PRACTICE POINTER

Process mapping the patient journey through health care: an introduction

Timothy M Trebble,[1] Navjyot Hansi,[1] Theresa Hydes,[1] Melissa A Smith,[2] Marc Baker[3]

[1]Department of Gastroenterology, Portsmouth Hospitals Trust, Portsmouth PO6 3LY
[2]Department of Gastroenterology, Guy's and St Thomas' NHS Foundation Trust, London
[3]Lean Enterprise Academy, Ross-on-Wye, Herefordshire
Correspondence to: T M Trebble
tim.trebble@porthosp.nhs.uk

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This paper provides a practical framework for reconfiguring the patient's journey in hospital from the patient's perspective

Healthcare process mapping is a new and important form of clinical audit that examines how we manage the patient journey, using the patient's perspective to identify problems and suggest improvements.[1 2] We outline the steps involved in mapping the patient's journey, as we believe that a basic understanding of this versatile and simple technique, and when and how to use it, is valuable to clinicians who are developing clinical services.

Box 2 | The eight types of waste in health care[13]

Defects—Drug prescription errors; incomplete surgical equipment
Overproduction—Inappropriate scheduling
Transportation—Distance between related departments
Waiting—By patients or staff
Inventory—Excess stores, that expire
Motion—Poor ergonomics
Overprocessing—A sledgehammer to crack a nut
Human potential—Not making the most of staff skills

What information does process mapping provide and what is it used for?

Process mapping allows us to "see" and understand the patient's experience[3] by separating the management of a specific condition or treatment into a series of consecutive events or steps (activities, interventions, or staff interactions, for example). The sequence of these steps between two points (from admission to the accident and emergency department to discharge from the ward) can be viewed as a patient pathway or process of care.[4]

Improving the patient pathway involves the coordination of multidisciplinary practice, aiming to maximise clinical efficacy and efficiency by eliminating ineffective and unnecessary care.[5] The data provided by process mapping can be used to redesign the patient pathway[4 6] to improve the quality or efficiency of clinical management and to alter the focus of care towards activities most valued by the patient.

Process mapping has shown clinical benefit across a variety of specialties, multidisciplinary teams, and healthcare systems.[7-9] The NHS Institute for Innovation and Improvement proposes a range of practical benefits using this approach (box 1).[6]

Box 1 | Benefits of process mapping[6]

- A starting point for an improvement project specific for your own place of work
- Creating a culture of ownership, responsibility and accountability for your team
- Illustrates a patient pathway or process, understanding it from a patient's perspective
- An aid to plan changes more effectively
- Collecting ideas, often from staff who understand the system but who rarely contribute to change
- An interactive event that engages staff
- An end product (a process map) that is easy to understand and highly visual

Several management systems are available to support process mapping and pathway redesign.[10 11] A common technique, derived originally from the Japanese car maker Toyota, is known as lean thinking transformation.[3 12] This considers each step in a patient pathway in terms of the relative contribution towards the patient's outcome, taken from the patient's perspective: it improves the patient's health, wellbeing, and experience (value adding) or it does not (non-value or "waste") (box 2).[14-16]

Process mapping can be used to identify and characterise value and non-value steps in the patient pathway (also known as value stream mapping). Using lean thinking transformation to redesign the pathway aims to enhance the contribution of value steps and remove non-value steps.[17] In most processes, non-value steps account for nine times more effort than steps that add value.[18]

Reviewing the patient journey is always beneficial, and therefore a process mapping exercise can be undertaken at any time. However, common indications include a need to improve patients' satisfaction or quality or financial aspects of a particular clinical service.

How to organise a process mapping exercise

Process mapping requires a planned approach, as even apparently straightforward patient journeys can be complex, with many interdependent steps.[4] A process mapping exercise should be an enjoyable and creative experience for staff. In common with other audit techniques, it must avoid being confrontational or judgmental or used to "name, shame, and blame."[8 19]

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- Using the new UK-WHO growth charts (*BMJ* 2010;340:c1140)

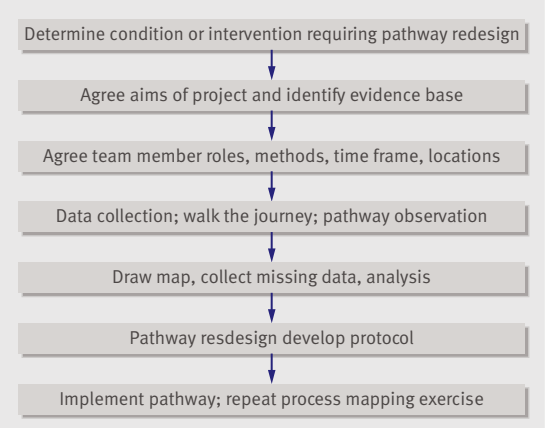

Fig 1 | Steps involved in a process mapping exercise

Preparation and planning

A good first step is to form a team of four or five key staff, ideally including a member with previous experience of lean thinking transformation. The group should decide on a plan for the project and its scope; this can be visualised by using a flow diagram (fig 1). Producing a rough initial draft of the patient journey can be useful for providing an overview of the exercise.

