

EXPERIENCE EXCHANGE

A single-case study of carer agency

Ian Kinchin *¹, Iain Wilkinson ²

¹University of Surrey, Guildford, United Kingdom

²Surrey and Sussex Healthcare Trust, United Kingdom

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ABSTRACT

This paper highlights the role of single case methods in focussing on the learning needs of a marginalised group—family caregivers. It analyses the role of carer agency to help healthcare professionals view key incidents as inclusive learning opportunities for professionals, patients and carers. Through circumstance, one of the authors found himself to be in the position of primary carer for his elderly father whilst simultaneously engaged professionally in dialogue about clinical pedagogy. The paper presents a post hoc research design, using participant observational data of a single-case study, triangulated with reference to professional practice and current research literature. The primary data source for this paper is a carer’s autoethnographic narrative that was constructed during, and then reflecting back on a period of extended participant observation. The importance of carer agency in sustaining patient care is discussed as a factor in shared decision-making, facilitating a deliberative model of physician-patient relationships. The paper showcases the high degree of resonance with the research literature that can be generated from a single case study whose teaching value goes beyond its clinical generalizeability.

Key Words: Carer agency, Autoethnography, Expert patient, Carer education

1. INTRODUCTION

“Our textbooks had almost nothing on aging or frailty or dying. How the process unfolds, how people experience the end of their lives, and how it affects those around them seemed beside the point. The way we saw it, and the way our professors saw it, the purpose of medical schooling was to teach how to save lives, not how to tend to their demise. . . Yet within a few years, when I came to experience surgical training and practice, I encountered patients forced to confront the realities of decline and mortality, and it did not take long to realize how unready I was to help them.” Gawande^[1]

increasingly accompanying him to various clinical appointments. As the time passed, I found that Dad appeared to be keeping lots of information in his memory about who he was seeing and why, what they said and what the outcome was. However, I needed to make notes to ensure I was not forgetting details and was able to maintain a complete picture of my father’s conditions so that if I was asked I would know what was going on. I realised the importance of this recorded information on the occasion that Dad was admitted as an emergency after he had fallen and hit his head: an incident where I had to provide information to the emergency department team. This collection of notes, dates and anecdotes started to evolve into something more analytical and reflective, including not only the procedural details that I needed for information, but also notes to myself about what I was observing and feeling at the time. This was sometimes,

During the final two years of my father’s life, I found myself

*Correspondence: Ian Kinchin; Email: i.kinchin@surrey.ac.uk; Address: University of Surrey, Guildford, United Kingdom.

“worry”, and sometimes “anger” and “frustration” as my father’s health deteriorated and I found myself feeling that I was simultaneously becoming less useful and more important – a tension that contributed to my emotional response to the situation. I realised after some time, that I was creating an autoethnographic account of my journey with Dad in the final years of his life. This reflective process continued for some time after my father’s passing and contributed to my own grieving process. This paper represents an analysis of that journey. It is not written with the intention to expose incidents of either excellent or poor care that my father received, but to highlight an alternative structural perspective on patient care that might help to improve professional behaviour to make it centred more on the learning needs of both patient and carer. This is not the first autoethnography written by a son about the death of his father,^[2,3] but it is unique in being written by a son who has also formally studied clinical pedagogy. This autoethnography therefore offers a unique educational perspective on the learning potential of a difficult situation where other methods of data collection would not have been feasible.

2. AUTOETHNOGRAPHY

In contrast to the typical clinical educational research that values large sample sizes to gain statistical significance and generalizability, the value of autoethnography is starting to be recognised as a way of developing deep personal insight to particular perspectives that cannot be gained by traditional means. These studies focus on the culture in which an individual is situated and reveal stories that would otherwise go unheard.^[4,5] Autoethnography seeks to make relevant those aspects of being that are typically suppressed by analytic strategies which “draw a veil of silence” around emotions and human factors that would otherwise be bracketed out of the research process.^[6] As a research framework for health education practitioners, Acosta *et al.*^[7] have drawn from analytic^[8] and collaborative^[9] autoethnography in order to maximise rigor and trustworthiness of studies. The work presented here fits with this framework. It exhibits the three characteristics of analytical autoethnography listed by Anderson^[8] to maximise methodological transparency. That the autoethnographer is:

- (1) A full member of the research setting.
- (2) A co-author of the published text.
- (3) Committed to an analytical research agenda.

