“Frustrating disability”: The lived experience of coping with the rehabilitation phase following flexor tendon surgery

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Abstract
Challenging rehabilitation regimes following flexor tendon surgery require patients to complete an hourly exercise regime and wear a thermoplastic splint constantly for four to six weeks. Building on earlier research by the first author the data from his interviews of five peoples’ experiences and meanings of their rehabilitation was re-analysed using a phenomenological lifeworld approach. The individuals were found to cope in different ways and degrees with the frustration of disability. Three themes—“struggling-adapting”, “retreating-battling” and “denying-accepting”—capture something of the ambivalence of their experience. The findings also provide insight into how flexor tendon injury, and subsequent surgery and rehabilitation, impact on individuals’ lifeworlds. Damage wreaked on daily life comes as a surprise. In different ways, they are all challenged to come to terms with the shock of pain, disability and the double trauma of surgery and rehabilitation. The challenge also involves an emotional and social struggle as personal relationships are disrupted. Three types of phenomenological analyses—narrative, lifeworld and thematic—are presented as iterative, deepening elaborations. Together they offer a more holistic, if still tentative, picture highlighting the relevance of attending to peoples’ personal, social and practical responses beyond simply focusing in reductionist ways on physical function.

Key words: Disability, existential issues, hand surgery, lived experience, phenomenological analysis, rehabilitation.

Introduction
Extrinsic flexor tendon surgical repairs to the hand, designed to enable a return to pre-morbid function, still prove a great challenge to hand surgeons (Amadio et al., 2005). Outcomes of primary flexor tendon repairs remain hard to predict, due to adhesion formation, risk of tendon rupture and joint stiffness (Tang, 2007). In addition, patients vary in their adherence to the post-operative rehabilitation regimes that seek to maximize their chances of regaining functional use of the repaired tendon(s) (Strickland, 2000). Even when these regimes are closely followed, outcomes can still range from excellent to poor (Tang, 2007).

Controlled Active Mobilisation post-operative rehabilitation regimes are most commonly used following this extrinsic flexor tendon repair surgery (Petingill, 2005). From the patients’ perspective, this regime means that they are required to take on board new concepts about tendon healing as well as complete an hourly exercise regime and wear a thermoplastic splint constantly for four to six weeks. They have to cope with the practicalities of having reduced use of the injured hand for up to three months while struggling with their pain and trying to negotiate their daily life in the face of uncertain outcomes. The challenges of the rehabilitation regime mean that compliance (increasing the likelihood of positive outcomes) is variable.

Much of the current research on outcomes of post-surgical interventions focuses on physical function. This assumes that positive psychological and social outcomes follow inevitably; but is this always the case? What actually happens to individuals as they cope with the challenges of injury, surgery and rehabilitation? Why do some individuals comply with their rehabilitation regimes while others do not? What do their injury and rehabilitation mean to individuals, and what impact does it have on their lives? What existential issues confront them?

To answer these questions, and gain a deeper understanding of the psychosocial factors limiting
the ability of patients to follow treatment, qualitative research approaches would seem to be called for. Armed with fuller, more in-depth descriptions of patients’ experiences, health professionals should be able to offer advice and rehabilitation more responsive to individuals’ physical, psychological and social needs. Some of the reasons for the variable improvements demonstrated among patients going through rehabilitation should also become apparent.

Increasingly, the personal life experiences of patients undergoing flexor tendon repair surgery and rehabilitation have been receiving attention. Chan and Spencer (2004) established the feasibility of using qualitative forms of enquiry with people who have suffered hand injuries. Their research explored the impact of traumatic hand injury and repair on occupational engagement and relationships using a mixed methodology. A number of measures of function and adaptation were used, including assessments of digital function (American Society of Hand Therapists, 1992), the disabilities of the arm, shoulder and hand (DASH), reaction to impairments and disability inventory (RIDI) (Livneh & Antonak, 1990) and semi-structured interviews. Data was collected monthly for one year. Chan and Spencer (2004) found that to include “the mind and spirit in hand rehabilitation requires individualisation of the interpersonal aspects of therapy in ongoing conversations with clients” (Chan & Spencer, 2004, p. 138) and that the patients’ ability to return to work was not the only outcome indicated as important to them. Other researchers have highlighted hand injuries as a significant source of stress and disruption in daily life. For example, Schier and Chan (2007) went further down the qualitative route, employing interviews within a case-study design. They followed three participants for one year after the onset of their injury. Retrospective analysis was conducted attending to their experiences of three major life roles: that of spouse, caregiver and/or worker. Hand injuries were found to have a major impact on daily routines. All three patients experienced depression and frustration because of their injuries, multiple losses and the way their role performance was hampered. The authors called for rehabilitation professionals to include patients in their own treatment programmes and to do more to attend holistically to patients’ roles, habits and activities. They argued that this inclusivity would have a positive impact upon compliance with treatment programmes.