The medical literature or questionnaire studies of patients' expectations and outcomes should be reviewed to identify value adding steps involved in the management of the clinical condition or intervention from the patient's perspective.[1 3]

Table 1 | Data collection in process mapping

Method	Description	Advantages	Disadvantages
Multi-disciplinary meeting[6]	Single or short series of meetings of representative staff, in a non-clinical environment[6]	Obtains results in a defined time; allows interaction between staff involved in the process	Depends on attendees' knowledge of patient journey; absence of direct observation
Walking the journey[16]	Following the normal route of the patient journey; one-to-one patient and staff interviews in the clinical environment	Allows a realistic assessment of the patient's journey, particularly if repeated; direct observation	Effectiveness is influenced by availability of staff time and openness of staff and patient's responses
Direct observation of patient journey	Following a patient's journey in real time with direct observation and informal interviews	Provides information from patient's perspective on patient journey	Time consuming and influenced by day to day variations in clinical environments and patient selection
Patient's self reported experience	Patients record their experience of the journey in real time	Represents patient's experience from patient's perspective	Depends on patient selection and expectations (elderly, sick, frail, or illiterate patients may be missed)

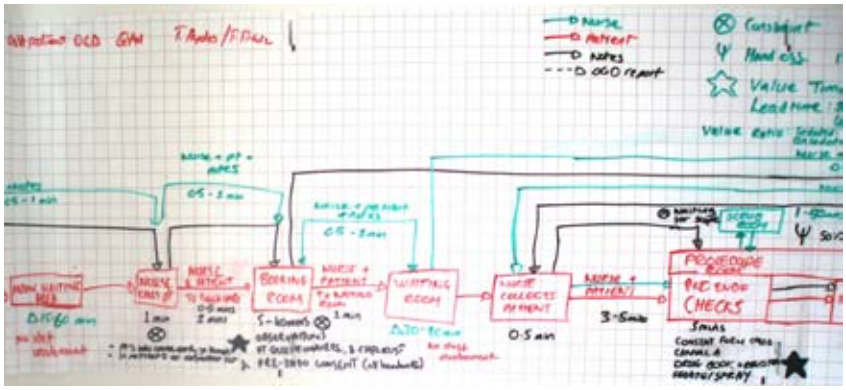

Fig 2 | Section of a current state map of the endoscopy patient journey

Box 3 | How to analyse a process map[6]

- How many steps are involved?
- How many staff-staff interactions (handoffs)?
- What is the time for each step and between each step?
- What is the total time between start and finish (lead time)?
- When does a patient join a queue, and is it a regular occurrence?
- How many non-value steps are there?
- What do patients complain about?
- What are the problems for staff?

Data collection

Data collection should include information on each step under routine clinical circumstances in the usual clinical environment. Information is needed on waiting episodes and bottlenecks (any step within the patient pathway that slows the overall rate of a patient's progress, normally through reduced capacity or availability[20]). Using estimates of minimum and maximum time for each step reduces the influence of day to day variations that may skew the data. Limiting the number of steps (to below 60) aids subsequent analysis.

The techniques used for data collection (table 1) each have advantages and disadvantages; a combination of approaches can be applied, contributing different qualitative or quantitative information. The commonly used technique of walking the patient journey includes interviews with patients and staff and direct observation of the patient journey and clinical environment. It allows the investigator to "see" the patient journey at first hand. Involving junior (or student) doctors or nurses as interviewers may increase the openness of opinions from staff, and time needed for data collection can be reduced by allotting members of the team to investigate different stages in the patient's journey.

Mapping the information

The process map should comprehensively represent the patient journey. It is common practice to draw the map by hand onto paper (often several metres long), either directly or on repositionable notes (fig 2).

Information relating to the steps or representing movement of information (request forms, results, etc) can be added. It is useful to obtain any missing information at this stage, either from staff within the meeting or by revisiting the clinical environment.