Additionally, collaborative autoethnography^[9] supports a dialogic, interactive process in which a researcher discusses and interrogates findings as a form of triangulation. In this paper, the comments raised within the autoethnography (written by

one author with the identities of a “son” and “educational researcher”) is triangulated with a secondary analysis by the other author (whose professional identities are as a “consultant geriatrician” and a “researcher of clinical practice”). Acosta *et al.*^[7] define their framework for collaborative and analytic autoethnography (CAAE) as:

“A form of scientific enquiry where practitioner-researchers investigate the contextualised self and other via personalised narratives, self-reflection, and dialogic discussions; and connect their new knowledge to socio-economic, cultural, and political determinants of individual and group beliefs, values, attitudes and behaviours.”

Whilst autoethnography does not meet the positivist expectation of generalizability, from a postmodern perspective, it is considered to be as valid as more traditional ethnographic approaches.^[10] Ellis^[11] has argued that an autoethnography’s generalizability is tested by the readers as they “determine whether or not a story speaks to them about their experience or about the lives of others they know”. Larsson^[12] describes how degrees of generalization from qualitative case studies can be achieved through acknowledgement of “context similarity” and “pattern recognition”, both of which are relevant to clinical scenarios. This resonates with comments offered by Giacomini and Cook^[13] about the interpretation of qualitative research in clinical education where “Clinical readers in particular need to judge the relevance of qualitative research reports to their own practice, interests, or patient care questions”.

Excerpts from the autoethnographic narrative are used here as prompts and illustrations of incidents that are then critiqued and analysed with reference to the appropriate research literature so that in the narrative the “focus shifts from participants and events in the observed world to an abstracted issue in an academic world” where the “writer assigns relevance to events beyond the field in which it took place to make them relevant in a given field of academic knowledge production” as described by Hood.^[14]

3. THE SINGLE-CASE STUDY

The single case study is a well-established method with precedents across the clinical literature.^[15–17] Its strength is to offer the intensive study of one individual. The richness of the data produced can be a valuable tool for the “bottom up” generation of research questions and identifying previously unnoticed phenomena of potential importance, which can otherwise be lost within inter-individual variance in order to develop theory inductively^[18] (see Figure 1). Kazdin^[19] pro-

vides a methodological overview of the ongoing relevance of the single case study in the clinical sciences. Flyvbjerg^[20] comments even more forcefully that: “a scientific discipline without a large number of thoroughly executed case studies is a discipline without systematic production of exemplars, and a discipline without exemplars is an ineffective one.” The single case study can also provide a powerful learning and teaching tool whose significance for learning is far greater than its lack of clinical generalizability might suggest, as it can elicit personal and emotional responses among learners

who relate to the character in the study, triggering reflections on professional practice.^[21–23] As commented by Franklin, *et al.*:^[24]

“In much clinical work the crucial question is ‘does the treatment work for this patient’, not ‘does the treatment work for the average patient?’. Only single-case designs allow rigorous objective assessment of treatment for the individual.”

