



International Journal of Health Care Quality Assurance

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Article information:

To cite this document:

Karen Newell, Chris Corrigan, Geoffrey Punshon, Alison Leary, (2017) "Severe asthma: emergency care patient driven solutions", International Journal of Health Care Quality Assurance, Vol. 30 Issue: 7, pp.628-637, <https://doi.org/10.1108/IJHCQA-09-2016-0127>

Permanent link to this document:

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Severe asthma: emergency care patient driven solutions

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Abstract

Purpose – Patients with severe asthma were choosing not to use the emergency department (ED) in extremis and were self-medicating when experiencing severe asthma, putting their lives at risk. This local issue reflected a nationwide situation. The purpose of this paper is to better understand the reasons behind patients' reluctance to attend ED and to consider practical solutions in a structured way.

Design/methodology/approach – Systems thinking (soft systems methodology) was used to examine the issues resulting in this reluctance to attend the ED. Once this tame (well-defined) problem was revealed, a potential solution was developed in co-production with patients.

Findings – Patients feared attending the ED and felt vulnerable while in the ED for several reasons. This appeared to be a well-defined and solvable problem. The solution proposed was an asthma patient passport (APP), which increased patient's confidence in their ability to communicate their needs while in severe distress. The APP decreases (from 12 to 5 steps) the work patients had to do to achieve care. The APP project is currently being evaluated.

Practical implications – The APP should be offered to all people with severe asthma.

Originality/value – By revisiting systems thinking and identifying problems, a solution was identified. Although methods such as soft systems methodology have limitations when used in wicked (difficult or impossible to resolve) problems, such methods still have merit in tame problems and were applicable in this case to fully understand the issues, and to design practical solutions.

Keywords Systems thinking, Quality improvement, Emergency, Asthma, Soft systems methodology

Paper type Case study

Background

Approximately 1,200 people with asthma die in the UK each year; 90 per cent are preventable (Asthma UK, 2014). The UK has a higher asthma death rate than similar countries and numbers have not reduced significantly in recent years (Levy *et al.*, 2014). The "Why Asthma Still Kills: The National Review of Asthma Deaths (NRAD) Confidential Enquiry Report" was published in 2014 (Royal College of Physicians, 2014). Its aim was to identify avoidable factors, recommend changes to improve care and reduce asthma deaths. The NRAD authors concluded that there are factors associated with the disease, its medical management and the patient's behaviour or psychosocial status, which contribute to death. Most deaths occurred before admission to hospital and most fatalities had chronically severe asthma (British Thoracic Society, 2014).

Local context

In conjunction with NHS Improvement, some work was undertaken around asthma re-attendance in the emergency department (ED) at one large London NHS Foundation trust

Conflict of interest: none declared. This work was unfunded.

The authors would like to acknowledge Stacian Gilbert, Rebecca Bunce, Janice Jones, Christeen Barnaby (asthma service users); Shenagh Hume (Allergy CNS), Fionna Moore (CEO, LAS) Katherine Henderson (ED Consultant), Tom Sagdahl (ED Matron), Nikki Helder (ED PDN) David Jackson (Consultant respiratory physician).



during 2010-2011. A local initiative (audit cycle) using increased general practitioner and general practice nurse communication, forming an action plan with patients and an ED pro forma for emergency care was initiated over a year. The initiative involved the patient experience team who facilitated work that elicited reasons for re-attendance. This initial improvement project yielded a 45 per cent decrease in 30-day asthma re-attendance (75 patients re-attended 143 times between May 2010 and April 2011 out of 888 adult attendances). Admissions were reduced by 60 per cent. Reducing asthma re/attendance and admissions indicates better asthma control and quality of life (British Thoracic Society, 2014).

Severe asthma patients were excluded from the original NHS Improvement work because they had unique needs. Asthma is known as severe when a patient has a confirmed asthma diagnosis and ongoing symptoms despite adherence to treatment. It is recognised by one or more near-fatal asthma episodes; e.g., previous ventilation or respiratory acidosis, previous admission for asthma especially in the last year, requiring three or more asthma medication classes, heavy β_2 agonist use and repeated ED attendances for asthma care (British Thoracic Society, 2014). Severe asthma cases in the hospital trust are fully medically optimised and are supported by specialist asthma clinic staff. They all have bespoke asthma action plans, which are drawn up between themselves and the asthma clinical nurse specialist (CNS). The plan outlines how to titrate asthma treatments according to symptom and when to access medical assistance.

