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Diagrammatic exploration as a bridge between observation and intervention in design and healthcare research

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Abstract

This paper describes the use of diagrammatic exploration to facilitate the transition from observational to interventional stages of a PhD study, and its potential to support collaborative work between design researchers and healthcare staff. The translation of ethnographic notes into diagrams of people, place, process and relationships enhanced the researcher's understanding of the healthcare context, made their assumptions explicit and highlighted the emergent research questions. The discussion and development of these diagrams with healthcare staff enabled a co-critique of the current rehabilitation model and gave staff experience in participatory methods in anticipation of future design interventions. The origination, presentation and co-development of these diagrams is discussed, with examples given.

Keywords: Participatory methods, rehabilitation, patient ownership, co-development, sense-making

Introduction

For many early career design researchers (ECDRs), the evolution of practice from a traditional design education (exploring solutions) to a research practice for the purposes of a PhD enquiry (exploring questions) is difficult. Design researchers working in healthcare environments will often begin with an ethnographic study of their focus area, borrowing and adapting methods from the social sciences to immerse themselves in this new study culture. With so much to learn, it can be difficult for students to move beyond this observational role on to a design intervention phase. This paper discusses the creation and shared development of diagrams to explore and make sense of data gathered in an ethnographic study of a spinal injury unit (SIU). This exploration was effective in creating a mutual understanding between the ECDR, her supervisory team and the SIU staff, whilst also bridging the perceived gap between 'observing' and 'intervening.'

Research Context

A spinal cord injury (SCI) results in partial or complete loss of function and/or sensation below the level of injury; impacting on a person's mobility, ability to perform activities of daily living independently, skin care and bowel, bladder and sexual function (Grundy and Swain, 2002). In 2013/14, the average length of stay in the host SIU for patients experiencing partial/total paralysis ranged from 4 to 5 months, depending on the level of injury (Queen Elizabeth National Spinal Injuries Unit for Scotland, 2014). During this time, patients progress along the rehabilitation pathway, learning techniques to manage their mobility needs and the bodily functions affected by their injury. A network of staff from medical, nursing, therapy, psychological and social departments within the SIU provide input during this journey. The diversity of the spinal cord-injured population, the varying effects of a SCI and the spectrum of success within treatment and rehabilitation all contribute to the individuality of each person's experience of living with and managing their spinal cord injury.

A previous pilot study which investigated the role of design in SCI rehabilitation was reviewed by Micheal Bierut, who stated that a 'strong case' was made for 'the relationship between design-thinking and having a sense of agency in one's environment and one's life,' (Campbell, 2011, p25). The doctoral study which provides the context for this paper draws on this relationship, and aims to help people with a SCI prepare for the 'problematic' post-discharge period (Macdonald, 2013) by testing if providing SIU inpatients with more opportunities to exercise agency over their own rehabilitation pathway, supported by design approaches, improves their outcomes. Identifying the appropriate site and type of intervention for this began with an immersive ethnographic study in the SIU, conducted by the ECDR over a 12-month period.

Contextual review of the host spinal injury unit

After conducting 12 informal, semi-structured interviews with senior staff across the host SIU, a total of 42 events across 17 different SIU activities were then observed during the contextual review, plus many ad-hoc meetings and discussions. This involved staff, volunteers, patients and their families both separately and together. Handwritten notes were transcribed and anonymised, generating 62 rich data sets. As the specific focus of the study was not yet identified, the data was highly descriptive in nature, considering the needs and experiences of staff, patients and family members. This was compiled into a report, using a hypothetical patient's journey through the unit to structure the data (i.e. describing the events that most patients experience in sequence, highlighting the different options available to the patient population according to their injury level). This was found to be useful in terms of gathering the data together into a single document, but less successful in enhancing the ECDR's understanding of the SIU context at a more abstract level, and the opportunities within that for designing appropriate interventions. The design-based supervisor suggested that creating visual representations of the situations described in detailed text form in the report could help to make better sense of the data, in a format that could be shared and discussed more effectively. The creation and use of these diagrams is described below.

Stage One: Sense-making through diagram creation for the PhD study

The ECDR began the process of diagram creation by re-reading through the contextual study report. This helped the ECDR to gain further familiarity with the data, reassurance that all of her experiences in the SIU were represented and to begin thinking about how better collective sense could be made of the data from these individual observational events. Whilst reading through the report a second time, the ECDR drew as many original diagrams as were required to cover the many different events observed and recorded in the written document – 79 in total. These sketch diagrams showed a combination of environment, process, tools and the role of and relationships between the people involved either in a particular situation or SCI rehabilitation as a whole.

