

# 'Just Normal': A Grounded Theory of Prosthesis Use

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A thesis presented to Dublin City University for the Degree of Doctor in Philosophy

By

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## Declaration

I hereby certify that this material, which I now submit for assessment on the programme of study leading to the award of Doctor in Philosophy is entirely my own work, and that I have exercised reasonable care to ensure that the work is original, and does not to the best of my knowledge breach any law of copyright, and has not been taken from the work of others save and to the extent that such work has been cited and acknowledged within the text of my work.

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## Operational Definitions

A list of definitions is provided here for terms that are used in this thesis.

*Acquired limb absence:* The result of the removal of a whole or part of a limb, through injury or a surgical procedure.

*Amelia/Meromelia:* See *congenital limb absence*.

*Amputation:* See *acquired limb absence*.

*Amputee:* Individuals with limb absence often refer to themselves as amputees, and sometimes 'amps'. Whilst an amputation is associated with acquired limb absence, individuals with congenital limb absence may also sometimes refer to themselves as amputees too. It may be difficult to determine whether this is because an individual's congenital absence is due to congenital amputations (such as being caused by amniotic band syndrome) or whether this is more due to an individual's identification with a dominant 'amputee' population.

*Artificial limb:* See *prosthesis*.

*Attachment site:* Part of the individual's body that the prosthesis attaches to. This is commonly the terminating end of a residual limb that is then covered by an enveloping socket.

*Bilateral:* Involving two sides. In the context of this study, bilateral limb absence is an absence of both upper limbs or an absence of both lower limbs. A person may also be a bilateral prosthesis user in the sense that prostheses are worn on both sides.

*Congenital limb absence:* Individuals that were born with partial or complete limb absence. This may be due to congenital amputations during pregnancy or a limb never developing. Undeveloped limbs may later be fully or partially amputated to better accommodate a prosthesis.

*Disability:* The definition used in this thesis is that of the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF), which states that disability is: 'an umbrella term for impairments, activity limitations, and participation restrictions, denoting the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors).' (World Health Organization, 2011, p. 303).

*Function:* Function is often used within the amputation and prosthetics research literature to refer to physical abilities, such as being able to walk or grasp objects with a prosthesis, and often this is distinguished from cosmesis or other things that a prosthesis can afford. However, function is a broad term and the definition in this thesis is that of the WHO's ICF (2011) which considers 'all human functioning' to fit with their categories of 'body functions and structures', 'activities' and 'participation' (p. 5).

*Limb absence:* The absence of a whole or part of an upper or lower limb. This term is used to collectively refer to both individuals with acquired limb absence and those with congenital limb absence.

*Limb difference:* An inclusive term describing any difference in a limb that differs from the norm of a regular biological limb. In this thesis, limb difference may refer not just to difference due to the partial or complete absence of a limb, but also the inclusion of a prosthesis that similarly means that a person's limb is different from the 'norm'.

*Limb-fitting centre:* A place where individuals go to be fitted with a prosthesis. These locations are often the practices of prosthetists that include rooms for consultations as well as workshops for the fabrication and adjustment of limbs. These centres may be attached to public or private hospitals, they may be independent rehabilitation services centres, or they may be attached to a particular prosthesis manufacturer.

*Limb loss:* See *acquired limb absence*.

*Prosthesis/prosthetic*: An artificial part of the body. In the context of this thesis, a prosthesis is delimited to a whole or part of an upper or lower limb (part or an entire arm or leg), and so excludes other prostheses (breast implants, artificial eyes, heart valves, etc). The term *artificial limb* (sometimes shortened to *limb* where it is apparent what is being referred to) is used interchangeably with this.

*Prosthesis user*: An individual that makes use of an artificial limb.

*Prosthetic solution*: A term employed to refer to the particular prosthesis an individual uses. Some individuals refer to the part that acts as an artificial substitute for a biological limb as the prosthesis, referring separately to the socket, liners, or other parts or materials. This term is used in this thesis to refer to all aspects of the artificial limb.

*Prosthetist*: An individual who practises the design and fitting of prostheses for individuals with limb absence. Sometimes referred to as a rehabilitation professional.

*Residual limb*: The distal part of the body to which a prosthesis is commonly attached. Residual limbs vary in location, length, and mass. Residual limbs may change in mass over time, particularly soon after an amputation. Residual limbs are often referred to as *stumps* by individuals with limb absence.

*Socket*: The part of the prosthesis that connects to the individual, often partially or completely enveloping a residual limb to give a firm attachment.

*Stump*: An informal term for a *residual limb*, particularly following amputation.

*Unilateral*: Involving one side. In the context of this study, unilateral limb absence is the absence of either one upper or lower limb, or part of one of these. Since unilateral limb absence is the most common form of limb absence, it is not usually explicitly mentioned when describing the characteristics of a sample of individuals with limb absence, whereas *bilateral* is used to foreground and differentiate individuals with the absence of more than one upper or lower limb.

## Abstract

### ‘Just Normal’: A Grounded Theory of Prosthesis Use – Philip Jefferies

A significant number of individuals around the world live with limb absence and use prosthetic technologies to assist and enable them in various ways about their lives. The aim of this study was to enhance our understanding of prosthesis use through exploring a core concern of prosthesis users and to develop a theory of how this concern is managed. By employing classical Grounded Theory methodology (Glaser, 1978, 1992, 1998, 2001, 2003, 2005, 2009, 2011a, 2013, 2014; Glaser & Strauss, 1967), data from 24 participants that used upper- and/or lower-limb prostheses were collected and analysed. These individuals were interviewed using a flexible, unstructured interviewing style. In addition to interviews, data from internet forums, blogs and autobiographical texts were also included, all of which were analysed in accordance with the established procedures of Grounded Theory methodology, which included open and selective coding, theoretical memoing, and theoretical sampling.

A main concern of being ‘just normal’ emerged through analyses, and the data were further explored in order to develop a theory of the resolving of this concern. *Just normal* is the condition of being and living in ways that persons variously perceive are ‘about right’; that are sufficient, that are fair, and generally how things ‘ought to be’ for them, as they see it. Three modes of *just normal* were identified, which were: *preserving* being just normal, where persons manage threats to their ability to be this way, *redressing* to just normal when this is judged to be lacking and so persons bring themselves into alignment with this, and *persevering* with just normal, accounting for how persons keep going with living just normally and despite difficulties that may accompany this.

The theory provides a novel perspective on users of prostheses and elucidates the benefits and challenges of living with artificial limbs, as persons make efforts to live in ways they see as fitting with what they consider is *just normal*. Such an understanding has the potential to facilitate multidisciplinary teams involved in the appropriate fitting of prostheses, inform goal-setting in rehabilitation, and how to

manage further consultations. The theory links to existing research and goes beyond this in providing an understanding of what compels prosthesis users to act in particular ways. It also has the transferrable potential to related areas of living with assistive technologies, the experience of disability more broadly, and beyond.

## Chapter 1: Introduction

Nobody realizes that some people expend tremendous energy merely to be normal. (Camus, 2010, p. 80)

### Just Normal

The core contribution that this thesis presents is the theory of 'just normal'. This is an 'emergent' theory, developed through a Grounded Theory analysis of accounts of prosthesis users. The theory addresses a concern that is central in the area of prosthesis use, indicating how persons are continually engaged in resolving this concern, and how they do so in varied ways. This resolving theory is argued to provide a means of usefully interpreting a range of scenarios in the substantive area of prosthesis use and beyond.

The main concern and central concept in the theory is 'just normal'. 'Just normal' is, in essence, the quality of something being 'about right' – that something can be judged by a person as fair and sufficient. This also means it is 'good enough', and can be judged by knowing about the variability of the thing such that persons know whether a particular occurrence of something is acceptable. So when persons seek to be 'just normal', or to live 'just normally', this may involve living in ways that they perceive are right, reasonable, fair or sufficient, and this is informed by knowing how this could be otherwise. Being 'just normal' is not necessarily about optimising one's circumstances, but instead that a regular day-to-day being is in accordance with how a person views things at least *ought* to be; that it shouldn't be 'too much to ask' to be able to be a particular way.

The thesis discusses the theory of 'just normal' in detail, exploring the variation in this core pattern, and in doing so elaborates how 'just normal' can be considered a pervasive concern for prosthesis users. Once fully understood, a theory of 'just normal' can be used to helpfully interpret a number of important contexts within prosthesis use.

Ten chapters document the development of this study and help to substantiate the claim that 'just normal' is a pervasive pattern in the accounts of prosthesis users

involved in this study, and that this is an important and useful discovery for the area of prosthesis use. Over the course of these chapters, the work underpinning this is elaborated through exploring what is known about limb absence and prosthesis use, leading to the rationale for the research study and the proposal for the development of the theory, the explication of the methods and processes involved in this, followed by a discussion of the main emergent theoretical product of the thesis, which is then explored and critically evaluated. A specific breakdown of each chapter is now presented, enabling an overview of the content and purpose of each.

### Thesis Conspectus

In *chapter two*, the substantive area of prosthesis use is introduced. This involves a discussion of the nature of prosthetic limbs and the contexts within which individuals might use them. The extant literature on the psychosocial aspects of limb absence and prosthesis use is identified and discussed, leading to the rationale for the present study.

In *chapter three*, the Grounded Theory methodology that guided the research is introduced. An overview of different epistemological and methodological versions of Grounded Theory is given before a justification and elucidation of the use of 'classical' Grounded Theory methodology. This chapter also involves discussion of issues of preconception, emergence, and openness to theoretical discoveries.

In *chapter four*, the application of the methodology is described and design decisions are elucidated. In particular, data collection and analysis procedures are elaborated. The sources of data involved in the study are identified and explanation is given to how these were interrogated. This chapter also involves contending with ethical considerations and managing the development of the emerging theory.

In *chapter five*, the main concern and resolving core category of the theory of *just normal* are outlined and are examined in the context of prosthesis use.

*Chapters six, seven and eight* involve discussion of the categories that substantiate the theory, where the key conceptual processes of *Preserving, Redressing, and*

*Persevering* are explored with reference to illustrative accounts. These chapters are dedicated to discussing each of these in turn.

In *chapter nine*, the significance of the emergent theory is explored, foregrounding the key discoveries of the study. Prominent aspects of the theory are discussed in relation to areas highlighted in the research literature and scenarios indicated to be important by prosthesis users themselves. The theory is also explored in terms of how it compliments and extends other conceptual and theoretical accounts in the area of prosthesis use and beyond, and how fresh insights are brought to these discussions.

Concluding this thesis, *chapter ten* provides a critical discussion of the theory of *just normal*. This involves evaluation against the criteria of Grounded Theory methodology, which include the need to ensure good *workability, relevance, fit, and modifiability*. In conjunction with chapter nine, this enables a judgement of the worth of the theory. Within this chapter, proposals are also given for further development of the theory and subsequent investigation in the substantive area and beyond.

## Chapter 2: Prosthetics

### Introduction

In this chapter, the area of prosthesis use is introduced and explored. This involves a review of the research literature that has investigated limb absence and prosthesis use and illuminates the varied qualities of artificial limbs and their users. This review leads to the rationale for the empirical work that was undertaken in this study.

### Limb Absence and Prostheses

Prostheses are adaptive and enabling entities used by a significant number of individuals worldwide. The word itself has roots in Greek, meaning ‘an addition’, from ‘pros’ meaning towards and ‘tithenai’ to place (Oxford University Press, 2014). A prosthesis can therefore take any shape or form in providing something that would not normally be there. In particular, this thesis is concerned with limb prostheses. These are used by individuals who have an absence of one or more limb regions, and so the ‘addition’ that the prosthesis provides is for an absent arm or leg, or part of these.

The aetiology of limb absence itself is varied, but can be categorised as acquired or congenital absence. In acquired limb absence, persons have lost a limb, and this may be due to trauma (e.g., motor vehicle or work-related incidents, warfare injuries, self-harm), dysvascularity (e.g., diabetes mellitus or cardiovascular disease), infections (gangrene), tumour or cancer, or neurological disorders (polio, diabetic neuropathy). In many of these cases, limb loss due to amputation is a life-saving surgical procedure. In cases of congenital limb absence, a limb may be lost prior to birth due to complications in pregnancy (e.g., amniotic band constriction) or to teratogenic agents (e.g., thalidomide). However, congenital limb absence may also be due to a lack of limb development, possibly also due to teratogenic agents or to genetic variation, and so congenital cases can be more inclusively defined as the absence of a limb at birth. Persons with either form of limb absence are often informally referred to, and often refer to themselves, as ‘amputees’, despite

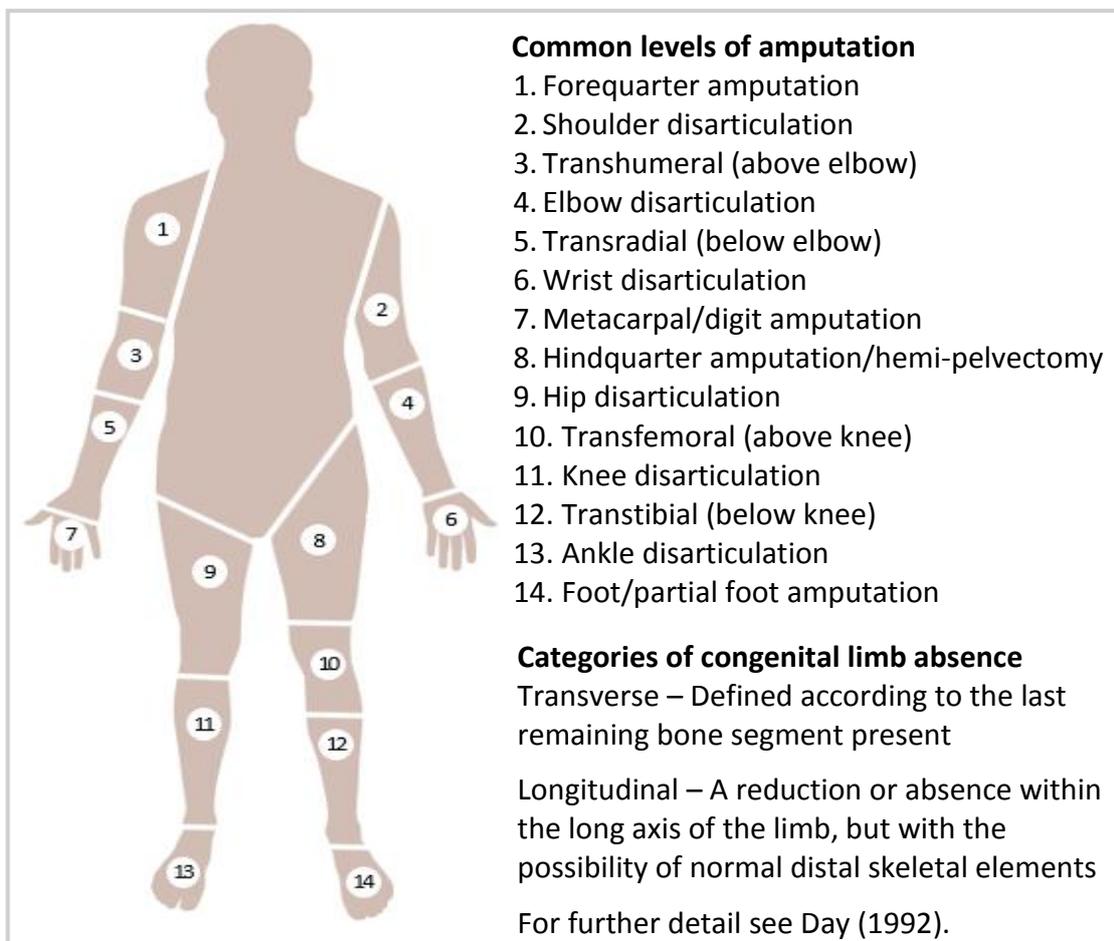
including congenital cases in their number where a limb was not lost (a case in point being the Amputee Coalition of America, a national organisation supporting individuals who “have experienced amputations or were born with limb difference”, Amputee Coalition of America, 2014). Additionally, individuals may be born with limb difference and later undergo related amputations, such as in cases where medical professionals suggest a prosthesis could provide greater physical function than is currently possible for an individual due to their limb difference. For clarity, in this thesis I refer to ‘persons with limb absence’ as the collective term, and refer to acquired or congenital limb absence where relevant.

The incidence of limb absence varies globally, though is hard to precisely quantify due to the varying causes of limb absence as well as many countries not keeping adequate records of hospital amputations (Esquenazi, 2004). A report in 2005 indicated that 1 in 190 people live with limb loss in the US, and estimates suggest this currently summates to two million individuals, a figure projected to reach 3.6 million by 2050 (Ziegler-Graham, MacKenzie, Ephraim, Trivison, & Brookmeyer, 2008). In the UK, statistics concerning limb absence are not currently collected, but the United National Institute for Prosthetics & Orthotics Development (2013) reported that nearly 6,000 individuals with limb absence were referred to prosthetic centres in 2010-11. Limb absence statistics are also not officially collected in the Republic of Ireland, but a national representative organisation recently claimed that there are over 5,000 individuals living with limb absence in this country (Amputee Disability Federation Ireland, 2014).

Acquired limb absence is the most prevalent form of limb absence. The Limbless Statistics report for 2010-11 indicates that only 4.8% accounted for congenital cases in the UK, but this report is limited to those referred to centres for prostheses and so does not capture individuals with limb absence who may not opt for a prosthesis (United National Institute for Prosthetics & Orthotics Development, 2013). However, reports from the US appear to reflect this rate, where it is claimed that 158,000 individuals per year undergo amputations (Dillingham, Pezzin, & MacKenzie, 2002), compared to only 1,500-4,500 children per year who are reported to possess congenital limb difference (Smith, 2006). There is also a

difference in the prevalence of the region of limb absence. Smith (2006) reports that less than half of cases of children born with congenital limb absence in the US involve the absence of a lower limb, while Ziegler-Graham et al. (2008) estimate that lower-limb absence accounts for approximately 65% of individuals in the US who have lost a limb. In the UK, the Limbless Statistics report indicates that 91% of individuals referred to prosthetic centres in 2010-11 had lower-limb absence compared to only 7.9% with upper-limb absence. Of those with lower-limb absence, 1% were individuals with congenital limb absence and 79% had acquired limb absence. Of the upper-limb absence referrals, 49% had acquired limb absence, while 26% possessed congenital limb absence (the remaining percentages were classified as “no data” United National Institute for Prosthetics & Orthotics Development, 2013). While limb absence tends to be broadly distinguished within the literature as ‘upper’ or ‘lower’, there are varying levels of limb absence within these, and figure 1 below indicates the common categories of these.