More fully committing to qualitative methodology, Niall Fitzpatrick (2007) (the first author) used a phenomenological approach to describe the lived experience of five people coping with the consequences of flexor tendon injury. In his analysis of participants’ meanings, four general themes were highlighted:

i. Minimizing the impact of the injury—participants attempted to minimize the impact of their injury at both emotional and practical levels.

ii. Struggling and coping—loss of confidence and motivation was particularly evident just after surgery and after splint removal as, in both cases, participants had not expected the degree of disability experienced.

iii. Eliciting help—all participants required help from others to participate in activities of daily living.

iv. Feeling dependent—all reported feeling challenged by the impact of their loss of roles and self-care abilities.

Increasingly practitioners and researchers are calling for a focus on lifeworld and lifeworld-led care where understandings of health/illness and caring practices are guided by individuals’ experiential meanings: for example, via phenomenological and narrative studies which seek insights into lifeworld phenomena (Todres, Galvin & Dahlberg, 2006; Dahlberg, Dahlberg & Nystrom, 2007). The lifeworld—Husserl’s (1970) Lebenswelt—can be defined as the world that is lived and experienced, a world of meaning which encompasses (among other dimensions) a person’s sense of self, embodiment, relations with others, spatiality, temporality, project, discourse and mood-as-atmosphere (Ashworth, 2003, 2006). It is “a world that appears meaningfully to consciousness in its qualitative, flowing given-ness; not an objective world ‘out there’, but a humanly relational world” (Todres et al., 2006, p. 55).

Recognizing the likely significance of this humanly relational realm, we set out to elaborate and deepen the findings of Niall’s original study (Fitpatrick, 2007). Using an existential phenomenological lifeworld approach to analysis, we sought to unfold further meanings his participants had attributed to their lived experience of flexor tendon repair. Further explication is always possible given that our understanding of others can never be totally certain. It is always possible to see more in data when approached at a different time or when another researcher offers a new view. As Dahlberg et al. (2007, p. 350) suggest, “lifeworld research is limitless … meanings that can be understood from the lifeworld are always incomplete”.
Method

Research design

The core of this research centred on the data arising from Niall’s original research with five individuals who offered accounts of their lived experience over weeks of having to wear a splint and do exercises following flexor tendon repair surgery (Fitzpatrick, 2007). In an iterative process, we both undertook to develop and deepen the original analysis.

An existential, phenomenological lifeworld approach was employed in our secondary analysis aiming to describe the participants’ experiences and meanings (Ashworth, 2003; Giorgi, 1985; Dahlberg et al., 2007). This approach does not study the body as “an organic object”; rather it studies “the experience that people have of their bodies” (Polkinghorne, 1989, p. 45). A lifeworld approach seeks to explicate human experience (phénomena) as manifested in concrete situations. It asks, how is the experience lived and known by the experiencer? How is it given to them? It is through the everyday lived world that the very meaning of a person’s existence emerges (Valle, King & Halling, 1989). This is the pre-scientific, pre-reflective lifeworld where self and world are seen to be co-constituted (Dahlberg et al., 2007).

The approach we used in our analysis included a process of attempting to suspend presuppositions and go beyond the “natural attitude” of taken-for-granted understanding. Past knowledge was restricted in order for us to be more fully open to participants’ meanings elicited in the original research interviews. Here we tried to retain an open, discovering way of being to be open to, and possibly surprised by, new meanings as they arise (Dahlberg et al., 2007). Critics often misunderstand this bracketing process as an effort to be unbiased and objective. Instead, the aim is to attempt to see the world differently and attend more actively to participants’ views. Through a continuous, iterative struggle, the researcher seeks to become aware of, and then manage, the impact on the research of lingering pre-understandings and evolving understandings (Finlay, 2008).

Participants

As relatively little qualitative research has been published in this area, the participants in the original study were chosen to allow for variation in the set of descriptions elicited. A convenience sample of two men and three women, ages ranging from 23–54 years, was recruited from a London hospital. All five participants had undergone extrinsic flexor tendon repair to one hand. Of the five, two also had damaged digital nerves.

Ethical considerations

Ethical clearance for the original study was gained both from the first author’s workplace Research Ethics Committee and from the University Ethics Committee monitoring the research being conducted for MSc courses.

Participants were approached at the point of discharge from the therapy/rehabilitation team. As the prospective participants were all treated by (and therefore known to) the first author, a colleague was brought in to invite the participants to take part in the study in an effort to minimize any sense of coercion. Information about the proposed study was given to prospective participants in written and verbal form prior to them agreeing to take part in a study to see how they have managed their everyday life. All five who were approached expressed interest in taking part in the interviews. Confidentiality was maintained at all times and participants’ names have been changed to maintain their anonymity.

Data collection and analysis procedures

In the original research, Niall utilized unstructured interviews and kept a reflective diary (to record reactions, thoughts, feelings and opinions throughout the research process). The open-ended interview format, lasting approximately an hour, took place at a time and place of each participant’s choosing. (Three chose their own homes, one his workplace and one opted for the first author’s workplace). Participants were invited to tell their story of how they managed in their everyday lives while going through their demanding rehabilitation of wearing a protective splint for five weeks and carrying out recommended exercise protocols. Interview questions were kept to a minimum with questions largely flowing from participant’s own responses. Participants were encouraged to describe and elaborate concrete situations such as “what did you do to enable yourself to get to sleep?” Participants’ expressions were assumed to reflect perceptions of their lifeworld while the idiographic approach adopted as a starting point made no assumption of an intersubjectively shared reality across these individuals. All interviews were tape-recorded, transcribed and analysed.

