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Editorial

Patient migration, access to expertise and optimal patterns of care ☆

The paper by Dama et al. in this issue, on patterns of access to specialist care in relation to the place of residence in Italy, provides food for thought about the planning of services for children and young people with cancer and, potentially, for patients with other rare forms of cancer.[1] The data were based on an analysis of the registry maintained by the Italian Association of Pediatric Hematology and Oncology (AIEOP). The concept for the study was simple – how many children (aged 0–14 years) registered with cancer by centres affiliated with AIEOP were treated in specialist centres in the same region of the country as their residence? There are two significant observations. First, that a significant minority of children were treated outside the network of AIEOP centres altogether and, second, that some regions of the country seemed less able to keep patients for treatment within their region of residence. Understanding the reasons for these findings is deceptively complex but this study provides the opportunity for some reflection.

Centralisation of care for children with cancer has contributed to the very significant improvement in outcome seen over the past 30 years.[2] Intuitively this seems correct: these are individually rare diseases for which treatment is often complex and intensive, and on that basis centralisation of care should promote expertise and a better understanding of the wider needs of these young people and their families. The evolution, in most developed countries, of a national network of specialist centres for the care of children and young people with cancer has also promoted research, in particular, in clinical trials for which there is good evidence that this has provided a specific component of the trend for improved survival.[3] Nevertheless it is of concern that, overall, the AEIOP registry captured only 75% of children with cancer, based on the estimates of national incidence, and that some diagnoses were referred for specialist care more systematically than others. There was particularly low registration of children with CNS tumours (45%), which must raise a question about the place of treatment for this group of patients who collectively not only have a worse survival rate than most other diagnoses but also have greater long-term morbidity and health care needs. Previous data from the United Kingdom (UK) showed similar findings,[4] although more recent registration rates have approached those for leukaemia and solid tumours.

Parents and young people themselves want the best possible outcome for the treatment of their disease and are willing to travel long distances to achieve this. This is illustrated by the data presented by Dama et al., which show a general trend for the migration of patients from central and south Italy to the treatment centres in the north. It is not clear why this was the case, but the authors reflect on the uneven distribution and speculate that the capacity not only to retain their own regional cases but also to accommodate those from elsewhere makes the centres in the north of Italy more 'appealing' although they provide no definition of how this might be judged either by families or by clinicians. There might be an assumption that this equates to a measure of quality but there are no data to support this. Historically, the development of centres of excellence in paediatric oncology, as in many areas of specialist medical care, derived from the energy and vision of individuals who created services to which patients migrate. A contributing factor, supported by the observation that this trend reduced with time, might be that the earlier development of specialised facilities in centres in the north of the country created expertise, which is now being balanced by the more recent development of additional capacity for specialist care elsewhere. Although, as Dama et al. imply, the measurement of patient migration is important to guide health care policy, this may only be a proxy for a more fundamental set of measures, which relate both to outcome and to patient satisfaction.

The 21st century brings increasing demand for equity and choice in all health care systems, but how can these be delivered for rarer diseases and achieve optimal outcomes within existing health care resources? What is the best model for the care of children and young people with cancer? It might be argued that the number of patients seen each year in an individual centre could reasonably be taken as a proxy both of acquired expertise and of economy of scale – but there is no clear evidence for this. Moreover, such criteria do not take into account geographical constraints on patient movement

☆ Editorial on Dama E, Rondelli R, de Rosa M, et al. Patterns of migrations and access to childhood cancer care centres in Italy. A report from the hospital based registry of the Italian Association of Pediatric Hematology and Oncology (AIEOP).

and nor do they eliminate the need for direct measures of the quality of care and outcome achieved in an individual institution. There are also good data that having a child with cancer places high financial demands on the family that go beyond any direct cost of care.[5] Some of this relates to the need for many families to spend long periods of time away from home in specialised institutions, but this itself should not promote the argument that local care ought to be provided in all settings.

Compromise is needed and work being undertaken in the UK may offer a useful model. In 2005, the National Institute of Health and Clinical Excellence (NICE) published guidance on 'Improving Outcomes for Children and Young People with Cancer'.[6] This promotes a model of care built around the designation of centres of specialist expertise (Principal Treatment Centres) and provides guidance about the pattern of service delivery from those centres. The definition of an optimal service was a judgement based, where possible, on an evidence base or, when unavailable, on professional consensus. Parent users of paediatric oncology services were part of the group who developed the guidance, and the range of resources required to deliver care was enumerated. The guidance assumes that access and equity are paramount principles, but the issue of location of treatment is also addressed in one of the core tenets of the guidance, namely that 'the aim is for safe and effective services as locally as possible, not local services as safely as possible'. This approach endorses the concept of shared care, a model of care by which all patients are referred to specialist centres for diagnosis and treatment planning but at some point after that, care may be devolved back to the child's local health care community for some/all of the subsequent treatment. Achieving this depends on the complexity of the treatment required and on the availability of appropriately skilled and resourced local units. Shared care is not a new concept but it has been incompletely described and evaluated.[7,8] It can be delivered at different levels of complexity and can provide substantial advantages to families who need to maintain the integrity of their family life and give the attention required towards the needs of other children, schooling and jobs. Shared care centres too must be evaluated against predefined quality standards, although measurement of outcome based on the survival statistics is always going to be challenging, given the small number of patients and the diversity of diagnoses across the field of paediatric oncology.

There are many factors which influence outcome,[9] but is it now time for all European countries to explore this model of care? This would require agreement about specifications for the designation of Principal Treatment Centres and the promotion of the concept of shared care. It would be necessary to safeguard robust networks for participation in clinical trials. If this were to be achieved, it could ensure that all children get safe and effective services as locally as possible and the measurement of patient migration as described by Dama et al. would become part of a planned approach to service delivery and not a phenomenon driven by historical provision and unmeasured perception.

Conflict of interest statement

None declared.

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