At this point, the ECDR no longer needed to refer to the academic report, and could begin to condense the original collection of sketch diagrams. Each diagram was revisited and assessed by the ECDR for meaning and clarity. Of the original 79 diagrams, 10 were discarded (after being deemed incomplete or to contain information that was better represented elsewhere) and the remaining 69 diagrams were assigned an identifying number (1-69). Each numbered diagram was then revisited to consider the main themes that were represented within it. These themes were compiled into a list with their corresponding diagram numbers, by reviewing each diagram in turn and either adding its number to an existing theme or creating a new one. In this way, the collection of 69 diagrams were sorted into 14 groups within 7 main themes, including; environment; projection; context; working relationships; goal planning; agency; and models of practice. So, for example, one item on the list could read as '*Theme: Working Relationships. Sub-group: Transfer of Ownership. Related diagrams: 5, 9, 36, 41.*' The ECDR could then bring together

all of the sketch diagrams relating to a particular group and draw 1-2 summary diagrams; creating the final set of 36 diagrams to represent the findings of the observational study. Each diagram was scanned into a PDF document with a short, explanatory paragraph and sent to both of the ECDR's supervisors for review and comment.

This first stage of diagram development was crucial for developing understanding and communication within the supervisory team. Clearly, it is important to describe the healthcare context in both macro and micro levels to the design-based supervisor, so that he can support the ECDR appropriately. In this project, the supervisor based in healthcare also found the diagrams demonstrated a sound understanding of what happens within the SIU quickly, clearly and concisely. Knowing that the ECDR has achieved this understanding allows both supervisors to discuss opportunities for the interventional stage with the student confidently. As such, we can describe this first stage of diagrammatic exploration of an observational study as a sense-making activity for the nature of the PhD itself, for the ECDR individually and with her supervisory team.

Stage Two: Sense-making through diagram co-development within the SIU

Due to the participatory approach adopted in this study, any proposed intervention would require input from healthcare staff through a co-design process (Sanders and Stappers, 2008). As such, eight senior staff members from across the host SIU were individually invited to discuss and co-develop these diagrams further. Whereas Stage One aimed to make sense of the data with the supervisory team for the purposes of the PhD study, Stage Two focussed on making sense of what is happening in the SIU, with staff and volunteers.

Prior to the interviews with SIU staff, the majority of the hand-drawn diagrams were digitally reconstructed using InDesign© and Photoshop©. However, some of the original diagrams (relating to agency theory) were omitted from this new set, as the aim of these interviews was to discuss the observational data only. One set of diagrams was printed for each interview, and shared between the ECDR and staff member during the discussion. At the start of each interview, the ECDR explained that this was a feedback and developmental session, and encouraged the staff to interrupt the explanation of each diagram to concur, dispute or expand upon it. Although blank paper and pens were available to alter the diagrams or to draw new ones, each staff member preferred the ECDR to do the drawing – perhaps highlighting a methodological gap to empower or give confidence to the staff to do this themselves, thus possibly reducing any researcher bias.

Whilst some diagrams were simply explained by the researcher and confirmed by the staff member, others were able to highlight the assumptions of the researcher while yet others elicited discussions or anecdotal evidence that may not otherwise have been triggered. All of the diagrams, however, contributed to developing a mutual understanding between the ECDR and the SIU community, not only of past observations but also of potential directions for future work. This is best exemplified in fig. 1, below, which depicts the diagram created to represent the Goal Planning

Meeting (GPM); where a patient, their care team and usually one or two people important to the patient (e.g. spouse, parent) meet regularly to review progress and set rehabilitation goals for the few weeks following the GPM.

