Resilience Ex Machina: Learning a Complex Medical Device for Haemodialysis Self-Treatment

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ABSTRACT
Resilience, the ability to bounce back or manage sufficiently despite ongoing adversity, has received considerable interest from several domains over the last two decades. A concept that is easily and widely applicable, it has evolved a variety of nuanced interpretations. Recent work in the systems theory and resilience engineering domains has moved towards some sharper definitions. This paper discusses and develops these definitions, and by contrasting with robustness, applies them as an approach for HCI evaluation. Observational data from a hospital training environment is used to examine how patients learn to operate home haemodialysis devices, and how patients’ safety is managed and maintained. This paper concludes that to improve recovery of adverse situations within the home, there is a necessity for design to support the acquisition of resilient reaction as a skill, in hand with temporal management. These ideas are developed in conjunction with the consideration of how technology can support, or nudge, the expression of resilient behaviours.

Author Keywords
Resilience; Human Error; Medical Devices; Haemodialysis

ACM Classification Keywords
H.5.3 Group and Organization Interfaces - Computer-supported cooperative work, Evaluation/methodology, Synchronous interaction, Theory and models

INTRODUCTION
Over the past two decades the concept of resilience has received attention in various domains such as psychology, ecology, systems theory, and safety engineering. In particular, the recent arrival of resilience engineering [4] has stimulated a new research impetus, with many published papers investigating resilience characteristics of a variety of complex systems. As a concept resilience is one that has suffered loose definition, with re-contextualisation across domains leading to various nuanced interpretations. Resilience and resilience engineering appear exciting as theoretical instruments of systems analysis, but what does it mean to apply these instruments to HCI (human computer interaction) at levels of fine granularity? The title of this paper is a play on the Latin phrase ‘Deus Ex Machina’ or ‘God from the Machine’. This phrase refers to a scaffolding device used behind the scenes in ancient Greek theatre, which lowered an actor playing a God onto the stage who saved the day. Often used by playwrights of the age to resolve a badly written plotline where the hero faced certain death, the phrase was employed disparagingly by critics. Considering HCI and the design of sociotechnical systems, what should a resiliently engineered design aspire to; does such a design expect that there be some ingenious intervention saving the user and system from certain failure? If not, who engineers resilience within a socio-technical system, is it the system designer, user, or other actors? How can resilience expressed from the ‘machine’?

This paper evaluates observational data obtained from a case study of a home haemodialysis (HHD) medical training environment. Resilient activities are identified and explored as to how they can yield insights into system safety and performance. A specific focus examines the strategies and behaviours of the actors inside the system in making the system safe, and also in how they cope with the transfer of responsibility of HHD device operation. Resilience engineering encompasses a variety of potentially applicable concepts, which are initially contextually reviewed. Topical discussion in resilience engineering theory argues for the definition of resilience as largely the ability to manage functional trade-offs in order to combat adverse events [6][5]. The concept of robustness is introduced and contrasted with this in order to sharpen the conceptual distinction. Design considerations are drawn and the locus of resilience reflected upon.

Resilience and Robustness
De Haan et al. [3] demonstrate that resilience is a concept that is highly correlated with short timescale system recovery after shocks or disturbances. A resilience engineering (RE) perspective aims to determine the factors behind successful system operation and thus improve recovery performance. Resilience can be considered something that a system does, not what a system has [4]. In contrast, conventional safety perspectives focus on the root cause of system failure, the fixing of which progressively improves system robustness.
RE consists of a broad range of concepts, of which resilience is one, that examine how to avoid and anticipate complications, minimising the need for recovery. Hollnagel et al. [4] offers four principles (anticipation, monitoring, learning, response) considered instrumental in this endeavour. Regrettably, as a consequence of the wide-ranging and nuanced use of the resilience concept, it was observed that almost every action can be considered ‘resilient’ [2]. To clarify, Wears [6] makes the distinction between 1st and 2nd order resilience, where 1st order resilience that ‘many would not consider resilience at all’ is described as simple corrective measures concerned with stability. 2nd order resilience is considered by Wears to include responding to unforeseen situations, and also monitoring and anticipating for related threats or advantageous opportunities. Morel et al. [5] also explores resilience as decision making, describing resilient behaviours as a trade-off between risk and reward founded upon the level of experience of actors within the system.

