

Abstract submission
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TITLE OF PAPER

Measuring reluctance to care: dilemmas, discoveries and directions

AIMS

The purpose of this paper is to explore why it is important but difficult to measure reluctance to care (RTC), to identify aspects of lay cancer carers' reluctance, and to discuss the implications of these findings.

METHODS

RTC is increasingly relevant in the de-institutionalisation of care for chronic illnesses, including cancer. It is an unwelcome, under-developed and under-estimated concept. Potential indicators of RTC identified in a systematic review included a perceived lack of choice and disruption to lifestyle. These indicators occur as items within an instrument designed to measure carer burden. A sample of lay cancer carers (n=98) were surveyed prospectively during the patients' final year. Their responses were analysed to identify differences in RTC, by spousal relationship and by gender.

RESULTS

In general, spouses were more willing and motivated to care. Non-spouses felt less choice about the role (p -value = 0.001 at 3 months to the patients' death). Female carers felt less choice than male carers, and found it more disruptive and stressful. Male carers felt less resentful than female carers about caregiving (p -value = 0.028 at 12 months).

IMPLICATIONS

These results were limited by the extent to which the burden instrument measured RTC, whether reluctant carers continued as patients deteriorated, carers' willingness to disclose their feelings, and the quality of the carer-patient relationship. Nonetheless, they suggest that RTC occurred, and that carers can feel simultaneously reluctant and committed. This creates a moral dilemma between respecting individual autonomy to take the role and protecting against caregiving adversity. With further clarification of the concept, a comprehensive measure of cancer RTC can be developed.