Work Productivity and Activity Impairment of Caregivers of Huntington's Disease Patients in the US and EU5: Evidence from the Huntington's Disease Burden of Illness Study (HDBOI)

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Introduction

- Huntington's Disease (HD) is a rare, neuro-degenerative disorder with individual's experiencing long term disability due to their condition.
- Affected individuals as well as their family members and caregivers are significantly affected by the HD diagnosis.[1]
- People with HD universally require caregiver support during their lifetime which is often associated with a large caregiver burden.

OBJECTIVE

This research explores the burden associated with caregiving by means of a set of questions, including the Work Productivity and Activity Impairment Specific Health Problem (WPAI-SHP)[2] tool, and descriptively explores differences by disease stage.

Methods

- The HDBOI is a retrospective, cross-sectional dataset that captures clinical information, medical resource, quality of life, and WPAI-SHP of a cohort of HD participants and caregivers.
- Countries included in the study were Germany, France, Italy, Spain, the UK and USA.
- Data was collected via **Patient and Public Involvement and Engagement (PPIE-Caregiver) questionnaire**; an optional questionnaire completed by the caregiver of HD participant.
- Participants were categorized as early, mid, or advanced stage by the treating physician. Physicians were provided with the Unified Huntington's Disease Rating Scale Total Functional Capacity score[3] and corresponding disease stages to guide their assessment of disease stage.

Outcomes

- The **WPAI-SHP** tool was administered to assess the impact of HD on caregivers' productivity and activity.
- It is a validated and widely-used instrument for measuring the impact of a condition on an individual's or caregivers' work and activities during the previous seven days.[2]
  - This 6-item instrument measures the following, as experienced by the caregiver of HD participant during the previous seven days: (i) work time missed, (ii) impaired productivity at work, (iii) impairment in daily activities, and (iv) overall work productivity loss (WPL)
- WPAI-SHP caregiver outcomes were explored by disease stage.
- Other outcome variables included were the impact of participant's HD on career of caregiver and informal and formal caregiving patterns.

REFERENCES

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Results

Sample characteristics

- The analytic sample was comprised of 503 HD caregivers who completed the WPAI-SHP, of which 35% were caregivers of early-stage (ES), 36% of mid stage (MS), and 29% of advanced stage (AS) participants.
- The mean age of caregivers in the PPIE-C sample was 48 years.
- The partner/spouse was the most commonly reported main caregiver (48%), followed by a parent (19%).
  - In most cases care was provided by a relative, with only 12% of caregivers being a non-relative or contracted caregiver.
- Within the PPIE-C sample 66% of caregivers reported being employed, while approximately 34% were not employed, and this was largely similar across disease stages (See **Table 1**).

Table 1. PPIE-Caregiver sample and employment status: total and by disease stage*

	Full Sample		Early Stage		Mid Stage		Advanced Stage	
	N	Percent	N	Percent	N	Percent	N	Percent
PPIE-C sample	503	100	178	35	179	36	146	29
Employed								
Yes	333	66	115	65	119	66	99	68
No	170	34	63	35	60	34	47	32

*as defined by treating physician

Table 2. Work Productivity and Activity Impairment Specific Health Problem outcomes by disease stage*

	Full Sample			Early Stage			Mid Stage			Advanced Stage		
	N	Mean	Std. Dev.	N	Mean	Std. Dev.	N	Mean	Std. Dev.	N	Mean	Std. Dev.
Percent overall activity impairment	503	47%	0.23	178	42%	0.25	179	48%	0.21	146	52%	0.22
Work time missed	320	12%	0.20	114	6%	0.12	112	13%	0.21	94	17%	0.24
Impaired productivity at work	318	44%	0.25	114	39%	0.26	111	47%	0.24	93	46%	0.23
Overall work productivity loss (WPL)	318	49%	0.27	114	42%	0.28	111	52%	0.25	93	54%	0.25

*as defined by treating physician

WPAI outcomes

- All WPAI-SHP outcomes were increased for carers of participants in later stages of disease, as displayed in **Table 2**.
- Overall **impairment in caregiver daily activities** increased with participant's disease severity: 42% in ES, 48% in MS, and 52% in AS.
- Likewise, for caregivers who reported being employed for pay (N=333), **overall impaired productivity** at work increased with participant's disease severity: 42% in ES, 52% in MS, and 54% in AS.

Results continued

Table 3. Impact of caregiving duties on career of caregiver and total hours of formal and informal care

	Full Sample		Early Stage		Mid Stage		Advanced Stage	
	N	Percent	N	Percent	N	Percent	N	Percent
Alternate career								
Yes	38	19	14	22	12	16	12	18
No	168	81	51	78	62	84	55	82
Prevent career progression								
Yes	111	54	34	52	43	58	34	51
No	95	46	31	48	31	42	33	49
Prevented from working more hours								
Yes	121	59	35	54	39	53	47	70
No	85	41	30	46	35	47	20	30
	N	**Mean (SD)**	**N**	**Mean (SD)**	**N**	**Mean (SD)**	**N**	**Mean (SD)**
Total Hours Formal Care	58	28 (31)	20	21 (14)	21	24 (22)	17	43 (48)
Total Hours Informal Care	324	34 (40)	121	31 (40)	120	33 (39)	83	41 (41)

Impact on caregivers and formal and informal care

- A total of 37 (7%) respondents had to stop working because of their caregiving duties and 206 (41%) reported that their duties have impacted their career.
  - Of the 206, approximately 59% were prevented from working more hours, 54% prevented from career progression, and 19% were required to choose an alternative career (See **Table 3**).
- High levels of **informal care** were reported, with an average of 34 hours of informal care per week.
- The average number of **formal care** hours per week was 28, and this was greater at later stages of disease. Larger increases in formal care were observed when moving from MS to AS when compared with informal care (See **Table 3**).

Conclusion

- Results from the HDBOI study show a considerable work productivity impact on caregivers of HD participants which increases as disease progresses.
- The careers of caregivers were impacted by their caregiving duties, highlighting the impact on society and caregivers themselves.
- Productivity losses and activity impairment are linked to informal care, and overall productivity losses moving from MS to AS are not increased substantially, as there was an increase in formal care when moving from MS to AS.
- Efforts should be made to address the needs of HD caregivers to help improve productivity outcomes for caregivers and society.

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