Health of young and elderly informal carers: analysis of UK census data

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Concern has been mounting about the health and welfare of people who provide informal care for family or friends with chronic illness. In particular, young and elderly people—vulnerable groups in their own right may be carrying a heavy burden.

The extent of the problem is not well known because estimates have been pieced together from ad hoc local studies and household sample surveys. These estimated that young carers in the United Kingdom numbered between 10 000 and 50 000,¹ and that about one in 20 older people in Great Britain spent long hours caring for sick family members.²

In 2001, for the first time, the decennial UK census asked the entire population about caring responsibilities and general self rated health. We analysed the answers to these two new questions to explore carers' wellbeing.

Participants, methods, and results

Census data released in May 2003 showed that 57.7 million people were resident in households in April 2001 in the United Kingdom. See bmj.com for the questions concerning carers and general health. Tabulations by age and sex from each of the census offices were aggregated to give an estimate for all residents in the United Kingdom.³⁻⁵

About 5.9 million people provided informal care for another person (table). Of these, only 3.3 million (56%) were in good health. Conversely, 70% of people providing no care were in good health.

Of all children aged between 5 and 15, 114 000 (1.4%) provided informal care (53 000 boys and 61 000 girls). Of these, 18 000 provided 20 hours of care or more a week, and nearly 9000 provided at least 50 hours. The health of 773 children under 16 providing 20 or more hours of care was rated "not good."

Of people aged 65 and over, more than a million (12%) were informal carers (498 000 men and 539 000 women). Of these, more than a third (382 000) cared for at least 50 hours a week. Less than a third of older people with this heavy burden of care were themselves in good health and more than a quarter (103 000) rated their health as "not good."

Even the oldest age group (>85) included substantial numbers of carers (44 000), more than half of whom were providing at least 50 hours of care a week. The health of a third (8000) of these heavily burdened carers was rated as "not good."

Comment

More young and old people acted as informal carers in the United Kingdom in 2001 than previously estimated: 114 000 children aged between 5 and 15, and more than one million people aged 65 and over. In terms of the hours of care provided, nearly 9000 children and 381 000 people aged at least 65 provided at least 50 hours of care a week. Many would consider this an unacceptably heavy burden for children and pensioners. Paid employees, rather than informal carers, would have been in contravention of the European Working Time Directive. That many of these children and pensioners were not in good health themselves is further cause for concern.

Our analysis has the advantage of covering the entire population of the United Kingdom. It cannot, however, show the impact that this burden of care has on the lives and future wellbeing of young and elderly people. For deeper insight, qualitative studies need to continue and the results be used to develop policy.

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Number of people providing care by sex, age, general self rated health, and hours a week spent providing care, United Kingdom, 2001

	Good health			Fairly good health			Not good health		
	1-19 hours	20-49 hours	≥50 hours	1-19 hours	20-49 hours	≥50 hours	1-19 hours	20-49 hours	≥50 hours
Males									
5-15	37 781	3 225	3 079	6 350	822	654	731	113	234
16-64	917 886	112 444	148 476	366 820	62 236	94 923	114 829	27 528	63 606
≥65	114 265	17 319	51 279	110 922	26 434	80 096	35 496	12 310	50 043
Total	1 069 932	132 988	202 834	484 092	89 492	175 673	151 056	39 951	113 833
Females									
5-15	42 462	3 893	3 525	7 869	960	870	950	165	261
16-64	1 197 010	175 278	258 599	566 448	119 205	202 011	150 663	40 165	89 537
≥65	118 340	16 943	52 993	124 824	26 852	93 751	38 925	13 179	53 357
Total	1 357 812	196 114	315 117	699 141	147 017	296 632	190 538	53 509	143 155

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The census questions about caring and general health are on bmj.com