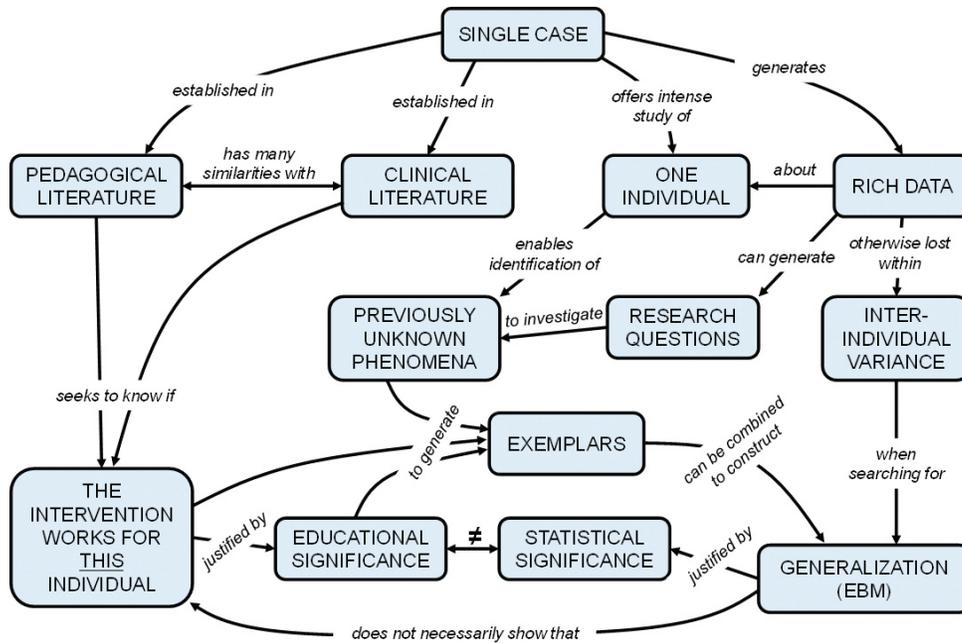


Figure 1. An overview of the single-case study approach

In this particular case, the “carer/autoethnographer” also had an alternative professional identity as an academic in higher education who had previously written on the subject of clinical pedagogy.^[25,26] This autoethnography was interrogated (and hence triangulated) by the second author who has a professional role as a consultant orthogeriatrician who has also recently completed an MA in Higher Education.^[27] In consequence, the two authors are able to draw on additional voices from personal practice and from the research literature to contextualize and add critique to the autoethnographic case study. The additional professional perspective of the autoethnographer is helpful to the research process, as observed by Dirndorfer Anderson and Fourie^[28] it “enables us to experience things that healthcare professionals would not necessarily be sensitive to.” As noted within the autoethnographic narrative that provides the data for this paper:

“... from my time spent as a visitor I was able to reflect on the experiences on the ward

and viewed incidents from a particular clinical education standpoint. Rather than being distractions from the smooth operation of well-rehearsed chains of clinical practice^[26] I was observing a number of critical incidents as potential teaching moments – for the patient and for the carer. However, it appeared these were not recognized as such by the majority of hospital staff who engaged with Dad as they were not looking at them through the same lens.”

As a result of the multiple roles of the authors within this research process, the “voices” within the text necessarily have to oscillate between “participant”, “observer” and “analyst”. Where possible this is indicated to the reader, for example by the use of text formatting to distinguish between participant (indented text) and analyst (full-width text). However, we have to acknowledge the inevitable blurring of boundaries between these roles, particularly if we regard learning and

caring as intertwined.^[29] We have, therefore, left some interpretation of roles to the reader to avoid cluttering the text with directorial distractions that would detract from the story being told and disrupt the flow within the text for the reader.

The observations that inform this paper were largely undertaken whilst the patient was receiving treatment in a National Health Service hospital, where he had been referred by his General Practitioner. During a number of stays over a three year period, he was either in a specialist ward for stroke rehabilitation, cardiology or gerontology, and was frequently moved between these during stays. At each visit he was under the care of a different consultant and varying groups of nurses that rotated every few days. Other specialists (social workers, dieticians, occupational therapists) were not involved in his care. Physiotherapists were involved in his care during later stays after an intervention by his next of kin. Observations cover the final weeks of his life when Dad decided to end treatment and return home, during which time he was visited by his General Practitioner and a community nurse.

4. ETHICAL CONSIDERATIONS

Whilst no other parties were directly involved in the writing of the autoethnographic narrative analysed in this paper, we acknowledge that autoethnography still has the potential to raise ethical concerns.^[30] Chang^[31] has commented that protecting the privacy of others, who may appear as “associates” or “background characters” within an autoethnography may be more difficult than in clinical studies that involve human subjects. This is because the identity of the autoethnographer cannot be bracketed out from the research.^[32] We have, therefore, made every effort to avoid comments that could lead to the identification of “others” within the narrative.

5. EXPERTISE AND LOCATION

Muncey^[33] argues that, “an autoethnographic account should attempt to subvert a dominant discourse”. From the carer’s perspective that informs this article, the dominant discourse within the hospital environment feels like it is about exclusion of carers from patient care dialogue. A purely biomedical perspective has been criticised by Bensing^[34] as an approach in which “the uniqueness of patients, their individual needs and preferences, and their emotional status are easily neglected”. The problem has been stated very clearly by Greenhalgh *et al.*:^[35]

“Even when patients are ‘informed’, ‘empowered’, and ‘health-literate’, (and especially when they are not), they rarely inhabit a world of controlled experiments, abstracted variables, objective measurement of pre-defined outcomes,

average results or generalised truths. Rather they live in the messy, idiosyncratic, and unpredictable world of a particular person in a particular family context.”