A subsequent secondary analysis—i.e. the one reported here—was then undertaken by both authors a couple of years later. We both tried to retain an open, discovering way of being, rather than rigidly
following pre-set analytical procedures (Dalhberg et al., 2007).

Although Linda Finlay (the second author) had not been present during the interviews, she returned to the transcripts and still tried to engage reflexive, bodily empathy (Finlay, 2005) as part of attempting to retain an open and reflexive approach.

The main aim of this data analysis was to reveal themes from the general naïve descriptions. The analytic method suggested by Wertz (1983) generally guided the procedure: First the transcriptions were systematically and repeatedly read in an attempt to become empathically immersed in the individual descriptions. In attempting to discover the meanings in the description from the participants’ point of view, analysis then slowed down. An effort was made to linger over particular meaning units and then amplify them. This was followed by a process of active and open reflection and elaboration, which aimed to explicate recurrent themes experienced by individuals and to highlight commonalities between them.

The analysis process occurred in stages, bringing new riches at each iteration. First, an individual narrative was created for each participant, drawing on verbatim quotes. These narratives are a re-wording, rather than re-working, of the narratives developed in Niall Fitzpatrick’s original research. They are offered here to provide context for readers as they highlight individuals’ particular histories and experiences.

Second, we then tried to highlight explicitly existential lifeworld dimensions of embodiment, identity, lived time, lived space, and sociality (Ashworth, 2003, 2006). These interlinked ‘fractions’ acted as a lens through which to view the data as we sought to capture and highlight a collective sense of the existential lifeworldly themes.

Third, an additional thematic analysis was attempted to deepen the exploration of meanings and to move beyond the original themes first presented by Fitzpatrick (2007). The aim was to convey a sense of the participants’ lived experience more generally.

Findings and analysis
The findings are presented to reflect the three different but interlinked types of analysis—narrative, existential and thematic—which emerged because of deepening phenomenological reflection. The findings from all three stages are given here as they highlight different facets and offer different insights into the participants’ lived experiences.

1. Individual narratives
The five narratives briefly summarized below highlight the individuals’ different personal responses, given their particular life and circumstances, to their injury and resultant disability. The narratives show how the crisis caused by the traumatic injury pervades the individuals’ lives.

“John’s” story. John is a 23-year-old care worker who tripped and fell through a glass table on his wedding day.

It is only when John begins his rehabilitation that he starts to have a real understanding of what exactly is damaged and what this will mean for him during rehabilitation. As he must wear a splint constantly for five weeks to protect the repaired tendons, the impact on his life is considerable. He cannot return to work, he is reluctant to go out with his family and friends, he finds it difficult to manage his own personal care. John describes how “everything took longer, like having a shower. I felt like an 80-year-old man”.

He is aware that he needs assistance from family and friends and feels guilty that he must rely on support from his new wife. He is also aware that during his rehabilitation time he is not interacting with family and friends in his usual way. At home, he feels bored. When he leaves the house, he feels he has lost his anonymity: strangers continually ask him about his injury, and why he needs to wear the splint. He fears others are negatively judging him and perhaps seeing him as dangerous or prone to fighting. This is not the image he wants to portray, preferring instead to keep a “low profile” and mind his “own business”. Therefore, despite the considerable risks involved, John leaves his house without wearing his protective splint. The anonymity of “normality” provides a comforting cloak.

He views his rehabilitation time as a battle; something to be overcome without complaint and with a determination that will win out in the end. In place of work, John uses his time to read widely and learn to write with his non-dominant hand.

“Sally’s” story. Sally is a 22-year-old fashion design student who cut flexor tendons and a digital nerve in her right dominant hand. Following her discharge from hospital, her alcoholic boyfriend asks her to leave their shared flat. She moves into a squat, where she lives alone. Despite encountering major difficulties with daily living, she is determined to manage on her own and is reluctant to accept help from anybody; while she gets some help from neighbours and friends, this is on her terms. In the end,
however, she gives up trying to live independently and goes to stay with her parents. She feels mixed about this return to her parents and prefers to frame the move as “allowing her parents to ‘faff’ over her” instead of the move being about her needing help. During her rehabilitation, she finds work a struggle, given her inability to write or do practical hands-on fashion designing.

‘Dawn’s’ story. Recently married, Dawn has injured her tendons with a broken glass milk bottle following a slip on the pavement outside her house. She returns to work only one week after surgery, despite being advised to take six weeks off. This is because she thinks her colleagues will underestimate the severity of her injury and take a dim view of her going on sick leave. She goes as far as to show her boss a photograph of her injured, “as he was wondering what on earth I could have done to have that big splint on”.