The leading cause of upper-limb loss is trauma (92%) while for lower-limb loss vascular complications account for the majority of cases (78%) (Ziegler-Graham et al., 2008). Individuals with lower-limb loss are typically in their 60s or older at the time of amputation (Roberts et al., 2006), whilst individuals with upper-limb loss tend to be younger (60% are between 21-60 years old) (Dudkiewicz, Gabrielov, Seiv-Ner, Zelig, & Heim, 2004). Older age means individuals with lower-limb loss often present with other co-morbidities, such as diabetes and cardiovascular disease, leading to poor survival rates following an initial amputation (Dillingham, Pezzin, & Shore, 2005; Icks et al., 2011). Furthermore, it has been claimed that whilst trauma-related amputations may be decreasing, the increasing prevalence of obesity, which is linked to diabetes, and the growing global population living to older ages, linked to dysvascular conditions, mean that the incidence of amputation is expected to steadily increase (Ziegler-Graham et al., 2008).



*Figure 1. Common categories of limb absence*

For individuals with limb loss, the prescription of a prosthesis is the most common form of intervention in their rehabilitation. Individuals with congenital limb absence may use prostheses, with some being fitted in early childhood and others taking them up later in life. Depending on the aetiology of a person's limb absence, artificial limbs may be obtained in order to restore function or to provide function if this part of the body was never present. The discussion now moves to consideration of the varied nature of artificial limbs.

## Prosthetics

Prosthetic limbs are artificial extensions of the body that take the place of absent biological limbs. They can be dynamic entities, operated by the user through bodily movements, manual adjustment, or myoelectric signals, or they can be static, non-mechanical appendages. Prostheses tend to be wholly removable, through decoupling oneself from a suspension socket or releasing a strap, though some

individuals undergo osseointegration, where a limb is surgically connected to bone. However, osseointegration may only involve the bonding of an anchor which an artificial limb can then attach to, meaning a prosthesis is also largely removable. Fundamentally, a prosthetic limb has the scope to include all manner of ancillaries that may be mechanical or non-mechanical in their nature and that may resemble or may not resemble a biological limb. An illustration of the variety of contemporary prostheses is given in Figure 2 below.



*Figure 2. Collage of various contemporary prostheses<sup>1</sup>*

In recent years, prosthetic technology has developed significantly. The incorporation of new materials such as carbon fibre and metal alloys has enabled artificial limbs to become lighter and more durable, requiring less energy and exertion on the part of the user. Many limbs now afford more degrees of freedom in movement, consequently affording new levels of dexterity. The shape and form of limbs has also developed, and it is now possible to have cosmetic covers made for limbs that make them virtually indistinguishable from their biological

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<sup>1</sup> Images were sourced via Google images and had been labelled for re-use.

counterparts, matching skin tone, texture, veins, hairs, fingerprints, tattoos, or other custom requirements. Such improvements in prosthetic technology have the potential to enable individuals far more than in decades prior.

The industry itself has also seen a significant shift in value and operation. In 1990, the orthotics and prosthetics industry reportedly generated \$700m in the US (Pederson, 2001), of which artificial limbs constitute a significant proportion. A decade later, the industry was estimated to be valued at \$2.6bn (Hanger Orthopedic Group, 2012). In a market analysis white paper, McGimpsey and Bradford (2010) reported that the US prosthetics market alone drew \$1.45bn in 2006, and they estimated this would reach \$1.85bn by 2013. Together with accompanying services, this market in the US alone is valued at \$5bn annually.

Industrial competition and user expectations have been said to be the drivers of technological developments both in Europe and the US, leading to the formation of several multinational organisations that manufacture and supply prostheses (McGimpsey & Bradford, 2010). Today there are also a vast number of small companies in Europe and the US that provide prosthetic services and innovating new technologies that continue to improve prosthetic provision (McGimpsey & Bradford, 2010).

Despite the prevalence of suppliers and the multitude of varieties of prostheses currently being produced, there are restrictions on what is obtainable. Developing countries often have limited resources with which to provide public prosthetic provision, meaning many people may not be able to access prosthetic limbs at all, or if they can, these will be fairly basic (Bigelow et al., 2004; Strait, 2006; Swartz & MacLachlan, 2009). In other parts of the world, restrictions are also found, often relating to financing limbs. Quoting a study estimating costs for service members suffering limb loss in the American military, the Limb Loss Task Force/Amputee Coalition (2012) report that five-year prosthesis-related costs for a person with a lower-limb amputation would be around \$230,000, while for upper-limb this would be approximately \$117,000, and for multiple limb loss costs could be as high as \$450,000. While the US military may provide financial assistance to obtain prostheses, civilians in need of artificial limbs may be dependent on third-party

insurers or healthcare plans, which can often limit availability or options when a limit is set on what may be funded (Biddiss, McKeever, Lindsay, & Chau, 2011; Limb Loss Task Force/Amputee Coalition, 2012). McGimpsey and Bradford (2010) report that financiers also tend to question the need for more expensive limbs if cheaper alternatives appear to suffice. Explaining the meaning of differently priced limbs, the authors state that between \$5,000-7,000 will afford a lower-limb prosthesis enabling an individual to become a 'community walker', while upwards of \$20,000 will enable walking 'without having to think about every step' (p. 11). In a Canadian study, Biddiss et al. (2011) surveyed upper-limb prosthesis users about the costs incurred by their prostheses (n=109), finding that of the 40 individuals that incurred costs themselves, a prosthesis cost an overall average of \$9,986 per limb, where electric prostheses cost an average of \$12,156, body-powered prostheses cost \$4,532 and passive/static limbs cost \$6,694.

In addition, a prosthesis is rarely associated with a singular cost, but rather is ongoing as limbs require replacements, repairs and modifications. Nair, Hanspal, Zahedi, Saif and Fisher (2008) found that individuals with transfemoral amputations required an average of 0.96 new prostheses, 3.27 new sockets, 2.31 major repairs, 3.36 component changes and 21.85 minor repairs over a 10-year period, while individuals with transtibial amputations required an average of 1.4 new prostheses, 2.9 new sockets, 3.2 major repairs and 14.1 minor repairs. Biddiss et al. (2011) reported that individuals using upper-limb prostheses incurred an average yearly maintenance expense of \$3,179 (range = \$100-\$10,000). While Nair et al. suggest that the relatively recent introduction of 'modular' prostheses that improve repair and adjustment processes may go some way towards reducing costs through avoiding total replacement, these figures indicate that prosthetic provision is a costly affair, and the projection of a rise in limb absence prevalence indicates that supporting this is a growing concern for healthcare providers and third-party reimbursers alike.

Like difficulties in quantifying limb absence, it is similarly hard to know the number of individuals using prosthetic limbs due to the variety of ways that artificial limbs can be acquired. Prostheses can be prescribed and obtained under healthcare

systems in countries that have such systems, but in Ireland this is typically only for the first prosthesis, and thereafter any prostheses must be paid for by other means, unless the individual qualifies for a HSE medical card, though limb absence itself is not an automatically qualifying criterion (HSE, 2013). Individuals may also be referred or refer themselves to private prosthetic centres that obtain or manufacture limbs themselves, and they may also contact manufacturing companies as direct customers. In addition to this, there are growing reports of individuals fabricating their own limbs, given the right materials, expertise and motivation (e.g., ABC News, 2014; BBC, 2013), though these tend to be less sophisticated. In the next section, the discussion moves to an exploration of the use and non-use of prostheses.

### Prosthesis Use and Non-Use

Not all persons with limb absence will use a prosthesis. Statistics quantifying proportions of persons that use and do not use prostheses are largely non-existent, though in a market analysis white paper, McGimpsey and Bradford (2010) claim that of the nearly two million individuals in the US that are estimated to be living with limb absence, 1.5 million are users of prostheses, leaving a quarter of a million that are not. However, the authors do not account for how this number was arrived at and so these figures must be considered with caution. Reviewing the research literature, Raichle et al. (2008) note that reported prosthesis usage ranges between 27-56% across studies for individuals with upper-limb amputations and 49-95% for lower-limb amputations, though the equivocality of studies limits further interpretation.

One way of assessing prosthesis use can be through considering rates of successful fittings, or in other words, the proportion of individuals referred to prosthetic services that could actually be fitted with a prosthesis. Fletcher et al. (2001) report rates across studies of 50-90% for successful fittings in older patients with lower-limb amputations. The incidence of failure to fit has been attributed to health-related issues (such as cardiovascular disease), cognitive debility and unsuitable residual limb sites. Fletcher et al. (2001) also found that successful lower-limb

fittings could be predicted by marriage, a younger age, living with other family members, and a more distal limb absence. However, two main limitations of quantifying rates of usage in this way are that the data do not include those who do not seek a prosthesis in the first place or who are not referred for fitting. In addition, a successful fitting does not necessarily denote ongoing usage.

In exploration of ongoing usage, rates of retention and abandonment have been investigated in the literature. Biddiss and Chau (2007a) reviewed studies undertaken in the previous 25 years in upper-limb use, determining in the paediatric population that an average of 45% of body-powered limbs would be rejected compared to 35% of electric limbs. In an adult population, rejection rates of 26% for body-powered limbs and 23% for electric limbs were reported. In their subsequent study (n=242), Biddiss and Chau (2007b) determined that a fifth of those surveyed in Canada had abandoned their limb, and that origin of limb absence, being female, and having bilateral limb absence were factors implicated in predicting rejection. Those rejecting their limbs expressed dissatisfaction with the state of available technology, specifically in comfort and physical function. The researchers also determined that shorter time to fitting (see also, Biddiss & Chau, 2008) and being involved in the selection of the limb could facilitate ongoing use.

Rates of abandoning lower-limb prostheses are similarly significant, with one study (n=396) reporting 33% of Canadian individuals with lower-limb absence abandoned their prosthesis in the first year, with 16% having never worn it (Gauthier-Gagnon, Grisé, & Potvin, 1999). The researchers indicated that many reject a limb on the basis that it has a poor fit, but will not have sought adjustments even when centres were close and appointments to do so are 'readily available'. Commenting on this, Schaffalitzky (2010) suggests that this indicates a tendency to abandon a limb regardless of fit, and so other factors may be at play. In the US, Dolezal, Vernick, Khan, Lutz and Tyndall (1998) surveyed lower-limb prosthesis users (n=142), linking non-use to being black (African-American), lower levels of education, unemployment, comorbidity of diabetes mellitus and peripheral vascular disease, use of a walking frame, and the experience of phantom limb pain.

Furthermore, the use of a prosthesis varies in terms of how often a person uses a prosthesis they have been fitted with. Khoury (1983) surveyed individuals with acquired upper- and lower-limb absence in Jordan (n=100) and determined that out of the 56 fitted with a prosthesis, 32 'always' wore their limb, 11 wore it 'occasionally' and 13 never wore their limb. Khoury found that being male, educated, and having a lower-limb prosthesis were factors most associated with use reported as 'always' or 'occasionally'. Those who elected not to use their limb or used it infrequently claimed that it was 'heavy', 'painful', 'poor fitting' or 'unoperational'. In the US, Pezzin, Dillingham, MacKenzie, Ephraim and Rossbach (2004) reported that 94.5% of individuals with acquired upper- and lower-limb absence (n=935) that they surveyed used a prosthesis and used it 'extensively', entailing at least 71 hours per week (+/- 41 hours). Over three-quarters of their sample reported that they were generally satisfied with their prostheses, but just under a third expressed dissatisfaction with comfort. The authors also identified that a shorter period between amputation and prosthesis fitting was associated with frequency of usage and satisfaction with the limb.

Frequency of usage has also been explored separately for upper- and lower-limb prosthesis use. In terms of the frequency of upper-limb use, Davidson (2002), noted a large discrepancy in the literature, reporting 'regular' use that ranged between 35-81%. While Davidson did not elaborate on a definition of regular, an earlier study involving the author reported that 37% of upper-limb users surveyed in Australia (n=27) were 'regular' users, explained as using a prosthesis for eight or more hours per day (Jones & Davidson, 1995). In addition, this study indicated 18.5% were 'occasional' users, which involved wearing the limb only for 'specific purposes, such as to check the fit, for social occasions or for shopping' (p. 439). The researchers state that the significant variation in usage rates could not be adequately explained by other extant research, but in her survey of Australian upper-limb prosthesis users (n=70), Davidson (2002) determined that 56% wore their prosthesis 'once in a while' or 'never', and found that there was a moderate association between the amount of time spent wearing a limb and satisfaction with the limb. In a further study in the US, 107 upper-limb prosthesis users were

surveyed about their limb usage, the results of which indicated that having a proximal amputation and lesser level of phantom limb pain were associated with increased usage of an artificial limb (Raichle et al., 2008).

The frequency of lower-limb prosthetic usage has also been measured under varying criteria in the literature. Bilodeau, Hébert and Desrosiers (2000) reported that 81% of surveyed individuals in Canada (n=65) wore their prosthesis on a daily basis, of which 89% wore their limb for six or more hours per day. Lesser use was associated with older age, being female, possessing a wheelchair, level of physical disability, cognitive impairment, poorer perceptions of health and dissatisfaction. However, Kauzlarić, Kauzlarić and Kolundžić (2007) have reported an average of 5.5 hours use for individuals they surveyed in Croatia (n=46), which ranged between 3-10 hours. Greater frequency of usage, however, has been correlated in the US with younger age, employment, being married, distal amputation, amputation due to trauma, and a lack of phantom limb pain (Raichle et al., 2008).

These studies indicate that the incidence of prosthesis use, including the frequency of use to complete abandonment for both upper- and lower-limb prosthesis users, varies significantly, and while some predictors of these have been put forward, they have not been adequately accounted for in the literature (Biddiss & Chau, 2007a; Raichle et al., 2008). Given that a prosthesis can be viewed as a fundamentally enabling technology, or 'adjuvant in daily-life activities' (Vasluian et al., 2013, p. 1), as it provides a level of function for persons with limb absence that they would not otherwise have without a limb, being without a prosthesis indicates being deficient of this function. A lack of use or 'underutilisation' in this way has been interpreted by some as potentially problematic (e.g., Gunawardena, Seneviratne, & Athauda, 2004; Schaffalitzky, Gallagher, MacLachlan, & Wegener, 2012), and could lead to tension when considerable funds from another party have been committed to financing a limb.

There is therefore a pressing need to develop a richer picture of prosthesis use in order to understand what may account for variable usage. Doing so involves a deeper understanding of the person that uses a prosthesis, and this involves exploring factors related to adaptation and adjustment to the loss of a limb as well

as to the acquisition and adjustment to an artificial limb (Gallagher, Desmond, & MacLachlan, 2008).

## The Psychosocial Aspects of Limb Absence

### *Acquired Limb Absence*

The loss of a limb can be a life-changing event, and the research literature details a diverse and widespread range of extensive effects that are associated with acquired limb absence, affecting the person at the physical, psychological and social functioning level (Desmond et al., 2012; Fishman, 1949; Horgan & MacLachlan, 2004; Williamson, Schulz, Bridges, & Behan, 1994). In particular, the permanent loss of a limb means that persons experience functional impairment, finding themselves physically restricted (Schoppen et al., 2003), they may experience pain as a consequence of the amputation (Ephraim, Wegener, MacKenzie, Dillingham, & Pezzin, 2005), alterations to their body image (Gallagher, Horgan, Franchignoni, Giordano, & MacLachlan, 2007), their self-concept (Grobler, van Schalkwyk, & Wagner, 2006), their sexuality and relationships with others (Geertzen, Van Es, & Dijkstra, 2009; Ide, 2004; Williams et al., 2004), and restrictions from community and wider social participation (Gallagher, O'Donovan, Doyle, & Desmond, 2011; Medhat, Huber, & Medhat, 2010).

Studies have also indicated the presence of depressive symptomatology post-amputation in 13-35% of cases (Atherton & Robertson, 2006; Desmond & MacLachlan, 2006; Gallagher & MacLachlan, 2000a). In particular, the two years following an amputation are reported to present an elevated risk (Horgan & MacLachlan, 2004; Singh et al., 2009), but some have noted that depression may remain elevated for up to 10 years after the loss of a limb (Bodenheimer, Kerrigan, Garber, & Monga, 2000). The experience of depression in limb absence has also been found to be linked with other negative psychosocial outcomes that include elevated general anxiety (Atherton & Robertson, 2006; Donovan-Hall, Yardley, & Watts, 2002; Livneh, Antonak, & Gerhardt, 1999; Singh et al., 2009), body image anxiety (Fisher & Hanspal, 1998; Rybarczyk, Nyenhuis, Nicholas, Cash, & Kaiser, 1995), feelings of vulnerability (Behel, Rybarczyk, Elliott, Nicholas, & Nyenhuis,

2002), diminished self-esteem (Donovan-Hall et al., 2002; Dunn, 1996), phantom limb pain and neuroticism (Badura-Brzoza et al., 2006), general pain (Ide, 2011), lower levels of perceived health and social support (Ikram, Iqbal, Bin Ayez, Zaheer, & Matee, 2014; Rybarczyk, Dnyenhuis, Nicholas, Alioto, & Blair, 1992; Senra, 2013), greater self-awareness of impairment, lower identification with the impairment (Senra, 2013), and lower perceived quality of life (Asano, Rushton, Miller, & Deathe, 2008; Rybarczyk et al., 1995).

Anxiety is also commonly associated with the loss of a limb, and similarly this is prominent soon after the loss of a limb, but is not generally found in long-term follow-ups (Horgan & MacLachlan, 2004). Atherton and Robertson (2006) determined that 30% of individuals undergoing amputations (n=67) exhibited symptoms of anxiety in their post-operative period, which they note is significantly elevated compared to a 12.6% morbidity rate observed in the general adult UK population (Crawford, Henry, Crombie, & Taylor, 2001). Anxiety in individuals with limb loss has also been linked to body image disturbance (Atherton & Robertson, 2006; Breakey, 1997b; Fisher & Hanspal, 1998), activity limitation (Callaghan, Condie, & Johnston, 2008) and self-consciousness (Atherton & Robertson, 2006; Donovan-Hall et al., 2002).

