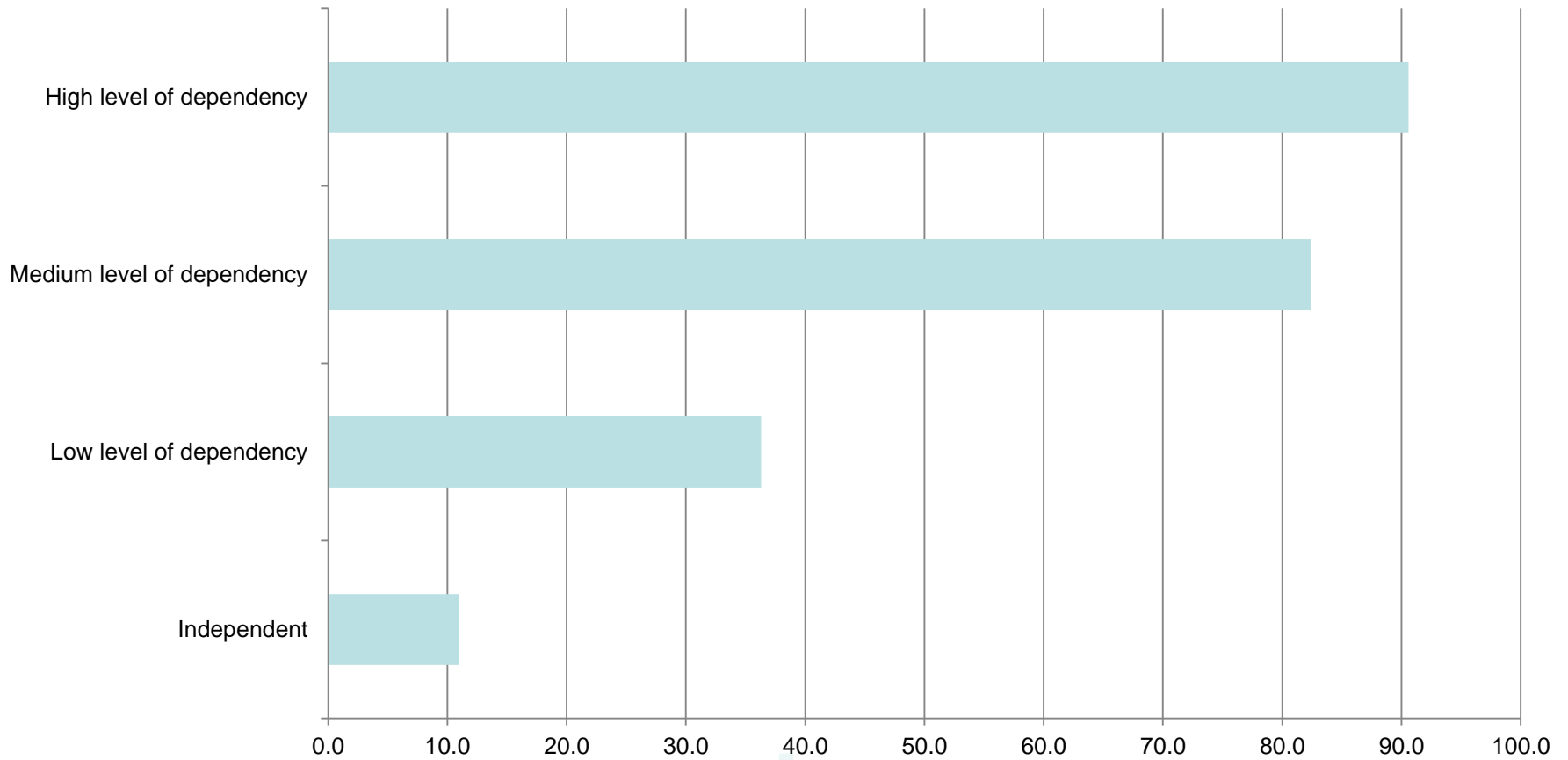
Level of dependency and caring



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% of PLWPD with carers