Her own grasp of her injury and its seriousness comes from her interaction with surgeons, nurses and therapists over time. She becomes low in mood and thinks that she will not regain the use of her hand again and will have to “coddle it forever.” Fearing further injury, she restricts her movements and stops wearing her high heels. She no longer goes into her garden because this involves negotiating steps, and she avoids buses unless she is sure she can get a seat. However, she manages to overcome this sense of uncertainty. With the support of her new husband and of her father, who lives nearby locally, she determines to regain some semblance of normality even when wearing her splint by trying to participate in as many of her usual activities as possible.

Although Dawn is able to manage most tasks, each one takes much longer than usual and this has a cumulative impact on her ability to complete all her daily activities. However, the support from her family enables her to get through rehabilitation.

‘Adam’s’ story. Adam is a 54-year-old chef who has cut his flexor tendons at work. Once he is told about the healing process and the length of time that the rehabilitation will take, he realizes he will be unable to carry out the physical and manual aspects of his work so he arranges cover. He views his splint like a “badge . . . it let people know the seriousness of my injury”.

He occupies himself during this initial phase of inactivity by doing administrative work and by overseeing the running of the kitchen. Being one-handed for five weeks proves a major inconvenience. He has great difficulty sleeping, dressing, washing and using public transport, to cite some examples. Adam is all too aware of the “carrying” he is getting from colleagues and housemates, accepts this assistance gratefully. However, when it comes to personal care activities such as showering and dressing, he refuses help. He keeps people at a distance despite the risks of further tendon damage.

He appreciates the clear information he was given during his first visit to casualty, and he feels he has a good understanding of the planned progression. As a result, he follows it scrupulously. He is pleased with the level of support he receives from housemates and colleagues and adapts well, managing as best as he can in the difficult circumstances. For example, unable to manage the zips and buttons on his trousers, he switches to wearing tracksuit bottoms for five weeks and so maintains his independence.

‘Jane’s’ story. Jane, a fifth year architectural student, has damaged flexor tendons to her thumb when building an architectural model for her final dissertation.

For the first week following the operation, Jane does not want to accept that the injury has happened—not least because she begins to realize how much her daily life will be disrupted. She feels her life is in limbo. Her inability to participate in her usual roles makes her feel bored and frustrated, and she swears a good deal. For example, unable to manage, she cuts it off. She worries that her search for jobs will be jeopardized, as she will now need to repeat her final term.

She also senses the detrimental effect her situation is having on her housemates, who must now spend time looking after her. Jane is all too aware that it is her housemates who push her to do her painful exercises, supporting her with humour. They call her thumb “Hercules” and liken the demands of the exercises to one of “Hercules’ seven tasks”. Seeking to regain some balance in her life, she repays her housemates by helping with their studies and doing the cooking.

2. Existential dimensions: Shared lifeworlds

The five narratives reveal something of the participants’ individual battles through the rehabilitation process as they fight to regain control of their arms and reclaim their lives. While their stories are unique, some commonalities of experience can be identified. The narratives demonstrate something of the profound impact made by their injuries and the
subsequent surgery and rehabilitation on their lifeworld.

This section explores five particular existential lifeworldly themes—of embodiment, identity, temporality (lived time), spatiality (lived space) and sociality (lived relations with others)—experienced by all the participants.

In terms of their embodiment, each participant struggles with their pain. Every movement brings the person’s vulnerability to awareness and powerfully restrains normal movements. The pain is an ever-present horizon, its presence constantly intruding. “The essential quality of all pain is its embodied painfulness”, says Madjar (2001, p. 268). “It occupies a space within the very fibres of one’s body and makes it inseparable from the essential self.”

The participants also struggle with the challenge of having to cope one-handed. “The body” Cassell (2001, p. 371) notes, “participates in everything.” The participants’ stories show that when one part of the body malfunctions, the person’s life is de-railed (albeit temporarily). When the body’s functioning is disrupted, daily life activities and relationships all have to be reorganized.

Participants must confront the fact that their comfortably familiar body can no longer be taken-for-granted. New ways of ‘being-in-the-world’ have to be negotiated. As Mazis puts it:

All the projects that were echoes of what my body could do without any thought ... have been put out of play, as the disorientation or weakness or pain absorbs me and undercuts these avenues of involvement. (Mazis, 2001, p. 206.)

With their arm trapped in a large intrusive splint, they are constantly reminded of the presence of that splint. Their arm is no longer their arm. Instead a new appendage has appeared—one that prevents them acting and living in their world comfortably. When the splint is removed for the required exercises, the arm still feels alien with its attendant pain and restricted hand movement. Both the splint wearing and the exercise regime contribute to a sense of disconnection: the injured limb feels ‘split off’ from the rest of the body. The participants learn to observe and examine their arm as a disconnected object. They see themselves as others have seen them and look (at a distance) through a “medical gaze”, assessing function, pain and progress—Sartre’s notion of “being-for-others” (1969).