Developing this distinction in this paper this 1st order resilience is considered to be equivalent to the established concept of robustness or ‘adaptive robustness’ [3]. This concept is associated with continuity of system operation, but is not linked with any additional anticipatory or trade-off activities managed by actors outwith system design. In this sense monitoring and anticipation are applicable to both robust and resilient interpretations. A process of monitoring tackles expected (robust) and unexpected (resilient) system events in the present. Anticipation through requisite imagination [1] supports robust design and underpins the capacity for resilient recovery.

**Home Haemodialysis Training**

Recent advances in technology have led to a renewed effort to encourage capable renal patients to switch from hospital treatment to self-care at home. Hospital treatment for end stage renal disease (ESRD) typically involves patients attending 3 dialysis sessions per week, each of 5-6 hours duration. HHD benefits patients in that life and care quality improves, while also incurring reduced cost to healthcare providers. Patients who are offered HHD training must be able to demonstrate a range of competencies on completion. Operation of the medical device (Figure 1a), along with the various procedures and artefacts surrounding use (Figure 1b/c), is challenging, with the most capable and dexterous (Figure 1d) patients selected for the program. Due to a projected future increase in number and age of dialysis patients, it is important to discover ways for reducing the learning burden regarding the safe use of such devices. Furthermore, limited research has examined how the design of these machines can support a learning process that assists with transfer of the experience of safe use and recovery.

The activity of dialysing can be thought of as being analogous to an aeroplane flight. There are many safety procedures, preparations, and actions at the beginning and end. Equally, in the middle there are long periods (4-5 hours) of quiet treatment time where the blood is cleansed. This time is punctuated intermittently by monitoring activities, or the occasional device alarm. The systematic structure of haemodialysis treatment consists of independent patient and device procedural setup tasks, with the human-machine interface being the ‘fistula’; a surgically constructed access chamber located within the patients’ arm, where inserted needles allow blood exchange to take place.

Considering the home dialysis context, the home device environment is unique and offers potential for unusual occurrence. Dialysis patients are highly resistant to equipment change, as they have worked hard to obtain consistent and safe device practices through iterative cycles of appropriation and customisation. The focus of this paper is on examining the process of safety enskilment in such an environment. In this endeavour it is considered that:

**Robustness** concerns itself with the continuity of a system function, including adaptations in order to maintain that function.

**Resilience** describes the management of trade-offs in which a variation in system function takes place for the purpose of recovery from an event.

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**Figure 1:** a) Home haemodialysis machine. b) Device artefacts. c) Patient artefacts. d) Handling lines & syringes.
METHOD
The context for this observational study was a specialist training suite situated within a dialysis unit in a London hospital. The suite contained two home dialysis units placed side by side, with the training nurse seated opposite.

Observational data was collected by the author who attended every session of a four-week training course conducted for two patients. Patients attended the course 3 times a week for approximately 5 hours per session. Patients’ start times were staggered by 1 hour in order to assist the training nurse in supporting device setup and completion tasks with each patient individually. Consequently, 2 discrete task sets were observed per session by the author, along with any alarms and difficulties encountered during dialysis. Notes on dialogue, artefact photographs, and training materials were also gathered. The patients were selected as an opportunity sample based upon those attending the hospital course over the duration of the study. Both male patients were of similar age (65) and had been undergoing dialysis for approximately 18 months. Patient 1 worked together as a team with his wife who provided assistance. Patient 2 has no family support and so learnt independently.

A thematic analysis of the data was conducted, and the sensitising concept of resilience-robustness applied. Prominent themes were initially drawn out from the data, before cyclically returning and identifying themes of robustness, resilience, monitoring, and anticipation. In addition to the observational data, the author also drew upon an auto-ethnographic component derived from his active participation with the patients in operating the machine, learning procedure, and identifying events. Field notes were reviewed daily, reflecting on taught procedure and the operation of artefacts and actions not understood. This data was instrumental in understanding particular incidents through reflection, and in probing depth of patient knowledge as opposed to procedurally robust learning from training materials. Semi-structured exit interviews were conducted with the training nurse, patients and spouse.

RESULTS
Analyses reveal a variety of robust and resilient activities. Supplementary HHD themes identified correspond well with prior studies [7]. A clear distinction can be drawn between the activities in that the patients specifically focused on procedural robustness, whereas the trainer would additionally attempt to impart resilient practices. However, the extra ‘work’ of resilience activities were interpreted as optional in comparison with ‘essential’ procedures. Robustness strategies observed were:

Customisation for Robustness: Patient 2 often overlooked the final step after initiating treatment, which is to inject anti-coagulant into the tubing. He created a storage position out of the tubing for the anticoagulant container tube in order to keep it in his line of sight (Figure 2a).