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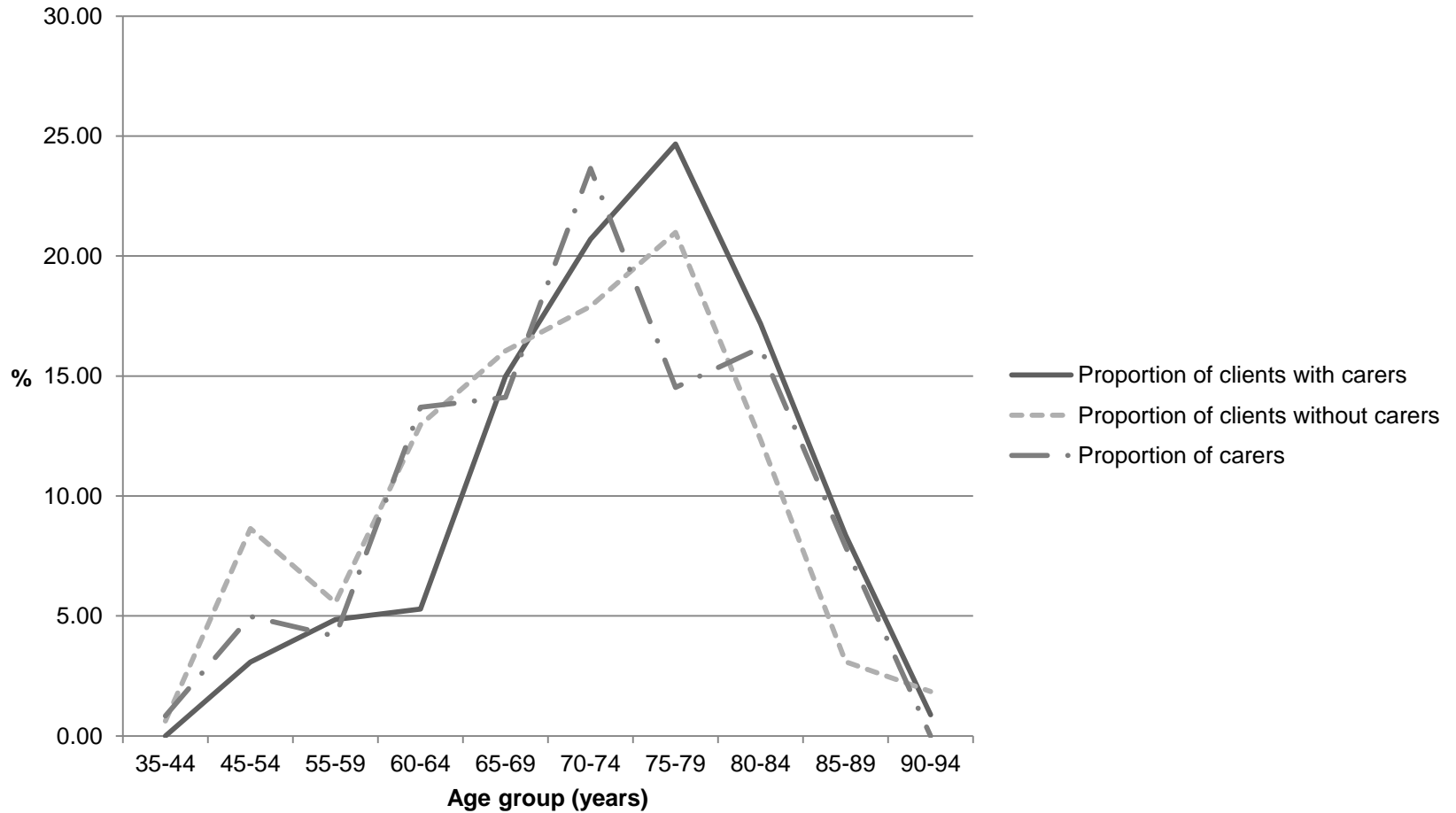
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Age distributions for PLWPD and their carers