There are also indications that levels of Post-Traumatic Stress Disorder (PTSD) in individuals experiencing the loss of a limb are higher than that which may be found in the general population. Desmond and MacLachlan (2006) surveyed ex-service members in the UK with lower-limb loss and found that 24.6% of their sample (n=582) reported symptoms of PTSD. In a similar survey, Doukas et al. (2013) found 14.8% of their sample of US service members (n=324) deployed in the recent conflicts in Afghanistan and Iraq and who underwent unilateral lower-limb amputations screened positive for PTSD, with 10% for bilateral limb amputations. Similarly, Graham, Parke, Paterson and Stevenson (2006) surveyed persons who had suffered upper- and lower-limb loss as a result of terrorism in Northern Ireland (n=75) and found that 67% reported symptoms of PTSD. PTSD is normally associated with limb loss due to trauma more than any other aetiology (Cavanagh, Shin, Karamouz, & Rauch, 2006), and remains a concern if individuals experiencing

traumatic limb loss do not receive appropriate intervention. Cheung, Alvaro and Colotla (2003) contrasted individuals with lower-limb amputations (n=25) to those with upper-limb amputations (n=30), determining those with upper limb amputations displayed significantly higher rates of depression and PTSD symptomatology. The researchers suggest the extensive significance of the hand in the relationship with the world (self-care, self-expression, communication, occupation performing) means that the loss of an upper-limb impacts on the individual across numerous different domains, arguably having an overall greater impact on the person.

Individuals with acquired limb absence are also often reported to express dissatisfaction with their body image (Breakey, 1997a; Foort, 1974; Holzer et al., 2014; Parkes, 1975). In addition to being linked with depression (Breakey, 1997b; Rybarczyk et al., 1992, 1995) and general anxiety (Breakey, 1997b; Fisher & Hanspal, 1998), dissatisfaction with one's body image after the loss of a lower limb has been associated with lower levels of self-esteem (Breakey, 1997b), lower levels of life satisfaction (Breakey, 1997b), as well as reduced levels of physical activity (Tatar, 2010; Wetterhahn, Hanson, & Levy, 2002) and elevated phantom limb sensations (Alessandria, Vetrugno, Cortelli, & Montagna, 2011).

Quality of life has also been a focus for research involving persons who have lost a limb, but a recent systematic review on this was unable to come to a definitive conclusion reportedly due to poor study quality (Sinha & van den Heuvel, 2011). However, a follow-up study conducted by the review authors found that quality of life was lower in their sample of lower-limb amputees (n=605) than for the general population, and that higher quality of life was associated with employment status, use of a prosthesis, non-use of assistive devices other than a prosthesis (canes, crutches), lower residual limb and phantom pain, and other comorbidities (Sinha, van den Heuvel, & Arokiasamy, 2011). A further study involving individuals with lower-limb absence (n=368) similarly found that a higher quality of life was associated with an absence of comorbidities, lower residual limb and phantom limb pain, employment status and non-use of assistive devices other than a prosthesis, but also found associations with younger age, lower functional restriction, greater

adjustment to limitation, increased social adjustment and lower restrictions in athletic ability (Sinha, van den Heuvel, & Arokiasamy, 2014).

It is clear from these studies that there is a range of significant deleterious consequences associated with the loss of a limb. However, the loss of a limb is not necessarily a wholly negative experience. There are numerous cases of individuals using the experience to 'take stock' or to 'turn their life around' (e.g., Rigsby, 2009; Sabolich & Sabolich, 2001), and some achieving more than they consider they would have had they not lost a limb (Gow, MacLachlan, & Aird, 2004, p. 156). Collectively, these positive aspects can be termed 'post-traumatic growth' (see Calhoun & Tedeschi, 2006) and the research literature includes a number of studies that have determined positive experiences associated with the loss of a limb (Couture, Desrosiers, & Caron, 2011; Gallagher & MacLachlan, 2000b; Livingstone, van de Mortel, & Taylor, 2011). For example, in Oaksford, Frude and Cuddihy's (2005) study, ten out of twelve of their participants with lower-limb absence described positive aspects about the loss of their limb, including an increased appreciation of the kindness of others, being more likely to help others out, an increase in patience, and a better appreciation of disability. In a study by Saradijian, Thompson and Datta (2008), men with upper-limb loss (n=11) indicated high self-worth through taking pride in self-perceived positive adjustment, considering their capabilities and their abilities to perform tasks and fulfil roles that were important to them. In Gallagher and MacLachlan's (2000b) study (n=104), nearly half of their participants considered that something good had happened as a result of their amputation, and that an ability to find positive meaning was associated with higher ratings of physical capability and health, lower levels of athletic activity restriction, and higher levels of adjustment to limitation. It is therefore important to consider that while the loss of a limb may be an unwelcome life experience often leading to undesirable physical and psychosocial consequences, there is also the potential for positive change.

Current perspectives in rehabilitation have also acknowledged the potential impact of sociodemographic, clinical and psychosocial variables that may vary from person to person and that may interact with factors associated with the loss of a limb (T. R.

Elliott, Kurylo, & Rivera, 2002; Livneh, 2001). In exploration of sociodemographic and clinical factors, researchers have assessed the impact of age, gender, cause and level of amputation, and the experience of related pain. In terms of age, researchers have suggested that older individuals fare better after the loss of a limb, inferred through lower reported levels of depression (Phelps, Williams, Raichle, Turner, & Ehde, 2008; Williamson et al., 1994), anxiety (Livneh et al., 1999; Singh et al., 2009) and PTSD (Phelps et al., 2008). Horgan and MacLachlan (2004) note that some studies have failed to find an association between age and depression following the loss of a limb (Behel et al., 2002; Rybarczyk et al., 1992), but interpret a broader age effect as a reflection of older persons being more accepting of undesirable bodily changes at their age than younger individuals, who may not respond as well to activity restriction and changes in appearance.

Potential gender differences have also been investigated, though no differences have been observed in terms of depression (Behel et al., 2002; Phelps et al., 2008; Rybarczyk et al., 1995), quality of life (Asano et al., 2008; Gallagher & MacLachlan, 2004; Rybarczyk et al., 1995), or post-traumatic growth (Phelps et al., 2008). However, Phelps et al. (2008) reported that women displayed greater PTSD symptomatology in their study of individuals (n=83) with predominantly lower-limb absence (97.4%), though the researchers noted this was not a robust finding and further research is warranted to clarify this.

Associations between limb loss aetiology and psychosocial outcomes have also not been found across measures of depression and PTSD (Kratz et al., 2010; Phelps et al., 2008; Rybarczyk et al., 1995), quality of life (Gallagher & MacLachlan, 2004; Rybarczyk et al., 1995), or post-traumatic growth (Phelps et al., 2008). However, some have indicated that chronic diseases such as diabetes or PVD may lead to more negative outcomes (Demet, Martinet, Guillemin, Paysant, & André, 2003; Desmond & MacLachlan, 2006; Williams et al., 2004). For instance, in a study of individuals with upper and lower limb amputations (n=539), Demet et al. (2003) found that amputations due to vascular conditions were significantly associated with social isolation. Similarly, in a study of individuals with lower-limb loss (n=89) Williams et al. (2004) discovered that limb loss due to non-traumatic injury was

associated with lower levels of social integration. However, in these cases it is difficult to determine the extent to which poorer outcomes following an amputation are due to the loss of a limb or related to an underlying medical condition related to the amputation. For instance, in a sample of individuals undergoing lower-limb amputations (n=68), Singh et al. (2009) found that the incidence of co-morbidities upon rehabilitation admission significantly predicted depressive symptomatology 2-3 years later, and this underscores the importance of taking existing conditions into account when considering limb loss outcomes.

The level of limb loss could also be expected to have some bearing on psychosocial adjustment to acquired limb absence, given that a greater loss of limb extremity could be equated with greater functional impairment, as well as increased energy expenditure when using a prosthesis (Waters, Perry, Antonelli, & Hislop, 1976). However, studies have failed to find an association between level of limb absence and psychosocial adjustment (Asano et al., 2008; Behel et al., 2002; Breakey, 1997b; Unwin, Kacperek, & Clarke, 2009; Williamson et al., 1994). Coffey (2012) notes that this is in keeping with the literature on chronic illness and disability which has repeatedly indicated that measures of physical impairment tend to be poor predictors of well-being (e.g., Albrecht & Devlieger, 1999; Maybury & Brewin, 1984).

The potential impact of pain associated with an amputation has also received attention in the literature. One kind of pain that is experienced following limb loss is phantom pain (the experience of pain in anatomical areas no longer present), and is said to occur in 50-80% of amputations (Flor, 2002). In addition, the incidence of pain in a residual limb is also reported frequently in the literature (Ephraim et al., 2005; Gallagher, Allen, & MacLachlan, 2001; Williams et al., 2014), and studies have indicated the risk to adjustment posed by both forms of amputation-related pain (Jensen et al., 2002; Murray & Fox, 2002; Pell, Donnan, Fowkes, & Ruckley, 1993; Whyte & Carroll, 2004). In further exploration of this, Whyte and Carroll (2004) surveyed individuals who had lost an upper or lower limb (n=315), determining that psychosocial dysfunction was significantly predicted by a greater intensity and duration of associated pain. Similarly, Gallagher et al.'s (2001)

study of individuals with lower-limb amputations (n=104) indicated that the incidence of associated pain was linked to lower levels of adjustment to limitations. In addition to sociodemographic and clinical factors, researchers have also explored the impact of psychosocial variables following the loss of a limb. This literature has determined significant associations between greater adjustment following the loss of a limb and greater perceived social support (Asano et al., 2008; Unwin et al., 2009; Williamson et al., 1994), social activity (Asano et al., 2008), perceived control (Dunn, 1996), sense of coherence (Badura-Brzoza, Matysiakiewicz, Piegza, Rycerski, & Hese, 2008), public self-consciousness (Atherton & Robertson, 2006; Williamson, 1995), self-esteem (Breakey, 1997b; Donovan-Hall et al., 2002; Varni & Setoguchi, 1996), lower perceived vulnerability (Behel et al., 2002), perceived social stigma (Rybarczyk et al., 1995), and greater levels of hope (Unwin et al., 2009) and optimism (Dunn, 1996).

In addition to this, the influence of differing coping strategies following the loss of a limb has also received attention. Livneh et al. (1999) explored the use of differing coping strategies in a sample of individuals with acquired limb absence (n=61), determining that an 'active problem-solving' approach to coping with stress (e.g., planning, positive reinterpretation, seeking social support) was associated with positive psychosocial adjustment, whereas emotion-focused coping (e.g., venting emotions, social withdrawal, self-criticism) and disengagement were linked with psychological distress and a poorer acceptance of disability. This was somewhat reflected in the study by Desmond and MacLachlan (2006), who sampled war veterans who had lost a lower limb (n=796) and determined that stressor avoidant strategies were associated with psychological distress and poor adjustment, while greater problem-solving was associated with lower-levels of depression and anxiety, and seeking social support with lower levels of depression and greater social adaptation. Similar results were observed by Desmond (2007) in her subsequent study of older males with upper-limb loss (n=138).

In a related investigation, Dunn (1996) explored salutary responses to upper- and lower-limb amputation (n=138) and found that individuals finding positive meaning about their limb loss tended to fare better than those unwilling or unable to see a

'silver lining'. Specifically, finding meaning in the loss of a limb was associated with lower levels of depression, while perceiving greater control over disability and dispositional optimism were linked to lower levels of depression and greater self-esteem. Dunn suggested that realising positive aspects could then help individuals to better come to terms with their situation – that it would foster 'acceptance' and help persons adjust.

A more recent series of studies have explored differential responding to limb loss through employing Self-Regulation theory (Coffey, Gallagher, & Desmond, 2014a, 2014b; Coffey, Gallagher, Desmond, & Ryall, 2014a; Coffey, Gallagher, Desmond, Ryall, & Wegener, 2014b; Dunne, Coffey, Gallagher, & Desmond, 2014). Self-regulation is the process of monitoring and managing discrepancies persons perceive between desired and actual states of being, and according to the Dual Process model (Carver & Scheier, 2000) employed in these investigations, these discrepancies are said to be managed through tenaciously pursuing goals (goal assimilation) or through engaging in flexible goal adjustment (goal accommodation). In this literature, the loss of a limb is considered to constitute a discrepancy that persons are prompted to manage. Using this approach, Coffey, Gallagher and Desmond (2014b) determined that individuals with lower-limb loss (n=64) who had stronger tendencies toward goal pursuit on rehabilitation admission would display higher physical and psychological quality of life six months after discharge, whereas those with stronger tendencies toward goal adjustment would later report lower ratings of perceived disability and higher environmental quality of life. In a related inquiry with individuals with lower-limb loss (n=98), Coffey, Gallagher, Desmond and Ryall (2014a) found that goal pursuit was significantly associated with positive affect, while goal adjustment was inversely associated with negative affect, indicating the utility of goal adjustment strategies in buffering against difficulties during rehabilitation. Moreover, these studies indicate that different goal management strategies influence subjective well-being in different ways. In exploration of the value of particular goals, Coffey, Gallagher and Desmond (2014a) determined that individuals with lower-limb loss (n=64) rated goals associated with interpersonal relationships, independence, and well-

being, as most important to them, and that the importance of goals was predictive of decreased depressive symptomatology and social adjustment at six months post-discharge. In addition, higher goal disturbance was predictive of poorer general and social adjustment, while greater goal disengagement was predictive of decreased depressive symptomatology. Coffey et al. note that while goal attainment could continue to be a focus for rehabilitation, it is also important to consider the utility of promoting goal disengagement for inaccessible or unrealistic goals following the loss of a limb.

Overall, this body of research indicates that the loss of a limb can be a highly impactful life experience and may lead to a range of negative outcomes, though there is also the potential for positive post-traumatic growth. Studies have also indicated that a number of sociodemographic and clinical factors impact an individual's adjustment to the loss of a limb, and specifically there are indications that poorer outcomes are associated with a younger age, an existence of comorbidities, and the experience of associated pain. There are also a range of psychosocial factors indicated to interact with adjustment outcomes, and the appraisal and encouragement of engaging differing goals and coping strategies may be advantageous to different individuals, depending on their particular circumstances post-limb loss. This research enables an overview of the psychosocial aspects of acquired limb absence, but a more complete picture of limb absence also involves considering the potentially unique features of congenital limb absence.

### *Congenital Limb Absence*

In contrast to limb absence due to limb loss, congenital limb absence has received markedly less attention in the research literature. In addition to this group being much smaller, congenital limb absence means that a person is born without the limb present, and so this imbalance of research may be because there is not an instance of loss and a resulting adjustment period to investigate. However, a number of studies have indicated difficulties that persons with congenital limb absence may yet experience as a result of an absent limb.

One study described children aged 8-16 with congenital limb absence (n=140) who reported higher perceptions of stigma and social exclusion than for children with other chronic health conditions (Ylimäinen, Nachemson, Sommerstein, Stockselius, & Norling Hermansson, 2010). Linked to this, studies have also suggested that adolescents with congenital limb difference possess a greater risk of depression, anxiety and diminished self-esteem (Varni, Rubinfeld, Talbot, & Setoguchi, 1989; Varni & Setoguchi, 1996). However, as development of a self-concept in youth occurs with the absence of a limb, it is integrated into a perceived body image and thus persons are said to develop a hardiness toward their limb difference which may not be so prominent in those experiencing limb loss (Rybarczyk & Behel, 2008). Additionally, as persons grow up experiencing stigma they are said to adapt to this and become better at managing further occurrences, thus becoming more resilient in adulthood (Frank, 1988). In some exploration of this, Krantz, Bolin and Persson (2008) investigated stigma-handling in women with congenital upper-limb absence (n=unspecified; multiple data sources), determining that individuals would employ a variety of strategies in managing daily life which were focused on controlling the information about one's status that deviated from the normality of a particular situation. These helped to avoid the 'micro-stresses' resulting from the reactions of others when limb difference was realised and so protected personal well-being.

One recent study explored the 'life situation' of Swedish individuals with congenital upper- and lower-limb absence (Sjöberg, Nilsagård, & Fredriksson, 2014). The researchers found few differences between this group (n=117) and the greater population in terms of health and activity levels and pursuits, though more were in employment than the national average. Additionally, a greater proportion of participants were in professions requiring theoretical expertise and fewer in construction or manufacturing professions than the national average. These findings link to that of Michielsen, van Wijk and Ketelaar (2011) who found that Dutch adolescents with limb difference (n=56) did not differ from a control group in terms of reported quality of life, but did report less activity diversity, in particular lower social and skill-based activity. This suggests that individuals with congenital limb absence may avoid pastimes and vocations they feel their limb difference does

not dispose them to, and indicates potential activity and employment-related barriers associated with an individual's limb difference.

This modest literature gives an overview of some of the unique features of congenital limb absence and indicates potential differences between this and that of acquired limb absence. In particular, growing up without a limb may mean that individuals are better able to manage difficulties posed by limb absence that may be experienced by both groups, such as the stigma of disability, and for individuals with congenital limb absence, the potential difficulties involved in the loss of a limb will not be experienced. However, in terms of individuals coming to use prostheses, there is no reason to suspect differences between these groups, and indeed, the literature does not tend to separate these groups in analyses.

In summary of this section, the research reports a range of significant psychosocial features that accompany the absence of a limb. A number of factors are linked to the loss of a limb and to a consequent adjustment process, and these may be important to attend to in rehabilitation contexts. While persons with congenital limb absence may not experience adjustment to limb absence in the same way that those with acquired limb absence do, difficulties may instead be experienced at more formative stages in their lives. However, a number of factors conspire to complicate an integrated understanding of the psychosocial aspects of limb absence. In particular, definitions of psychosocial adjustment vary between studies or remain undefined (see Horgan & MacLachlan, 2004; Murray, 2010, p. 82) and heterogeneity in design and poor study quality limits the consolidation of some areas of this knowledge (McKechnie & John, 2014; Sinha & van den Heuvel, 2011). Despite this, a broad overview is enabled of the varied psychosocial features of limb absence and thus some of the features relevant to an understanding of users of prostheses. In addition to this, the adoption of an artificial limb has also been associated with a range of psychosocial phenomena in itself, and this constitutes the following discussion.

## The Psychosocial Aspects of Prosthesis Use

The literature exploring the psychosocial adjustment to the use of a prosthesis and prosthesis use outcomes is relatively small compared to that which has investigated the psychosocial aspects of limb absence. However, many studies that explore limb absence either include prosthesis users or combine users and non-users in samples without recognising the importance of investigating the potential impact of an artificial limb in itself.

For instance, a prosthesis enables or enhances function towards that which a biological limb would otherwise provide, and thus the use of a limb will have an impact on a person who would otherwise be without this, across a range of domains (e.g., see Cook & Miller, 2012; MacLachlan & Gallagher, 2003). To consider the framework of the WHO's International Classification of Functioning, Disability and Health (ICF; 2011), the enabling properties of a prosthesis can be considered to support individuals across all three domains of *body functions and structures*, *activities*, and *participation*. For example, a prosthesis can provide a sense of bodily completeness and support gendered identities (Murray, 2008), it can facilitate activities of daily living, as well as support socialising and participation, and gesturing and partaking in rituals (Hall & Orzada, 2013; Samuelsson, Toytari, Salminen, & Brandt, 2012). Furthermore, studies exploring lower-limb prosthesis use have determined that an improved quality of life is associated with use of a prosthesis but not with other assistive technologies, indicating that there is something distinctive about the use of an artificial limb compared to use of other aids such as walking sticks or crutches (Sinha et al., 2014, 2011).