To evaluate these plans locally, service user interviews were conducted, which showed that patients valued the asthma action plan, but there was usually awkwardness around when and how to access emergency medical care. Exploration revealed that patients were putting their lives at risk because they had such a tough time in ED and they preferred to stay at home, and take high bronchodilator therapeutic doses. Patients said they avoided the ED, even in extreme respiratory distress, for several reasons:

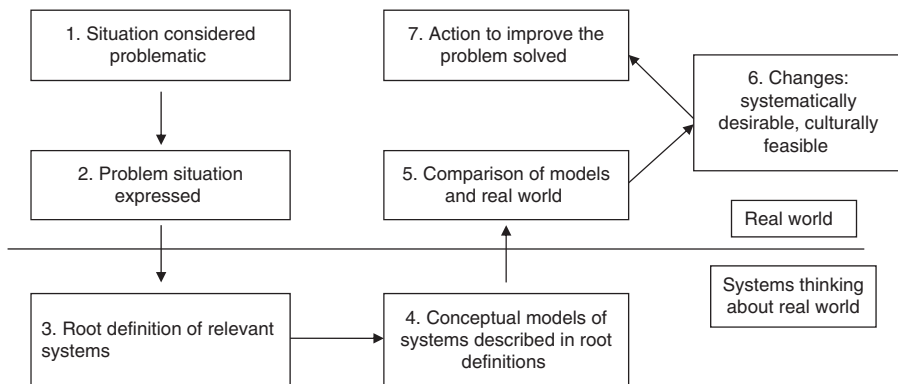
- (1) feeling vulnerable or fear in the ED when they are least able to talk; i.e., when unable to say what they needed, which caused more distress;
- (2) they are asked the same questions many times and felt that they are not always listened to;
- (3) treatment is not always escalated as quickly as they felt it needed to be; and
- (4) patients had no choice about which ED the ambulance service staff took them; consequently, they elected to use either their own or public transport even when in severe respiratory distress.

Understanding this experience structured the problem and therefore this study. A soft system thinking approach (Checkland, 2001) was used to identify the specific problem and then construct a satisfactory and sustainable solution. Soft systems methodology (SSM) was chosen as it helps conceptualise, define and address problems and is particularly useful in people oriented systems, and allows issues to be considered from a more holistic whole systems perspective. Once workable solutions had been identified, a plan-do-study-act (PDSA) cycle was used as a quality improvement approach (Langley, 2009).

Methods

To understand the problem more fully, SSM was applied (Langley, 2009; Checkland 1981). An overview can be seen in Figure 1. Soft system methodology originated in systems engineering and has been in use for over 30 years. It attempts to foster learning and problem understanding through stakeholders rather than attempting to solve a pre-determined problem. Initially, meetings and interviews are held to understand the

Figure 1.
Soft systems
methodology –
Checkland's seven
stage overview



problem situation and identify relevant systems after which conceptual system models are generated. These models are used as a basis for debate and can lead to feasible and desirable changes, which can be actioned. Whilst it is commonly considered that general systems thinking has not delivered the anticipated healthcare changes, applying systems thinking to tame (well-defined) problems has been beneficial in many areas (Checkland, 2001).

Results

Identifying the problem locally

- Step 1: situation considered problematic.

From local interviews, patients with severe asthma did not appear to be seeking emergency medical help when they needed to. This behaviour is associated with avoidable harm/death (Levy *et al.*, 2014). The NRAD report into avoidable asthma deaths (British Thoracic Society, 2014) states that 45 per cent (87) of the 195 people who died did so without seeking medical help or before emergency medical care could be provided. Previous hospital admission for asthma occurred in 47 per cent (90 of 190). In total, 19 (10 per cent) of the 195 died, within 28 days of discharge from hospital after asthma treatment. At least 40 (21 per cent) who died had attended an ED with asthma at least once in the previous year and 23 had attended twice or more. In total, 39 per cent appeared to have severe asthma. Among 195 patients who died, 155 patients had their asthma severity estimated from the information available. Patients were divided into three categories: “severe”, “mild” and “moderate”. In total, 39 per cent were classed as “severe”. The report states that it is likely that many patients who were treated as having mild or moderate asthma had poorly controlled undertreated asthma, rather than truly mild or moderate disease. The NRAD report (British Thoracic Society, 2014) and local patient experience work underlined having a personal asthma action plan. During co-creating an asthma action plan process, the asthma CNS often felt resistance from severe asthma patients around when and how to access emergency medical care, which needed exploring. The asthma CNS felt that patients were putting their lives at risk because they had such a tough time in the ED. Owing to the challenging time in the ED, they preferred to stay at home and take high doses of bronchodilator therapy (Asthma UK, 2004). The reasons behind this decision had not been considered systematically within this service. Trust staff currently care for around 800 severe asthma patients per year. Defining the problem revealed that it had been characterised as a tame problem (Rittel and Webber, 1973) in that the problem can be articulated with a clearly desired outcome – that

