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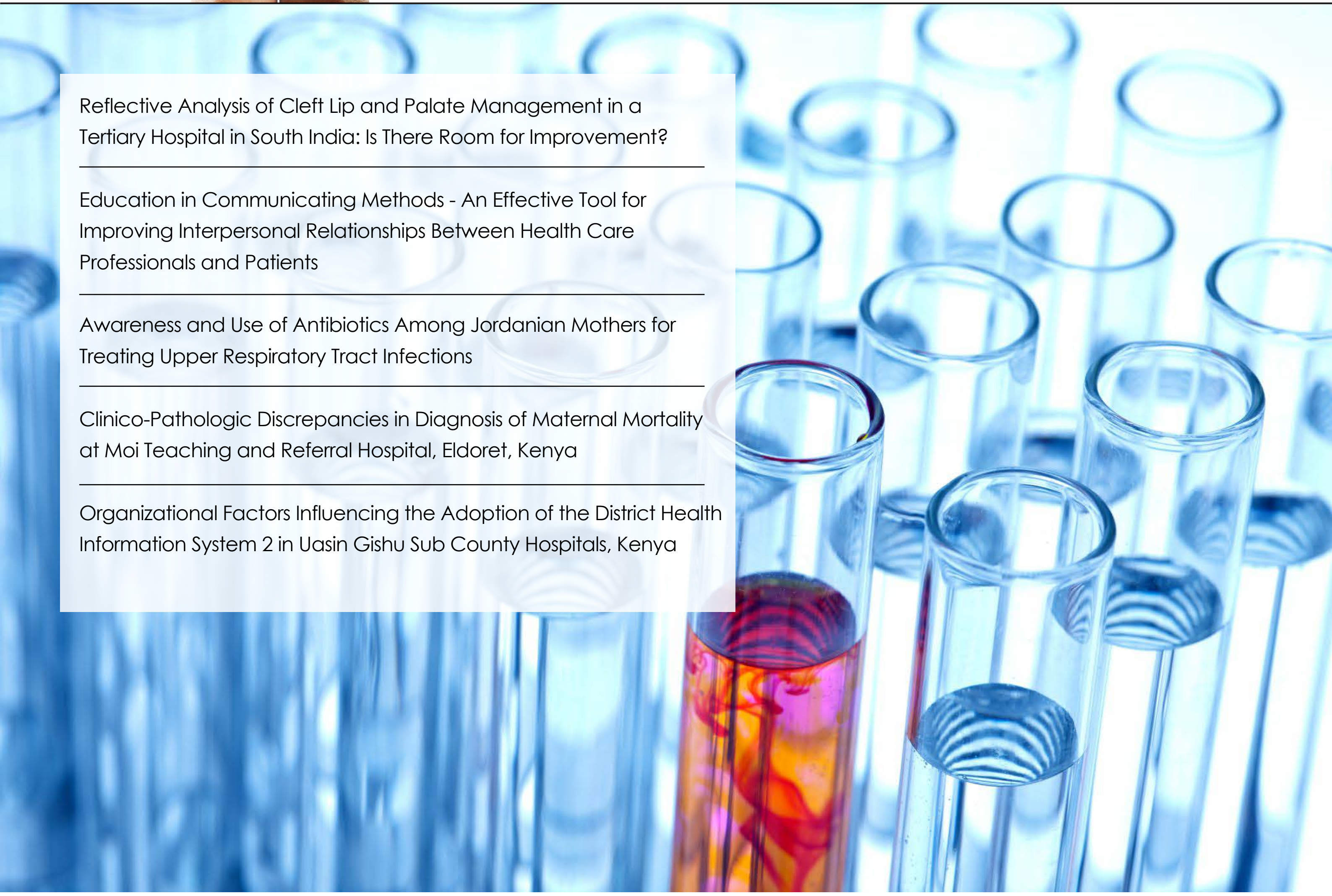

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Reflective Analysis of Cleft Lip and Palate Management in a Tertiary Hospital in South India: Is There Room for Improvement?