However, there may also be associated issues with the use of a prosthesis, given that it is an imperfect substitute for a biological limb. For example, issues of comfort and limitations in physical functioning often leave individuals disappointed with the state of the technology, and this has been linked to device abandonment (Biddiss & Chau, 2007b). The weight of carrying an artificial limb can also fatigue individuals quicker than without one (Whyte & Niven, 2001), and in addition, persons using prostheses tend to remain in a cycle of follow-up consultations in order to maintain the technology they use, which may be undesirable

consequences of the adoption of an artificial limb. There may also be differences in how the technology is received, for instance, where a prosthesis could be viewed as embodying independence and ability, while others may consider that a limb embodies disability because it reminds or represents what they are unable to do without it (Gow et al., 2004). There are also indications from the research that a view of oneself may be antagonised by the use of a mobility aid, as generally these are associated with stigma of aging and disability (Aminzadeh & Edwards, 1998). It might therefore be inferred that the use of a lower-limb prosthesis in particular may in fact contribute to a negative self-perception if considered this way. However, use of upper- or lower-limb prostheses can help to minimise the difference between a visual perception of oneself prior to limb loss compared to post-limb loss, and also reduce a perception of feeling different from others, in turn reducing concern of social situations and the perceptions of others (Gallagher & MacLachlan, 2001; Lundberg, Hagberg, & Bullington, 2011; Saradjian et al., 2008), as well as fostering bodily confidence and engagement in situations more likely to reveal the body (Donovan-Hall et al., 2002).

A prosthesis may therefore have a significant impact on a body image construct (Rybarczyk & Behel, 2008), and for some who consider themselves incomplete without the presence of all limbs, a prosthesis can support a more complete body image. However, users of prostheses who have experienced limb loss are said to possess three body images: one intact body prior to limb loss, one minus the limb, and one with a prosthesis fitted (Breakey, 1997b; Shontz, 1974), and these may not be easily reconcilable. Furthermore, for individuals with congenital limb absence, the introduction of a prosthesis may be antagonistic to a body image they consider is already satisfactory (Batty, McGrath, & Reavey, 2014; Gallagher et al., 2008, p. 3).

One study determined moderate to high negative correlations between body image disturbance and overall lower-limb prosthesis satisfaction (n=44), indicating the importance of a limb that the individual feels is worth using (Murray & Fox, 2002). The researchers in this study also found that along a satisfaction sub-scale, lower physical functional satisfaction was correlated with higher levels of body image disturbance in men, whereas for women, physical function, aesthetics and weight

were correlated with body image disturbance. The researchers suggest that prosthesis use for women was important for sustaining a sense of femininity, where appearance and weight could be important factors in a limb, in addition to the physical function that both genders were found to value.

Investigations of body image tend to have focused more on individuals with lower-limb difference, but Rybarczyk and Behel (2008) suggest that because upper-limb prostheses arguably afford poorer physical function and bodily aesthetics compared to the capacities of lower-limb prostheses, these may be linked to lower satisfaction and so have implications for body image. Also, a lower-limb prosthesis can be worn underneath clothing, intentionally or unintentionally disguising usage, and so enabling social presentation much like others, but this option is not easily afforded to users of upper-limb prostheses (Desmond, 2007). Dudkiewicz et al. (2004) provide some corroboration of this in their study of upper-limb users (n=45), where over 70% reported dissatisfaction with their prosthesis that related to functional and cosmetic complaints, and this can be contrasted to the study by Webster et al. (2012) who found lower-limb users were generally satisfied with their prostheses (n=87; p. 1499). Furthermore, in a comparison of users of PVC upper-limb prostheses and more realistic silicone limbs (n=17), Carroll and Fyfe (2004) found little difference in body image scores but noted that those using the PVC limbs had significantly higher depression scores, highlighting the impact of aesthetics in upper-limb prostheses and that the impact of a prosthesis may be influenced by the type of limb used.

Finally, a number of psychosocial factors have been associated with improved adjustment to an artificial limb, including greater social support, lower social discomfort, lower perceived social stigma, the meaning attributed to and the acceptance of an amputation, and lower public self-consciousness (Gallagher & MacLachlan, 1999, 2001; A. Hill, Niven, & Knussen, 1995; Livneh et al., 1999; Rybarczyk et al., 1995; Williamson, 1995; Williamson et al., 1994). Individual differences across these factors may impact how well a prosthesis is integrated into an individual's life.

Considering these features and this literature, it appears that the use of a prosthesis can be both enabling and problematizing, and there may be aspects of both in usage depending on the type of limb used and predisposing factors of the individual themselves. An important critique of the literature is that researchers investigating prosthesis-related outcomes often do not attempt to control for important factors associated with the absence of a limb, such as those noted in the previous section (e.g., associated pain) and which may impact an adjustment to a limb or ongoing usage. Similarly, those focusing on limb loss outcomes do not tend to control for prosthesis use either, and from the studies above a prosthesis may be expected to have a bearing on particular psychosocial outcomes. For example, studies indicate the impact of a prosthesis on a body image construct, and Donovan-Hall et al. (2002) note the relationship of a perceived body image to psychosocial outcomes including depression, anxiety and self-esteem. Thus when studies refer to 'amputees' or persons with limb absence then later describe these individuals as users of prostheses (e.g., Miller, Speechley, & Deathe, 2001; Unwin et al., 2009; Williamson et al., 1994), or involve prosthesis users and persons with limb absence that do not use prostheses and do not separate these groups in analyses (e.g., Demet et al., 2003; Hagberg & Brånemark, 2001; Pell et al., 1993), or do not specify whether sampled individuals used prostheses or not (e.g., Richardson, Glenn, Horgan, & Nurmikko, 2007; Thompson, Sayers, Reid, Underwood, & Bell, 1995; Wegener, Mackenzie, Ephraim, Ehde, & Williams, 2009), the literature becomes difficult to bring together and discrepancies in findings difficult to account for.

However, from the literature reviewed in this section and the previous one, it is clear that limb absence is the basis for a range of physical and psychosocial consequences for the individual, just as a prosthesis may be associated with such outcomes. However, it is difficult to disentangle the particular effects of each, or how one may interact with the other, and this is complicated by studies that do not control for such variables, or do not make clear what they consider adjustment to involve, and which hamper efforts to consolidate research findings. Linked to this literature however, and providing some clarity about the experience of limb

absence and prosthesis use, a further body of research has sought to examine the perspectives of prosthesis users and to explore the meaning of these experiences as prompted by the individuals themselves.

### Perspectives of the User and Meaning in Prosthesis Use

Recently, researchers have argued for the need for a more person-centric approach to understand limb absence and prosthesis use. Tending to employ qualitative methodologies, existing studies taking this approach explore the experiences of limb absence and prosthesis use from the perspective of the individuals themselves, as well as providing the meanings individuals ascribe to the use of their prostheses, and their perceptions of disability and health. In a systematic review of this literature, Murray and Forshaw (2013) synthesised the outcomes of fifteen qualitative studies (de Oliveira Chini & Boemer, 2007; Gallagher & MacLachlan, 2001; Hamill, Carson, & Dorahy, 2010; Liu, Williams, Liu, & Chien, 2010; Livingstone et al., 2011; Lundberg et al., 2011; Murray, 2004, 2005, 2009; Oaksford et al., 2005; Reed, 2004; Saradjian et al., 2008; Senra, Oliveira, Leal, & Vieira, 2012; Sjö Dahl, Gard, & Jarnlo, 2004; Sousa, Corredeira, & Pereira, 2009). The framework derived from this review is used to explore this literature and is extended with other related and more recent studies that use this approach.

The first area identified by Murray and Forshaw (2013) concerns the emotional response to limb loss and the prospect of prosthesis use (de Oliveira Chini & Boemer, 2007; Gallagher & MacLachlan, 2001; Hamill et al., 2010; Liu et al., 2010; Livingstone et al., 2011; Murray, 2004; Reed, 2004; Saradjian et al., 2008; Senra et al., 2012; Sjö Dahl et al., 2004). Individuals are said to feel overwhelmed, as well as vulnerable and afraid. Thoughts about their bodies ranged from experiencing it as 'strange' to 'mutilated' (p. 1137). Persons experiencing limb loss also express worries about the future and in particular a concern about becoming a burden to others. A further study by Norlyk, Martinsen and Kjaer-Petersen (2013) adds to these findings, where the researchers identified that the loss of a leg meant that individuals (n=12) experienced a drastically altered 'lifeworld', described as the tacit aspects of existence that many of us take for granted. Perceived reductions to

freedom and independence were considered as indications of a 'shrinking' lifeworld, and these led to despair and a 'painful sense of loss' (p. 8). Feelings of inferiority were also experienced when individuals found they were not able to do some of the same things as before, though the researchers note that individuals also expressed a hope of eventually regaining 'lost territory and personal independence' (p. 4). Norlyk et al. also gave consideration to the disruption of identity, identifying that the loss of a limb could leave individuals feeling 'alienated' from their bodies, and without the same connection to the world as they had prior to their loss. The researchers also indicate that individuals lost their ability to live through their bodies 'unreflectively', but that a prosthesis enabled the prospect of feeling 'whole again'. Ligthelm and Wright (2014) also identified a range of responses to the loss of an upper-limb (n=8), from outright 'denial' to an apparently emotionless 'pragmatic assessment... with a view of 'going on'' (p. 103). The researchers indicate that these may be variously experienced at some stage as coping mechanisms and that acceptance was a process that was seldom found to come quickly in this context.

Studies included in Murray and Forshaw's review also involved discussion of the shock and disappointment experienced by individuals when they first saw the prosthesis they were coming to use, and this reminded them of the reality of their new physical circumstances. Early prosthesis use was then met with mixed reactions, as persons considered what a prosthesis could enable as well as how they could be limited by their new limbs, and often dependent on them. In a related study involving internet discussions with prosthesis users (n=155), Murray (2013) described that individuals tend to come to prosthesis use with little knowledge and experience of the area, and so are dependent on professionals to support and guide them in this regard. Interviews with lower-limb amputees (n=8) conducted by Ostler, Ellis-Hill and Donovan-Hall (2014) similarly foregrounded the uncertainty indicated by individuals about their circumstances and their future following an amputation, and when this related to their rehabilitation they sought information from similar others and direction from rehabilitation professionals (see also Sjö Dahl, Gard, & Jarnlo, 2008). The findings from these studies foreground the

unanticipated and disorienting experiences encountered following the loss of a limb and when facing prosthesis use, and which underscore the importance of appropriate information and support.

The second area identified in Murray and Forshaw's framework includes studies that have explored an adjustment process (Gallagher & MacLachlan, 2001; Hamill et al., 2010; Liu et al., 2010; Oaksford et al., 2005; Saradjian et al., 2008; Sjö Dahl et al., 2004). Linking to the previous area, persons are said to initially not know what it means to be 'disabled' and this prompts difficulties in coping after the loss of a limb. Without more comparable experiences, the loss of a limb would sometimes be equated to bereavement and this would help individuals accept their circumstances. Social comparisons were often engaged to enable a more positive appraisal of an individual's own circumstances, particularly when considering those perceived to be worse-off. Individuals also recognised the impact of their own outlook and sought to adjust this through trying to adopt and maintain a more positive attitude and a sense of optimism in order to improve their well-being.

In subsequent research, Norlyk et al. (2013) found that as time went on, rather than 'getting things under control', a sense of loss would initially escalate as persons encountered more domains of life affected by the loss of their limb. For instance, a person who has lost an arm may perceive difficulties with two-handed tasks, but as more and more of these are encountered as persons go about their lives there may be a cumulative effect. This might also be extrapolated to prosthesis use, where persons may later discover some of the limitations that accompany a limb (e.g., fatigue through carrying a limb, finite charge in powered limbs, etc.) and these may also have a detrimental impact on the individual. However, persons may similarly discover unexpected benefits through the use of a prosthesis, such as acquiring a lower-limb prosthesis primarily for mobility, but then realising the benefit of others not recognising limb difference when wearing the limb under clothing. Additionally, in a study by Mathias and Harcourt (2014) involving female lower-limb prosthesis users (n=4), the researchers found that their participants initially harboured worries about dating and meeting potential partners following the loss of a limb, assuming others would consider them inferior

to 'normal' women when they discovered their limb difference. However, they later discover their assumptions to be too severe or that issues did not exist at all, much to their relief. These studies foreground an unsettled period following the loss of a limb and when beginning prosthesis use where persons may encounter unexpected difficulties but similarly discover benefits to their new circumstances or that perceived difficulties are non-existent or less intense.

The third area in Murray and Forshaw's framework involves studies that have identified the importance of family and friends in adjustment and coping (de Oliveira Chini & Boemer, 2007; Gallagher & MacLachlan, 2001; Hamill et al., 2010; Liu et al., 2010; Livingstone et al., 2011; Oaksford et al., 2005; Saradjian et al., 2008; Senra et al., 2012; Sousa et al., 2009). These relationships were described as cherished by individuals and largely supportive, but had the potential to be sources of negativity if there was conflict in decision-making relating to rehabilitation. A sense of 'normalcy' and 'humanness' was found to be strongly influenced by the perceptions and actions of others close to the individual, such that if individuals found they were treated normally by friends and family, they would feel more normal themselves. Related to this, persons tended to indicate the desire to continue relationships in the manner prior to the loss of a limb, and more importantly that despite an acquired limb difference, others perceived and treated them as they were before. In their subsequent study, Ligthelm and Wright (2014) also identified the importance of close family members in supporting a person following the loss of a limb. In particular, they noted that individuals would describe relying heavily on others early on for support and assistance while they discovered how to adapt to their circumstances and become more independent.

Other studies have also focused on the importance of an individual's relationships with rehabilitation professionals. For instance, research has indicated that rehabilitation processes are perceived as most beneficial when the individual feels that they are conducted in a way they perceive is personal and that they are appropriately involved (Elnitsky, Latlief, Andrews, Adams-Koss, & Phillips, 2013; Sjö Dahl et al., 2008). An earlier study by Nielsen, Psonak and Kalter (1989) also found that individuals would change prosthetists if they perceived their input into

the session had been ignored, and who linked the perceived resolution of problems to longer consultations and greater patient involvement (n=21). Nielsen et al. reported these findings more than 25 years ago, but research has since indicated that individuals continue to perceive problems in their interactions with rehabilitation professionals and with the quality of communication in particular (Sjödahl et al., 2008). Murray (2013) also found that patients often described engaging passively early on, realising only later that there were invitations or opportunities to engage as a partner in decision-making processes, though the gap in skill and knowledge was perceived to have hindered this anyway. Individuals in this study also described being unsure about what was appropriate to discuss with the prosthetist, and were further deterred when the prosthetist themselves did not use a prosthesis. These difficulties in communication with the prosthetist led to greater online interaction with perceived similar others as individuals put forward their issues for comments and discussed those of others. Over time, Murray describes that some would determine what and how to convey their needs, but for others, this remained an ongoing issue, relating to persons feeling they were not valued or listened to. When disparities emerged between expectations and results, an adversarial interaction could then develop where individuals did 'battle' with prosthetists in order to try to get what they needed or wanted done, going 'armed' with information in order to try to get 'demands' met.

Murray (2013) also identified that individuals would tend to encourage others who had posted about problems with their consultation experiences to try to talk or continue to try to talk to their prosthetist about these. Those offering advice tended to come from a position where they themselves had overcome initial difficulties and had reached a point where satisfying communication was possible. Individuals would sometimes persevere with difficult relationships, but if difficulties persisted, switching prosthetists in search for a more compatible relationship was an alternative. Norlyk et al. (2013) also explored the relationship between patient and professional and described that while individuals received practical support from professionals about how to physically function, they felt alone and 'left to themselves' in dealing with their altered circumstances. Similar comments were

provided by Sjö Dahl et al. (2008) from their interviews with lower-limb prosthesis users (n=11), who described individuals expressing the importance of both 'technical' information from professionals as well as empathetic and emotional support. Together, these studies indicate the importance of the quality of relationships with those close to the individual. These latter studies also indicate the additional importance of good holistic working relationships with rehabilitation professionals as well as the utility of support groups.

The fourth area in the framework relates to the social experience of limb absence and prosthesis use (Gallagher & MacLachlan, 2001; Murray, 2005, 2009; Saradjian et al., 2008; Sjö Dahl et al., 2004; Sousa et al., 2009). Studies exploring this discuss the importance of prostheses and clothing in enabling some control over the reactions of others towards an individual's limb difference. For instance, when an individual's limb difference was noticed by others, reactions could be stigmatising, and the perceptible discomfort of others could prompt use of a prosthesis or to disguise an artificial limb in order to avoid this. A prosthesis could be perceived as a means to enable greater social participation, and to enable it in 'normal' ways, as persons considered they would be perceived and treated differently depending on their use of a prosthesis and whether others recognised their limb difference. This could sometimes lead to ongoing concealment in order to be treated ordinarily and to be seen foremostly as a person rather than being defined by disability. However, such concealment meant that difficulties could arise later with those naïve to another's limb difference when ongoing contact increased chances of discovery, or necessitates this, such as with romantic or intimate partners. While initial concealing can help individuals avoid being defined by their limb difference, revealing could become a source of anxiety as contact increases. Persons would sometimes feel they harboured a 'secret identity' and that they were torn between deception and the potential undesirable consequences of the 'truth'.

In their subsequent study, Mathias and Harcourt (2014) found that young female lower-limb prosthesis users described an increasing confidence with their prosthesis as being linked to the likelihood of revealing their limb difference to others. In addition, individuals described choosing not to conceal their prosthesis

use when dating, using their upfront-ness about their limb difference as a means to screen potentially unsuitable partners. However, even when becoming more confident about their prosthesis use, individuals would continue to flexibly switch between concealing and revealing, depending on the situation and if they were experiencing difficult 'moments' (p. 397). Krantz et al. (2008) provide further detail to this in their study involving women with congenital upper-limb absence (n=unspecified; multiple data sources). The researchers discovered that individuals employed a range of stigma-handling strategies that managed the information about themselves in order to avoid deviating from what the researchers termed an 'ad-hoc normality' – or what persons consider is normal for a given situation. Thus persons would conceal their limb difference depending on whether delaying potential discovery was adaptive to the context. At other times, when it was judged that interaction with others in a specific situation would be ongoing and the importance of their limb difference would not be expected to incur stigma, or would quickly diminish over time, individuals would be more likely to reveal their limb difference.