Analysing the data and problem solving

The map can be analysed by using a series of simple questions (box 3). The additional information can be added to the process map for visual representation. This can be helped by producing a workflow diagram—a map of the clinical environment, including information on patient, staff, and information movement (fig 3).[18]

Redesigning the patient journey

Lean thinking transformation involves redesigning the patient journey.[21 22] This will eliminate, combine and simplify non-value steps,[23] limit the impact of rate limiting steps (such as bottlenecks), and emphasise the value

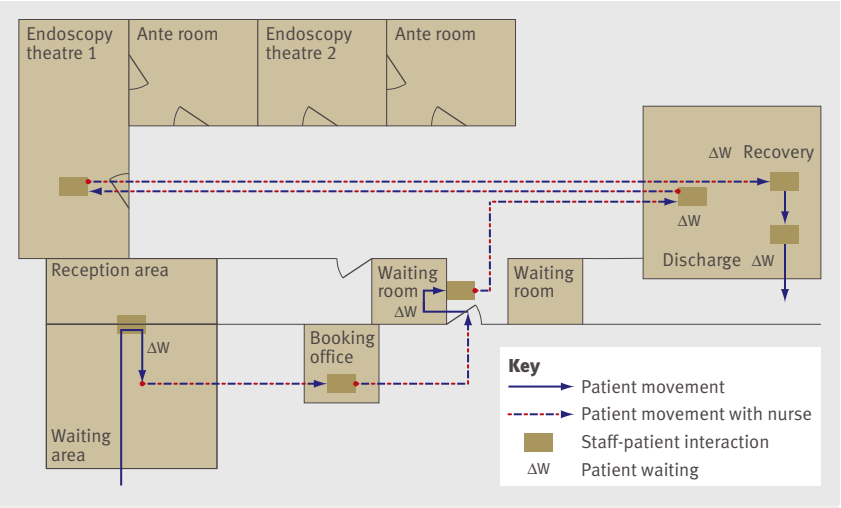

Fig 3 | Workflow diagram of current state endoscopy pathway

adding steps, making the process more patient-centred.[6] It is often useful to trial the new pathway and review its effect on patient management and satisfaction before attempting more sustained implementation.

Worked example: How to undertake a process mapping exercise

Preparation and planning

South Coast NHS Trust, a large district general hospital, plans to improve patient access to local services by offering unsedated endoscopy in two peripheral units. A consultant gastroenterologist has been asked to lead a process mapping exercise of the current patient journey to develop a fast track, high quality patient pathway.

Table 2 | Patient journey for non-sedated upper gastrointestinal endoscopy

Step		Minimum (minutes)	Maximum (minutes)
1	Patient referral is received in endoscopy department requesting an outpatient endoscopy		
2	Endoscopy administration team send appointment letter to patient		
3	Patient receives appointment letter		
4Δ	Patient arrives at outpatient reception desk	1	5
5≠	Details confirmed by receptionist	2	3
6Δ	Takes seat in waiting area	5	60
7≠	Admitted by admitting nurse (who may also be discharging patients). Consent and health questionnaire	5	30
8Δ	Takes seat in waiting area. Transfer to recovery area	5	30
9≠	Pre-procedure checks in recovery unit (further review of questionnaire)	2	3
10	Baseline observations	2	5
11Δ	Wait in recovery for transfer to endoscopy suite	5	30
12≠	Transfer to endoscopy suite (?by trolley) (25 metres)	1	1
13	Endoscopist completes consent (form partly filled in)	2	5
14	Position patient; prepare patient (observations checked again)	2	2
15	Throat spray administered	1	2
16	OGD endoscopy performed (the procedure)	3	10
17	Check observations post-procedure	2	3
18	Transfer to recovery (on or with a trolley, by nurses from endoscopy suite)	2	3
19	Recovery on a trolley: check observations	2	3
20	Transfer from trolley to waiting area		
21Δ	Wait for nurse to discuss post-procedure	5	120
22≠	Post-procedural advice; findings and report discussion by nurse	5	30
23	Home		

Δ=wait, ≠= bottleneck

In the absence of local data, he reviews the published literature and identifies key factors to the patient experience that include levels of discomfort during the procedure, time to discuss the findings with the endoscopist, and time spent waiting.[24-27] He recruits a team: an experienced performance manager, a sister from the endoscopy department, and two junior doctors.

The team drafts a map of the current endoscopy journey, using repositionable notes on the wall. This allows team members to identify the start (admission to the unit) and completion (discharge) points and the locations thought to be involved in the patient journey.

They decide to use a "walk the journey" format, interviewing staff in their clinical environments and allowing direct observation of the patient's management.