Panikkar M

Institution
University of Birmingham, 9,
St. Wilfrid's Road,
Bessacarr, Doncaster,
DN4 6AA

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Abstract

The management of Cleft Lip and/or Palate requires a complex multidisciplinary team approach to provide integrated care to patients and their families. Orofacial clefts can cause significant long term psychological and functional effects on patients if not treated in a timely and effective manner. These include poor dentition, hearing impairment, speech disorders and difficulty forming social relationships. Robust evidence exists exploring the epidemiology, post-operative outcomes and timing for each surgery, however, there appears to be a lack of qualitative research evaluating current management strategies in the developing world. In this report, I aim to explore the standards of Cleft care delivered at the Amrita Institute of Medical Research and Sciences Hospital in Kochi, India and reflect on possible strategies to establish an optimal treatment regimen for patients. I was also able to compare and contrast two healthcare systems to highlight the challenges faced by healthcare professionals working within resource constraints.

Key Words
Cleft; Lip; Palate; Management; Kochi

Corresponding Author:
Ms Mohini Panikkar; E-mail: mohinipanikkar@gmail.com

Introduction

Cleft Lip and/or Palate (CL+P) is the most common congenital cranio-facial abnormality, affecting approximately 1 in 700 live births worldwide and 1 in 413 in the South Indian population [1,2,3]. The aetiology is thought to be multifactorial with both genetic and environmental factors impacting head organogenesis[4]. This complex developmental process is sensitive to disruption at various stages. An untreated CL+P can be a highly debilitating condition affecting speech and feeding as well as increasing perinatal mortality[5,6]. Many developing countries lack the appropriate resources to provide holistic care to CL+P patients, causing a lifelong functional and psychological impact.

Management

The management of cleft deformities is centred around a multidisciplinary approach and continues throughout the first 20 years of a child's life. Specialties involved include maxillo-facial and plastic surgeons, orthodontists, speech and language therapists, ENT surgeons, psychologists, paediatricians, paediatric dentists and geneticists. Whilst no official clinical guidelines currently exist for India, their CL+P management is loosely guided by the UK's NICE guidelines, though adapted according to resources and surgeon's preference[7]. Treatment aims include repairing the birth defect, ensuring normal development of hearing, speech and language, proper feeding and good dentition whilst preventing and treating psychological issues.

The main components of CL+P treatment are highlighted in this timeline:

A study conducted on 80 CL+P patients in Chennai, another South Indian city, revealed that 35% of patients suffered from periodontal disease, highlighting the discrepancy between treatment aims and reality[8]. Another study assessing dental health in 4-6 year olds conducted in North India highlighted significant differences in over-bites, caries and gingival health between cleft and non-cleft patients[9]. A nationwide survey conducted with 293 Cleft Surgeons in India suggested that there is currently a lack of interdisciplinary communication between specialties which may compromise quality of care[10]. Another relevant finding comes from a three-centre Indian study which concluded that there is a lack of uniform protocol when caring for patients with CL+P, resulting in a large variation in quality of treatment[11]. Finally, a study in Thailand looking at patient Quality of Life after Cleft surgery showed that patients were most concerned about the psychological impact they had faced and with reducing the size of their surgical scars[12]. Though this research begins to uncover some of the main