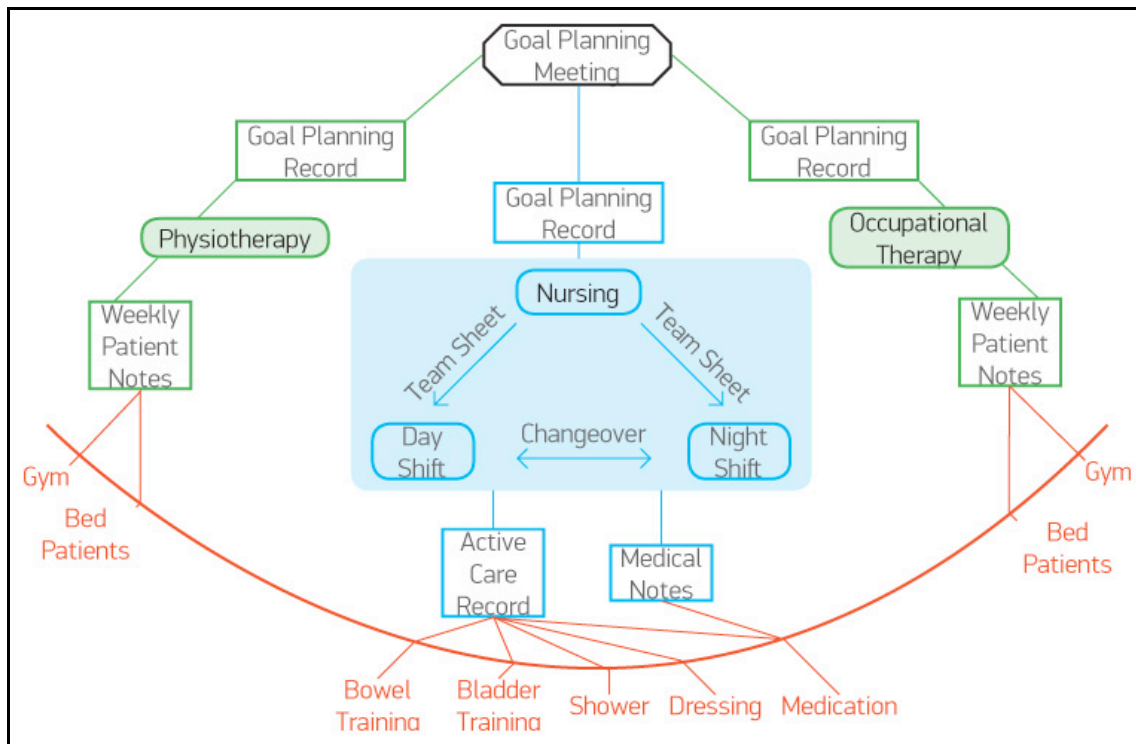


Figure 1: A diagram of the people and tools used within a Goal Planning Meeting. Individual patient activity (here shown in red) is recorded by SIU staff in departmental notes. Each care team member then summarises a patient's progress in their goal planning record before each meeting, and uses this record to report back to the rest of the care team and to inform any decisions made about the patient's rehabilitation.

The GPM is a key part of rehabilitation for the majority of patients, and an opportunity to take more ownership over the management of their injury by being included in decisions made about their care. However, by mapping out how all of the individuals involved contribute to the GPM, there is arguably a distance between the patient activity (shown in red) and the meeting itself; raising the question of whether the meeting structure supports patient participation. The diagram located this issue in the process rather than in the people involved, as the records of progress (in their current format) require staff mediation and possibly restrict opportunities for patients to take charge of the meeting. The ECDR and staff were able to tentatively explore an opportunity for change through a discussion anchored in a known context. Indeed, constructive discussion of this diagram suggested an opportunity to introduce designed materials to reduce this 'distance', support different types of interaction and encourage collaborative decision-making; confirming the GPM as a potential site for intervention.

Conclusion

This paper has shown how the creation and co-development of diagrams has supported an ECDR's transition from observational to interventional stages in the PhD journey. The initial creation and gradual consolidation of the diagrams to explore what was observed encouraged question-centric modes of thinking, actively reflecting on the SIU context without prematurely inferring a problem and a potential solution. As diagrams are able to show the relationships between people, tools and processes simultaneously, they are particularly suited to complex research contexts such as healthcare and were able to communicate a sound understanding of the SIU to both supervisors quickly, clearly and concisely.

Inviting staff to comment and alter the researcher's diagrams during these developmental stages also inferred a sense of trust and shared ownership of the project, in anticipation of future participatory interventions. This process also maintained a sense of transparency in the methods used and allowed the researcher to give feedback to the SIU community sooner, in accordance with the adopted philosophy of participatory design (Simonsen and Robertson, 2013). By extending this method of 'sensemaking', the researcher was able to reach a 'consensual understanding' (Jones, 2013, p26) with the host SIU staff. Presenting the design researcher's observations to healthcare staff as a visual, tangible material to work with navigated potentially problematic differences in language and work culture, supporting rich discussions and utilising the invaluable experience of the SIU community.

Whilst design communities might recognise the diagrams as 'boundary objects,' acting as 'diagnostic, reflexive and dialogic mechanisms linking key people within organisations,' (Wiig *et al*, 2014, p142), healthcare professionals from fields of psychology may see interesting resonances in methods of 'formulation' and its ability to provide an 'overall picture or map... of something that is not possible to see all at once' (Butler, cited by Johnstone and Dallos, 2014, p8). Both fields are arguably concerned with utilising the knowledge and experiences of people from a range of disciplines and backgrounds, with discussion through and around a shared, physical material. In this context, the ECDR and SIU staff used this shared material to verify the findings to date, discuss abstract ideas equally, recognise the hard work and successes of the SIU, elicit the various (and sometimes conflicting) priorities of the many people involved in SCI rehabilitation and identify potential opportunities for co-designing interventions. The anticipated involvement of SIU patients in later stages of this study will extend and test this participatory approach further, where these diagrams may form the basis of the first iteration of 'prototypes' and used as 'learning tools' to 'explore, evolve and/or communicate ideas,' (Coughlan *et al*, 2007, p3).



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