As participants’ injuries heal and rehabilitation progresses, they also have to contain their impatience and fears. If they do not carefully attend to the restrictive rehabilitation protocols regarding exercise and the need to prevent movement by wearing the splint, they risk tendon rupture and permanent damage to their limb. In carrying out every daily activity, they are forced to confront the risks of their situation.

All the participants have to give up, or at least severely modify, their work and they lose their independence in their domestic/personal care activities. For instance, Jane’s whole life has to be put on hold as she is forced to postpone her architectural college course and planned future career. Losses such as these, impact profoundly on the participants’ sense of identity. Our identities are shaped by what we do and how we do it, so any threats to our abilities to carry out our daily lives competently becomes a threat to our identity (Christiansen, 1999). As normal life roles and valued projects are relinquished, a new “disabled” persona begins to emerge. Forced inactivity and constrained movement makes life both boring and frustrating.

Being forced to wear a splint for five weeks similarly changes the participants’ sense of embodied identity and further thwarts their ability to carry out normal life. John feels he is stigmatized and negatively judged by others, while Adam views his splint like a badge. Dawn enjoys the extra attention she receives but feels the presence of the splint is a distinct inconvenience (for example, it interrupts her and her husband’s sleep).

Lived time becomes structured by the rehabilitation protocols and various recovery milestones. Each week becomes a new stage that has to be managed and coped with emotionally. Each stage is a reminder that there is more to be coped with and more to overcome. All the participants have to cope with the reality of rehabilitation as a long drawn out process—it feels endless. None of them had fully appreciated how long their arm would take to heal or that the five weeks of wearing the splint was just one stage in their recovery.

The participants are forced to live in the moment of constraining protocols and slowed time. Every task they attempt to do takes time—much longer than normal and longer than they expect. Yet, haunted by uncertainty about what function they will regain, they also have an eye to the future. Participants have to come to terms with their injury, the resultant disability and the compromises that need to be made. Some give themselves time others push for progress. While Dawn tries to catapult herself into the future by determinedly returning to work just one week after surgery, John lives one day at a time, unable to plan for any future.

In terms of spatiality, all the participants have to cope with a risky new world of “restrictive potentialities” (Merleau-Ponty, 1962, p. 143). Their worlds shrink as choices and capabilities are diminished
while risks are amplified. Dawn, fearing further injury, restricts her movements and everyday activities. John stops socializing with family and friends and gives up valued hobbies and sports.

The participants’ relationships with others are also affected—in both subtle and dramatic ways. The participants understand that their bodily injury is also a wound to, or at least a disruption of, their relationships. While grateful for support from family, friends and colleagues, the participants also resist the changed relationships that such dependence brings. Each struggle to cope with a paradox: that only by accepting help and having others do things for them can they function somewhat normally. Yet relationships with others cannot help but change as family and friends are drawn into doing more work and personal tasks for the injured person. Adam accepts others’ support gratefully but draws the line at personal care. For Sally, assistance from others is a “last resort”; something to be resisted as far as possible.

Participants’ relationships are also affected by the difficulty others have in grasping the traumatic quality of the injury and rehabilitation experience. Dawn, for instance, struggles to convince her colleagues of her disability given her general suspicion of people who take sick leave. When the splint is finally removed, family, friends and colleagues have unrealistic expectations. As Adam explains, “They assumed I was back and over it.” Sympathy along with practical help may well be withdrawn, and this reinforces the injured person’s sense that others do not understand.

3. Thematic analysis: Ambivalent, ambiguous experience

Three themes “struggling-adapting”, “retreating-battling” and “denying-accepting” capture something of the lived experiences of these participants.

Struggling-adapting. For the participants, every hour of every day is a frustrating struggle: physically, emotionally, practically and socially. All five struggle to cope with their pain and to manage the inconvenience of their disability. Hampered by their intrusively large splint, they struggle to do their normally taken-for-granted daily living activities one-handed. Every little task takes longer to do and basic self-care—washing, dressing, cooking, cleaning—become difficult, even impossible. Yet somehow, the individuals find a way through. Jane cuts her hair to make it easier to manage; Adam switches to wearing tracksuit bottoms to avoid zips.

The individuals’ struggle to maintain their daily activities is an active one. “For human reality, to be is to act, and to cease to act is to cease to be” (Sartre, 1969, p. 476). Therefore, it is for the participants: struggling becomes striving. Jane does extra cooking and helps her housemates with their studies. John uses his extra time to read and learns to write with his other hand.

With each week of rehabilitation, the participants encounter fresh challenges as they seek to cope with, and adapt to, the frustrations of a disrupted life. When the splints are at last taken off, a nascent sense of relief, release and freedom is soon replaced by further disappointment when it is clear that disability persists and that only more pain and more exercise schedules lie ahead.

Retreating-battling. Illness, says Toombs (1993, p. 96) “is a state of disharmony, disequilibrium, dis-ability, and dis-ease which incorporates a loss of the familiar world.” The trauma of the original injury and surgery is followed by the dawning awareness of multiple losses; despair and anxiety accompany the realisation of dis-ability. The loss of function, of confidence and motivation, of daily roles and activities, and of taken-for-granted physical safety, all push the individual to retreat from the life they once lived. As Toombs (2001, p. 253) notes, “The person with a disability is tempted severely to curtail involvements in the world.” The person may also feel pushed by others to withdraw. Either way, they feel forced into leaving a familiar world.

