OUT OF CONTROL? EXPERIENCES OF TRANSITIONS BETWEEN CARE SETTINGS AT THE END OF LIFE FOR OLDER ADULTS WITH HEART FAILURE: A QUALITATIVE STUDY

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Background Transitions between care settings have been associated with poor continuity and quality of care for older people. Movements between places of care occur frequently in the months before death, making them an important influence on well-being and health status. People with heart failure may be particularly likely to experience frequent, unplanned admissions to hospital.

Objective To explore and understand experiences of care transitions for older adults with heart failure at the end-of-life.

Design In-depth qualitative interviews with 35 people with heart failure, lung cancer or stroke. Framework methodology was used for data analysis.

Participants Fifteen adults aged over 75 years with heart failure, whose hospital clinician answered “no” to the question, would you be surprised if this patient dies within the next 12 months? Half the participants were from socially disadvantaged backgrounds.

Findings Participants described how they struggled to have control over many of their end of life experiences. Their ability to negotiate their role with professionals, family and the wider world was threatened by their biographical experiences and physical helplessness. Long-standing relationships with family doctors were threatened by their biographical experiences and physical helplessness. Long-standing relationships with family doctors were threatened by their biographical experiences and physical helplessness.

Conclusions Notions of choice and empowerment prevalent in current health policy discourses appeared to have little relevance to the lived experiences of the older adults in this study. Without an understanding of biographical and social context, analyses of how older people experience health and social care at the end-of-life risk promoting concepts of individual control that many older adults do not enjoy. If end-of-life care policies are to produce equitable outcomes, they must go beyond simple solutions to address the complexity of relationships older adults have developed with health services over their lifetimes.

VALIDITY AND RELIABILITY OF TWO INDICATORS OF SOCIOECONOMIC POSITION IN A POPULATION SURVEY OF OLDER ADULTS

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Objective There is increasing interest in measuring the influence of socioeconomic position (SEP) across the life-course. However, there are few cohorts that encompass the whole life-course, so many studies use data from cross-sectional studies, hence the need for ensuring the accuracy of recall of the SEP measures used. The aim of this study was to investigate the reliability and validity of two measures of SEP: education and longest job.

Design Prospective cohort study.

Setting Large population survey of older adults from the general population in North Staffordshire, UK.

Main Outcome Measures Health Questionnaire (HQ) including a four-part question on education and a five-part question about the longest job.

Participant In two pilot studies, random samples of patients aged 50+ registered with different general practices were mailed a HQ (nested test–retest repeatability studies were included; n=500; n=160). In the main study, all patients aged 50+ registered with three different general practices were sent a HQ at baseline. 6 years later, 3410 respondents consenting to further contact were mailed a follow-up HQ; a subsample of these participants took part in independent qualitative interviews, which included a reconstruction of critical landmarks in their life-course. Ethical approval was granted for all stages of the study.

Analysis Validity was assessed by: percentage completion; internal percentage agreement within each set of questions; percentage agreement of qualitative and quantitative data for age left school and longest job questions; comparing age left school data with historical change in legal school leaving age. Reliability of both questions was calculated from the pilot repeatability studies using ICC and k, with 95% CI.

Results The adjusted response to all stages of the study was good (62–84%). In the main surveys, completion of the age left school and longest job questions was excellent (94–98%). Internal agreement within each set of questions was good (education: 80–97%; longest job: 95–100%). Comparison of survey and interview data showed good agreement for age left school (85%) and longest job (95%). The change in age left school data concurred exactly with the change in legal school leaving age implemented in 1947. Reliability from pilot test–retests was excellent for recalled age left school (ICC=0.95; 95% CI 0.93 to 0.96) and substantial for longest job (k=0.69; 95% CI 0.55 to 0.83).

Conclusion The age left school and longest job questions in this study are valid and reliable measures.