Gawande^[1] goes on to comment on how advances in clinical science have “turned the processes of aging and dying into medical experiences to be managed by health professionals”. This is a complex issue to address across the multi-disciplinary team who will be looking after a patient and who may bring different professional perspectives on patient-centeredness. In relation to physiotherapists, Mudge *et al.*,^[36] have commented that the profession is “characterised by a ‘body-as-machine’ (biomechanical) perspective”, and that person-centred practice poses a number of challenges for colleagues who “lack readiness and confidence to recognise shared expertise of patients”. Therefore, in such a complex context the role of the carer as advocate and confidant to help interpret and personalise the biomedical discourse and to help sustain the patient,^[22] seems to be largely compromised:

“On reflection, it became apparent that, as a carer in the system, ‘what’ you were was a function of ‘where’ you were. I had only thought of myself as a ‘son’, but was labelled as a ‘carer’ when accompanying my father to medical appointments over the years. However, once I go into the hospital to see Dad, my identity changed again. I am no longer seen as a ‘carer’ with an active interest or a role to play, but a ‘visitor’ who is only allowed to observe passively and not get in the way of the treatment.”

It was also evident in the hospital that although Dad had managed his own care and medication for the previous twelve years, his experience and expertise were not seen to be valid within the hospital environment. Indeed the imposition of the label ‘carer’ is something that might be avoided by the patient and the carer as it brings with it an acknowledgement that care is needed for someone who can no longer maintain independence^[37] – not a good prospect for someone whose chief aim is to get back home. This was clear when it came to managing his INR by adjusting his daily dosage of Warfarin:

“When asked about his typical daily dose he said ‘usually 7 or 7.5 mg’. To which came the reply, ‘Let’s start you on 4 mg today’. Despite further discussion in which I verified what Dad was saying, Dad was put on 4mg with the consequence that his INR reading went outside

the desired range for the next few days. It was stabilized a week later when the professionals found that 7.5 mg ‘seems to do the trick’.”

Dad was evidently angry that his knowledge of his own condition, even when corroborated by his “carer”, had been ignored and was concerned that generic actions taken in the hospital that didn’t fit his personal circumstances would ultimately slow down his recovery and his return home. In this case both patient and carer felt disempowered.

6. “TALKING ABOUT” OR “TALKING TO”

“Dad was of the generation where ‘doctor knows best’, and had always accepted medical advice without question. Doing so had served him well for most of his life. In the final 15 years of his life he had survived three major medical incidents on the way: an aortic valve replacement; an emergency removal of a necrotic gall bladder, and a stroke that hospitalized him for nearly three months. During all this, Dad stayed mentally alert. Whilst his mental faculties stayed sharp right up to his eventual passing, his body was slowly giving in. The heart valve was wearing out and this was leading to complications with his kidneys. Dad knew what the final scenario would be. Like many older people, Dad became less inhibited about what was on his mind, and eventually this included comments to clinicians that questioned their clinical decisions.

There were a number of occasions in hospital where Dad was annoyed by staff talking ‘about’ him within earshot rather than talking ‘with’ him or ‘to’ him. There were occasions where Dad said, ‘you could always ask me!’ to the staff. There were two occasions where he was more than ‘annoyed’. One where two members of staff came to change his mattress in the middle of the night and tried to do this without waking him up. This left him shaken and angry. And one where the team of overseas nurses opted to conduct their changeover meeting in another language. Dad just felt sidelined from his own care.

The situation was so different when he was in his own home at the end of his life. Here he was addressed with respect. Indeed, even the day he died, the district nurse who had been with him at the end continued to talk to him in the same respectful manner after he had passed

away.”

The ideas expressed within the narrative above link with the models of the physician-patient relationship discussed by Emanuel and Emanuel.^[38] Those authors considered the paternalistic model in which the physician is seen as the patient’s “guardian”, or as Dad put it, “doctor knows best”, a philosophy commonly encountered among older patients.^[39] This evolved into something more akin to the interpretive model and then towards the deliberative model in which the physician is viewed as a friend. Dad’s concept of the physician’s role changed from guardian to adviser/friend as his health deteriorated, with a shift in the power differential between the two. Whilst the evolution may have progressed slowly, there were critical incidents in which change was more rapid – moving home and deciding to end symptomatic treatment was one of those. Not only did the physician-patient relationship change, but so did the physician-carer relationship:

“Suddenly, the discussion is all about ‘being comfortable’ and ‘respecting the patient’ – not things that were centre stage whilst he was in hospital. It seems like now that the therapeutic angle is not in the way, the ‘care’ can somehow start to shine through. It’s as if taking the professionals out of their usual habitat allows them to see the patient and the carer clearly for the first time, without the view being obscured by procedures, protocols and paperwork. I felt this was also when the clinical staff first noticed me, even though I had been there all along.”