The result is a diminishment, a shrinking of life. Without everyday roles and activities, life’s landscape feels barren and boring. “Being ill”—or in this case, injured—“is above all alienation from the world” (Buytendijk, 1974, p. 62). Sally is forced to give up her work for several weeks, as she can no longer fulfil commissions. She cannot even express her fashion ideas through her drawing. John retreats from socialising with his family and playing his sports. Jane abandons the final term of her college, putting her life and her future on hold. Dawn, beset with “visions of myself molly-coddling my hand for life,” stops going out and gives herself up to the care her husband and parents offer.

At some point, the retreat must be halted if rehabilitation is to be successful. Therefore, the battle begins. The individual takes a stand to fight, to get through, to subdue the enemy (the injury, the pain, the disability). The injured person moves forward, determinedly and positively re-engaging with life. Dawn ignores the risks involved in going back to work. Helped by his wife “out of love” to do his exercises, John finds that this support fuels his determination to “beat the injury”.

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Denying-accepting. As normal life roles and valued projects are relinquished, a new “disabled” persona begins to emerge. One particular lesson that needs to be learned is to accept bodily limitations or risk further long-term damage. However, finding the appropriate level of function and the safe way to move is difficult, not least because mind and body seem to be pushing in different directions. Somehow, the individuals need to find a way to enact their disability while still hanging on to the person they once were.

It can feel easier sometimes to deny there is a problem. With that denial, the individuals can once more claw back some sort of normality into their life. The risks and long-term costs of not accepting disability are pushed away. It is as if they gain a sense of stability and normality by trying to “pass” as the person they once were. People with disability often strive to maintain “normal” functioning by minimizing and disguising their problems—a point picked up by several commentators (for example, Charmaz, 2000; French, 1993).

Therefore, Dawn returns to work at her hair-dressing salon just one week after surgery despite being advised to take six weeks off. After her initial fear that her “hand was wrecked”, she determines to reclaim her life. Despite the risks involved in pushing herself, she refuses to take more time off work. John feels awkward and tense in public and does not like revealing he is disabled to others. Somehow, feelings of shame arise in the gaze of others (Sartre, 1969).

The experience of being cared-for is double-edged (Frank, 2000). When people find themselves injured or disabled, the fact that they need help stirs a cocktail of contrasting emotions within them. In all probability, they will feel grateful for the care and support they receive. However, such dependence will be realized with varying degrees of resistance. Feelings of guilt, loss of dignity and vulnerability may push an individual to resist others’ help.

Although accepting care from others also involves conceding some degree of dependence, care is also experienced positively as a source of strength and support. Each of the participants sought and received help from others—in different ways and to different levels. Adam accepts a large amount of support from his work colleagues and housemates. John, too, relies greatly on support from his new wife, family, colleagues and friends. Even Sally eventually draws on her family’s support by returning to live in the parental home.

At different points in the rehabilitation, all five participants in our study begin to accept their current level of disability and to respect the risks involved if they do not comply with the rehabilitation advice. They accept that treatment and recovery will take time—longer than they had originally appreciated. They begin to come to terms with the multiple traumas and losses experienced and they understand that compromises in their lives are necessary. They learn to expect the frustrating inconveniences and work around them, appreciating the love and support offered by others. They accept the uncertainty surrounding the degree of function they will eventually attain, recognising that they may never regain the level of arm function they had prior to the trauma. Eventually, they can acknowledge, even celebrate, their progress and achievements.

The lifeworld following flexor tendon injury and surgery—a synthesis

The lived experience of the rehabilitation phase following flexor tendon injury is challenging emotionally, practically and socially. Every hour of every day is a frustrating, painful struggle. The person has to cope with the pain and trauma (of the injury, the surgery and the exercise programme) as well as the challenge of one-handed living. The rehabilitation process is experienced as never-ending as future function looms uncertain. The experience is captured, at least in part, by the phrase ‘frustrating disability’. The disability confronted is both frustrating to experience and needs, itself, to be frustrated and fought against.

The participants’ lifeworlds are affected by the different ways this ‘frustrating disability is frustrated’. When the body’s functioning is disrupted, daily life activities and relationships all have to be reorganized. The individual is engaged in a project of coping with a disrupted life and a damaged body, which has become an obstacle to immediate, easy, unmindful engagement in the world. “A breakdown of one’s body means a break down of life . . . Bodily dissonance is a conflict of wanting and not being able to”, says Dahlberg et al. (2007, p. 44).