Data collection

The junior doctors visit the endoscopy unit over two days, building up rapport with the staff to ensure that they feel comfortable with being observed and interviewed (on a semistructured but informal basis). On each day they start at the point of admission at the reception office and follow the patient journey to completion.

They observe the process from staff and patient's perspectives, sitting in on the booking process and the endoscopy procedure. They identify the sequence of steps and assess each for its duration (minimum and maximum times) and the factors that influence this. For some of the steps, they use a digital watch and notepad to check and record times. They also note staff-patient and staff-staff interactions and their function, and the recording and movement of relevant information.

Details for each step are entered into a simple table (table 2), with relevant notes and symbols for bottlenecks and patients' waits.

Mapping the information

When data collection is complete, the doctor organises a meeting with the team. The individual steps of the patient journey are mapped on a single long section of paper with coloured temporary markers (fig 2); additional information is added in different colours. A workflow diagram is drawn to show the physical route of the patient journey (fig 3).

Analysing the data and problem solving

The performance manager calculates that the total patient journey takes a minimum of 50 minutes to a maximum of 345 minutes. This variation mainly reflects waiting times before a number of bottleneck steps.

Only five steps (14 to 17 and 22, table 2) are considered both to add value and needed on the day of the procedure (providing patient information and consent can be obtained before the patient attends the department). These represent from 13 to 47 minutes. At its least efficient, therefore, only 4% of the patient journey (13 of 345 minutes) is spent in activities that contribute directly towards the patient's outcome.

Redesigning the patient journey

The team redesigns the patient journey (fig 4) to increase time spent on value adding aspects but reduce waiting

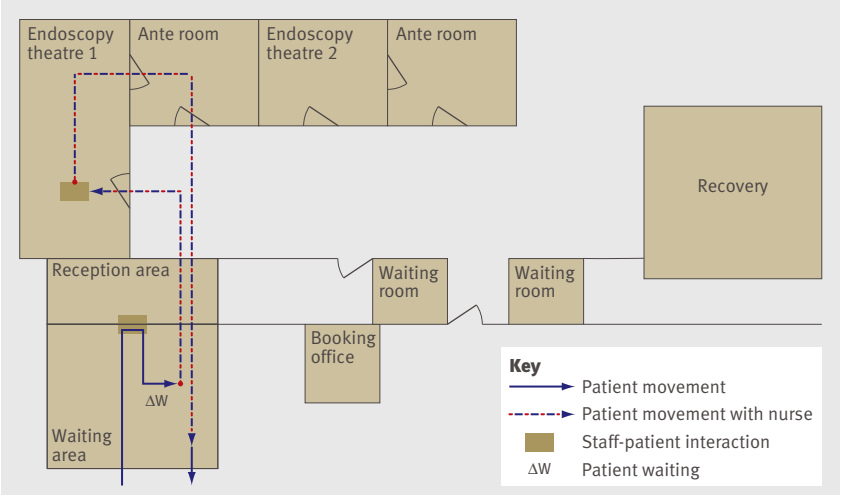

Fig 4 | **Workflow diagram of future state endoscopy pathway**

times, bottlenecks, and travelling distances. For example, time for discussing the results of the procedure is increased but the location is moved from the end of the journey (a bottleneck) to shortly after the procedure in the anteroom, reducing the patient's waiting time and staff's travelling distances.

Implementing changes and sustaining improvements

The endoscopy staff are consulted on the new patient pathway, which is then piloted. After successful review two months later, including a patient satisfaction questionnaire, the new patient pathway is formally adopted in the peripheral units.

FURTHER READING

Practical applications

NHS Institute for Innovation and Improvement (https://www.institute.nhs.uk)—comprehensive online resource providing practical guidance on process mapping and service improvement

Lean Enterprise Academy (http://www.leanuk.org)—independent body dedicated to lean thinking in industry and healthcare, through training and academic discussion; its publication, *Making Hospitals Work*[23] is a practical guide to lean transformation in the hospital environment

Manufacturing Institute (http://www.manufacturinginstitute.co.uk)—undertakes courses on process mapping and lean thinking transformation within health care and industrial practice

Theoretical basis

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Competing interests: MB is a senior faculty member carrying out research for the Lean Enterprise Academy and undertakes paid consultancies both individually and from Lean Enterprise Academy, and training fees for providing lean thinking in healthcare.