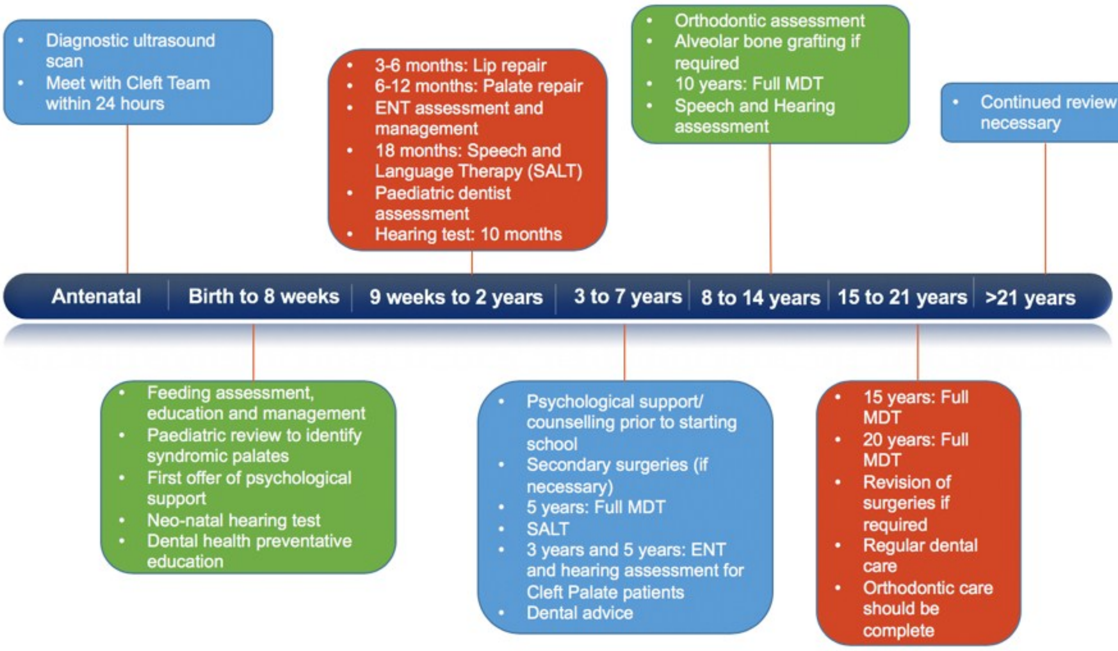

Figure 1: Timeline of Cleft Lip and Palate Management as per NICE Guidelines (2)

issues cleft patients in developing countries face post-operatively, it doesn't give an indication of which services are being provided and whether this adheres to clinical guidelines. There are also some aspects of management that little evidence exists for e.g. feeding assessment and management.

In this report I aim to use a reflective approach to evaluate CL+P management at AIMS Hospital in Kochi and use existing relevant literature, and my experience as a UK medical student, to highlight potential areas of improvement.

Methodology

I conducted my reflection using qualitative data from clinical observation. I used Gibbs's Reflective Cycle (1988) to allow me to analyse each stage of my experience and draw conclusions[13]. I initially considered a quantitative analysis. However, I realised this would limit my time in theatre, associated learning of surgical skills and the opportunity to interact with patients from a different part of the world.

Reflection

On a daily basis, I accompanied a surgeon on their post-operative ward round which they undertook alone. These consultations were brief, with the surgeon usually spending less than a minute discussing each case. Owing to greater financial pressures and serving a larger population, the wards were much larger than those in the UK with beds only a few metres apart, often with no wall/curtain separating patients. The majority of the time was spent conversing with the nurse to assess the patients post-operative progress and care. The consultant finished by asking a few questions to the patients' family usually about the patient's wellbeing, their knowledge of post-operative care and when they could return home. These experiences prompted me to reflect on the General Medical Council's Duties of a Doctor, in particular the importance of "working in partnership with patients" and "respecting patients' right to reach decisions with you about their care and treatment[20]." I speculated if external pressures, be they financial, social or political, were forcing these principles to become a lesser priority in order to maintain equality of patient care in an environment where the doctor-patient ratio is extremely demanding. Furthermore, I considered if a comparatively lower socio-economic and educational status of families may have impacted on the immediate population's ability to comprehend a Doctor's scientific explanations. It may be the case therefore that the expeditious and content-light nature of the ward round was actually an evolution of 'doctor behaviour' to ensure time is not wasted on actions that did not positively impact upon patient care. It could also be argued that it is unfair to expect high levels of comprehensive care delivery under significantly differing circumstances; a fairer comparison could be with the standard of care delivered in surrounding hospitals. Despite that, these hospitals often emulate their guidelines from NICE publications, therefore assessing their adherence to these guidelines seemed relevant.