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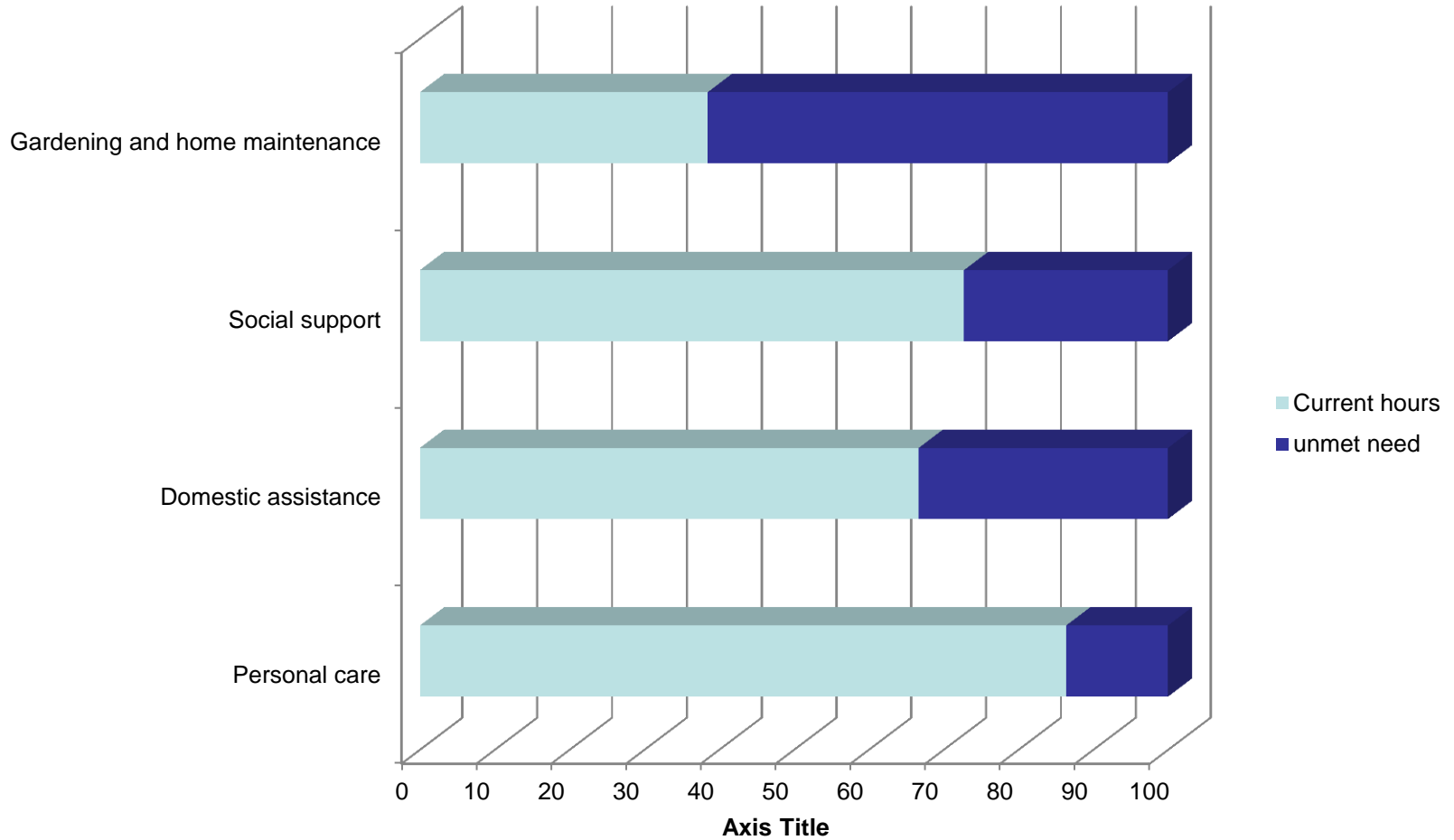
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Home support needs