Gawande^[1] wrote, “The waning days of our lives are given over to treatments that addle our brains and sap our bodies for a sliver’s chance of benefit. They are spent in institutions – nursing homes and intensive care units – where regimented, anonymous routines cut us off from the things that matter to us in life.” Dad had never read the book by Gawande,^[1] but it was clear that his views resonated strongly with Gawande’s comments:

“Dad chose to stop treatment and wanted to stay at home. This was a difficult decision, but one that Dad made with a full understanding of the consequences. He knew he didn’t have long to live, but he didn’t want to spend his last days in a hospital ward, surrounded by strangers and having conversations about drug rounds or physiotherapy. He wanted to be able to have whatever he wanted for dinner and whenever he wanted, and he wanted to watch the rugby on

TV. He asserted his control over the doctors at this point. He spent the last few weeks of his life living by his rules. His final words to me were, 'I just want to go now'. Within a few minutes, he had gone."

As observed by Johnson and Case,^[39] "Doctors typically engage in narrow problem-solving relating to disease, patients often view a disease as but one component of a complex social system of which they are part". It is clear that among all the other pressures of working in a hospital, healthcare professionals cannot engage sufficiently with each patient in order to gain a full appreciation of their personal "wider social system". In other words they are constrained in providing truly holistic care to patients. That is when the intervention of the carer becomes central in contextualising the medical context into the patient's world, acting as a buffer to the clinical decisions that have to be made, whilst also being closer to the "invisible" processes of dying that may be obscured by the more obvious, "visible" aspects of the physical process.^[40]

7. SHARED DECISION-MAKING

Shared decision-making is increasingly advocated as the preferred model to engage patients in the process of deciding about diagnosis and treatment when more than one medically reasonable option is available.^[41] However, although evidence suggests that shared decision-making can improve patient outcomes, it is reported that uptake to date has been sparse.^[42] In the case described here, the logistics made the process of "sharing" with the carer almost unworkable, with the carer excluded from the clinician-patient dialogue (and hence the decision-making process) even though the patient wanted to talk through scenarios with the carer to help clarify the choices to be made. Such family discussions are important as the clinical scenario is only part of the family discussion. As Gawande^[1] notes, "People with serious illness have priorities besides simply prolonging their lives. Surveys find that their top concerns include avoiding suffering, strengthening relationships with family and friends, being mentally aware, not being a burden on others and achieving a sense that their life is complete." This exclusion from the dialogue was evident as a source of frustration in the carer's autoethnography:

"At 'changeover time' (usually right in the middle of visiting time) we were all scooted out into the corridor for reasons that we could never really understand – 'patient confidentiality' was the reason most often used. This placed us [the cohort of visitors] all in the position where we

had nothing to do except swap stories and compare our family members' ailments. So any notion of confidentiality was only in the heads of the nurses. We were busy swapping notes in the hope that any fragments of information that we may glean might contribute to the pictures we were each trying to construct of what was going on with our loved ones. Comments such as, 'oh yes, we had that too. You need to ask xxx about xxx and then you might get somewhere', were commonplace. Once changeover was completed, we all then returned to our respective relatives to try to find out from them another piece of the puzzle. It all seemed quite bizarre."

The optimal clinician-patient-carer discussion triangle (see Figure 2(1)) simply could not take place synchronously as doctors' rounds and visiting hours were timed to ensure separation. This put the onus on the patient to relay the clinician's view to the carers at a later time, and then to return to the conversation with the clinician (see Figure 2(2)). During the intervening pauses, other staff (including nurses and physiotherapists) would be implementing aspects of the old and/or the newly agreed regime (depending on the variable time delays in communication with various departments, some of which did not operate seven days a week) before final confirmation of a plan of action with the doctor. In addition, the connection between the clinician and the patient may be mediated (by junior doctors or nurses) so that the full picture is not necessarily passed on.

The model recorded within the autoethnographic narrative (see Figure 2(3)) shows how much the carers wanted to have access to information about their loved ones – information that is often lacking, particularly once the patient was at home.^[43] This desire for information led many carers to "unofficial" sources, to the extent that they were trying to extrapolate from the experiences of others around them. Whilst this was helpful in clarifying procedural issues to those who were new to the routines, there were inherent dangers as their interpretations and extrapolations may not have been clinically correct. Carers' feelings about the protocols observed chimed with the comments by Dirndorfer Anderson and Fourie^[28] who describe: "Seemingly illogical information practices, and the emotions and feelings accompanying the desire to know more about how to care for a loved one". The emotions generated are often not positive in this situation whilst the model is additionally problematic as, through a process of "Chinese whispers", it may lead to the construction of false stories that are not only inaccurate, but may be clinically unhelpful and misleading. However, it would

appear that this model is not unique to the case described in this paper:

“However, this process did confirm to me that my experiences as a carer were not unique. Indeed, they were also not unique to this particular hospital as some of the patients had been transferred from other hospitals where carers volunteered to me that they had encountered the same regime in place. It felt like the professionals and the carers were being positioned on opposing teams, with those having the knowledge also having the power.”