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A PATIENT'S JOURNEY

Recovering from severe brain injury

D J B Thomas, Martin Skelton-Robinson

Hillingdon Hospital NHS Trust, Uxbridge, Middlesex UB8 3NN

Correspondence to: D J B Thomas
drdthomas678@btinternet.com

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This is one of a series of occasional articles by patients about their experiences that offer lessons to doctors. The *BMJ* welcomes contributions to the series. Please contact Peter Lapsley (plapsley@bmj.com) for guidance.

In May 2008 Dai Thomas had a road accident resulting in severe brain injury. This is the record of his thoughts and feelings during rehabilitation, accompanied by the perspective of the neuropsychologist who treated him

I was involved in a serious road traffic accident in May 2008. I was amnesic after the accident and have no memory of it. I am told that a stag jumped into my open top Lotus 7 sports car in Epping Forest. I lost control of the car, hit a tree at speed, and sustained a severe brain injury. It took the fire brigade an hour and a half to cut me out of the car, and paramedics recorded my Glasgow Coma Scale score as 9.

At the local accident and emergency department I was found to have numerous soft tissue injuries and a fractured right mandible, maxilla, and clavicle. A magnetic resonance imaging scan of my brain showed bilateral frontal and temporal lobe contusions. I had a grand mal seizure. I was transferred to a neurosurgical unit and spent several days in intensive care. My family were told on my admission that I might die, and subsequently that I would never again be able to care for myself. I was transferred to the rehabilitation ward in the hospital where I had worked as a consultant physician. As a patient I had excellent treatment, and the kindness and concern of the staff were most striking.

I remained amnesic for 10 weeks. I was unaware of my clinical condition. My only memories from this period were of a fabricated world I had created, populated by family members and in-laws. It was semi-dark, and I could not contact anyone directly—with the exception of the luminescent Crossie, an imaginary young daughter who was living several miles away from home. I wanted her to come back to live with me. Some have suggested that she may have represented the cross of Christianity or a "cross" I had to bear. During the amnesic period I spoke, sometimes appropriately, but I have no memory of this. However my wife says she saw glimpses of my previous self.

The fog clears

The fabricated world was all I had, and it seemed very real. As my memory started to return I realised that all the family members it featured were dead and that

BOX 1 | A DOCTOR'S PERSPECTIVE

My first clinical meeting with Dai was three days after his transfer to the rehabilitation ward some five weeks after his head injury. His article gives little impression of the severity of his cognitive and behavioural injuries at this time, not surprisingly, as he has no recollection of this part of his life. When I met him he had largely lost his identity, his sense of modesty, and his ability to communicate sensibly.

This clinical picture prevailed up until about the end of July 2008, when the period of post-traumatic amnesia ended, and there was rapid recovery of cognitive function. Going from being almost unfit to undertake psychometric testing to returning to scores on standard tests of cognitive function (WAIS-III, WMS-III, DKEFS) close to, or at, his premorbid level happened in just two months, though some measures of his language ability, for example the Similarities subtest of WAIS-III, did not recover as quickly, nor to quite the expected level.

At the initial assessment I expressed a gloomy prognosis to his family and his employer. However, I was completely and agreeably mistaken, and the first lesson for me was a much increased distrust in the value of relying on standard indices of severity when giving a prognosis for head injury.

Dai's article refers to the contribution of therapists, but it should be stressed that the unit where he was placed is not a dedicated brain injury rehabilitation unit, but one that offers rehabilitation for a variety of chronic medical conditions. In fact, Dai was assessed for and declined to attend the local brain injury unit. I thought his decision wise because he would not have fitted in with the much younger people likely to be attending the unit, some of whom would have had marked behavioural problems and a very poor prognosis.

The reader needs to be aware that Dai, as soon as he was able (early August 2008), set about designing his own rehabilitation strategies with the therapists as his advisers. His rehabilitation was therefore very much self determined. This fact emphasises the second lesson for me: the influence of premorbid personality on recovery. In October 2008 Dai described himself to me as follows: "Quiet, unassuming, sympathetic, hard-working, not volatile or demonstrative." He failed to mention his modesty, his love of learning, and his pride in the care he had given to his patients over many decades. I suspect that a patient with a less positive set of personality traits would have been much less likely to achieve the same outcome after a severe brain injury.

The third lesson concerns age and prognosis. Physiology documents the adverse effects of age on the brain. The obvious inference is that younger people with traumatic brain injury are likely to have a better prognosis than older people. But this ignores the influence of previous learning. Positive personality traits, which are likely to assist in recovery, will be less firmly established in a younger person. They will not have become, as does a person's written signature, an over learnt habit almost impossible for the brain injury to eradicate. Dai's seniority may in fact have been an advantage in his recovery.