distressed patients feel able to go to the ED. The problem can be stated as a gap between what is and what ought to be – the latter agreed by professionals and patients: Severe asthma

- Step 2: problem situation described.

Soft system methods help to formulate and structure thinking about problems in complex human situations by applying systems thinking about things that happen in the real world. It is most usefully carried out by the people immersed in the problem situation, in this case, people with severe asthma and the asthma CNS who provides expert help to guide and facilitate the process. The asthma CNS facilitated a focus group with the patients and the allergy CNS to gain a situational insight. The findings from the group echoed the asthma plan evaluation themes:

- (1) feeling vulnerable and afraid;
- (2) asked the same questions repeatedly when least able to talk;
- (3) unable to say what they need when least able to talk;
- (4) feeling that they are not always listened to;
- (5) life-saving treatments are not always escalated as quickly as necessary;
- (6) healthcare staff do not always appreciate the attack's severity; and
- (7) individual fears; i.e., being left alone in a cubicle when they think they are dying.

After an initial meeting, process mapping was introduced to explore the issues (Newell *et al.*, 2014). Process mapping revealed that 12 separate actions were required to gain treatment when self-presenting to the ED and 13 if brought by ambulance (Figure A1) (Newell *et al.*, 2015):

- Step 3: root definitions.

It was agreed by the co-production group that “something needed to be done”, thus a project team was established to set out a shared purpose and vision. The project's aim was that patients with severe asthma would seek emergency help appropriately. A further aim was that if patients with asthma went to the ED, then they should feel that they were being taken seriously and be able to work with staff to achieve the best outcomes. Returning to SSM to help achieve these aims, several questions are posed:

- (1) What the system will do?
- (2) How it is done?
- (3) Why it is being done (long-term aim)?

Underpinning these questions is a transformation process in which something is changed or transformed into something else, which revealed the system requirement: to encourage people with severe asthma to go to the ED when they need to for the right treatment, in the right place, at the right time without fear. Once the problem has been defined, the SSM CATWOE checklist (Checkland, 2001) was used to solve problem:

- (1) Customers: it was the asthma CNS's duty to listen carefully to what patients with severe asthma had to say about seeking emergency help and contribute to enabling ED and London Ambulance Service (LAS) staff to understand patients' needs.
- (2) Actors: those involved in the situation and in partnership with them, to act on what had been discussed. How might they react? What is their stake in improving the situation?
- (3) Transformation: so that the patient group would change their behaviour and go to ED when they needed to. Staff reacted in a way that reassured and met patients' needs rather than increasing their distress and fear.

- (4) Weltanschauung (this is the right thing to do): because not to do so put patients at risk – they say they are already at risk and want to do something about it.
 - (5) Process owners: all stakeholders: patients with severe asthma; ED clinical, ED reception, and LAS staff; asthma professor; patient experience team; communications and patient publications.
 - (6) Environmental constraints: NRAD (British Thoracic Society, 2014) describes how people with asthma were needlessly dying because patients failed to recognise the asthma attack’s severity, healthcare staff’s failure to recognise attack severity and inappropriate or under-treatment. It was fundamental that any plan took these constraints into account.
- Step 4: conceptual system models described in root definitions.

Drawing out a conceptual model highlights many reasons why the patient group were not going to ED and not understanding how component parts fit together (Figure 2).