These studies foreground the benefits and challenges of living with prostheses in the context of social participation. The value of prostheses in enabling 'normal' social interaction is evident, but so too are the difficulties persons experience in managing concealment and an ongoing risk of discovery. The use of a prosthesis, which may inadvertently disguise an individual's limb difference, may be perceived as useful for avoiding stigma, but may also lead to tension if an individual feels the need to later reveal this.

The fifth and final area in Murray and Forshaw's framework concerns the way in which prostheses can facilitate the expression of valued identities (de Oliveira Chini & Boemer, 2007; Gallagher & MacLachlan, 2001; Liu et al., 2010; Lundberg et al., 2011; Murray, 2004, 2009; Saradjian et al., 2008; Senra et al., 2012; Sousa et al., 2009). Studies linked to this determined that while many equate the loss of a limb with the gaining of a label of disability, individuals tended to feel that a prosthesis could help rebuff or diminish this. A prosthesis was considered restorative if it helped to regain functions displaced by limb loss, such as being able to partake in

routine activities once more or returning to work. Self-worth was also boosted by the enabling properties of the prosthesis in providing functionality and autonomy and partly recovering what persons considered had been lost. Considering the possibility of what prostheses could provide enabled favourable comparisons to able-bodied individuals, although persons recognised some differences persisted, and those who had lost limbs considered they were not altogether the same as they were before. As regular and important life events were experienced in ways supported by use of a limb, a prosthesis would be 'woven in' to lives and new identities were forged while others were regained. Similarly, Ostler et al. (2014) suggested individuals with lower-limb loss would seek to replace their limb through use of a prosthesis, but a return to normality was not always considered to have been achieved. While some valued activities could be returned to, there were always ways in which limb absence and the prosthesis presented differences to prior lives, and the researchers considered individuals would engage a process of negotiating a 'new normal'.

In this final area, Murray and Forshaw also identified a typology of possible forms of prosthetic embodiment that have implications for recovered selves. These range from perceiving the prosthesis as a tool, to a part of the body, and also as a 'part of me'. In the former, more conscious and laboured usage characterised conceiving the limb as an implement external to the body, while conceiving of the limb as a part of the body involved considering how the limb approximated the anatomical limb in certain regards. If persons perceived a prosthesis as pivotal to a personal and social identity, it tended to be seen as 'natural' and a part of the user (see also Mills, 2013). These forms of embodiment were variously perceived as adaptive or problematic by the individuals, depending on what they sought to achieve with a prosthesis.

In summary of this section, qualitative research investigating the perspectives and experiences of prosthesis users reveals a further wealth of insights about what it is like to live with limb absence and to use a prosthesis. Furthermore, while the first three areas of research identified in Murray and Forshaw's framework link to much of the quantitative work conducted in the field that has explored the impact of limb

loss and early prosthesis use, the latter two areas shed some light on the ongoing experiences of living with a prosthesis. In particular, the fourth area concerning social interaction illuminates what it is like to live with a prosthesis on a day-to-day basis, as persons routinely manage their presentation and the information they share with others about their limb difference. The fifth area also provides some indications about further experiences through discussions of how prostheses helped to variously recover identities or helped develop new ones and similarly how persons use artificial limbs to regain normalcy or find a 'new normal'. Considering the broader literature in prosthesis use has mainly focused on reactions to limb loss and early experiences of prosthesis use, such an understanding of the further experiences of prosthesis users is enlightening. However, this is an emerging understanding from a modest body of research and further work is required to develop a richer understanding of the ongoing experiences of living with a prosthesis.

The next section completes the overview of the literature. This involves discussion of prosthetic practice, where there is a focus on 'outcomes' research. This leads to the premise for the present research.

### Evidence-Based Practice in Prosthetic Services

Gallagher and Desmond (2007) observe that in the field of prosthetics, there is an increasing acknowledgement by prosthetists and other relevant healthcare staff of the need to evaluate practice, particularly in the assessment of patient outcomes. By doing so, the progress or the status of the individual can be evaluated, and this has been linked to improvements in quality of life through consequent efforts to improve quality of care and quality of health (Szabo, 2001). Furthermore, having measurable outcomes also enables the comparison of treatments, interventions and service delivery (Deathe, Miller, & Speechley, 2002) and so helps to enable a more cost-effective approach to rehabilitation (Larner, van Ross, & Hale, 2003), as well as the potential to inform policy-making and the expenditure of public funds (Lindner, Nätterlund, & Hermansson, 2010).

However, there is little consensus on what should be assessed after the fitting of an artificial limb. Wolfe et al. (2008) note the tendency of research to focus on physical outcomes, such as working towards a particular level of mobility in lower-limb prosthesis users or a level of aptitude in manipulating objects for upper-limb users, and this was at the expense of other outcomes, such as the psychosocial (see Stevens, Fross, & Kapp, 2009). Gallagher and MacLachlan (2001) describe how recent research has sought to redress this, but many contemporary studies that have sought to develop psychosocial outcome tools tend to have a narrow focus, often exploring a single construct, and that different constructs/outcomes are explored across studies, use differing combinations of measures, or examine outcomes in different ways to others. Lindner et al. (2010) also note that some tools have yet to be validated and so it is not clear whether scores obtained actually reflect the individual's status on a stated dimension.

Such a multiplicity of potentially important variables, ways they are measured and critiques of these measures reinforce the notion that there is no clear guidance about what evidence should be translated for use in prosthetic consultations. This is an issue if practice is to adopt an evidence-based approach to guiding and assessing consultations – something that has been criticised for being lacking in the past (Ramstrand & Brodtkorb, 2008). Indeed, Deathe et al. (2002) report that nearly a third of centres providing prosthetic services in Canada (n=44) that they contacted did not formally assess any particular outcome measure. Turner-Stokes and Turner-Stokes (1997) reported comparable findings (n=182), and noted that centres cited a lack of time and not knowing what to collect as the reasons for not formally assessing outcomes (see also Andrysek, Christensen, & Dupuis, 2011).

Related to this, a body of research that has developed models for matching individuals to assistive technology has foregrounded the unique qualities of the individual that are important to attend to when considering particular technologies (Scherer, 2002, 2014; Scherer, Jutai, Fuhrer, Demers, & Deruyter, 2007). These studies emphasise consideration of the needs, values and goals of the individual in determining an optimal match, and therefore present a further consideration for prosthetic practice alongside what might be agreed as normative standards for

rehabilitation. An understanding of an individual's values, preferences, and their own conception of their rehabilitation, is to gain an insider account of the user of the prosthesis and so to enable the means to better accommodate the individual in potential ongoing rehabilitation efforts. This is becoming a more prominent point of investigation in recent years, and has been implicated as one of three important components in evidence-based practice in order to improve rehabilitation (alongside clinical expertise and integrating current research) (Sackett, Straus, Richardson, Rosenberg, & Haynes, 2000). However, like the lack of clear recommendations for outcomes to measure, similarly there is no real evidence-based guidance about how professionals should go about trying to understand the needs, values or goals of the individual.

Using a repertory grid analysis, Schaffalitzky et al. (2009) investigated the values and preferences of upper- and lower-limb prosthesis users in the US (n=4), in order to determine what they considered important in an a limb. The researchers discovered a highly nuanced set of preferences and evaluative criteria across cases, indicating the individuality of prosthesis users and the corresponding need for professionals to treat individuals as such in consultations. NiMhurchadha, Gallagher, MacLachlan and Wegener (2013) performed a Delphi study involving upper-limb prosthesis users as well as rehabilitation professionals (n=53), and reported a disconnect between the research literature and what both professionals and prosthesis users considered important in consultations and in prosthesis use. The lack of consensus over many of the factors indicates a need for a greater understanding between professionals and patients, but additionally, the agreed factors, including 'a patient's feeling of control over the rehabilitation', 'resilience', 'expectations', 'sense of humour' and 'social skills', indicate the need to give greater scrutiny to these psychosocial and environmental variables that have not presently received much attention in the literature.

This discussion foregrounds the issues facing the translation of research knowledge into prosthetic practice. Practice could benefit from this knowledge, providing a better understanding of the individuals that come to use artificial limbs and the experiences they may encounter, in order to adapt consultation approaches,

identify appropriate technology and to consider rehabilitation goals and further consultation targets accordingly. However, despite burgeoning research in recent years, inconsistencies and a lack of consensus about how to aim for or measure 'success' remain, and these obfuscate broader messages about how to develop practice.

### Locating the Present Study

Taken as a whole, the body of prosthesis use research provides an insight into the diverse and important psychosocial features accompanying the use of artificial limbs. Common areas of concern are identified and light is shed on the breadth of issues experienced by persons that use prostheses. However, there remain some significant difficulties complicating an overview of the area. Reports of the prevalence of prosthesis use and the frequency of usage vary and are not satisfactorily accounted for (Raichle et al., 2008). There is also little agreement in terms of the prevalence of clinically significant psychological morbidity in individuals with limb absence, either in the early post-amputation period or beyond (Desmond et al., 2012; Desmond & MacLachlan, 2006). Divergences in findings may be attributable to heterogeneous study samples, in addition to divergent study designs, which make comparison and consolidation of findings problematic (Cavanagh et al., 2006; Horgan & MacLachlan, 2004; Sinha & van den Heuvel, 2011). A conclusion that can be drawn from this overview of the literature is that the field of prosthesis use identifies a broad range of psychosocial phenomena associated with the use of artificial limbs, but a precise understanding of these is rendered difficult by the current state of the research. This has consequences for informing further enquiry as well as supporting evidence-based approaches to practice.

To address this, developing an original perspective for further approaches to the area or for reappraising the evidence is a worthwhile endeavour, and one which can come from the development of theory. Theory has properties of guiding research and organising empirical knowledge (Marx, 1963) and is therefore useful for the field of prosthesis use as it currently stands. Theory also contends with

multiple variables, again, particularly useful given the plethora of factors associated with limb absence and prosthesis use. Dunn and Elliott (2008) have specifically called for the development of theory in rehabilitation psychology to inform the multidisciplinary practice of rehabilitation, noting that much of the extant research is largely atheoretical, where there is a focus on identifying differences between groups but then struggling to account for why such differences exist.

Theory is often loosely defined and interpreted liberally but there is some consensus in the scholarly literature that it goes further than a concept (e.g., Glaser & Strauss, 1967; Maxwell & Mittapalli, 2008; Wacker, 1998) and is richer than a theme. Taking the definition from Grounded Theory methodology, theory is multivariate and consists of concepts, but these are interrelated (the relationships constitute hypotheses), and are accounted for by a core theoretical category that the concepts stem from (Glaser & Strauss, 1967). The production of individual concepts remains useful - indeed as Murray and Forshaw's (2013) review indicates they can be important and insightful ways of being able to consider action in an area - but they are limited in scope compared to theory. Theory has the advantage of capturing and parsimoniously accounting for a substantial amount of action within a given area. If of a sufficient breadth, theory can accommodate what may appear to be quite divergent behaviours or experiences of persons, offering a conceptually integrative perspective of action in an area. For instance, Philbin's (2009) theory of *identity commitment* accounts for both acceptance and rejection of medications and psychiatric identities in the context of psychosis. Theoretical investigations can also flesh out extant concepts, such as those already identified by qualitative inquiries, as their variation is explored and accounted for, bringing new ways of considering action to light. The potential relationships between known or emerging concepts may also be explored to enable an understanding of their potential interplay. For example, Charmaz's (1995) theory of chronic illness which explores and connects some familiar notions of chronic illness in new ways to understand variation in how persons respond to their condition.

The development of theory can also prompt thought about directions for further work in an area in which it is developed or employed, which may also indicate

expansions of an employed or developed theory. For example, in Cutcliffe, Stevenson, Jackson and Smith's (2006) theory of suicidality, 'reconnecting with humanity' was described as a pattern of overcoming suicide and which begs further investigation for how this could be encouraged in order to reduce the incidence of suicide. Research driven by theory can therefore be used to inform research as well as for the development of evidence-based practice, where professionals can be provided an array of 'empirically-supported techniques' that can be derived from an understanding of the hypotheses of a theory (Dunn & Elliott, 2008, p. 10). This could be especially useful in prosthetic rehabilitation given that a lack of evidence-based practice has been a point of criticism in the past (Ramstrand & Brodtkorb, 2008). Finally, carefully developed theory also enables professionals and laypersons alike to interpret a variety of scenarios, helping to make sense of them as underlying processes are understood (this is explained further in chapter ten, but see also Glaser & Strauss, 1967).

Currently, there is a dearth of theory in the literature on prosthesis use, where few studies employ theory to inform their research and fewer have sought to produce any. Examples of studies employing theory include Callaghan et al. (2004), who developed a tool to assess attitudes and behaviour towards prosthesis use based on the theory of planned behaviour (Ajzen, 1991). Callaghan et al. (2008) then employed the Common-sense Self-Regulation Model (Leventhal, Nerenz, & Steele, 1984) to predict prosthesis use and activity limitation. A further series of studies that have invoked theory are those from Coffey and colleagues (Coffey, Gallagher, & Desmond, 2014a, 2014b; Coffey, Gallagher, Desmond, et al., 2014a, 2014b), who have also employed a form of self-regulation (the dual process model; Carver & Scheier, 2000).

In terms of producing theory, three studies were undertaken that used Grounded Theory methodology. However, it is questionable about whether these studies achieved the goal of the methodology and did in fact produce grounded theories. In Oaksford, Frude and Cuddihy's (2005) study of coping with lower-limb loss (n=12), the theoretical product is instead a thematic grouping of coping concepts according to their type, and the researchers admit they engaged a post-hoc sorting process of

their concepts largely for the purposes of diagrammatic representation (p. 272). Similarly, Livingstone, van de Mortel and Taylor's (2011) 'path of perpetual resilience', developed from analyses with individuals experiencing lower-limb loss (n=5), is actually a phrase coined to express a theme of chronology, produced after analyses and that 'unifies the concepts' (p. 27). A thematic grouping of concepts does not constitute a theory, and goes against Grounded Theory methodology which specifies the importance of developing a core theoretical category which is then accounted for through sub-core concepts (Glaser & Strauss, 1967). Only Reed's (2004) theory of 'mastering the challenge' appears consistent with the methodology, though this is focused on farmers who underwent upper-limb amputations and who were returning to work (n=16).

This research then, sought to develop new theory in order to inform both practice and further scholarly enquiry. To this end, Grounded Theory was selected as an appropriate explorative methodology to support the study. Grounded Theory is the systematic generation of theory from data in a substantive area, using a rigorous approach to data gathering and analysis. The product of a Grounded Theory study is rich and relevant theory addressing how individuals in a substantive area process and act on a main concern, and captures and accounts for variation in this responding.

Through application of the methodology, an in-depth conceptualisation of a main concern of prosthesis users and the actions they employ to manage this concern was produced. This encapsulates the theory of prosthesis use that this thesis presents and provides a new means of understanding the issues faced by the sizeable number of individuals with limb absence that are making use of artificial limbs. The decision to use a particular form of Grounded Theory methodology, and how I understood and applied this, is explained over the following two chapters.

## Chapter 3: Study Methodology - Grounded Theory

### Introduction

In this chapter, I discuss the rationale behind adopting a particular form of Grounded Theory methodology in order to undertake a study of prosthesis users. This chapter expands on the methodological principles of Grounded Theory, detailing how the study was approached and clarifying some areas of contention within the methodology. Chapter four continues this through discussing design choices, particular method processes and how these were executed during the study.

It is through a discussion of Grounded Theory methodology that the epistemological position that underlies this work can also be presented. However, in using Grounded Theory there are strong implications for epistemological considerations, and so I have chosen to address these together which also helps to illustrate how methodology and epistemology can be mutually informative. This is achieved by working through the tenets of Grounded Theory methodology and reflecting on epistemological aspects where appropriate.

A brief overview of the discovery and development of Grounded Theory methodology is given in order to establish the rationale for adopting the particular version of Grounded Theory in this study. This then moves to an exploration of the manner in which Grounded Theory studies should be approached, before discussion of the credibility of Grounded Theory research products.

### The Origins of Grounded Theory

The 1967 publication of *The Discovery of Grounded Theory: Strategies for Qualitative Research* (Glaser & Strauss, 1967) was a milestone in social research. At this time, there was a widespread tendency to regard sociological research as a way of verifying and refining 'grand theories'. Glaser and Strauss challenged this by arguing for the need to develop new theory that was relevant and carefully derived from data, rather than furthering what they perceived as largely deductive and speculative theory (p. 29). *Discovery...* was therefore published to provide an

alternative mode of research that supported the production of systematically-developed novel theory in a substantive area.

Glaser and Strauss were particularly critical of research where data appeared to be forced to fit an existing theory. In contrast, they argued that by adoption of the systematic procedures of the Grounded Theory, the development of an emergent theory that had both 'fit' and relevance was assured (Glaser & Strauss, 1967). In order to proceed with this new methodology, Glaser and Strauss argued that the researcher must be open to such emergent discoveries within the data, and identify any preconceptions they might have with potential irrelevance.

Furthermore, as indicated by the title of the 1967 text, *Grounded Theory* methodology itself was claimed to be a discovery. Glaser (2003) later explained how it was actually a 'write-up' of how the researchers had produced their critically acclaimed *Awareness of Dying* (Glaser & Strauss, 1965) and the subsequent *Time for Dying* (Glaser & Strauss, 1968) after being petitioned by others to reveal how they had gone about their investigations (p. 62). Glaser's background was from the University of Columbia, where he learned sociology as a student of Robert Merton, and inductive quantitative analysis from Paul Lazarsfeld, and previously he had studied techniques of 'explication de text' at the University of Paris. Strauss, on the other hand, studied sociology at the University of Chicago, under the tutelage of Herbert Blumer who was developing Symbolic Interactionism. It was this critical meeting of approaches that the discovery of the methodology has been attributed to (Glaser, 1992, 2003; Glaser & Strauss, 1967; Strauss, 1991).

At the time of writing, there are a number of versions of Grounded Theory available to those who find appeal in the approach. These are significantly dissimilar and so to avoid confusion and methodological 'slurring' it has been recommended that researchers undertaking Grounded Theory clearly state their version early in their work (Baker, Wuest, & Stern, 1992; Stern, 2009; Wilson & Hutchinson, 1996).