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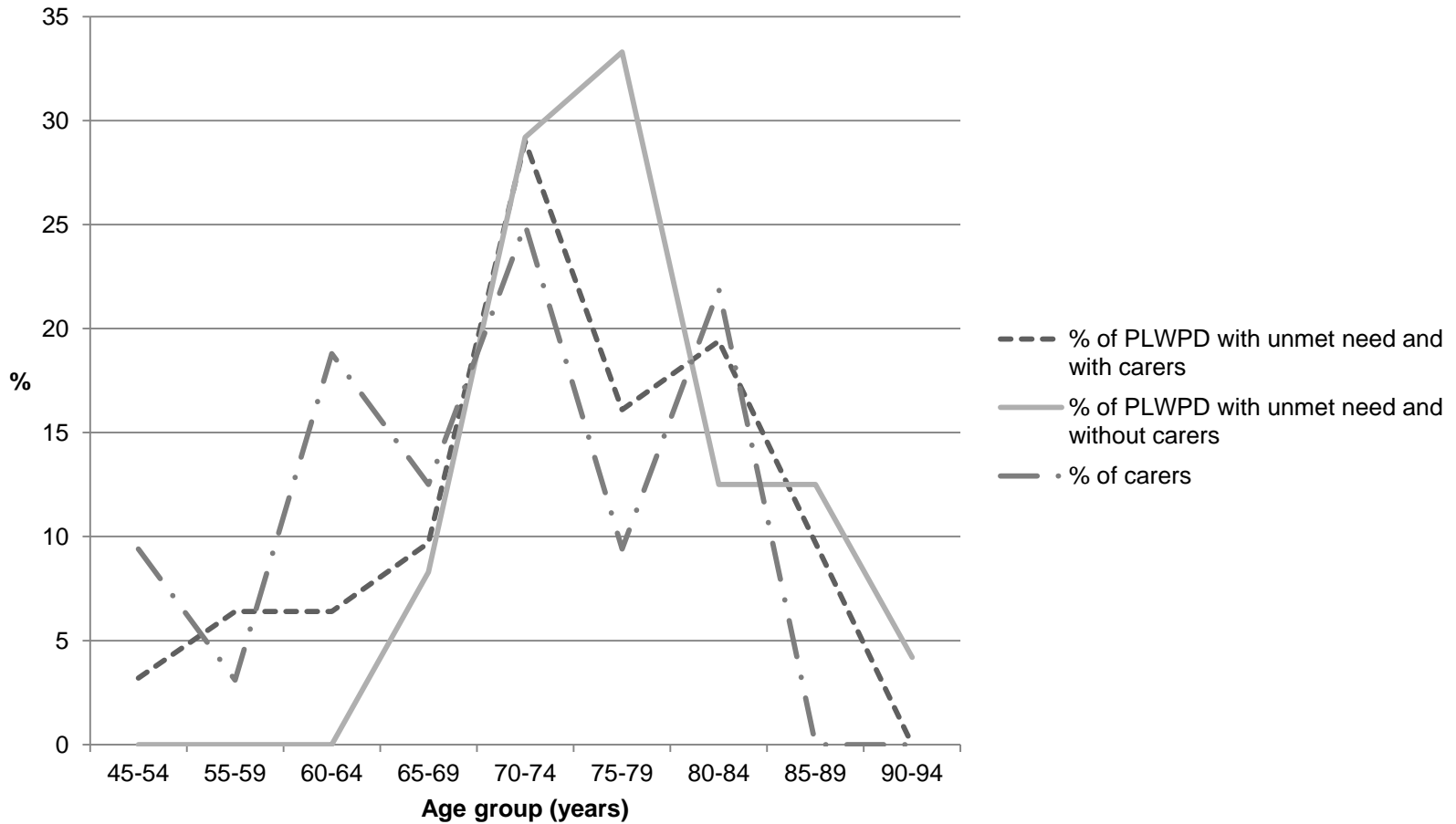
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Unmet need by ages of PLWPD and carers