The lifeworld is characterized by tensions: between feeling overwhelmed with pain while also denying it; between needing care from others while rejecting it; between enacting a new disabled identity while hanging on to a non-disabled identity; between curtailing involvement in the world while determinedly forging ahead; between fighting against the body while also protecting it and caring for it. Lived experience is ambiguous and ambivalent: Being involves struggling and adapting, retreating and battling, denying and accepting.
Discussion

Evaluation of the methodology

The use of phenomenological methodology in this project has proved invaluable to highlight the ambiguity and ambivalence of the participants’ experiences. As Dahlberg et al. (2007, p. 94) warn, researchers need to be “careful not to make definite what is indefinite”. Lifeworld research is characterized by its capacity to present the paradoxes and integrate opposites demonstrating holism (Dahlberg et al., 2007).

We would argue that this collaborative study has been enhanced by our different areas of skill, knowledge and expertise. (Niall is an experienced occupational therapist and hand therapist; Linda is an experienced phenomenological researcher who also supervised Niall’s Masters’ thesis). In reflecting upon the participants’ descriptions, we have each dramatized the action according to our own presence in the data (Churchill, Lowery, McNally & Rao, 1998). In the words of Merleau-Ponty (1968, p. 90), “There is no truth if one does not take into account, in the appraising of every statement, the presence of the philosopher [or researcher] who makes the statement.”

In the following passage, Niall Fitzpatrick reflects on his own development as a researcher during the course of the study:

My skills as a phenomenological researcher are still developing but I believe my occupational therapy background enabled me to engage the participants effectively in their interviews. I feel my training and experience allowed me a good insight into patients’ experience. I didn’t expect to be surprised at the results, but I was. ‘On reflection I quickly learned that I was initially approaching this study from my own perspective, expecting the patients’ views to confirm my own assumptions. This study allowed me to begin to change my stance by trying to gain a sense of the meaning of the injury from a patient’s perspective and not from my own. I wanted to be as critical as possible when reflecting upon each individual description. I tried to ensure a deeper insight into each description and attempted to put myself into their world and try to gain their meaning from it’ (Fitzpatrick, 2007, p. 100).

That my supervisor and myself jointly engaged in the lifeworld and thematic analysis has, I believe, deepened the analysis.

Linda Finlay similarly reflects on her contribution:

When I was supervising Niall’s dissertation, I was struck by the richness and potential of the narrative data. Niall began to tap this richness in his existential analysis. But I believed I saw further layers. I approached Niall after he had received his degree about the possibility of collaborating further to deepen and extend the existential and thematic analysis.

However, for me, this was not simply an academic exercise. I had a personal motive as well. Over the last three years I have struggled with a severe shoulder injury which has necessitated repeated surgery and a protracted, painful and challenging period of rehabilitation. I have wondered about exploiting that opportunity to conduct some more personal autobiographical research. In the end, I’ve resisted, not being convinced about the value of such research, let alone my skills to accomplish that more personal writing.

Yet, reading between the lines of Niall’s participants’ narratives I empathized. Inevitably my own experiences and empathy influenced—and possibly even inspired—my analysis. While Niall was inclined to gloss over the impact of the pain his patients experienced, I saw it in their every movement and throughout their rehabilitation. But was I ‘seeing’ my pain? I had to remind myself continually to keep focused on the participants’ experiences and stories, not mine. Niall had an important role to play here in monitoring this.

The three distinct though overlapping types of analyses have been presented as iterative, deepening elaborations that occurred developmentally. Rather than necessarily seeing these analyses in hierarchical terms, with the final thematic analysis of the lived experience being the ‘best’ or most complete version, we suggest that the different versions extend and elaborate each other. Each interpretative version simultaneously reveals and conceals, like variations upon a theme. The use of different methods of analysis has brought both visible and invisible aspects variously to life (Merleau-Ponty, 1968) as different meanings have assumed figural significance at different points. Put another way, different analyses highlight particular nuances and indicate various immanent possibilities of meaning as figural against a ground of other possible meanings. Taken together they offer a more holistic, if still emergent and tentative, picture. Any one analysis, says Churchill (2000, p. 164) can only be presented as a “tentative statement opening upon a limitless field of possible interpretations.”
Engaging the three-pronged analysis as a way of developing Fitzpatrick’s original narrative and thematic research, proved an interesting experiment. Different insights emerged at each iteration. The experiment highlighted the different opportunities and possibilities within different ways of approaching phenomenological analysis. Each type of analysis has its own strengths and limitations. For this reason, it is useful to attend critically to the status of each:

The narratives offer a way into the individuals’ particular lifeworlds, allowing the reader to grasp something of the personal impact of disability and how the individual coped given their particular circumstances. The injury and subsequent rehabilitation had a markedly different impact on each individual—a point that is well highlighted despite some commonalities. While the narratives are grounded in the participants’ descriptions and presented as reflecting the individuals’ reality, their constructed nature needs to be emphasized. Underpinning these apparently straightforward stories are other narratives which involve a complex but largely hidden negotiation between the storyteller and the interviewer. “Individuals negotiate how they want to be known in the stories they develop collaboratively” (Reissman, 2003, p. 8). Further, the story heard, interpreted and analysed by the interviewer (the first author in this particular study) is likely to heard, interpreted and analysed differently by another researcher.