Dr Martin Skelton-Robinson
smp43design@btinternet.com

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- Joint hypermobility syndrome (*BMJ* 2010;341:c3044)
- Endometriosis (*BMJ* 2010;340:c2661)
- Two hip replacements (*BMJ* 2010;340:c1502)

BOX 2 | ORGANISATIONS AND USEFUL WEBSITES

Brain injury (www.braininjury.co.uk)—A website providing information and links on brain injury and head injury, it focuses on legal issues such as compensation, personal injury, the Court of Protection, and the Public Guardianship Office.

Headway UK: the brain injury association (www.headway.org.uk)—A charity set up to support people affected by brain injury through a network of groups and branches throughout the UK and Channel Islands.

Crossie had never existed. I went through a second bereavement process for my absent loved family.

My daughter feels that my moving from a ward to a side room enhanced my progress. I began to recognise staff and visitors but could not remember names. I then realised I had forgotten facts like family birthday dates. I had forgotten who I was. I had lost all my mental geographical maps, so I could not be trusted to leave the ward.

I had been nursed one to one, but became embarrassed when I realised I was being accompanied in the toilet. This insight meant the one to one nursing could stop. I was now able to have physiotherapy, and discovered that I had physical disabilities. My balance was poor, I was clumsy, and I had a slight visual field defect.

My insight into my condition improved, and I began to realise what I had lost. I was told that my age, 60, would make recovery harder. I later realised that some memories were false.

My speech and language therapist was Australian. We talked about animal names being used for international rugby teams. I remembered the Australian Kangaroos rugby league team. As I thought of kangaroos I remembered my childhood in Wales with cows in the fields and, I thought, kangaroos in the forest nearby. I found myself theorising on how kangaroos had moved from Wales to Australia. When I realised my mistake I felt embarrassed, but those I told found it amusing.

I was originally upset when the therapist told me I was tangential in my conversational responses. It seemed she was trying to score points rather than help me. A little later, when I was talking to a colleague, I realised that I was indeed being tangential. I respected my therapist more after this. These insights initially had a very dispiriting effect on me, but they were to help me initiate a personal strategy for my recovery.

I called my personal strategy "being back at school" because I could not remember most of what I had learnt or been taught in life. I remembered school as being an ordered environment with expert teachers. It was similar in some ways to the structured rehabilitation programme I was now undergoing, starting the day with exercise followed by a therapy timetable. This strategy gave me great consolation as it was a pathway. By working hard I could regain much of what I had lost. I was starting in primary school again but could sequentially improve and progress through each year until I reached my pre-accident level. In therapy sessions I asked for homework to do in my room and then started setting my own homework.

I obtained my curriculum vitae, which showed how long I had been a consultant, how many papers I had published, and that I had been a Royal College of Physicians examiner and clinical director in medicine. It would be a very long journey to get any of this back. I then saw a psychologist who assessed my cognitive function. I realised I had to redevelop my thinking processes. I did this by reading, accessing the internet, doing Headway exercises (see box 2), playing Sudoku, and taking MENSA IQ tests.

A ray of light

After six months I thought that lost memories would be unlikely to return, but this was not so. First I had to relearn memory techniques, beginning with attention, repeating the process, and practising retrieval. I then found that I could remember my dreams again, and, where laborious attempts to remember things had failed, memory started to return spontaneously. This convinced me that memory was still stored; it was now a question of learning how to relocate it. It was as though I had an encyclopedia, but the index was missing.

I also found that experiential learning and memory were more efficient than abstract thought. Six months after the accident I visited London Zoo, remembering and learning a lot. A visit to the outside of a previous family home near Swansea triggered the memory of the contents of every room and the internal structure of the house, which I had previously tried to remember and could not. The sensory stimuli from sight, sound, and smell can be very strong. Being near the sea had a remarkable effect, with the sound and smell bringing back old memories.

I came to terms with age delaying my progress. I saw David Attenborough, who is 20 years older than me, talking about animals on the television. This made me realise that increasing age does not always destroy ability: other factors are important for success, such as innate skill and determination. This observation had the effect of increasing my perseverance, and I was able to see that early failure was not necessarily total failure.

My physical injuries resolved. I was able to jog again, and I wanted to resume playing golf. Jogging was easy: it was about getting fitter to run further. When I attempted to hit a golf ball on the practice ground my balance was poor, and every shot went far to the left. However, I was able to analyse what was wrong. I found it was my grip, and when this was adjusted I produced straighter shots.