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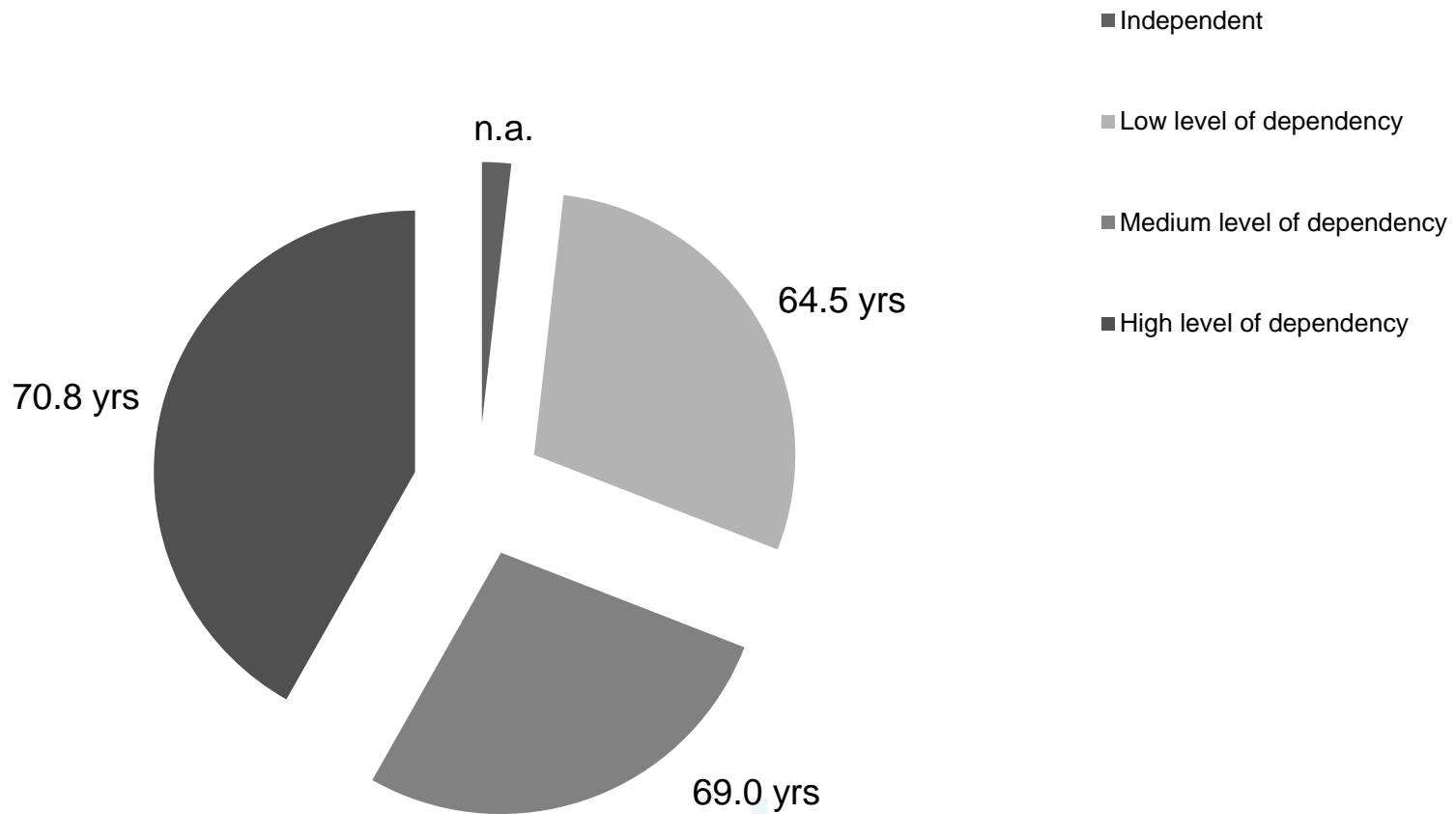
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Average age of carers for PLWPD with unmet need