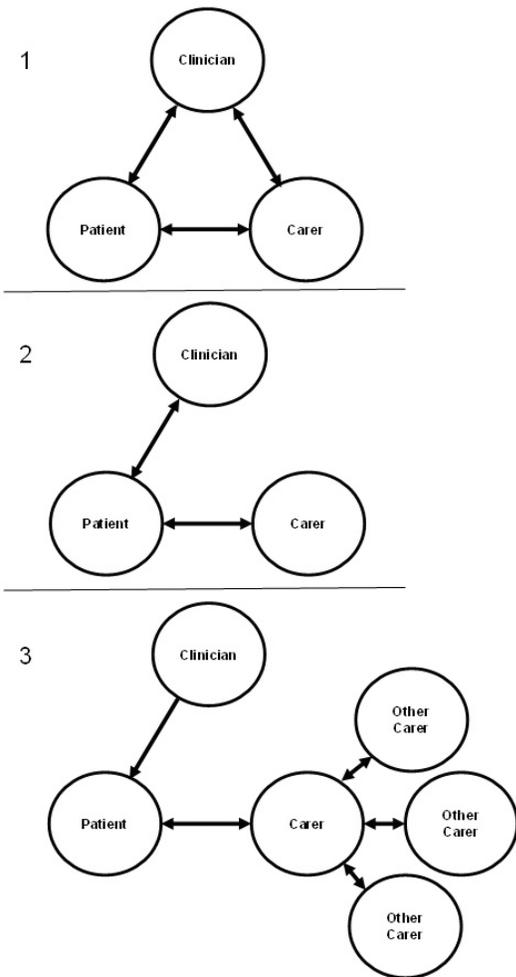


Figure 2. Relationship between clinician, patient and carer in decision-making. 1 represents an idealized triangle of synchronous discussion between the doctor the patient and the carer; 2 represents a more practical situation in which the carer and the doctor do not meet physically, but each have separate discussions with the patient; 3 represents the situation observed in practice where the patient receives information from the doctor and shares this in discussion with the carer who then compares notes with carers of other patients in the ward.

8. EXPERTISE OR AGENCY?

“Dad didn’t want to be considered an ‘expert’ on his own medical condition, but he did want to have sufficient understanding to be able to make informed decisions about his care and to take control of his life. I just wanted to help him.”

Whilst the concept of the “expert patient” has gained ground over the past decade,^[44,45] a similar acknowledgement of the value of the informed carer appears less visible in the literature. It seems that the central point of patient or carer “expertise” is the use of education that can promote self-management without the routine intervention by professionals. Rather than describing this as “expertise”, a term that raises concerns,^[46] a more useful term may be “agency”^[47] described by O’Hair *et al.*^[48] as “a state or condition where individuals become empowered to the extent that they understand the choices they want to make, advocate their own rights, take control of their own destiny and demonstrate the competency necessary for acting in their own best interest.” The agentic learner is seen as creating constructive changes in the learning environment and contributing to the flow of instruction.^[49] However, a carer is unlikely to develop learner agency in an environment that does not support its development. Therefore agency has to be seen as the relationship between individuals and their environment as described by Priestley *et al.*^[50]

“... we do not see agency as a capacity of individuals, that is, as something individuals can claim to ‘have’ or ‘possess’, but rather see it as something individuals and groups can manage to achieve - or not, of course. Agency is therefore to be understood as resulting from the interplay of individuals’ capacities and environmental conditions. This makes it important not just to look at individuals and what they are able or not able to do but also at the cultures, structures and relationships that shape the particular ‘ecologies’ within which they work.”

If placed within the appropriate context, agency could have a powerful effect of enabling the patient and the carer to link the salient points of the personal perspective (patient-centred discourse) with the biomedical (treatment) discourse (see Figure 3). Here “care” is seen to occupy the space that links caring as a therapeutic intervention (to the left) and caring as the nurse-patient interpersonal relationship (to the right).^[51] This positioning enables the carer and the patient to be active partners in linking the chains of clinical practice

with the networks of understanding that relate to the patients wider needs.^[25,26] The key factor within this model is the “care” that includes consultation with the patient and carer that allows them to relate the two halves of their model – something that is required for self-management of chronic or terminal conditions. The outcome of the personal network

of understanding is agency and independence to decide how to live or die, and when the link with the treatment needs to be cut. This resonates strongly with what Wheelahan^[52] has termed “powerful knowledge”, and could be summarised as knowledge that confers agency.

