

Towards a systemic understanding of a hospital waiting list

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Abstract

Hospital waiting lists in New Zealand have grown in size and attempts to reduce or eliminate them have been largely ineffective (Cooper, 1995). Strategies such as adding extra resources have been tried without lasting success. Part of the difficulty is that waiting lists are complex (Fraser, 1991), multifarious (Harvey, 1993) and messy. A systemic understanding is clearly needed.

Using data collected from a case study of a New Zealand diagnostic waiting list, this paper investigates the perspectives of waiting patients using Total Systems Intervention as a framework. The preliminary results of fifteen semi-structured interviews are presented and the metaphors which highlight what it is like to be on a waiting list are identified. A number of issues are surfaced. This paper concludes that the patient perspective is important if waiting lists are to be systemically understood.

Introduction

The cost of health care is rising while technology continues to offer more thereby continually fuelling demand. At the same time, hospital waiting lists continue to grow in size and attempts to reduce or eliminate them have been largely ineffective (Cooper, 1995). Finding better ways to manage waiting lists is essential and likely to remain an important issue well into the next millennium.

Waiting lists are influenced by a number of factors that have little to do with throughput (Fraser et al., 1993). Simple input-output models have proved unhelpful and little is known about what causes waiting lists or how waiting lists should be managed (Mullen, 1994). Policy decisions tend to be ineffective in solving the waiting list problem and can result in undesirable side effects. While intuitively an increase in funding seems to offer a solution, it not only fails to eliminate waiting lists but actually stimulates further demand. As it is generally accepted that waiting lists are conceptually complex, it is perplexing that policy makers continue to model waiting lists as simple input-output models using operations research and health economics based approaches.

Using data collected from a case study of a New Zealand diagnostic waiting list, this research seeks to better understand a waiting list systemically, going beyond simple

input-output models, by using the creativity phase of Total Systems Intervention (Flood and Jackson, 1991; Flood, 1995a; Flood, 1995b; Flood, 1996). The case study was carried out in an imaging department of a New Zealand base hospital. Access to imaging services is available to both specialists and GPs in the surrounding district as well as outlying towns. The diagnostic waiting list is the department's largest with approximately thirteen hundred patients waiting six to twelve months for an appointment. As a necessary condition towards a systemic understanding, the perspectives of five key stakeholder groups have been considered: consultant radiologists, imaging technologists, departmental managers, general practitioners (GPs) and waiting patients. As the study is still in progress, this paper presents only the patient perspective. The patient perspective is important for two reasons: first, it is clearly a crucial perspective; and second, it has been surprisingly neglected and is poorly understood. The perspectives of other stakeholder groups will be presented in other papers.

Ethical approval for this research was obtained from Massey University and the relevant Health Funding Authority ethics committees.

In this paper methodological issues are discussed and the results from fifteen semi-structured interviews are presented. Key patient issues are identified and a patient perspective is suggested. In conclusion, possible systemic implications of a patient perspective are discussed.

Methodology

The systems framework that underlies this research is Total Systems Intervention¹ (TSI). TSI is a meta-methodology for understanding and managing complex organisational problems or "messes". The philosophy and principles underlying TSI are discussed in Flood and Jackson (1991) and Flood (1995b).

TSI has three phases: creativity, choice and implementation (Figure 1). As this research aims to better understand a patient perspective, the creativity phase of TSI has been used to structure the research. The creativity phase seeks to systematically uncover issues about the system in focus: the diagnostic waiting list. With this understanding, a range of possible interventions can be identified to resolve the issues surfaced by the creativity stage. For the purposes of this research, patient issues were surfaced using semi-structured interviews which asked patients such open-ended questions as "what is it like being on a waiting list?" The transcripts were analysed using grounded theory (Strauss and Corbin, 1990) and from the ideas and images uncovered, core patients issues were determined.