I am working hard to improve my medical knowledge so that I might do some outpatient work. I am also improving my teaching skills and doing some local archive work. One of the great inspirations for me is Hippocrates. He said that no brain injury is too severe to despair of, nor too trivial to ignore.

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An earlier, similar article by Dai Thomas can be found at www.ijrt.co.uk (Thomas D. The journey back to effective cognitive function after brain injury. A patient perspective. *Int J Ther and Rehabil* 2009;16:497-501).

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EASILY MISSED?

Acromegaly

Raghava Reddy,[1] Sally Hope,[2] John Wass[1]

[1]Department of Endocrinology, Oxford Centre of Diabetes, Endocrinology & Metabolism, Churchill Hospital, Oxford
[2]Woodstock General Practice, Woodstock, Oxfordshire
Correspondence to: J A H Wass
john.wass@noc.nhs.uk

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This is a series of occasional articles highlighting conditions that may be more common than many doctors realise or may be missed at first presentation. The series advisers are Anthony Harnden, university lecturer in general practice, Department of Primary Health Care, University of Oxford, and Richard Lehman, general practitioner, Banbury. If you would like to suggest a topic for this series please email us (easilymissed.bmj@bmjgroup.com).

Acromegaly is a clinical disorder of adults characterised by changes in the face and extremities caused by excess growth hormone secretion. Growth hormone excess that occurs before fusion of the epiphyseal growth plates in a child or adolescent is called pituitary gigantism. In adults the excess growth hormone secretion is usually caused by a benign growth hormone secreting pituitary adenoma,[1] though it may occasionally (in about 15% of cases) be part of a genetic condition, such as familial isolated pituitary adenoma, multiple endocrine neoplasia type 1, or McCune-Albright syndrome.

Why is it missed?

The diagnosis of acromegaly is often missed because the condition develops slowly and insidiously, and it often has clinical features which are common in the general population, such as tiredness and musculoskeletal pain. The mean time to diagnosis is eight years, with a range of 6-10 years.[5] Studies have reported a high prevalence of certain conditions in patients with acromegaly[6] (see box), which may confuse the clinical picture as these too are common conditions in general practice.

Why does this matter?

Case series of patients with uncontrolled acromegaly suggest that their life expectancy averages 10 years less than that of the normal population.[7] Suppression of growth hormone below 1.67 µg/l with treatment has been shown to improve mortality, and growth hormone levels less than 1 µg/l are associated with a normal life expectancy.[8] The overall mortality of untreated disease is about twice normal,[8] and death is usually caused by cardiovascular or respiratory disease or cancer. The increase in mortality is influenced by the duration of symptoms before the diagnosis, the duration of the disease, older age, and the presence of complications at diagnosis.[9] Thus, the diagnosis and control of growth hormone hypersecretion, hypertension, and heart disease may improve the mortality rates. A delay in diagnosis also leads to greater skeletal disfigurement, as well as systemic manifestations.

CASE SCENARIO

A 44 year old woman, known to have type 2 diabetes mellitus, presented with backache and a six month history of sweating, increased sleepiness, more recent headache, and decreased vision. She attributed her tight rings and numbness in the hands to arthritis. In view of the latter symptoms and her suggestive facial features, her general practitioner thought that acromegaly was a possibility, and requested growth hormone and insulin-like growth factor-1 (IGF-1) to be measured. Both tests showed raised values, so she referred the patient to an endocrine centre for further investigation, and the diagnosis was confirmed.

HOW COMMON IS THIS CONDITION?

Acromegaly has an estimated prevalence of around 60 per million and an annual incidence of 3-4 per million.[2]

More recently a higher prevalence of about 130 per million has been suggested by a study in Belgium with more active surveillance for pituitary adenomas.[3] This figure is confirmed by our own study in Oxfordshire.[4]

The condition affects all races and both sexes, and the mean age at diagnosis is 40-45 years. However, larger, more aggressive tumours secreting growth hormone tend to present in younger patients. Patients with a family history of pituitary adenomas also present at an earlier age.

How is it diagnosed?