Adaptive Robustness: Patient 1 suffered a kink in the tubing carrying his blood to the dialyser. A consequence of this was that the device alarmed and stopped dialysing multiple times. In an attempt to prevent the line from kinking again, a fix was improvised where gauze was placed under the tubing for reinforcement (Figure 2b).

Shared Responsibility: While both patients preferred to work from memory, Patient 1’s wife made copious notes as she was ‘scared that the children would blame me if anything happened’. She quizzed patient 1 about procedures in order to strengthen memory and distribute responsibility.

Resilient practice is dependent upon acquired experience [5]. The trainer would encourage patients to attempt challenging steps within a safe environment:

Learning and Experience: In isolation Patient 2 decided to go ahead and connect himself to the machine as encouraged by the trainer (who was absent but nearby). He neglected to close one clamp on the tubing, which led to blood flowing freely out of his arm. A small amount of blood was lost but for him this was quite a shocking sight. However, it was also a valuable learning experience. He called it ‘learning the hard way’. This experience reassured the patient that adverse events are recoverable (Figure 2c).
Monitoring and anticipation processes were again split between ‘essential’ robustness and ‘optional’ resilience activities. Both patients were content to passively let the limited alarm functionality of the device inform them of any adverse events, instead of actively monitoring for potential troubles ahead. Patients separated resilience from robustness very early. ‘I just want to get the basics’ was a common response from Patient 1. Considering that if the device has been made ‘safe’ by increased procedural robustness, then this places strain upon the patients. This was particularly observed in Patient 1’s wife. At some point the level of strain requires redesign. Resilience enters the system through two main avenues; Patient knowledge and experience, and active monitoring and anticipation. The former is particularly emphasised within the training environment. The trainer purposely sits with her back to patients in order to allow them to make mistakes. Frequent exposure to failure allows one to develop confidence and strategies for coping with failure. Frequent exposure to small failures is therefore a good way for patients to develop resilient practice. In addition, patients also gained knowledge regarding rare circumstance. In the example with the kink in the tubing they responded robustly; after review with the trainer they would perhaps next act resiliently. The robust response to discard the tubing and restart is extremely time consuming. Alternately they could resiliently manage the situation by assessing and reconciling dialysis time remaining, the severity of the kink (with its potential for red blood cell damage through haemolysis), and the speed of the pump. Haemodialysis is also a particularly embodied practice. Resilient trade-off often requires awareness of the body’s physical limits in combination with decisions made on the machine. Patient 2 always dialysed for some ‘extra’ time. On occasion this made his hands cramp and so he required assistance to remove the inserted dialysis lines upon completion. This experience develops awareness of physical limits supporting potential future decisions.

RESILIENCE EX MACHINA

So how can we design to foster resilient practice from the machine? We can support the transfer of experiential practice, active monitoring, and diminish robustness strain:

System Education Points. There is potential for the designer to be aware of device error reporting as system education points, where device interruption occurs and discussion is likely to take place. An example of this was the observed use of the alarm points for imparting system knowledge by the trainer. The trainer would observe and let the patients make mistakes that were then captured by the device. Tracing back through cascading alarms developed deeper knowledge of machine operation.

Resilient Monitoring: There are opportunities for the development of device functionality to support (or nudge) the integration of resilience effort into those of essential procedures. Attention drawing interface designs can bolster scanning behaviours during device operation. The study device defaulted to displaying ‘Dialysis Time Remaining’.

Temporal Awareness: When responding resiliently, management of trade-offs occur with respect to time. Systems that support superior time tracking in order to assist timely decision-making are advantageous. When the device in the study undergoes power failure, there is a 30-minute battery reserve. Device power source and battery reserve time remaining are not displayed on the device.

CONCLUSION

HCI has long been concerned with the recovery from device error, but resilient error recovery in haemodialysis is itself a skill forged through experience. This ability is particularly important within unpredictable home environments. Design can assist with the transfer and development of resilient practice, while also reducing cognitive demand. Resilience can be expressed ‘from the machine’ through assisting trade-off recovery from adverse events in hand with augmentation of temporal awareness.

ACKNOWLEDGMENTS

Thanks to Ann Blandford, NHS staff and patients. Study conducted under NHS ethics (11/LO/0329) and supported by EPSRC CHI+MED grant (EP/G059063/1).

REFERENCES


