

Valuation of Lost Productivity for Individuals Diagnosed with Osteogenesis Imperfecta: Follow-up Findings from the Rudy Cohort Study in the UK

Sophie Cole, M Kassim Javaid, Rafael Pinedo-Villanueva

University of Oxford, Oxford, United Kingdom

OBJECTIVE

To evaluate the cost of lost productivity for adults with Osteogenesis imperfecta (OI) using the valuation of lost productivity (VOLP) questionnaire.

Osteogenesis imperfecta (OI) is a rare genetic condition which causes fragile bones, weakened muscles and other complications. If the symptoms are sufficiently severe this may impact the individuals ability to work and limit their employment opportunities. The valuation of lost productivity at baseline has been analysed and reported elsewhere.

METHODS

- We extracted data from RUDY, a UK based online rare disease cohort study.
- Participants completed the VOLP questionnaire which measures absenteeism, presenteeism, unemployment due to ill health, lost unpaid work, and the monetary cost of lost productivity to society in the previous three months.
- Participants were invited to complete a baseline, and then follow-up questionnaires every six months.
- Inclusion criteria were adults self-reporting with OI with a completed VOLP questionnaire at baseline and follow-up.
- The sample was split into two groups: (1) those who were employed or unemployed but of employment age, and (2) those who were retired.
- Lost productivity due to any ill-health was estimated as unpaid plus paid productivity loss (Figure 1).
- Unpaid productivity loss was defined as hours reported getting help with unpaid activities (household work, shopping, odd jobs & chores, childcare and volunteering) (Figure 1).
- Costs were calculated using the income estimate reported by the participants. If unknown, we used the mean income of UK wages for 2020 reported by the Office for National Statistics.

Figure 1: Components of lost productivity

Lost productivity due to ill-health									
Paid productivity loss			Unpaid productivity loss						
Absenteeism	Presenteeism	Unemployment caused by ill-health	Household work	Shopping	Odd jobs and chores	Childcare	Volunteer work		

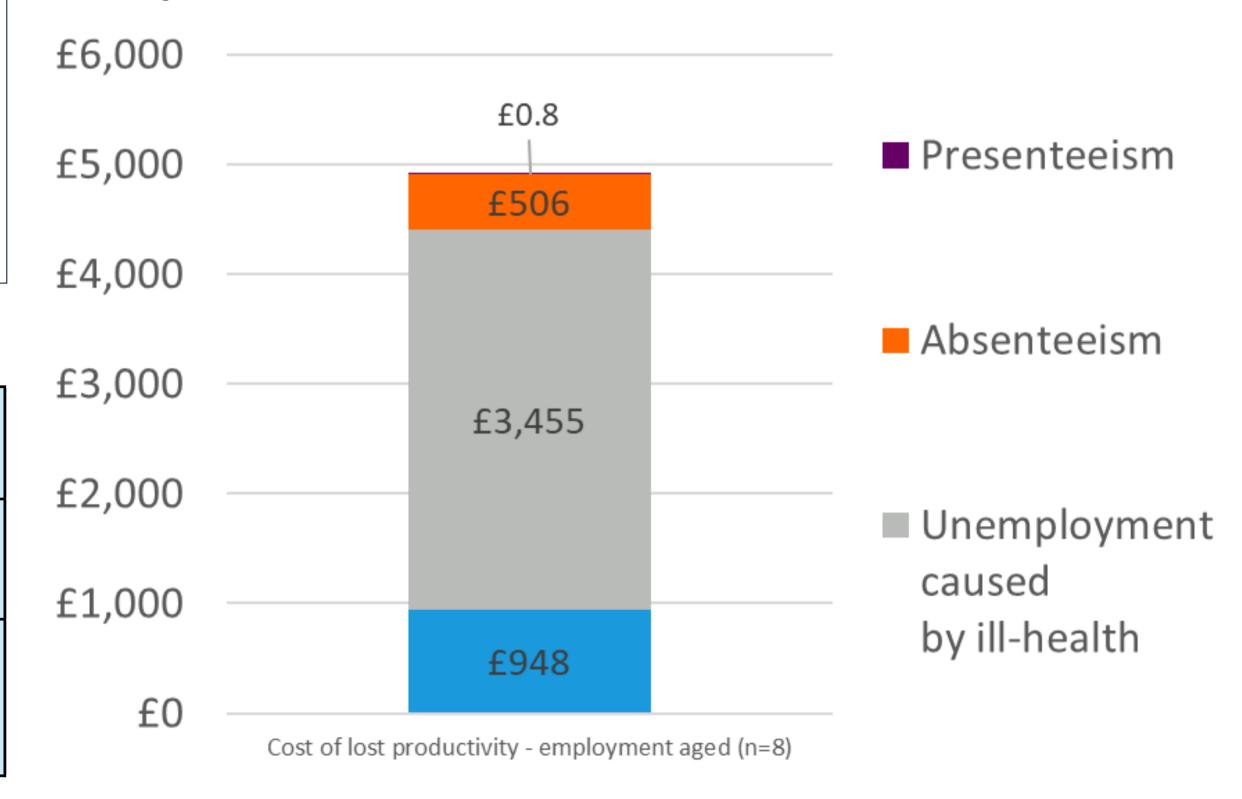
RESULTS

- The sample comprised of 12 participants, of which 5 were employed and, of the 7 unemployed, 3 reported being so due to ill-health and 4 reported being retired.
- 91.7% of the sample were female and the median age was 58 (range 33-76).
- Median time difference between baseline and follow-up was 5.7 months (range 1.9-10.1 months).
- Those who were retired did not report any unpaid lost productivity (Table 1).
- Of the recorded responses, only 2 participants reported absenteeism and 1 participant reported presenteeism at follow-up.
- Mean total cost of lost productivity over 3 months for those employment aged was £4,910 per participant with OI (Figure 2).

Table 1: Cost of lost productivity

	Employment	Retired	
	aged (n=8)	(n=4)	
Age (median (range))	48.5 (33-66)	67 (59-76)	
Gender (% female)	87.5%	100%	
Unpaid productivity loss	£947.70	£0.00	
Unemployment caused by ill-health	£3,455.25	N/A	
Absenteeism	£505.84	N/A	
Presenteeism	£0.77	N/A	
Total	£4,909.56	£0.00	

Figure 2: Mean cost at follow-up of lost productivity over previous 3 months



CONCLUSIONS

- Productivity loss for adults with osteogenesis imperfecta is significant and mainly driven by unemployment caused by ill-health.
- These costs should be included in economic evaluations of future treatments for the disease.
- Further work with larger samples is required to confirm these findings.

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RudyStudy.org

Contact: sophie.cole@ndorms.ox.ac.uk