INTRODUCTION – CUP Nihilism

CUP is not just a hidden cancer in the body but has been, for too long, a hidden cancer in the representation of the UK’s cancer picture. Until April 2011 you would not have seen Cancer of Unknown Primary (CUP) included in the top 10 cancers in Cancer Research UK (CRUK) or the UK Cancer Registries. This omission, with inadequate representation of incidence and mortality, without representation it is difficult to argue for funding and patient support on the basis of national statistics. For example, CRUK data for 2008, showing Research spend versus Mortality and Incidence by cancer site, omits CUP. Cancer Australia, by comparison, includes CUP in equivalent presentations (AIHW, 2008b).

CUP patients and their relations do not believe they are being treated equally: they believe they are not being treated fairly. They believe they are not being given the same opportunity as the public to receive research funding.

The 2008 data show CUP in the 10 most commonly diagnosed cancers as a proportion of total new cases for the UK – % of Total

- 11.9
- 13.1
- 13.9
- 14.8
- 15.3
- 15.5
- 16.0
- 17.1
- 18.4
- 20.1
- 20.4

Even by existing measures, CUP falls firmly within the top 10 cancers in the UK, on usual ICD-10 C79 to C80: See Table 1 above –

CUP does not have a discrete classification within the International Classification of Disease (ICD) nomenclature. The WHO ICD codes, which capture registrations of CUP in the UK, are usually ICD-10 C79 to C80: See Table 2 above –

However, there is no international agreement. The Australian CUP data are based on C70 (Malignant neoplasm of other and unspecified sites) and C71 (Malignant neoplasm of other and unspecified sites), C79 (Malignant neoplasm of respiratory system and interstitial tissue) and C80 (Malignant neoplasm of digestive organs). The WHO enter ICD-8 in a group defined as unspecified sites for the purposes of ICD coding. The WHO (2007).

Research amongst UK Registrars in 2011 indicates that there is a lack of clarity in defining CUP. (Binysh, Osborne & Symons, 2011). Responders indicate that the Hospital Episode Statistics (HES) data input from MD/Ts is inconsistent. It is likely to be caused by the lack of rules for recording CUP leading to variability between MD/Ts in terms of the precision of the coding of the disease. The WHO International Classification of Disease for attributing a probable site-specific diagnosis when further investigation is needed. Inadequate evidence suggests that CUP patients reviewed at MDTs are often classified as having a secondary malignant neoplasm of unspecified sites (C77) – 20.1% of new cases (AIHW, 2008a).

Potential guidelines on CUP have been published (Binysh, Osborne & Symons, 2011. Echoing the recommendations of the NICE Guideline, data and coding definitions for MUO and CUP should be developed to enable greater consistency in the reporting of CUP in cancer research programs in Australia 2003 to 2005. (AIHW). 2008 (a).

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WHAT CONSTITUTES CUP?

The NICE Guideline (NICE, 2010) represented CUP as the 4th most common cancer mortality in England and Wales based on 2006 data. Following its publication, CRUK included CUP in their incidence data for 2007. For 2007 Cancer Research UK figures using ICD-10 – C79-80 codes showed CUP as the 6th most common cancer for males and 7th for females, representing 3.5% of cases (CRUK, 2011).

At 4% of cancer diagnoses, CUP incidence in the same as, or more than, those with known cancers such as kidney, stomach, leukaemia, pancreas, ovary, and malignant melanoma. Recent figures released by CRUK for 2008 – Table 1 above – C79 to C80 show an apparent picture but the reporting of the data is recognized as problematic and we would anticipate an increase in future years as the syndrome is captured more fully following the recommendations of the NICE Guidelines. The 2009 data show CUP in the 10 most commonly diagnosed cancers as ‘other sites & CUP’ – C79 to C80.

The Australian Institute of Health and Welfare is not in a position to capture the true incidence of CUP. CUP incidence in 2008 stood at 3% of all cancers (whereas 1% for melanoma) and although a relatively uncommon cancer, CUP is in the top 10 for those dying from cancer (Binysh, Osborne & Symons, 2011). Mortality at 8.8% made CUP the 3rd most common cause of cancer death (see combined CUP in Australia. (AIHW, 2008b).

CUP patients have the double agony of a cancer diagnosis and the recognition that it is a condition that is little understood. Initiatives such as Cancer of Unknown Primary (CUP) have been launched consistently and for its apparent lowly on the canvas of the national cancer picture. The nihilistic approach to CUP where practised by clinicians and statisticians - the hope that the "too difficult" problem will be solved by chance or disappear - is unacceptable, scientifically and in relation to patients. Uncertainty in mortality is often seen as failings and in CUP diagnosis is a failure of diagnosis rather than a diagnosis in its own right. It is only by capturing the data fully following the recommendations of the NICE Guidelines.

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There are new initiatives presently underway in the UK that should encourage greater recognition of CUP in national statistics and presenting CUP fully and fairly that action, in particular research, can be encouraged.

The incidence and mortality of CUP is falling nationally and internationally (AIHW, 2008b).

The UK has lagged behind other countries such as Australia, in representing the problem of CUP. Historically, CUP may have been overlooked on the basis of clinical and anatomical reasons; often seen as failure; and a CUP diagnosis as a failure of diagnosis rather than a diagnosis in its own right. It is only by capturing the data fully following the recommendations of the NICE Guidelines.

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