I have chosen to adopt Grounded Theory methodology as prescribed by Barney Glaser, the 'co-discoverer' of Grounded Theory, and as described in his authored and co-authored texts (Glaser, 1978, 1992, 1998, 2001, 2003, 2005, 2009, 2011a,

2013, 2014; Glaser & Strauss, 1967). This version has been variously termed 'classical', 'traditional', 'orthodox' or even 'Glaserian' due to Glaser's ongoing dominance of this form of the methodology.

In Grounded Theory, researchers seek to identify a main concern of individuals within a particular area and to account for how this concern is resolved. Through a systematic approach to the research, patterns within data from this area are identified and conceptualised, as well as exploring how the patterns may vary and what may account for the variation, and through this a theory of resolving the core concern is developed. The particular processes involved are discussed further in chapter four.

While this is the crux of Grounded Theory, there are differences between versions, and a critical discussion of the different versions of Grounded Theory and thus their divergent key characteristics will help to frame the rationale for this decision and will also illustrate my theoretical orientation that guides the operationalization of the methodology. In presenting this, brief consideration of Anselm Strauss's ('co-discoverer' of Grounded Theory) elaborations of Grounded Theory are discussed as they are found in the texts he co-authored with Juliet Corbin, as well as discussing the more contemporary 'Constructivist Grounded Theory' and 'Situational Analysis' versions that place greater emphasis on epistemological considerations.

### [Strauss and Corbin's Grounded Theory](#)

Following the publication of *Discovery* in 1967, the broad guidance given to researchers seeking to develop their own grounded theories led to petitions for clarification and further instruction on how this could be best achieved. Glaser later released *Theoretical Sensitivity* (Glaser, 1978), in which he elaborated the procedures of 'theoretical sampling', coding and 'memoing', and foregrounded notions of 'theoretical coding' and 'theoretical sensitivity'. Strauss responded to requests for elaboration through the release of his own book, *Qualitative Analysis for Social Sciences* (Strauss, 1987). However, it was in 1990 that he and one of his former students, Juliet Corbin, released their comprehensive guide to Grounded Theory in the form of *Basics of Qualitative Research: Grounded Theory Procedures*

*and Techniques* (Strauss & Corbin, 1990). Many scholars agree that this was one of the more poignant events in the history of the methodology, as it led to the schism between Glaser and Strauss.

Strauss and Corbin set out to deliver a publication that described how to conduct Grounded Theory studies in a clear and straightforward manner (p. 12)<sup>2</sup>. In presenting this elaboration, the authors gave guidance for how a researcher might conduct their studies that was in accordance with the original principles of Grounded Theory. However, they also presented ideas for analysis, namely a process of 'axial coding'. Whereas open coding in the early stages of a Grounded Theory study causes the data to fracture into labelled incidents, axial coding was developed as a means to resolve this by putting the data back together in new forms through making connections between incidents, concepts, and their properties. These connections are made in relation to the 'paradigm model'; a model that prompts the researcher to ask key questions about how data relate to each other (see Figure 3) (Corbin & Strauss, 2008; Strauss & Corbin, 1990, 1998).

When *Basics...* was first published, Glaser wrote to Strauss, imploring him to retract the text. In addition to claims of a personal injustice rendered through intellectual property infringement and a lack of consultation, he believed the methodology itself had been wronged. He dubbed their new version 'full conceptual description', claiming that following their guide forced creation of theory that was not emergent, as he believed Grounded Theory should be (Glaser, 1992). When *Basics...* remained unretracted, Glaser published a text solely aimed at 'correcting' the propositions within it (Glaser, 1992) and then returned in force to methodology writing, producing a succession of texts that gave his own advice to researchers considering employing Grounded Theory in their work (Glaser, 1998, 2001, 2003, 2005, 2009, 2011a, 2012, 2013, 2014).

While Glaser (1992) gave critical commentary to most of Strauss and Corbin's (1990) work, the crux of his criticism is most strongly levelled at the technique of

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<sup>2</sup> This enforces the notion that Discovery was neither of these things. Holton (2009) suggests that it is easy to initially see the guidance in Discovery as 'loose and perhaps even messy or confusing' (p.43), further encouraging researchers to be steered by later elaborations in a chosen version.

axial coding and the paradigm model. These allow some structure and stability to a study of an explorative nature where a researcher can quickly be overwhelmed with the possibility of analyses going in any number of directions, but recommending such specific assessments of the data regardless of their relevance is said to lead to deduction and preconception in the production of theory (Glaser, 1992; Kendall, 1999). For example, by compelling the researcher to consider data in terms of 'consequences', 'intervening conditions', or 'action strategies', attention may be diverted from what may be prominent in the data, and equally may be directed to areas that may not be relevant at all. Furthermore, Glaser suggested following the process would result in 'an over-conceptualisation of a single incident' (Glaser, 1992, p. 40).

In grounded theory we do not link properties and categories in a set of relationships denoting causal conditions, phenomena, context, intervening condition, action/interactional strategies and consequences. This would be preconception and forcing theoretical concepts on data to the max. The grounded theorist simply codes for categories and properties and lets whatever theoretical codes emerge where they may. To use this model out of hand will merely give the appearance of making the analyst think systematically about data and relate them in complex ways. In actuality it teaches the analyst to force a full conceptual description on data with no questions about whether the links are relevant to any emerging theory that really explains how the participants process their main concerns. (Glaser, 1992, p. 63)

As will be discussed in the next chapter in the section on theoretical coding, it is more congruent with Grounded Theory principles to instead consider such ways of working with the data as options to be invoked as and when they appear relevant to analyses.

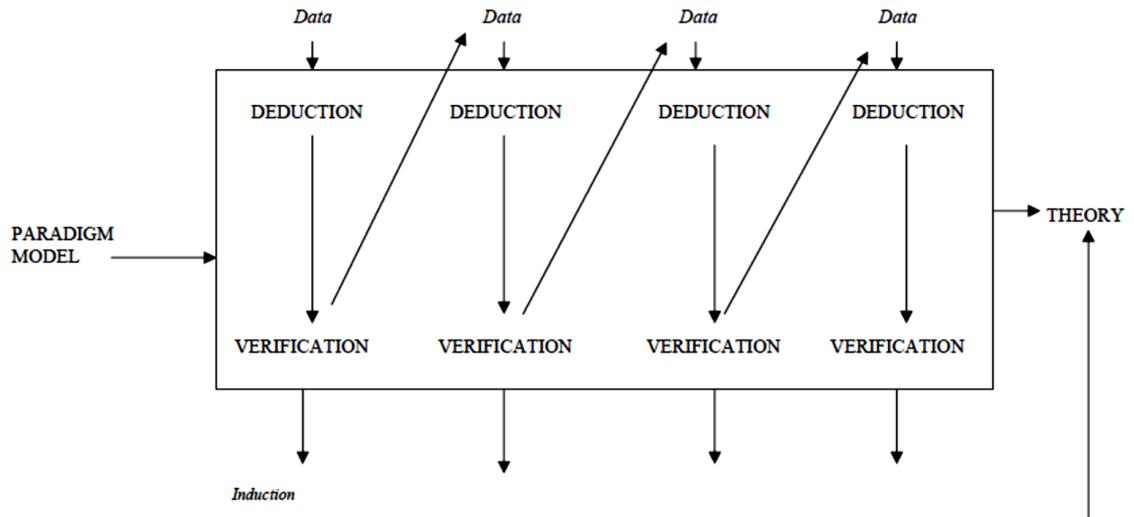


Figure 3. Strauss and Corbin's (1990) paradigm model

Despite indications of inconsistencies with original Grounded Theory principles, researchers adopting this version of the methodology have produced a plethora of insightful studies (see Strauss & Corbin, 1997). Kendall (1999) notes that Strauss and Corbin's version appears to excel best where depth of description and exploring all possible contingencies within the data are desirable qualities in a study, and so where 'full conceptual description' may be a desirable quality in a study. As Glaser (1992) suggests, such an approach 'is fine, but it is not grounded theory' (p. 3). Furthermore, in *Discovery*, it was emphasised about the integration of the theory that it 'is best when it emerges, like the concepts. The theory should never just be put together' (p. 41). Given the value of potentially emergent concepts, and moreover, an emergent theory that could account for a range of actions in the substantive area of prosthesis use, Glaser's methodological elaborations appeared to be a better approach for this study.

### Epistemology-Driven Remodellings

In recent years, some have questioned the theoretical underpinnings of Grounded Theory. Among these, Bryant (2002) felt that Grounded Theory had fallen behind the times and needed to be revitalised, claiming that it was 'steeped in a scientism largely undermined in philosophical terms in the 1970s and 1980s' (p. 34). Bryant's arguments draw on the changing state of methodological discussion in qualitative

research where there is a growing body of literature that is conscious of epistemological positions and their potential impact on qualitative research strategies. 'Positivist' Grounded Theory methodologies as advocated by both Glaser and Strauss, Bryant argued, required rethinking.

There are two prominent versions of Grounded Theory that have since emerged that foreground epistemological concerns. These are useful to consider, both in relation to reinforcing the decision to use classical Grounded Theory methodology and as a basis to discuss epistemological concerns and how to manage these. In one of these versions, Kathy Charmaz, a former student of Glaser, looked back to Grounded Theory's Symbolic Interactionism roots and argued for a reworking (or 'reclaiming') of the methodology along 'social constructionist' lines (Charmaz, 2005, 2006). This version eschewed what was labelled as a traditional 'naïve realist' perspective that Glaser and Strauss were said to advocate (Denzin & Lincoln, 2005). Charmaz (2006) instead proposed Constructivist Grounded Theory, a remodelling driven by interpretivist philosophies that advocates relativist considerations of multiple social realities.

Constructivist Grounded Theory encourages viewing the production and analyses of data as the result of the shared experiences between the researcher and the sources of data. This encourages researchers to acknowledge that they are part of what they are studying and not separate from it, prompting considerations of a co-constructed reality between researcher and participant (Charmaz, 2006). In order to achieve this, Constructivist Grounded Theory researchers are encouraged to take a 'reflexive' stance, such as noting their dispositions that may potentially shape the data, and by viewing any analysis as firmly situated in time, place, and culture. Constructivist Grounded Theory researchers should also emphasise eliciting participants' 'definitions of terms, situations, and events' in order to realise the implicit meanings and assumptions of those in a substantive area (p. 32). By employing these techniques, researchers are said to be able to interpret the meaning of the lives of participants with a 'more textured, denser understanding' (p. 35).

Constructivist Grounded Theory, as presented in *Constructing Grounded Theory* (Charmaz, 2006), is an attractive reworking of Grounded Theory, as unlike *Discovery* it is expressed in a clear and carefully paced form. Charmaz also comes across as a researcher deeply attuned to her participants, demonstrated in one way through her efforts to preserve their voice in her resulting work (see Charmaz, 1973, 1991, 1995). To an extent, the same can be said for the second epistemology-conscious version of Grounded Theory: *Situational Analysis* (Clarke, 2005).

*Situational Analysis*, developed by Adele Clarke, a former student of Anselm Strauss, is an extension of the ideas of Strauss in his work on social worlds. It primarily differentiates itself from traditional accounts of Grounded Theory methodology by acknowledging the 'postmodern turn', stating that analyses are locked to a specific time and place. Therefore, strikingly, the generation of theory is absent from *Situational Analysis*, replaced by social 'maps' that encourage the researcher to consider differences over commonalities in concepts, and emphasises exploration of the situational, social world, and positional aspects of substantive areas.

Clarke states that an emphasis on investigating variation is absent in Glaser and Strauss' individual methodological accounts, and by contrast, is the central strength of her reworking (p. xxxiv). While there is some truth that overt statements about the search for variation were somewhat overlooked in *Discovery...*, variation is central to Grounded Theory. According to Glaser (2001), a concept is only properly understood when the way it varies is understood. Furthermore, theoretical sampling, the process by which more information on a conceptual pattern is obtained by the researcher, is a method process specifically employed as a means of seeking and accounting for variation.

Clarke (2005) also states that the products of Grounded Theory methodologies advocated by Glaser and Strauss are modelled through a *basic social process* (the form taken by the theory is a processual model of stages), and this form is imposed and limits their flexibility. Despite the large proportion of extant Grounded Theory studies utilising the basic social process (e.g., see Glaser & Kaplan, 1996), it is but one theoretical coding family (these are explained further in chapter four) which

Glaser suggested could serve as a means of helping to relate concepts to each other and structure a theory (Glaser, 1978). Glaser (1978, 2005) has outlined a number of other possible coding families a researcher may find have good emergent fit for modelling a theory, and he noted that there may be many more, such as the 'typology' and 'continuum' families, which particularly foreground the variability of phenomena in their structure<sup>3</sup>.

Aside from these particular qualms, the claim that objectivist/positivist perspectives overlook important features in an analysis is a recurring feature in epistemology-driven revisions of Grounded Theory. In a sense, this can make these versions appealing, and yet the same can be achieved with Grounded Theory as it was originally conceived. Glaser suggests that features such as bias and the impact of the researcher have a place in Grounded Theory studies, but only when analyses indicate their relevance. Thus rather than foregrounding them as in Constructivist Grounded Theory, they should be considered as just one potential form of data ready to be subject to the constant comparative method of Grounded Theory analysis (Glaser, 2007a).

Furthermore, claims of being able to better explore data using particular epistemological lenses can, paradoxically, be limiting. In response to the announcement of Constructivist Grounded Theory, Glaser (2002b) called it a 'misnomer', claiming that centralising constructivism leads to an obsession over continual attempts to escape bias as the researcher is required to repeatedly explicate the effects of a particular time, place and people that data originates from. Additionally, foregrounding a particular epistemological perspective leads to the danger of falling foul of the same problems of axial coding: that there is the risk of demoting or overlooking what might be important emergent aspects of analyses in favour of procedurally investigating specific factors that are thought to impact analyses (such as interpretation), regardless of their relevance.

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<sup>3</sup> A typology was created in what could be considered the first 'official' grounded theory (Glaser & Strauss, 1965). In this study, Glaser and Strauss developed a typology of awareness of dying contexts to account for the variation in awareness of dying.

It is also interesting that proponents of epistemology-driven Grounded Theory state that they hold the products of classical Grounded Theory studies in high regard (e.g., see Bryant, 2003; Charmaz, 2006), when one might expect criticism of 'biased' or 'naïve' interpretations. Instead, the conceptual products of older Grounded Theory studies are still revered and enjoy ongoing relevance (e.g., the use of awareness contexts from Glaser and Strauss' (1965) study in Carlander, Ternstedt, Sahlberg-Blom, Hellström, & Sandberg, 2011).

This leads to a further point of discussion, that supporters of epistemological-remodellings, in particular those that favour a postmodern approach, indicate that conceptual work derived from particular persons, times, and places, are limited to these confines; that 'situated knowledge' is produced (Clarke, 2005, p. 294). In contrast, Glaser (2002b) argued for a 'conceptual reality' where concepts could be seen to fit with differing situations in differing times. He argued that concepts such as 'credentializing', 'cultivating', 'spiritual power abusing' or 'pseudo-friending', which were developed in Grounded Theory studies, would 'just go on, no matter the bias[ed] take on them that may emerge' (p. 4). More emotively, he wrote:

Conceptual reality DOES EXIST. For example, client control is real; cautionary control is real; social structural covering is real. These processes and a myriad of others discovered in Grounded Theory research, impinge on us every day. Just go to the doctor, drive a car or go into surgery and/or take on the Catholic Church and the reader will see the reality of these researches and apply the conceptually, generated theory. (p. 8)

While Glaser's notions of concepts being 'real' may grate with contemporary epistemological discourse, his point was more that concepts developed through a grounded theory, once understood by others, could then be observed beyond this immediate data. So conceptual work derived from data from particular prosthesis users could be understood by researchers and individuals in a substantive area alike, and that this would have some resonance with them where they may consider the concepts elsewhere. An advantageous reading of this argument

therefore, is that concepts are 'real' in the sense that their fit with what is actually going on in a situation is achieved.

In addition, part of the reason for undertaking a Grounded Theory study was to develop a theory of prosthesis users that would have some fit and utility when considering prosthesis users more broadly. This is therefore a key strength of Glaser's Grounded Theory that epistemology-driven remodellings struggle with.

Consequently, epistemological revisions do not provide a persuasive argument for adopting an alternative Grounded Theory methodology. Constructivist Grounded Theory and Situational Analysis highlight some useful techniques and considerations for the data, but these are merely possible tools to employ in a Grounded Theory study, analogous to the coding families. At the worst, an overemphasis may confuse or stifle researchers into trying to determine every property of their positionality, referred to by Glaser (2001) as the 'reflexivity paralysis'. In sum, as Philbin (2009) identifies, once Grounded Theory is understood as being capable of utilising any epistemological position, such remodellings struggle to differentiate themselves and offer anything more than the classical version. Rather than addressing the difficulties posed by commitments to openness and flexibility that accompany the methodology, there is likely a greater appeal in challenging an imagined straw man of a naïve Grounded Theory, setting oneself up as a 'champion in a fight against positivism and objectivism – those perennial "reds under the bed" in qualitative methodology literature' (p. 36). These difficulties, posed by the methodology and dealt with insufficiently by other forms of Grounded Theory, form the basis for the next section.

### Not Knowing and Being Open

While Glaser's elaborations of Grounded Theory can be received as the basis for rejecting epistemological-remodelled versions of the methodology, there remains some vagueness around how to manage issues of relevance, flexibility and openness that these versions highlight and that are important to clarify in a Grounded Theory study. For instance, when or how the relevance for incorporating particular lenses (e.g., constructivist, feminist) is 'earned' or 'indicated' by analyses

is an important consideration (see Clarke, 2005, p. 75). Addressing this involves understanding how to approach and engage a Grounded Theory study.

Glaser (1992) suggested that researchers approach their studies at a point of 'not knowing' (p. 50). Some have taken this idea of 'now knowing' to a logical extreme, suggesting it implies a *tabula rasa* approach, and is thereby a naïve and unrealistic instruction (e.g., Clarke, 2005; Dey, 1999). It is fair to say we cannot 'un-know' the things we may know about something and cognitive psychology teaches that understanding novel phenomena requires the accommodation of existing schema to build upon (Piaget & Cook, 1952), thus questioning the possibility of pure induction. But this was not what Glaser was getting at. While seemingly sceptical of this approach, Dey (1999) admits that 'there is a difference between an open mind and an empty head' (p. 251) and this is what Glaser was recommending when he suggested that a researcher 'should just not know as he approaches the data' (p. 50). 'Not knowing' can be practically received as adopting a stance of acceptance and possibility, and likewise doing one's best to avoid pre- or early commitment to, or rejection of, theoretical possibilities.