Clinical manifestations

Initial presentation may be with non-specific symptoms such as tiredness, sweating, and musculoskeletal pain. Some degree of suspicion of acromegaly is required when certain conditions are diagnosed (box), especially against a background history of a change in facial features or other acromegalic changes—for example, of the hands. Excess growth hormone stimulates increased hepatic secretion of insulin-like growth factor-1 (IGF-1), which causes most of the clinical manifestations of

Complications of untreated acromegaly

The following common conditions may warrant checking for acromegaly if other clinical features suggest it, or may be screened for once acromegaly is diagnosed:

- Respiratory: sleep apnoea (20-80%, presenting with daytime somnolence, and due to anatomical changes affecting craniofacial bones, soft tissues, respiratory mucosa, cartilage and muscles)
- Cardiovascular: hypertension (40%, pathogenesis unclear but growth hormone causes salt retention), cardiomyopathy, arrhythmias, heart failure
- Metabolic: diabetes mellitus (19-56%, due to increased insulin resistance), lipid disturbances, hypercalciuria
- Musculoskeletal: arthropathy (20-50%, due to degenerative osteoarthritis of back and weight-bearing joints), carpal tunnel syndrome (20-52%, due to oedema of the median nerve in the carpal tunnel and soft tissue growth)

Other conditions to consider screening for on diagnosis of acromegaly:

- Gastrointestinal: colonic polyps, colorectal cancer
- Possibly increased risk of other malignancies such as lung, thyroid, breast, etc

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Previous articles in this series

- Ectopic pregnancy (*BMJ* 2010;341:c3770)
- Testicular torsion (*BMJ* 2010;341:c3213)
- Bronchiectasis (*BMJ* 2010;341:c2766)
- Endometriosis (*BMJ* 2010;340:c2661)
- Biliary atresia (*BMJ* 2010;340:c2383)

KEY POINTS

Acromegaly often presents with non-specific symptoms and conditions such as tiredness, sweating, and musculoskeletal pain

Clinical presentations like carpel tunnel syndrome, sleep apnoea, with associated coarse acromegalic facial features and symptoms like headache, sweating, an increase in ring or shoe size, should trigger the suspicion for acromegaly

Raised serum growth hormone and IGF1 measured in general practice and a lack of growth hormone suppression on an oral glucose tolerance test (in hospital) confirms the diagnosis

The pituitary tumour is localised using magnetic resonance imaging

Transphenoidal pituitary surgery is the first line of treatment

acromegaly, such as acral and soft tissue overgrowth in almost all adult patients. The most noticeable feature is usually a change in facial appearance with enlarged supraorbital ridges, a wide nose, and prognathism; it is often useful to ask to see old photographs. Patients often have enlarged hands and feet, supraorbital ridges, prognathism, interdental separation, and macroglossia. About 50-80% have increased sweating. The symptoms and signs of an enlarged pituitary fossa include headache and visual field defects.

Investigations

A simple blood test for growth hormone and IGF-1 measurements done in general practice can often suggest the diagnosis if the values are raised and should prompt referral for more definitive diagnosis. Growth hormone stimulates hepatic IGF-1 production. Random growth hormone levels below 0.4 µg/l, and normal IGF-1 values matched for age and gender effectively exclude the diagnosis.[8] Lack of growth hormone suppression (<0.33 µg/l) on an oral glucose tolerance test confirms the diagnosis, suggesting autonomous growth hormone secretion, usually from a pituitary tumour.

Magnetic resonance imaging of the pituitary gland is used to localise the tumour, and a tumour proves to be the cause in almost 99% of cases.[10] Most tumours are larger than 1 cm (macroadenoma), and these respond less well to surgery and medical treatment.

Screening tests performed in hospital for complications of acromegaly include measurement of glucose, calcium, remaining pituitary function, visual fields, echocardiography, colonoscopy, and polysomnography (if there is clinical evidence of sleep apnoea).

How is it managed?

The primary treatment is hypophysectomy carried out by an experienced pituitary surgeon. This gives the best outcome, rendering growth hormone into the safe range in 70-90% of patients with microadenoma and in 45-50% of those with macroadenoma.[11] If this fails, medical treatment with somatostatin analogues (octreotide or lanreotide) is started to reduce growth hormone and IGF-1 levels to normal, and such treatment is successful in 50-60% of cases.[12] If unsuccessful, a dopamine agonist such as cabergoline, or very rarely a growth hormone receptor antagonist like pegvisomant, is added. At this stage radiotherapy may be considered, but this is a slow treatment and takes a few years to normalise growth hormone levels. Patients with acromegaly should be kept under review, probably for their lifetime, for recurrence (5.4% at 10 years after surgery)[13] and for complications of the disease and treatment (such as hypopituitarism following radiotherapy).

To summarise, acromegaly is a condition often subject to considerable delay in diagnosis, that leads to significant mortality and morbidity which adversely affects the quality of life. It can be improved with treatment. We believe that the time to diagnosis can be shortened by clinicians asking specific questions to evaluate the different causes of the characteristic common conditions.

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