Case 1*:* During one of these ward rounds, I met patient A, a 4-month-old female who had undergone surgery for an isolated cleft lip. Her mother explained that she had recovered well from the operation and she was very pleased with the result. When discussing the next stage of her treatment plan, the surgeon mentioned that she would need a follow up appointment in a month to review her progress/functionality and assess her wound. He also offered a SALT assessment alongside the follow up, but the patients' mother declined explaining that "her daughter can't talk yet anyway" and was concerned about additional costs. He finished by reminding her that she could switch from spoon feeding to breast feeding as patient A now had the appropriate anatomical mechanisms in place.

In the UK, SALT assessments can be conducted at any point between 9 weeks and 2 years of age, though usually conducted at 18 months after speech has developed. Though I thought that accepting the mother's refusal perhaps embodied the GMC "respecting patients' right to reach decisions with you about their care and treatment"[14], I noted that it may have been a good opportunity to educate the patient's mother on the importance of this assessment, and reassure her that the earlier patients begin SALT the greater chance of success[15].

After the ward round, I spoke to Patient A's mother to validate what she had been told regarding her care over the next few years and to understand any concerns she may have. She explained that the SALT assessment had been previously mentioned but she wasn't convinced it was necessary at this time. She wasn't aware that patients with cleft deformity were more susceptible to poor dental health or hearing problems. Her greatest concern by far was the psychological impact her daughter would face in later life particularly when arranging a marriage. The nurse accompanying me explained that in many rural villages, such as the one Patient A had travelled from, people believed that congenital abnormalities were a punishment from God for parents' poor behaviour in a past life, leading to many parents exercising constraint on their child's social interaction. A study conducted in rural India by a charitable organisation confirmed this stating 84% of people ascribed their child's cleft to "God's will." This study also stated that marriage prospects were a major concern for parents from this socioeconomic background[16]. Overall, Patient A's mother was very pleased with the level of care her daughter had received at the hospital. This afforded me the opportunity to reflect on the challenges confronting the NHS in the face of a general population with a greater degree of scientific literacy on average, or with greater access to information on various forms of available care.

In this scenario, patient A's mother's primary concern was the aesthetic outcome of her daughter's surgery, and the psychosocial impact this would have in later life. Whilst a natural concern, I believe the significance of functional recovery could have been better highlighted to her. Patients can only reach decisions in their best interests when they are fully informed. I do not think that the present challenges faced by the Indian healthcare system would negate the need for this to be a top priority; nor would the conscientious doctors themselves want it to be. Furthermore, this drive for complete patient education is unlikely to come from patients themselves, due to the doctor-centred nature of the predominantly privately-funded healthcare in India: I often found that the respect patients and their families hold for doctors reduces their likelihood to contest their advice.

Case 2: Patient B was a 4-year-old male, born with a unilateral cleft palate. He was brought in by his parents for a hearing assessment prior to him starting school. His mother had noticed that he was slow to respond to her instructions which she initially attributed to behavioural issues but had begun to wonder whether it was related to his cleft palate surgery. His father was a doctor at a nearby hospital so understood the importance of making sure his son attended all of his assessments. His parents had received feeding advice prior to his birth and had even purchased a specific bottle designed for infants with cleft palates. Patient B's palate repair took place when he was 8 months old, after which he received SALT, an ENT assessment, paediatric dental assessment and more recently he was offered a counselling session to help him cope with any stigma he would face at school. His parents were very impressed with the care he had received but later revealed that they did have a relative who was well known to staff. The doctor then went on to examine Patient B's hearing. On clinical examination, he did show some signs of conductive hearing loss for which he was referred to ENT for further assessment. In this case, his parents greatest concern was him not being able to concentrate at school and his education being affected as a result.