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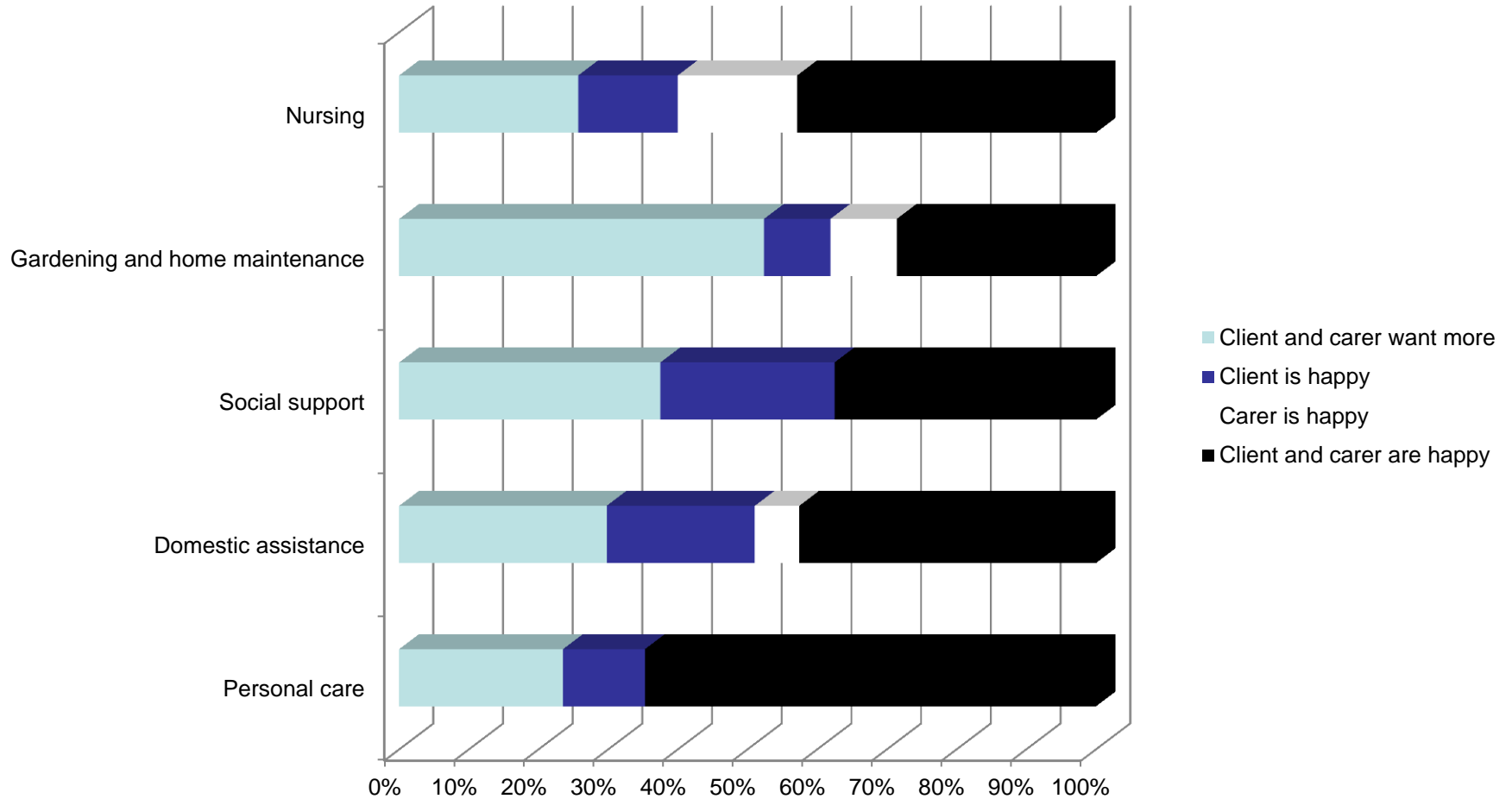


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PLWPD and carer agreement on current and unmet needs



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- PLWPD
 - 46.5% expressed dissatisfaction with current support or uncertainty about future support
- Their carers
 - 81.3% of carers agreed that the person they cared for could not manage without them

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Take home message



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Staying at home, with all needs met, is cheaper than residential care or hospitalisation.

Staying at home is preferred by PLWPD, their carers and health and allied health professionals and care workers.

However staying at home requires **increased support** in the home, particularly **personal care**, and this is especially important as PLWPD and their carers are ageing.

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