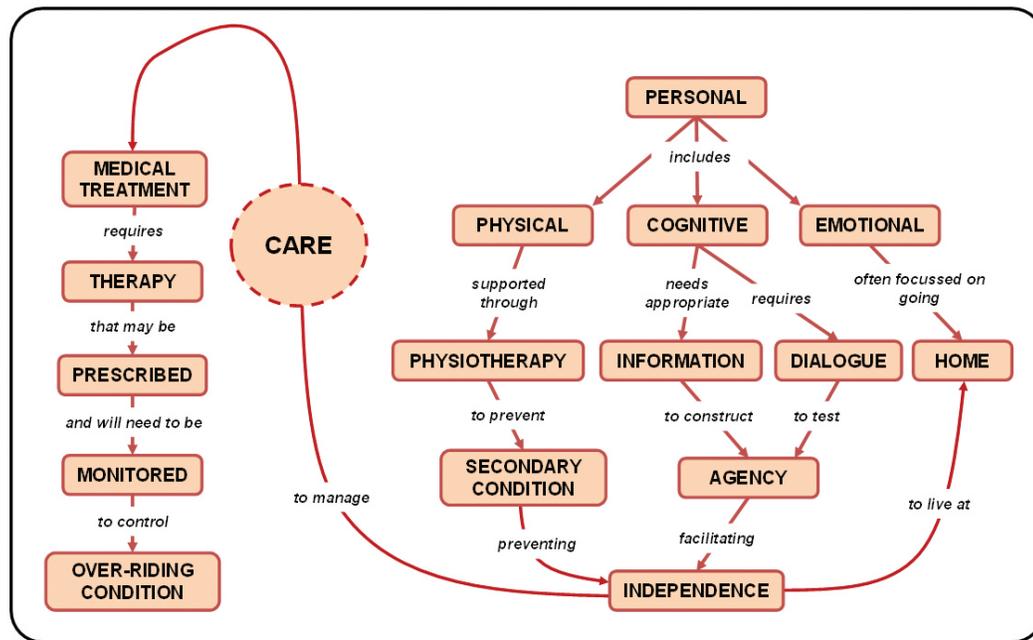


Figure 3. Chain of medical treatment (the health professional focus) juxtaposed against the network of personal understanding (the patient focus)

The distance in Figure 3 between the chain of medical treatment (to the left), and going home (on the right) is important, as these were the polar opposites in Dad’s eyes here. From his perspective, the medical treatment was preventing him from going home (in the short term) rather than facilitating it (in the longer term). The link between the treatment and getting back home was a difficult one to translate, and it is exemplified in Figure 3, possibly because “going home” was seen by the clinical staff as part of the treatment chain to the left, but was perceived by Dad as part of the wider network to the right. Proctor *et al.*^[53] note that in practice, hospital discharge approaches “frequently translate into assessment schedules, documentation, check lists and communication processes characteristic of bureaucratic systems and of technical rationality” that resonate with the linear sequence to the left of Figure 3. The problem with this technical rational focus, as Dad discovered, is the “unsuccessful hospital discharge” in which Dad found himself back at square one and back in hospital a few weeks later. Resolving this, as Dad understood intuitively, “requires a fundamental change in focus from disease management as a central measure of

health and success in hospital discharge, to a focus on communicative action within a framework of ethical decision making designed to promote quality of life for all people involved in the discharge process.”^[53]

9. CONCLUSION

The concept of care is central to the development of nursing practice, but has been (and remains) a slippery concept that is difficult to nail down.^[54–57] In line with the dual processing perspective of expert clinical practice,^[58] caring needs to be viewed simultaneously as the interaction between “interpersonal interaction” and “therapeutic intervention”,^[51] so that it may add coherence to the complex experiences of being a patient and being a carer. The central position of “care” (as indicated in Figure 3) is exactly where one might anticipate finding a threshold concept to allow it to perform its integrative function.^[59] This integrative function needs to be recognized by the various professionals involved in the treatment and care of the patient so that it works by adding structure to the information provided to facilitate understanding. Information without understanding simply adds

to confusion, uncertainty and anxiety.