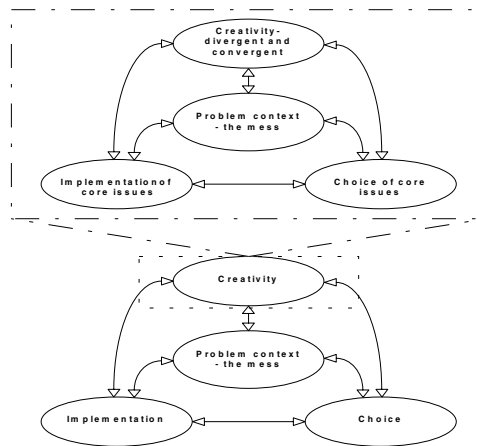


Figure 1: Creativity, choice and implementation (adapted from Flood, 1996)

In order to obtain a sample of approximately fifteen to twenty patients, ninety waiting patients (comprising a representative mix of age, sex and condition) were mailed invitations to participate in the research. Each invitation contained an information sheet and a consent form. Patients were excluded only if they were under the age of eighteen or lived outside the city where the imaging department was located. Fifteen signed consent forms were returned. Two invitations were returned unopened and one patient phoned to say that he had received his scan privately and was not on the public waiting list. All fifteen consenting patients were interviewed by the researcher. Each interview took approximately thirty minutes to complete and was tape recorded for later transcription. The transcribed comments were coded and grouped according to which issue was raised. Particular attention was paid to patient metaphors as they allowed the researcher to extract key issues.

Findings

What issues did the semi-structured interviews surface? A recurring theme that emerged from the patient interviews was that uncertainty was a major problem for patients. The primary source of uncertainty centred on the patient's condition. For most patients, this uncertainty resulted in worry or anxiety. One patient, after discovering a worrying lump, remarked: "God your imagination goes wild". Other patients with less obvious symptoms also expressed concern:

"If there is anything seriously wrong with you it would be too bad wouldn't it. Did you see the death notice in the paper the other day?"

"I can't see what's going on inside me. I think even though its not a major problem there is that little worry being a sole care-giver for three children. If something goes wrong with me you are left in the lurch. Its just not knowing what's going on"

Not all patients, however, were worried. Some patients - mainly those waiting for a cardiac scan - were largely unconcerned simply because they did not feel ill.

“It [waiting] hasn’t really troubled me because I don’t think that I’m very ill whatever the doctor says. I don’t feel very ill but if I was ill I might be anxious.”

The other source of uncertainty was that patients were unsure of when they would have their scan. Being classified as routine, apart from legitimising the wait, gave patients little indication of how long they might wait for their scan. For some patients this was just as worrying as not knowing what could be wrong with them. In fact, from a patient’s perspective both sources of uncertainty were equally troubling.

The absence of information from the imaging department was a common source of frustration for the patients. The department did not tell patients how long they could expect to wait and in a surprising number of cases (possibly due to administration errors) the imaging department did not acknowledge that the GP’s referral had been received. This “unboundedness” often increased patient anxiety and in some cases patients felt that they would not receive their scan at all.

“I actually wondered at one stage if my GP hadn’t made the appointment for me”

Patients - particularly those who felt increasingly ill - were angry at the imaging department. To them, the waiting list was a barrier that prevented them from getting well.

“They didn’t know what was wrong with me. That was the problem so they wanted to do the scan to find out...like they were stopping me from getting better”

Frustration often gave way to resignation. A number of patients felt trapped. One patient described waiting as being:

“Stuck in a traffic jam. Its out of your control. You can’t do anything about it. You just have to go at the speed that everybody else is going at”

Waiting was forced by circumstance. For routine patients there were only two options, “go private” or become more ill. Obviously, neither option was attractive to patients. In fact, a number of patients were not confident that the hospital would give them a scan if they became more ill. One patient who “wasn’t coping” remarked:

“I was grossly annoyed that I wasn’t seen as a priority by the system. How could I let the system know that I was in fact worse and not coping...what do I need to do to get them to notice me?”