This has implications for addressing a constructivist/'objectivist' debate, and I find it useful to believe that an appropriate position can be found somewhere between. A belief in discovery, linked to 'not-knowing', informs this, as discovery, to me, means a stance of considering a level of induction is possible, whilst acknowledging that existing knowledge or the tendencies of a researcher will always have some degree of influence. This is not an area explicitly addressed in the methodology, but something I believe is important for a researcher themselves to understand and delineate so they might recognise how phrases like 'earned relevance' might actually work in practice.

With an approach of openness to discovery, upon entering the field I adopted a strategy of asking broad, open-ended questions to stimulate participants to share their experiences with me, trying to give them the best platform for discussions to go all manner of directions. I then began to analyse the data with regard to all manner of theoretical possibilities, some which remained for further analyses, but many of which did not. Glaser (1998) noted that at this point, the researcher must

grapple with 'chaos', not knowing what the emergent theory may look like, and they must code and memo the data in 'all ways'. So there can be moments when a particular perspective can appear a useful tool to draw upon in analyses, but techniques of the method such as the constant comparative method (elaborated further in chapter four) that continually require a researcher to check the fit of conceptual work as analyses go on, keep this deductive element in line (or reveal "bias distortion" as Glaser, 1998, p. 142 put it). In some instances, writings in various directions did not continue to 'pattern out' in the data, and so these lines of inquiry were not pursued further. At other times, they did, and their inclusion was 'earned'.

Fostering openness requires that a researcher must believe in the possibility of discovery and tread lightly in the presence of data, considering what may be conceptually novel and downplaying the conceptually known. To this end, particular epistemological or theoretical perspectives were not invoked from the outset of the study, but I took time to familiarise myself with many over the course of the study, and where they appeared useful ways of exploring the data I engaged them. This is a position consistent with Grounded Theory methodology, linking an initial 'not knowing' with possibility and discovery through openness. It is also a way of interpreting 'emergence', a further contentious term ubiquitous in Grounded Theory methodology writings.

For instance, a theoretical product of a Grounded Theory study is said to be 'emergent', and this is an important part of the methodology, with Glaser even writing an entire text that discussed the concept of emergence, pitting it against a 'forcing' opposite (Glaser, 1992). In Grounded Theory, when 'emergence' is employed to describe the development of a theory, it refers to what comes from the dynamic relation of analyses and data. Emergence does not 'just happen' but is thus worked, and a main concern and resolving theory are said to be emergent because they come from the work that goes in to analysing the data through identifying patterns, conceptualising these, and returning to the data to inform the way that analyses can be refined. However, an emergent theoretical product does not result from specific questions asked of the data, or the application of

predetermined frameworks, but instead is from worked analyses where the researcher has strived to keep open throughout and consider the data for various possibilities, and followed these through with adherence to the specific method processes. Emergence thus goes right through a Grounded Theory study and is underpinned by being open.

### The Credibility of Grounded Theory Studies

For those engaged in critically analysing and furthering the broad field of qualitative methodology, a dominant and ongoing concern is about how to ensure and convey quality research products. One of the more widely-known addresses to this problem was given by Lincoln and Guba (1985, 1999), who suggested that a matter of 'trustworthiness' is the core concern of qualitative researchers.

How can an inquirer persuade his or her audiences (including self) that the findings of an inquiry are worth paying attention to, worth taking account of? What arguments can be mounted, what criteria invoked, what questions asked, what could be persuasive on this issue? (Lincoln & Guba, 1985, p. 290)

For Lincoln and Guba, managing trustworthiness means ensuring 'credibility', 'transferability', 'dependability' and 'confirmability', which roughly match up to conventional criteria of 'internal validity', 'external validity', 'reliability' and 'objectivity' respectively. The authors suggest that these could be achieved through a number of processes, such as 'member checking', where work is taken back to the participants involved a study to test theoretical categories or interpretations. An 'audit trail' is another measure such that others reading the work would be able to see each step of the research process in reaching the final product, including decisions and justifications for each decision. 'Referential adequacy' was also recommended whereby a researcher would identify a portion of relevant data to be left out of analyses, then to be returned to after to compare a research product to in order to identify inconsistencies and gaps.

So there are a number of additional processes that can be attached to a qualitative inquiry to encourage trustworthiness, and while these appear sensible recommendations in the pursuit of good qualitative research (some consider it the “gold standard”; Polit & Beck, 2014, p. 322), it is questionable about the lengths a researcher must go to in ensuring and conveying credible research. For Glaser (2003), this was too far:

It is, of course, the almost hysterical pursuit of trying to solve the worrisome accuracy problem by an external, unrelenting accountability requirement imposed on honesty, skill and ability.....Their [Lincoln & Guba’s, 1985] hysterical approach to the worrisome accuracy quest forgets that we are all human after all doing the best we can. QDA [Qualitative Data Analysis] and GT research, both, are always as good as far as it goes and both stimulate further research to help, in part, corrections to make it better. (p. 147)

So Glaser took issue with these measures and with Lincoln and Guba’s lumping in of Grounded Theory with other forms of qualitative inquiry, having described it himself as a ‘general’ method, able to work with qualitative or quantitative data (or both) (Glaser, 1998). He vociferously claimed it to be a methodology distinct from other forms of qualitative analysis, and this has implications for both the way of going about the research as well as how the research product might be considered:

...This discussion, however it may be relevant to Qualitative Data Analysis (QDA) as it evolves into constructivism, is not applicable, even relevant to GT (see GLASER, 2002b). First, LINCOLN and GUBA's (1985) discussion's underlying pattern simply focuses on changing views of worrisome accuracy, but always accuracy. It does not address the abstract nature of GT, which does not deal in facts or findings, but generates concepts that apply as explanations. The concepts are not facts, as I have reiterated over and over. They are variables that vary and are modifiable. They are integrated into a

theory, which results in interrelated categories and their properties, highly applicable but *not* factual. (Glaser, 2004, para. 2–3)

QDA and Grounded Theory have very different goals. QDA is concerned with descriptive detail, and thus accuracy is an appropriate, indeed, a fundamental condition. However, Grounded Theory is concerned with the conceptual and the development of theory through this. Therefore, an assessment of a Grounded Theory should focus on the theoretical product of the research, where criteria more attuned to conceptual critique would be appropriate. Grounded Theory provides four criteria for this kind of conceptual evaluation:

Does the theory work to explain relevant behaviour in the substantive area of the research? Does it have relevance to the people in the substantive field? Does the theory fit the substantive area? Is it readily modifiable as new data emerge? (Glaser, 1998, p. 17)

Grounded Theory has these clear evaluation criteria to judge a study by, and are supplemented by ‘conceptual parsimony’ and ‘scope of explanatory power’ (Glaser, 1992). The criteria also double as guiding principles throughout analyses to help craft a credible research product. In this way, provided the researcher has paid careful attention to these, and provided this is apparent to a reader also aware of the evaluation criteria, credibility is established.

According to Glaser (1998), ‘fit’ is synonymous with validity. In this manner, conceptualisation must adequately reflect the contributing patterns of data, and concepts are honed through the constant comparison of incidents, codes, theoretical categories and properties of categories that improve the appropriateness of the conceptualisation. ‘Workability’ is the need to ensure that the concepts and their relationship to each other sufficiently explain the full process by which a core concern is resolved by the individuals in a substantive area. ‘Relevance’ pertains to ensuring that a research product is recognised by those involved in the substantive area, as the theory and the constituent concepts should have an attraction that provokes instant ‘grab’. ‘Modifiability’ means ensuring that

a theory is flexible in such a manner that any further data or other theory, no matter how contrasting, can work with the present theory, ensuring its ongoing utility. Glaser asserted that 'new data never provide a disproof just an analytic challenge' (Glaser, 1998, p. 19) and in this way, grounded theories should be able to work, or adapted to work, with all manner of data. It is through considering these criteria during analyses in a Grounded Theory study and reflecting on how these were achieved afterward that the credibility of an emergent theory can be understood.

### The Style of Grounded Theory

Finally, the way that grounded theories are presented is important to discuss, in order to explain the stylistic choice of this thesis. One of the ways Charmaz's (1973, 1991, 1995) Grounded Theory research is appealing is through her emphasis on retaining the voice of the individuals that contributed to her work, and this is achieved through use of many of their accounts in her work and using them at length. This was a point of contention for Glaser (2003) who considered that her work was little more than a collection of accounts accompanied by 'a nod to pure GT by some conceptual description' (p. 178). According to Charmaz (2006), the Constructivist Grounded Theory approach she then went on to advocate placed such emphasis on 'stories in service of analyses' because they could provide 'counterpoints' to an 'authorial voice' and that of a 'disembodied technician'. Charmaz was apparently concerned about 'silent authorship replete with assumed neutrality, objectivist pretensions, and an absent author' (p. 174) and so working closely with numerous included accounts was one way of foregrounding an interpretivist position, reflecting 'voice [that] echoes the researcher's involvement with the studied phenomena' (p. 174). However, arguments for and against CGT aside, the actual style of these works remains perfectly compatible with Grounded Theory methodology. In fact, it may be preferable to some, like myself, who wish to give illustrations of the interchangeable indicators of concepts, bringing life to what would otherwise be largely dense and heavy-going conceptual writing (e.g., see Glaser & Kaplan, 1996).

The form of the analytical part of this thesis is therefore inspired by the works of Kathy Charmaz, and also those by David Karp (e.g., Karp, 1997, 2001, 2006). Karp often writes with an unattributed analytical style that is suggestive of employing Grounded Theory processes, though his work has been compared to a 'generic inductive qualitative model' and contrasted with Grounded Theory in order to draw out the differences (Hood, 2010). Nonetheless, like Charmaz, Karp writes in a way where accounts are carefully employed to introduce and to break up conceptual and theoretical discussions, and to illustrate the variability of patterns in a substantive area. This makes for compelling reading and is a stark contrast to grounded theories that involve purely conceptual writing and which are more akin to technical manuals of phenomena (see Glaser & Holton, 2007).

There can, of course, be a tendency to depend on accounts, or to suggest these are 'proof' or 'evidence' of concepts (see Hopwood, 2014, for a commentary on this), yet a good rendering of a grounded theory may just as easily be stripped of mention of any interchangeable indicators and still stand up to its criteria of evaluation. It is a balanced, careful use of quotations and illustrations that can help form a grounded theory that is readily observable as credible, and as a bonus, makes it potentially more palatable to other qualitative researchers who are used to seeing participant accounts in scholarly works.

Therefore, once it has been clarified that Grounded Theory processes are understood and adhered to, the final presentation of a Grounded Theory may take a range of styles. The style of this thesis differs from many traditional grounded theories and yet remains congruent with the principles of the methodology. In providing and working through accounts to break up the density of conceptual work, I hope to encourage readability and to also give a sense of some of the analytical processes of Grounded Theory in action.

## Conclusion

In this chapter I sought to give clarity to both Grounded Theory methodology and the reason for selecting the particular form of the methodology. The merging of epistemology and methodology remain popular in qualitative research practices,

and each perspective can have useful insights about how to approach data. For instance, post-modernist principles raise the question of how appropriate it is to abstract concepts from a particular context, and how far this can be taken. However, in this study these perspectives were treated as theoretical sensitivity resources with which to consider the data rather than serving as a guide for the conduct of the study.

Grounded Theory methodology as originally elaborated by Glaser and Strauss (1967) and subsequently by Glaser (Glaser, 1978, 1992, 1998, 2001, 2003, 2005, 2009, 2011a, 2013, 2014) remains a strong approach to research that is appropriate for this project. It includes the flexibility to incorporate constructivist and post-modern perspectives as and when appropriate, and so to not be driven by these, therefore going beyond versions that are. I neither rejected nor consciously adopted an overarching epistemological or theoretical framework in beginning this Grounded Theory research. Instead, the methodology allowed me to commence the collection of data with prosthesis users that I could analyse in an 'open' manner, a key benefit being to then consider various theoretical options that could be helpful in understanding the data and when developing the emergent theory. The next chapter continues this discussion of methodology, exploring the application of the method processes.

## Chapter 4: Applied Grounded Theory

### Introduction

In this chapter I discuss the methods employed in undertaking the study and developing the emerging theoretical product. This involves reflecting on the premise of the research, discussing the parameters of the study, how to access the study population, ethical considerations, and the techniques used to obtain and analyse the data. Specific study design and analytical processes are elaborated, enabling an overview of how the theory was developed.

As outlined in the previous chapter, a Grounded Theory study is said to work best through a process of 'doing' and this is a two-part revelation for the researcher, as it is only in the application of the methodology that the researcher can truly know both the concerns of those in a substantive area and the intricacies of the methodology itself (Glaser, 1998; Holton, 2009). This praxis approach is part of the 'delayed action learning curve' of extended immersion with the methodology before a good understanding is possible (Glaser, 1978, 2001, 2003). Accordingly, this chapter is framed in a manner that reflects the gradual development of the study design and the analytical product, with critical considerations at each stage of the process.

Particular consideration is given to three processes of Grounded Theory that are known to be particularly challenging. Hood (2010) refers to these as the Troublesome Trinity of Grounded Theory, which are: 1) theoretical sampling; 2) the constant comparison of data to theoretical categories; and 3) focusing on the development of theory via theoretical saturation of categories. These fundamental aspects of Grounded Theory differentiate the methodology from a generic qualitative induction process and are the elements that many are said to struggle with that instead result in 'Grounded Theory approaches'. Adherence to the full methodological package is necessary for the production of credible theory (Glaser, 1998), and so particular detail is given to each of these processes to underscore the importance of their careful application and to explain how I understood and managed them.

## Preconceptions and a Literature Review

One of the more widely-known principles of Grounded Theory is the assertion that a researcher should not immerse themselves in extant theoretical literature in a substantive area prior to data collection and analyses in that area. As was noted in the last chapter, doing so risks miring theoretical sensitivity by obscuring an ability to remain open to emerging main concerns, particularly those that may be novel to the literature. Existing theoretical perspectives may be adopted in the formation of a theory, and this would occur on a preconceived rather than emergent basis.

While Glaser recommended researchers steer clear of any theoretical literature in the substantive area prior to beginning a study, he approved of substantive non-theoretical readings and also recommended immersion in other theoretical works to enhance a researcher's theoretical sensitivity. Researchers may enhance their theoretical sensitivity from the theoretical literature in a substantive area, but this vastly increases the chances of preconceptions creeping into an analysis, hence the warning to avoid this. Dey (1999) and Clarke (2005) note that most researchers are typically somewhat informed about the theoretical works in an area they work in, and so will have a literature review of sorts going already. Glaser (1998, 2001) sought to address these concerns, as well as to acknowledge the pressures of funding and ethical applications that often require evidence-driven rationales in order for studies to be supported. He suggested that when possessing pre-existing theoretical knowledge or knowing that this could be gained prior to analyses, a researcher should ask themselves to honestly consider how entrenched they feel they are, and how capable they consider themselves of conducting an 'open' grounded theory that will not be compromised by this knowledge. One way of managing assumptions or pre-existing theoretical knowledge of an area is to write about this so as to have a record of prior assumptions as well as to compare analyses to (Glaser, 1998).

Preconceiving of an emergent theory is a possibility, but not an inevitability; however it is made more probable the more the researcher is read in a specific area. As Strauss (1969) said about his decision to use ambiguous terms in his work on identity, doing so enabled him to 'sense that I could better look around the

corners of my problems, and be less likely to slide down the well-worn grooves of other men's thought.' (pp. 9-10). Thus the less immersion in theoretical writing in a topic, the less likely a researcher is to find themselves searching for or repeating the work of others, and the more able they can be to consider what may be novel.

If taken as a chronological account of the development of the emergent theory, the layout of this thesis is misleading then, in that chapter two presents a review of the literature, including conceptual work in the area, when in fact this was actually delayed until the end of analyses when I began assessing how the emergent theory might fit with existing works, as specified by the methodology (Glaser, 1998).

However, from a presentation point of view, it made sense to include this information when introducing the area of prosthesis use. In fact, when commencing this study, I did not arrive with any knowledge of conceptual work in the area, and only atheoretical substantive works were included to support funding and ethical applications. As a researcher relatively new to the field, and given this state of affairs, I felt capable of being open about the conduct of analyses.

## Design

### *Study Aims*

Even with the best intentions, Grounded Theory studies are said to often begin 'research framed - inculcated in a theoretical framework – consciously or unawaredly' (Glaser, 2005, p. 3). So even if substantive theory is avoided, researchers may still harbour suspicions of processes they believe may occur. Considering the premise of the research enables recognition of how vested interests in the research may hinder or take precedence over emergence. I admit that I was initially drawn to studying users of prostheses through wondering about the effects of modern adaptive technologies on the individual, and this is somewhat reflected in my funding application. However, in then employing Grounded Theory methodology to facilitate the study, I was conscious that my assumptions may not feature in the emergent concerns of prosthesis users. A compelling argument for Grounded Theory is how there are many cited cases of Grounded Theory studies that end up revealing an entirely different concern of the

individuals under study to that which was initially suspected (Glaser, 1998, 2011b). Therefore it is important to try to be open and to ensure that study aims remain broad and congruent with Grounded Theory principles.

Accordingly then, the aims of this study were to:

- I. Identify and explore a main concern of individuals that use prostheses;
- II. Develop a theory that can effectively and credibly account for the way or ways in which individuals process and manage their concern.

#### *Inclusion/Exclusion Criteria*

Individuals that were aged 18 years or above that were using an upper- and/or lower-limb prosthesis and that had been using an artificial limb for at least one month were invited to take part in the study. Participants needed to have sufficient command of the English language to be able to express themselves and be capable of giving informed consent to take part in the study.

The amount of time per day or week that the individual used their prosthesis for was not important, provided the participants considered themselves to be actively engaging with the limb, as opposed to a person who owned a limb but never used it, and so was arguably not a 'user'. I also felt it important to ensure sufficient time had elapsed to ensure the individual had gained some familiarity with a prosthesis, and after discussion with researchers in the area, a period of at least one month's prosthetic usage was deemed necessary for an individual to be eligible for inclusion in the study. This was in order for the user to have spent time with their prosthesis and so be able to talk meaningfully about life with an artificial limb. It is also fitting with studies that have explored the psychosocial aspects of assistive technology use that have ensured participants possessed their devices at least one month prior to investigations (Brandt, Iwarsson & Ståhl, 2003; Chen et al., 2014).

Inclusion was limited to only those using upper- and/or lower-limb prostheses, meaning the exclusion of those who only used different kinds of prostheses, such as breast, penile or facial. The potential relevance of the resulting theory to other groups of prosthesis users is discussed further in chapter ten. These limbs could be whole artificial limbs (e.g., such as those that could be used by individuals that have

undergone a hemi-pelvectomy) or could be just part of a limb (e.g., for below-wrist limb absence).