Family caregivers provide more hands-on, day-to-day care than do any other individual and need not only access to information, but also the ability to process and act upon information in order to provide the best quality care for their loved ones.^[60] The importance of actively exchanging knowledge between professionals and carers has been emphasised by McPherson *et al.*^[61] to avoid the “constant struggle” that many carers refer to when discussing the difficulty of navigating a pathway through the web of services and processes embedded in the healthcare system. However, much of the literature on patient communication and the development of patient agency, fails to adequately recognise the role of the carer.^[62] Despite the genuine need for quality information, family care givers often battle for healthcare providers’ respect and to be treated as a full partner in the patient’s care.^[60]

The fragmentation and segmentation of information dispensed by various healthcare professionals across a multi-disciplinary team during the patient’s stay in hospital in this case study, initially made it more difficult to construct powerful knowledge that is needed by the patient and carer to help them manage the patient’s condition once he had been discharged and sent home. Providing a coherent framework into which elements of the information discourse can be slotted would offer patients and carers greater agency and enhance the effectiveness of the therapeutic alliance.

It was evident that a deeper understanding of the patient’s situation developed as a result of dialogue between the patient and his carer. This also helped them to clarify the chain of practice and the network of understanding (see Figure 3) in a manner that would help both to interrogate these elements as held by various healthcare professionals. The information that was generated by father-son discussions seemed to help busy professionals to see the patient as a “unique person” rather than as a “diagnosis”,^[63] contributing to the development of the so-called “communication bridge”.^[64] Many of the early problems encountered in this case study are echoed in the comments made by Murray *et al.*:^[65]

“Patients with cardiac failure rarely recalled being given any written information, had a poor understanding of their condition, and, in the absence of chest pain, did not connect symptoms like breathlessness and oedema to their heart. Professionals described complex strategies around giving information, wanting patients to understand their illness but also wanting to protect them from the negative connotations and potential seriousness of their illness implied

by cardiac ‘failure’. Prognosis was rarely discussed, and we found little acknowledgment that end stage cardiac failure is a terminal illness. Patients thought about dying in the context of ageing. ‘I know I won’t get better, but I hope it won’t get any worse’”

After a number of stays in hospital, Dad developed a clear understanding of the symptoms he was exhibiting and the seriousness of his condition, constructing a clear link in his mind between the medical treatment and its impact on the personal implications (see Figure 3). In my father’s case, the relationship between the physicians and the patient changed over time, but so did the relationship between physicians and carer. Whilst the carer in this case was in a position to obtain information via other academic routes, such self-initiated learning “does not necessarily transform the experience into a positive one”^[66] when the carer’s perception is that the clinical team missed opportunities to help in the construction of patient-carer-clinician therapeutic alliance. During the later phases of the transition in patient-physician relationship, the carer was included within the patient-physician dialogue (see Figures 2(1)) for the first time so that, “the patient is empowered not simply to follow unexamined preferences or examined values, but to consider, through dialogue, alternative health-related values, their worthiness and their implications for treatment”.^[38] Through this dialogue it was apparent that towards the end of his life Dad achieved a degree of agency that had not been afforded to him previously. The recognition that he was in control meant that his final passing was peaceful – he didn’t require anyone’s permission “to go”. It was not a cold, “clinical decision”, it was his. Whilst this played no part in “curing” Dad, it did transform the process of dying.

A monocular focus on one strand of the model offered in Figure 3 leads to the phrase often uttered by professionals, “there nothing more we can do”.^[39] This is not only considered by Johnson and Case as a form of cruelty, but also exemplifies an exclusive focus on the biomedical discourse to indicate that “treatment” has ended, not life. The focus on the therapeutic chain of practice (see Figure 3) also fuels the false hopes described above by Murray *et al.*^[65] However, as Warne and Hoppes^[67] have explained, “skilfully guiding clients to closure constitutes advanced end-of-life care”. When this happens, and both sides of the “caring coin” are joined up, both patient and carer achieve a greater level of agency and the relationship with the healthcare professionals feels much less tense.

The details presented in this single case study offer a parallel with the national debate in the UK about the end of life care.

Dad had experienced the Liverpool Care Pathway (LCP) for the care of the dying adult, as a carer when Mum died four years earlier. He was determined that his own end of life experience would be less “clinically focussed”, and was fortunate that in the final days of his life he retained mental capacity to understand and engage in the decision-making process. The recently published guidelines by NICE^[68] emphasise the need for discussion and shared decision-making

to be “understood by the dying person, those important to them, and those involved in the dying person’s care”. This paper may, therefore, help in providing a complementary text to support reflection on practice and professional development in the area of the dying patient and their immediate family carers.

CONFLICTS OF INTEREST DISCLOSURE

The authors declare that they have no conflicts of interest.

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