The importance of information was made explicit by two patients. It gave patients a sense of certainty. For one patient, waiting was like standing at a bus shelter:

“I might liken it to a bus where the service is different from the time table on the bus shelter and they actually now don’t run them as a day service any longer so I could be waiting all day. In fact a bus doesn’t come past at all”

The second patient, when asked why it was important that she knew how long she might wait, explained: “for me without it [information] was like I was standing still in the same place...it [waiting list] wasn’t moving”.

Even so, many patients were quietly confident that “eventually” they would receive their scan but only when the imaging department was ready: the patient had no say when they would be selected for an appointment. One patient’s quiet confidence was relayed in terms of the following metaphor:

“You know it [patient’s name] is going to come up eventually. Perhaps someone is coming to visit you but you don’t know when and it’s sort of way-way in the distance but they will just turn up when they are ready. That type of thing.”

Despite patients having a quiet confidence, worry caused by uncertainty coupled with no or little information about the waiting list caused patients to feel helpless and powerless. “Powerful others” had control. Patients could do little other than check their letter box for an appointment card. According to one patient “everyday you go to the letter box and you think, ‘my appointment’”. A number of patients felt depersonalised. They were “no more than a number” and that “no one seemed to care”. When the appointment card did arrive, patients were overjoyed: “Oh my God! Oh my God! Its finally here!”

How did patients cope with the uncertainty and loss of control? Patients utilised a number of coping mechanisms. A common strategy was to forget about being on a waiting list by pushing worries “to the back of the mind”. Patients became tolerant to waiting. The reason for forgetting, according to one patient, was pragmatic: “you can’t worry yourself senseless for six months”.

The effectiveness of this strategy depended on how frequent and severe patients’ symptoms were and what patients thought the symptoms may signify.

“You do tend to forget a bit in between, and something happens and its rears it’s ugly head again. Yes you have crook stomach again. I mean ah ha.”

Other patients used “positive thinking” and adopted fatalistic philosophies such as “things happen when they happen”. This strategy is similar to forgetting. One patient generated a pseudo-conflict: a strategy which encouraged her to be resigned.

“I come home with mixed anticipation about what might be in the mail. On the one hand wanting to have the procedure done...but the impending fear as well at what might be revealed.”

Another patient decided that she would postpone her decision to stop recreational running until she knew the results of her cardiac scan: at the time of the interview this patient had run two marathons.

Information about the waiting list also helped patients deal with waiting. One patient, after learning that the waiting list was at least nine months long, explained:

“I’m sure my GP wouldn’t have referred me if I was that sick. He would be saying to the hospital give me a scan.”

Considering that the imaging department is the most direct source of information, it is surprising that only a few patients actively rang the department and ask how long they would wait. Those who did were rarely satisfied with what the imaging department told them. For patients, contact with the imaging department was unhelpful and the explanation that appointments were allocated by medical priority made patients feel selfish or more helpless and powerless.

Patients commented on their GPs as sources of information or advocates. The GP was the most common source of information about the waiting list. However, information tended to be vague and in many cases was inaccurate.

“The only time he [GP] said anything about the waiting list was in June and he said you will probably have to wait some weeks”

Patients also questioned the effectiveness of their GP as an advocate. Patients felt that the GP had little say in how the imaging department allocated appointments. One patient, while reflecting on her waiting experience, said “I don’t know how much notice they take of GPs”. Another patient noted the passive approach her GP took when dealing with the hospital:

“My GP said well it was up to them when they could fit me in...my GP would just ring up and say ‘has such and such got one [appointment] coming? No. Okay’ then she would hang up”

Patients were told very little about how the waiting list was managed other than that scans were allocated to “worse off” patients first. Most patients, despite knowing little about the waiting list, consider it to be orderly, well structured and fair in the sense that they would be seen when it was their turn. Images included supermarket queues, bus queues and filters.

How is the patients perspective to be summed up? The patients perspective is characterised by dependence and ignorance about how the waiting list is managed; in essence, by powerlessness. Patients who wait are forced to conclude that their case is of low priority; they are not as badly off or as urgent as others. As a result, patients feel depersonalised.