Patients are not necessarily local to the trust and therefore need to use different EDs, and so a local arrangement was not an obvious solution. Another option was to have a national database of people with severe difficult to manage asthma so that the ambulance service and the various UK EDs had information about the patient, but this was impractical. Establishing such a system would be resource intensive because there is no common information technology infrastructure in the UK. Other long-term condition groups, such as people with learning difficulties and mental health problems and palliative care needs, were already using a patient passport as a collaborative communication tool and this had been found to be helpful in accessing services (Abbott *et al.*, 2015). A local Chronic Obstructive Pulmonary Disease (COPD) passport was being used and it was felt that the design had been well evaluated. The COPD passport is a z-card (a document with several information panels that folds down into a credit-card sized card that can easily be stored in a wallet or purse) that simply records relevant demographic and clinical information.

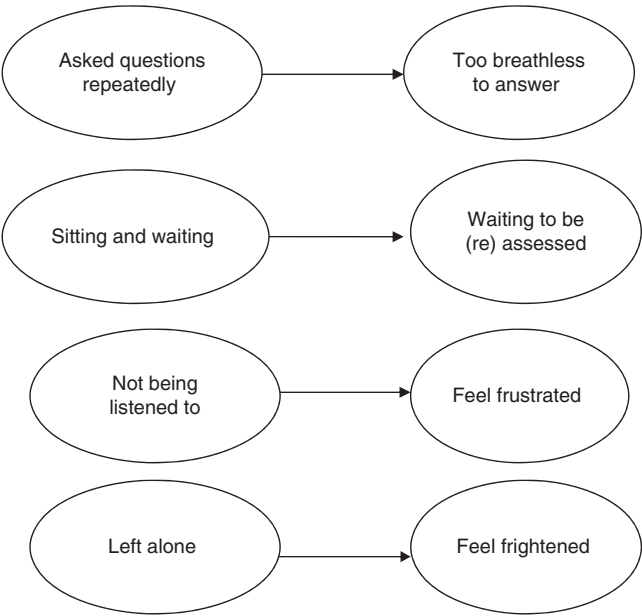


Figure 2.
Reasons why severe
asthma patients were
not going to ED when
they needed to

Where the asthma patient passport (APP) would differ from the COPD passport is that it would be designed by patients for patients and would also consider ambulance service and ED staff needs. The other crucial factor was the decision to use the model for improvement; i.e., implementing health service change (NHS Institute for Improvement, 2014). Every time a patient used the APP, his/her experience was fed back by the patient or other user (e.g. LAS) to the group and any suggestions were incorporated into the APP:

- (1) providing emergency information at the beginning;
- (2) adding a box for the asthma physician's signature to lend credibility;
- (3) changing the word "severe" to "brittle" as it is more commonly understood in those who do not specialise in asthma treatment;
- (4) having an explicit statement about what to do if arterial blood gases (ABG) are needed (as ED staff felt that gaining permission to undertake ABG's can be challenging at times);
- (5) adding a review date;
- (6) having a pre-hospital treatment section for the ambulance journey;
- (7) highlighting and dating previous ITU/HDU admissions;
- (8) adding a triggers section; and
- (9) designing watermarks that provide subliminal awareness information on crucial safety factors such as the silent asthmatic.

These suggestions won commitment from patients and various healthcare staff groups:

- Step 5: comparing models with the real world.

The problem examined was APP development and to compare this model with the real world. The APP made the patient journey through the ED more efficient. Patients brought in by ambulance went through a 13-stage process before the APP was introduced. With the APP in place, there are now only nine steps. Self-presenting patients also went through 12 steps before the APP was introduced and five afterwards (Figure A1). The APP streamlined the process by improving communication and allowing improved access and flow through emergency care, which reduced delay, ensuring that treatment was individualised and right first time, thereby improving quality and possibly lowering costs (Newell *et al.*, 2015):

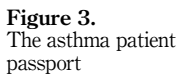
- Step 6: changes – systematically desirable, culturally feasible?

Does the solution work?

The APP was developed and piloted for three months with 15 patients. During this period, it was used 15 times by seven patients. After a positive feedback and some minor alterations based on the feedback, the APP was trialled for one year. During this time, regular meetings and consultations were held with patients, specialist nurses, ED and LAS staff, and the medical consultant who were consulted extensively throughout the trial period using this approach. Finally, an APP document (Figure 3) was devised that provided this patient group with the confidence to attend ED when appropriate, and assisted healthcare staff in treating them (Newell *et al.*, 2014).

Is it worthwhile?