I believe this consultation is a very good example of the high-quality holistic care provided at AIMS to many patients. Patient B was provided all the recommended assessments and advice at the correct times in accordance with UK NICE guidelines. Another key issue, that is evident when comparing this case to Case 1, is the financial strain

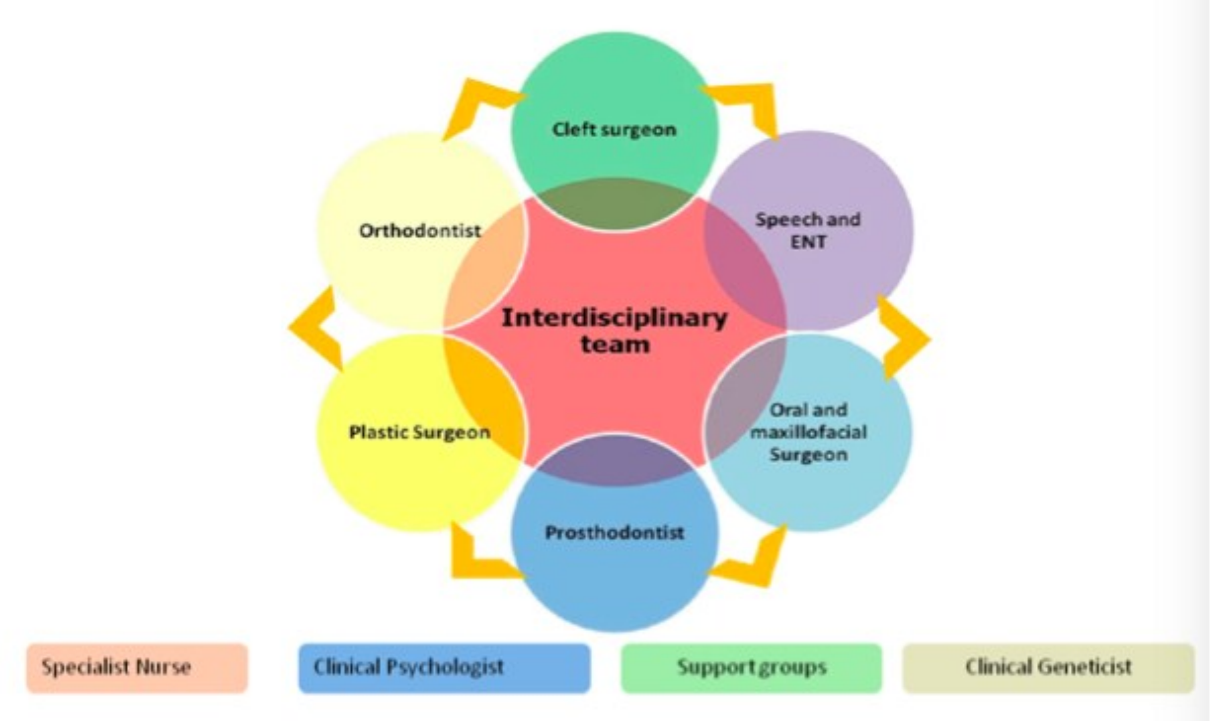

Figure 2: Specialties involved in Multidisciplinary Care[18]

families are under in private healthcare systems, as suggested by a study conducted in another South Indian state: Andhra Pradesh[17]. When considering the cumulative expense of these assessments and consultations alongside travel costs, parents may not be able to afford treatments beyond primary surgery. I was both surprised and impressed that the patient's mother was aware of the feeding bottle and asked the consultant whether that was something that is routinely advised or provided to patients. He explained that he routinely advises patients to cut an X in the teat of their bottle to enlarge the hole, allowing milk to flow more easily. However, his first meeting with a patient is often a few weeks before their surgery so parents who have used a 'spoon feeding' technique may not feel the need to change their feeding method. He highlighted that the lack of well-structured evidence-based guidelines, such as those produced by NICE, affected key aspects of care delivery; such as feeding aid education being omitted, either by human error or due to the assumption that rurally-located patients would be deterred by the extra costs. A 2016 study conducted in New Delhi by the Indian Council of Medical Research highlighted a lack of interdisciplinary approach in the majority of Cleft care centres[18]. I suggest this may be the reason behind the occasional variation in quality of treatment that I witnessed among patients in my daily interactions at AIMS.

