INFORMATION PROVISION AND THE WIDER EXPERIENCE OF CARE: A QUALITATIVE STUDY OF PATIENTS DIAGNOSED WITH LUNG CANCER FOLLOWING EMERGENCY ADMISSION AND THEIR CARERS

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Background 40% of patients with lung cancer are diagnosed following an emergency admission to hospital (DFEA), but little is known about this group. There are particular challenges in providing information in these circumstances. This paper reports preliminary qualitative findings from a mixed methods study seeking to describe the characteristics, needs and outcomes of patients with lung cancer DFEA admitted over one year to a University hospital.

Aim To explore patients’ and carers’ experiences of lung cancer DFEA, focusing on reports about information provision and needs.

Methods This study is in progress. Patients DFEA and their carers are invited to participate in a qualitative interview following completion of the Charlson co-morbidities index; Sheffield Profile for Assessment and Referral to Care holistic needs questionnaire and a modified 2012 National Cancer Patient Experiences Survey. Interviews usually take place following hospital discharge. Data are analysed using a grounded theory approach, aided by NVivo.

Findings From a target sample of 15 patients and 15 carers, to date we have recruited 10 patients (5m; 5f; aged 49–91) and 6 female carers (from 81 patients DFEA). One group of participants talk about their ‘need to know’; they report wanting information about all aspects of diagnosis, treatment and prognosis. A second group describe themselves as knowing ‘what the score is’, reporting no need for more information or not wanting to know ‘too much’. Some describe clinicians who respond well to their particular needs for information, while others reported non personalized responses: for example, the provision of information about treatment options when a cancer is too advanced for these. Where participants criticize information-giving, this influences wider perceptions of care.

Conclusion High levels of morbidity present challenges when studying this group. The experience of information provision shapes wider experiences of care for patients DFEA with lung cancer and their carers.