The existential analysis highlighting lifeworld dimensions proved valuable in emphasising how body and world are interpenetrated. The extra phenomenological depth and richness obtained is counterbalanced, however, by the way the five headings (of embodiment, identity, temporality, spatiality and sociality) overly structured and constrained the analysis. Care needed to be taken by the authors to stay open to lifeworldly experience as a whole. The fragments are heuristic only—what Ashworth calls “analytical moments of a larger whole” (2003, p. 151). Extra care also needed to be taken (by both authors) to not import presuppositions about the impact of disability in general on the lifeworld and to remain rigorously anchored by the participants’ words and experience.

The thematic analysis offered the opportunity to highlight even more of the ambivalences and ambiguities of lived experience. For instance, it captured the paradoxical situation experienced by the participants of both resisting and gratefully receiving help, of both accepting and denying disability. Yet, as the themes opened up possibilities, they also closed down other avenues. As with the previous analysis, the particular voices and experiences of the individuals blurred into the background and some individuals’ experiences were reflected in the themes better than others were. In addition, the analysis lost some of the meanings of the way the individuals’ responses evolved and changed over the course of the rehabilitation.

The study in perspective: Its contribution to the field

The participants’ stories provide a useful reminder that the post-trauma/surgery experience is replete with uncertainty, difficulty and contradiction: Surgery offers gains for the recipients but it also produces further additional trauma. Participants resist dependence, while also being grateful for, support from others. They feel a loss of confidence along with a sense of achievement in coping. Participants are both frustrated by the disability and are determined to frustrate the impact of the disability. They are engaged in a fight against and for their body and their previously taken for granted way of being in the world.

It bears emphasis that our analysis is based upon a very specific, small-scale study. All the participants were recruited from one catchment area and all had been treated in one particular clinic. Readers may consider to what extent findings might relate to other service users who have had tendon repairs. General themes revealed in this study thus need to be further examined in more depth in future studies.

Accepting these limitations, we would argue this study contributes to the literature on health care and hand therapy in several significant ways:

First, its findings provide further insights into how flexor tendon injury, and subsequent surgery and rehabilitation, impact on individuals’ lives as a whole. This focus on the lived experiences of service users makes possible a more thoroughgoing examination of how services provided by hand therapists are received. Findings show that it is insufficient to simply consider surgical and rehabilitation needs. Instead, social, practical and emotional needs need to be considered as well. Further, specifically embracing a lifeworld approach deepens understandings of the complex, ambivalent nature of peoples’ meanings.

Second, our findings bear out research by Schier and Chan (2007) and others about the need to approach hand injury in a more holistic manner. Embodiment is interpenetrated with identity, temporality, spatiality and relationships with others. In short, disability is “encountered in the context of . . . family, relationships, aspirations and history—the intersubjective and social realms of the lifeworld” (Finlay, 2003, p. 172). The participants’ stories
provide a useful reminder that it is important to look
at their experiences across a broad canvas rather
than restrict our attention to simple hand function.
We are reminded further to attend to psychosocial
dimensions concurring with Johnson (1993) and
Schier and Chan (2007) have similarly recom-
manded patients with hand injuries be offered
psychosocial assessment with the resulting benefits
of individualization of treatment.

Third, the study has revealed areas that require
further research. For example, the fact that patients’
mood states were especially affected at particular
stages (such as after removing the splint)—with
implications for the progress of their re-
habilitation—suggests a dimension in need of more
formal monitoring.

Fourth, our study highlights how heavily people
with serious hand injuries rely on family and friends
to help them through their rehabilitation phase. It
would therefore seem vital to identify the people on
whom patients will be dependent post-surgery and
to include them in the rehabilitation process (Fitz-
patrick, 2007). Equally it needs to be recognized
how mixed individuals feel about needing and using
their social supports. Individualized rehabilitation
programmes need to continue to respect the parti-
cular relational contexts involved.

Fifth, although the length of the rehabilitation
process is relatively short, this study reveals its
general impact to be extremely wide-ranging. For
this reason, service users’ specific daily life needs and
circumstances should to be considered when identi-
fying and negotiating coping strategies. Sally’s ex-
pertise of trying to cope alone suggests that the
 provision of support for people without access to
help from family and friends is limited. The use of
social services support for people with temporary
disabilities is scarce as such input is more often set
up for longer-term, chronic disabilities. Some hospi-
tal units do now provide short-term “hospital
aftercare services” that offer help with shopping
and housework (for example, for mothers with
young children). Even the simple provision of
adaptive equipment can keep service users indepen-
dent and reduce the risk of tendon rupture and the
ensuing costly surgical repair (Fitzpatrick, 2007).
These avenues could be valuably utilized to allow
patients to engage more readily with their therapy.

If health professionals commit to service users’
personal, social and practical responses, the frustrat-
ing impacts of disability stand a better chance of
being “frustrated”.

Acknowledgements

This paper builds on the research conducted by the
first author, Niall Fitzpatrick. The original narratives
and analysis, which have been reworked here, can be
found in Fitzpatrick (2007).

Declaration of interest: The authors report no
conflicts of interest. The authors alone are respon-
sible for the content and writing of the paper.

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