

Table S3. Impacts identified in the targeted literature review

Disease-related impacts	No. of article mentions (n=15)	Impact Salience*
Physical disability	10 (67%)	High
Social participation	10 (67%)	High
Sleep disturbance	10 (67%)	High
Emotional impact	10 (67%)	High
Family relationships	9 (60%)	High
Depression	9 (60%)	High
Anxiety	8 (53%)	High
Work disability	7 (47%)	High
Effect on daily activities	7 (47%)	Intermediate
Loss of independence	6 (40%)	Intermediate
Loss of leisure time	5 (33%)	Intermediate
Fear / Frustration	5 (33%)	Intermediate
Health care costs	5 (33%)	Intermediate
Coping with disease	4 (27%)	Intermediate
Embarrassment	4 (27%)	Intermediate
Negative body image	4 (27%)	Intermediate
Impact on sexual functions	4 (27%)	Intermediate
Other impacts	<3 (20%)	Low

*High corresponded to impacts mentioned in >50% of articles, intermediate to impacts mentioned in 25-49% of articles, and low impacts mentioned in <25% of articles.