The APP addressed four key areas that were most important to patients: being left alone; being unable to communicate their needs; feeling frustrated at not being listened to; being asked the assessment questions repeatedly at a time when they are too breathless to



Does the solution achieve its goals?

- Step 7: action to improve the problem situation.

The action taken was to implement the APP for patients with severe asthma attending one large London NHS Foundation trust. There are plans to undertake a multi-centre study using a mixed-methods approach, which will include an impact evaluation.

There is breadth and value in the SSM approach with the PDSA cycle in tame problems. Patient passports are common in other long-term conditions (National Quality Forum, 2015). The APP was specifically co-designed to meet an expressed need and it was the patients, and asthma CNS that drove the development process. The core group included patients, asthma and allergy CNSs, and it was the collaborative approach adopted by patients and wider team (including ambulance and ED staff) that helped to get it right. Inextricably connected with this was learning by doing, so that every time a patient used the APP, it was discussed with the asthma CNS and the APP was improved. The tame problem was that severe asthma patients were not accessing emergency healthcare when they needed to. The patient's perspective is highly relevant to efforts to improve healthcare quality and effectiveness (Frew *et al.*, 2011) and because all parties were involved in the creation process.

everyone benefited – a win, win, win for patients, clinicians and the healthcare system. The patients feel more secure and are more likely to go to the ED and get the right treatment, in the right place, at the right time. Healthcare staff have all the necessary information, which is individualised and easy to follow. The healthcare provider benefits because the process is leaner and outcomes are improved, which indicates a cost saving. The APP implementation is undergoing evaluation.

Conclusion

Systems thinking and SSM have limited applicability in the NHS because the methods have been applied to wicked (complex and unanswered) problems. Our work shows that there is some benefit to be gained from SSM application in tame, well-defined problems, to help understand and solve the problem.

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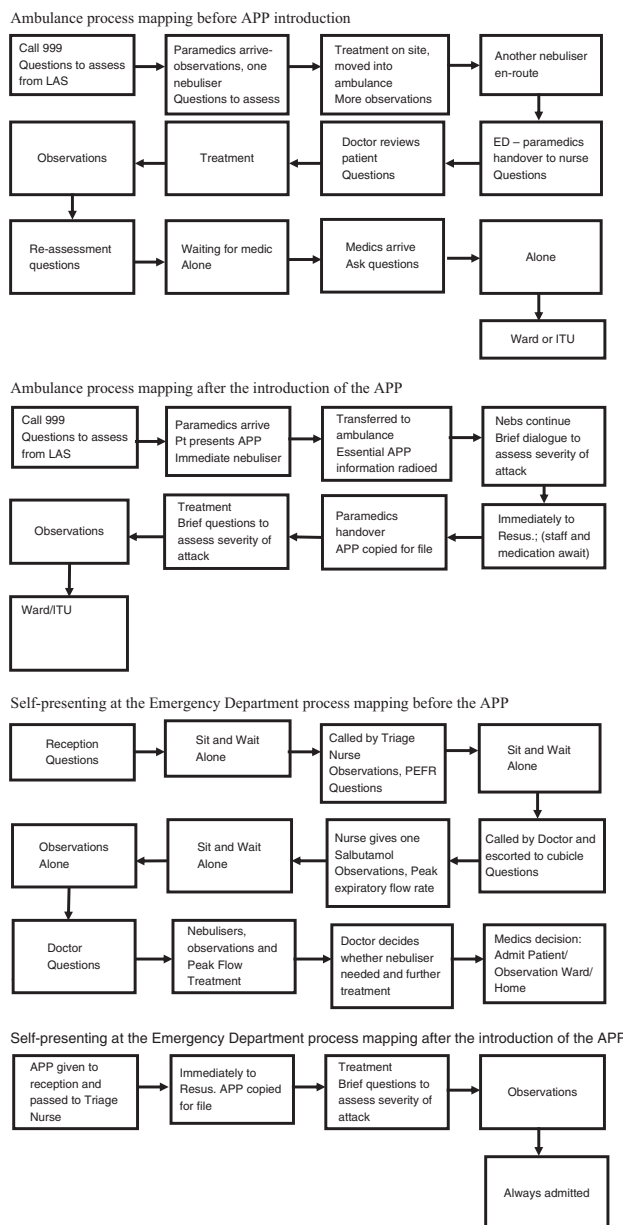


Figure A1.
Treatment brief
questions to assess
severity of attack

About the authors

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