Case 3: In my last week of placement, I informally interviewed a surgeon from the Plastics team to understand their awareness of the care they provide. He summarised what he believed to be optimum care for CL+P patients and mentioned that the department based their approach on NICE and American guidelines. This included surgeries, ENT and SALT assessments, Orthodontic and dental care, genetic assessment and psychosocial support. He felt that in his experience, each of these elements of care are delivered to a high standard and the majority of patients are very pleased with their outcomes. He highlighted that AIMS is the only unit in Kerala that provides comprehensive care for CL+P and therefore there is additional strain on doctors. He believed that this is the main reason quality of care can occasionally fall to sub-optimal levels. When asked about the interaction between different specialists he explained that, in his experience, the effectiveness of the multi-disciplinary approach was perhaps understated amongst his colleagues, and moving towards considering it essential to patient care, would be beneficial. As each day is incredibly busy, small but critical steps that can improve continuity of care for patients can get missed. However, having worked in a number of hospitals in India, he felt the Cleft care provided at AIMS is the most comprehensive and patient-centred. The department is very aware that many families are concerned about the psychosocial impact of their child's condition and therefore ensure all patients are operated on in a timely manner to meet targets, improving functional and aesthetic outcomes. Additionally, at AIMS, every child is assessed for Nasoalveolar moulding devices to assess whether these would be of benefit. Overall, he felt that the healthcare professionals at AIMS are very capable of running a highly-efficient, patient centred service. However, they may benefit from more structure, perhaps by developing their own regional/national guidelines, and an increased effort to improve interdisciplinary communication.

It was reassuring to hear that he was familiar with the NICE guidelines and that the majority of his management plan and aims were in line with this. I was pleased to learn that the majority of patients felt satisfied with their treatment, though I felt that a more quantitative data collection on this could validate, and also provide a baseline for, auditing exactly which treatments are offered to patients and which aspects of care need more promotion. It was interesting to note that the department's response to learning that psychosocial impact was their patients' greatest concern, was to adopt a preventative approach by ensuring surgeries were done on time. I also believe it is important to supplement this with a counselling service. A useful addition to this could be to offer an outreach programme to enable families living in rural locations the opportunity to access and benefit from this service.

Discussion

Undertaking this analysis and evaluation of the CL+P care delivered at AIMS has enabled me to witness the impactful work carried out by their healthcare professionals and begin to appreciate some of the challenges that arise when delivering a complex multifaceted management plan. This reflective process revealed that without national/regional guidelines, it is easy for healthcare professionals to miss important steps in the management plan. Additionally, financial and logistical pressures have fostered a system which stands to benefit from a greater focus on patient education and interdisciplinary communication, as well as a more significant role for the patient in deciding treatment options. Limited research exists highlighting to what extent CL+P management plans are adhered to, indicating a need for more quantitative research. Patient education and involvement could be introduced at the diagnosis stage to allow for an open conversation with parents, to help raise awareness of the condition and formulate a management plan for the first 20 years of their child's life. Though the principles behind effective Cleft management are universally applicable, the identified areas for improvement are specific to this hospital. Another limitation of my project is that I was unable to assess the quality of each component of the management plan to investigate the standard of care in this regard, again suggesting a need for further research.

I also understood the potential impact that local culture, socioeconomic factors and the financial infrastructure underpinning healthcare systems can have on delivery of high-quality care. Moreover, consistent systems that support clinical governance can make current standards of care obvious to those providing and receiving it so that actions can be taken to continuously improve it. Interestingly, I also observed very high levels of clinical leadership, motivation, commitment and morale amongst staff both at personal and team levels with less of a focus on targets and completion of documentation. The system operated at high levels of efficiency and utilisation, with minimal waste of resources and non -value-adding steps; something I noticed the more developed healthcare system in the UK is continually striving to achieve.

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