Discussion

TSI is fundamentally emancipatory and focuses on achieving human freedom or considered choice. It does this by reflecting on instances where organisational design, processes, culture or politics may limit meaningful participation for affected stakeholder groups. This research has looked at waiting patients.

The findings suggest that patients, despite being clients, have little active importance. An illustration is provided by one patient, who declined an interview as she believed that she was not on the waiting list. The patient later contacted the researcher:

“I’ve just had a call from the hospital to tell me I’m on the waiting list and I go in on Thursday. But the funny part is that I had the heart attack in April and I didn’t even know I was on the waiting list”

Patients want certainty. However, patients must contend with uncertainty as they are offered little information about expected waiting times or how the waiting list is managed. Most patients are passive and are obliged to play the patient patient.

“Be patient. Realise that there are people worse off than yourself”

Patient passivity and acceptance of the need to wait fits in well with the assumptions underlying operations research and health economics approaches. Waiting lists highlight the imbalance between supply and demand. As buffers of “work-in-progress”, waiting lists enable the utilisation of scarce hospital resources to be protected against statistical fluctuations such as patients who may fail to keep allocated appointments. Patients are the manufacturing analogue of “work-in-progress”. As such, patient concerns are at worst irrelevant or at best secondary.

What does the creativity phase of TSI suggest about potential choices of interventions to benefit waiting patients? The most obvious intervention is to provide patients with accurate information about the waiting list. “Boundedness” provides patients with a choice. For instance, patients can decide whether they can “afford” to wait.

“If I had know I was going to wait this long I would have had my scan privately”

“Boundedness” also helps patients to maintain a sense of control. It provides patients with a framework making waiting easier. “Boundedness” may also encourage patients to be realistic as they see that there is nothing they can do until their appointment. As uncertainty is part of an interacting set of issues, its resolution is not straightforward. Inaccurate or misleading information is likely to make the problem worse particularly if patients wait longer than they have been lead to believe. This will not only result in disappointment, but further exacerbate the patient’s helpless and powerlessness.

The creativity phase of TSI also highlights the coercive nature of the imaging system. Without information, the patients’ passivity is reinforced. For waiting patients, how the waiting list is managed is a black box. Nor do patients have a say in how the waiting list should be managed. Further, the patient’s advocate - the GP - seems to inspire little confidence in patients.

The asymmetry highlighted in this research has been largely ignored by waiting list researchers and shows the value of TSI as it is explicitly committed to maintaining a sociological awareness.

TSI also suggests that hard systems methodologies used by operations researchers and health economists are inadequate or incomplete because they do not address the issue of power. An appropriate systems methodology to address this dimension of the waiting list problem is critical systems heuristics (CSH) (see Ulrich, 1983). A CSH approach would allow the normative content of a social system design to be examined by testing the boundary judgements that policy makers and clinicians may make about waiting lists (Ulrich, 1991; Flood and Jackson, 1991). This perspective is likely to gain valuable insights into why waiting lists are managed, unlike queuing models which take the existence of waiting lists for granted. Further, CSH by considering patient boundary judgements sees patients as active participants rather than passive recipients of the health system.

Conclusion

This study has attempted to understand a diagnostic waiting list systemically by focusing on issues of concern to patients.

The patient's perspective has two important systemic implications for understanding waiting lists. First, the patient's perspective – the dependence, anxiety and powerlessness – is an interacting set of issues. As such it needs to be managed rather than ignored or solved. If providing information to patients is seen as an appropriate intervention, it will need to be accurate and relevant to patient concerns. Operations research and health economic approaches are essentially irrelevant to the patient concerns. Patients are not in fact "work-in-progress" but have to live with waiting on a waiting list.

The second systemic implication is that from the patient's perspective the imaging system is coercive. An appropriate systems methodology such as CSH may provide a more fruitful approach to the issue than current mechanistic interventions, if social as well as scarcity issues are to be managed.

1. Otherwise known as Local Systemic Intervention (Flood, 1996).

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