The literature in the field sometimes divides between upper- and lower-limb users, or between those with acquired or congenital limb absence, or loss of a limb through trauma or non-traumatic amputation (see Kratz et al., 2010). In this study, inclusion was informed on the basis of the research and by Grounded Theory principles – there was a need to understand users of prosthetic limbs, meaning individuals were sampled regardless of the region of their prosthetic limb, or the aetiology of their limb absence. A substantive area can take into account any group or groups of people, and so an emergent main concern will be an important concern for all persons involved, although sub-groups may have differing concerns if investigated separately. If, over the course of analyses, it is not possible to ascertain a main concern, then a project may need to be rethought. As it turned out, a main concern was established for prosthesis users, validating this decision to be inclusive.

#### *Identifying Participants and Recruitment*

Prosthesis users are a dispersed population and so present a challenge to sample. In this study, I recruited participants from a number of settings. An Irish prosthetics and orthotics centre connected me with a number of their clients, as did a consultant for an international artificial limb provider. Other participants were recruited through adverts and appeals to participate in the study via amputee support groups.

One organisation agreed to place a small advert in their newsletter, whereas others contacted individuals directly, passing on letters of invitation (Appendix A). For instance, clients at the prosthetics and orthotics centre were given the letter at the end of their consultation. All participants were provided with the same study information, giving a detailed breakdown of the nature and intentions of the study (Appendix B). Those consenting to take part were then invited to meet at a location of their choosing. If I was unable to meet with participants face-to-face, telephone (VoIP) interviews were arranged. In the case of two participants who lived in parts

of the world where significant time zone divergences meant phone calls were not possible, discussions were conducted via email.

### *The Sample*

Twenty-four participants were directly involved in the study: 19 male, 5 female. This sample size is congruent with extant Grounded Theory studies (Wilson & Hutchinson, 1996) though size is ultimately determined by the point at which theoretical completeness is reached, rather than going by a predefined number of participants or a particular volume of data (Glaser, 1998).

These individuals were aged 18-62. Five individuals had congenital limb absence and 17 had acquired limb absence (two were unknown). Thirteen participants had lower-limb absence, two of which were bilateral, and ten had upper-limb absence, all of which were unilateral. One individual had bilateral lower-limb absence and unilateral upper-limb absence. All participants except for this individual used prostheses where a limb was absent. This individual did not use a prosthesis for his upper-limb absence. A table of participant demographic information is included in Appendix C.

These individuals were each engaged in unstructured interviews, nine of which were conducted face-to-face, thirteen by telephone, and two by email. In addition to interviewed participants, sixteen autobiographical texts and one anthology of short autobiographical accounts were also included in the study, as well as seventeen blogs and forum posts from four discussion forums written by prosthesis users. Details of these further sources of data are also included in Appendix C.

### *Data Collection*

To identify a main concern of prosthesis users and the way that prosthesis users process and manage this concern, an advantageous starting point is through engaging first-hand with those using prostheses. To this end I sought to conduct one-to-one interviews with individuals. Though interview data is the most common source of data in Grounded Theory studies (it is often the only source of data), other forms of data can be useful, hence the inclusion of readily accessible autobiographical and internet data. A core tenet of Grounded Theory is that 'all is

data', meaning that all forms of information linked to a substantive area are potentially relevant to analyses, and even those outside a substantive area may be useful for comparative purposes. In this study, while face-to-face and telephone interview data was the primary and starting source of information, this was supplemented by the autobiographies and internet data. The management of each of these kinds of data are discussed below.

### Interviewing

Interviewing is the staple method of data collection in Grounded Theory (Backman & Kyngäs, 1999), as it allows the researcher to enquire about a main concern.

Interview sessions can assume a style of being structured, semi-structured, or unstructured. This can be thought of as a continuum of control and focus over the interview scenario to a loose, unguided exploration of emergent issues. There are advantages and disadvantages to either extreme, but pertinently to Grounded Theory it is important to be aware that the more structured an interviewing process is, the greater the risk of precluding discussion of the issues that could be most important to the participant. An advantageous interviewing style in a Grounded Theory study is therefore one that enables the flexibility and versatility to invite discussion that may go in any number of directions, and one that enables actively pursuing or investigating leads put forward by participants. I therefore began with an unstructured interviewing style, asking open-ended questions such as 'what is it like for you having a prosthesis?', aiming to give participants a broad scope to respond.

I asked broad questions in this vein, others of which can be found in a copy of the interview schedule (Appendix D). Since it is not possible to know in advance the main concerns of the participants of which to explore, I came to use the schedule mainly as a prompt for less forthcoming interviewees, and a guide for questions to begin interviews before participants' responses provided the basis for further questions.

To reduce the perceived formality of the interview situation, I offered to conduct interviews in more naturalistic settings, where possible, accompanying participants

to locations that they were familiar and comfortable with in order to put them at ease and so facilitate discussion (Ross, Renold, Holland, & Hillman, 2009). To this end, interviews took place in limb-fitting centres before or after consultations, or hotel bars or cafes. While this was not possible with the telephone interviews, I attempted to call at times when participants had said they would be at home and free to take the call, and encouraged emailed participants to reply only when they felt they had time to do so.

Glaser and Holton (2004) assert that Grounded Theory can incorporate any form of interviewing style; the most appropriate emerging as the study advances. This leaves the researcher open to consider various techniques. I opted for an unstructured style, intending that this would give participants a broad scope to take discussions in various directions. I also sought to minimise my contribution by listening more and using interviewer silences to encourage interviewee disclosure. These techniques required balancing and avoiding overuse, where interviewees could perceive a quieter interviewer as disinterested, detached, and silences uncomfortable.

Holstein and Gubrium (1995) recommend a more active interviewer approach. One feature of this is where the interviewer invites multiple perspectives on a topic through encouraging discussion of alternate viewpoints. This enables comments on a range of takes on an experience. However, while gaining multiple perspectives on a topic of discussion may be illuminating, it is reminiscent of axial coding and the practice of asking questions of the data that may be at the potential expense of relevance. Instead, I tried to find a balance between the poles of an over- and under-active interviewer, maximising the opportunities for participants to talk whilst retaining enough engagement to explore contributions and to ensure interviewees understood I was genuinely interested in their contributions.

Before I brought interviews to a close, I invited a final disclosure of any topic the interviewee felt pertinent for further discussion or that had not been discussed, asking questions such as 'is there anything we haven't covered that you think I should know?' This frequently prompted substantial extensions to the interviews, as participants appeared to consider whether they felt they had gotten their

accounts across appropriately, and added to this accordingly. Often, responses to this were of a different nature to the main discussion, as if the participants recognised that they had crafted the direction of the interview themselves, only to find when reminded of the nature of the interview that there were other things of relevance that had not fitted with the conversation but nonetheless deserved mention.

### Recording and Transcribing Interviews

All interviews were audio-recorded for the purposes of re-listening and transcribing. These are acts Glaser specifically advises against. Instead, the researcher is recommended to write 'session notes' during an interview and directly after it (Glaser, 1998). Transcribing, he argued, takes too much time, and the act of recording can undermine or restrict a sense of confidentiality (Glaser, 1998, 2001). However, these were more minor arguments in support of a greater concern of Glaser's that researchers could become more preoccupied with inclusivity and 'data accuracy' at the expense of data collection and conceptual analyses. In Grounded Theory, the main purpose of conducting any initial interviews is to discover a main concern and the core category that resolves it, and then to account for the variation within this concept. These were things Glaser argued would come quickly, and then a researcher would hear over and over again in different forms. These indicators of patterns will be recurrent by their nature, and so a researcher should not worry about 'missing' anything if interviews are not fully recorded, transcribed and coded as they will encounter them at some point during subsequent data collection and analyses. This also means such efforts are redundant if a concern and core category are quickly identified and analyses should instead turn to exploring these through selective coding and theoretical sampling (elaborated below).

However, as with the warning against engaging a theoretical substantive literature review prior to commencing analyses, it is the spirit of this message that is important and understanding this allows the flexibility to adhere more or less to Glaser's advice. As explained in chapter three, I intended to employ some quotations to help express some of the categories and variation within the theory,

so I explained to participants how I would find it beneficial to record the interview and to potentially use their words to this end, and all consented to this. In face-to-face interviews I then attempted to play down any perceived formality brought about by the intrusion of the recorder in face-to-face interviews by ensuring the device was out of sight. It was my hope that in the telephone interviews, as discussions progressed, participants would forget about the recorder.

I also felt that when re-listening and transcribing interviews, thoughtful consideration of the data could also potentially cut down the time taken to come across the conceptual patterns within the data. In addition, I also found that an undistracted reflection during re-listening not only promotes deeper consideration of a discussion, but it can help to improve an interviewer technique when re-listening to one's own conduct becomes difficult. These points led me to the decision to record and fully transcribe all interviews.

In terms of the session notes, I suspected writing these within the interview situation would have been too much for an unseasoned interviewer like myself, who would be focusing on what the participants were saying and responding accordingly, and I would also be less comfortable as an interviewee if an interviewer was making notes while I spoke to them. Instead, I limited my session note writing to only after interviews had ended, where I noted my thoughts on the interview, about what had been said and any pertinent observations I had made.

### Autobiographies

Autobiographical texts were a further source of data which I drew on over the course of this study. Like interviews, such data could be explored in early analytical phases and/or later drawn upon to elaborate variation within theoretical categories. These texts were analysed in a similar manner to the text from transcribed interviews, as was the internet data, and this is discussed in the analysis section below. I sourced these texts through searching bookseller catalogues for autobiographies that were written by prosthesis users.

## Internet Data

In addition to interviews and autobiographies, the internet presents a potentially rich source for data. I reasoned that because prosthesis users are a relatively small and dispersed population, these individuals are likely to use the web as a means of recording their experiences and connecting with each other. A brief search confirmed this, revealing a myriad of blogs and discussion groups varying in member numbers and forum activity. Using variations of 'amputee' and 'prosthesis' as keywords I came across a number of sites which were compared to the inclusion/exclusion criteria of the study. Seventeen blogs and four discussion forums were included in the study (see Appendix C).

However, data on the internet comes with its own distinct methodological considerations. Potential participants may be approached for data directly or in real-time, such as in a chat forum or by the researcher posting a call for information on a community page. New data may be obtained in this way, but may also be obtained through browsing existing discussions and blogs. In both cases it is difficult to verify participant demographic information. My inclusion criteria specified that individuals needed to have been using a prosthesis for a period of at least one month, and this was not always clear with internet data. Where it was not possible to ask individuals directly, I therefore strove to check whether blogs contained posts going back at least one month that suggested the individual had been using a prosthesis then, and likewise examined forum member post histories.

There are also a number of unique ethical considerations to be aware of with the use of internet data that merit discussion outside of the main ethics discussion. Robert Kozinets, in his development of a form of internet ethnography he terms 'netnography', discusses a number of these considerations (Kozinets, 2009). He notes that currently, there is a dearth of ethical guidance for web data collection and usage, and so researchers are best advised to take a conscientious approach when interacting with internet data. The British Psychological Society (2013) also offer some brief guidance for online research, but Kozinets discusses the principles of good practice at length in his text, and on this basis I employed his advice as the

guiding source for working with internet data, on top of Grounded Theory procedures.

Of these points, a few are worth clarifying. When conducting research studies online, consideration of a community is paramount, and the researcher should be aware that when they engage with users, they are entering a realm that some consider a safe haven for discussion between likeminded individuals. Many users consider these areas to be private and may not take kindly to intrusions from outsiders, even if it is clear that these discussion groups are not invitation-only or password-protected –they are readily accessible to anyone (Kozinets, 2009). With this in mind, and with an awareness that those with limb absence are routinely bothered by so-called ‘devotees’ (see Aguilera, 2000), I contacted moderators to seek permission to post prior to inviting comments in threads, and then announced my presence and intentions when posting.

The use of internet comments or posts as quotations also merits consideration. In interview scenarios, permission to record can be sought and quotations can be kept anonymous. On the internet however, some have expressed disdain upon discovering that comments they have made in an area they have considered private have been used elsewhere (Kozinets, 2009). Permission to quote may be requested from the original poster, but this is not always possible, particularly when posts date back over the years and accounts become inactive and disconnected from posters. Complete anonymity is also problematic, as the powerful nature of search engines mean that quotations can be traced back to their original source with relative ease. Kozinets recounts a study where a number of members of an online community were disgruntled with the fact that some of their group had taken part in an online ethnographic study. Some of these displeased individuals took it upon themselves to search and map out all used quotations in the resultant publication to the identities of their posters, presumably to highlight and ostracise the individuals that were willing to speak publicly about their group (p. 144). Kozinets considers that this kind of response would normally be confined to close-knit groups or where discussions are often of a strongly personal nature, and while

prosthesis user communities may share these qualities, I discovered that members welcomed my presence.

### *Computer Assistance*

There is much discussion of the use of computers and software in Grounded Theory projects. This is something Glaser (1998) also had something to say about. He expressed concern that researchers would believe that software packages such as NVivo (QSR International Pty Ltd, 2012) could help out with Grounded Theory analyses, and this is understandable given the increase in data analysis features with each version and that QSR advertise it as 'research software for analysis and insight'. While some qualitative inquiries may find these features of automated analysis useful, Grounded Theory requires the careful identification and conceptualisation of patterns from incident data which is beyond the most complex of current software algorithms. It is a fundamentally human task in its complexity – for instance, even at a simple level, phrases may differ yet share the same meaning, and contemporary programs are not yet close to mastering this beyond isolated instances. Within passages of text, across varying contexts, such patterns can easily go unrecognised. Proponents of computer-aided analysis in Grounded Theory that are aware of this suggest that programs are made best use of when they instead are used to help organise the research, such as through keeping track of multitudes of codes that are often generated in an analysis (e.g., Bringer, Johnston, & Brackenridge, 2006; Hutchison, Johnston, & Breckon, 2009). I certainly appreciated their utility when encountering this in my own analyses.

When limiting the role of software to that of organisational, Glaser (1998) remarked that software programs such as NVivo could be seen as an 'elegant pencil' for analyses (p. 185), and provided usage does not inhibit the fluidity of analysis, it has the potential to bolster efficiency. I found this to be the case when using NVivo to organise my work, as after uploading data to the package and beginning coding, I could quickly view summaries of my work to-date, which helped me to identify patterns in the codes I had produced and then attach memos to these. It was also beneficial to be able to quickly go from a concept I had memoed about and trace it back through codes that had contributed to this, to the data,

ensuring I kept my writing grounded, and also to point to potential illustrative quotations that could be employed in the write-up. In sum, I found it useful to have a sort of virtual scrapbook in which to house various forms of data and to store and index my analyses, the indexing facilitating further analyses, but the actual conceptual work underpinning this remained my sole manual task.

### *Ethical Considerations*

Ethical approval for the study was obtained from the Dublin City University Research Ethics Committee. To avoid undue pressure to participate when recruiting participants to the study, I contacted professionals and group leaders to help recruit individuals on my behalf. On this basis, leaders and staff contacted their members or clients and distributed the study information sheet to those individuals that expressed an interest in participating. Participants would then either contact me directly via telephone or email, or leaders would forward me the contact details of interested individuals. I would then either email or telephone these individuals and re-iterate the details of the study, confirming their continuing interest before arranging a time to conduct the interview. In cases of phone interviews, some of these interviews followed immediately after, but where it was possible to meet the individuals, we arranged to meet at a location convenient and acceptable to the individual. In both scenarios, prior to commencement of the interview, I enquired whether they had any questions about the study and requested consent. All participants were asked to sign a consent form prior to their involvement in the study and in the cases of telephone interviews, consent was requested verbally and again through return of scanned consent forms via email.

Prior to the interview, participants were reminded that they could withdraw at any time from the study without penalty. All participants were assured of confidentiality throughout the study. The only personal data requested were participants' names, their email addresses, and telephone numbers, in case further contact with them to explore topics was necessary. These details were stored separately from the interview data.

I explained to participants that when I produced the final thesis, pseudonyms would be used and any potentially identifying details would be removed. However,

I did remind participants that if a person referred them to the study, then they would naturally have an idea of their involvement, and it was also a small possibility that given the relatively small population of prosthesis users and specific prosthetic configurations, that some accounts would be recognisable to familiar others even when anonymised. I reassured participants that I would do my best to ensure any material quoted would be devoid of specificities where possible. No participants revoked their consent.

Interview data was recorded through an audio-capture device and copied to a computer, whereby the original recording was erased and the stored file encrypted to ensure confidentiality of all electronic records. No hard copies of the data exist and only the research team had access to the recordings and transcripts. These were labelled for erasure for five years after their creation, as per DCU personal data policy.

It was anticipated that participants would be at minimal risk to harm since the research employed non-invasive data collection procedures. However, I recognised that during interview sessions it would be possible that discussion may move towards sensitive topics, such as if a limb had been lost, which some may find distressing to talk about. In the event that a person became upset as a result of participating in the study, the information on the study information sheet directed the individual to relevant support systems (see Appendix B).

## Analyses

Analyses in a Grounded Theory study are iterative and incremental. In brief, the process begins with open coding where substantive codes are produced through comparing and contrasting incidents to determine patterns. These conceptual patterns are explored and their relationships with other patterns established. During this process, a concept that appears to account for many of the other concepts is also emergently developed. This is labelled as the core concept which organises the entire theory and is the category of action that manages a core concern of individuals in the substantive area. At this time, open coding switches to selective coding to help explore further concepts relevant to the core and to

reconceptualise and 'saturate' those presently identified. When all variation within the core category is accounted for then the theory can be said to have reached a level of 'theoretical sufficiency'. This section provides detail for each of these steps as I moved from the data towards the emergent theory, and examples of these processes in action are given in the appendices.

First, it is important to recognise the way in which a Grounded Theory analysis is underpinned by the constant comparative method. This is the process of comparing incidents throughout data to determine patterns that form the basis for the creation of theoretical categories. Constant comparison occurs at all levels of an analysis, not just to identify categories, but to refine them through comparison with others, other properties, and incidents. Glaser and Holton (2004) note the three important ways that constant comparison occurs:

Incidents are compared to incidents to establish underlying uniformity and its varying conditions. The uniformity and the conditions become generated concepts and hypotheses. Then, concepts are compared to more incidents to generate new theoretical properties of the concept and more hypotheses. The purpose is theoretical elaboration, saturation and verification of concepts, densification of concepts by developing their properties and generation of further concepts. Finally, concepts are compared to concepts. The purpose is to establish the best fit of many choices of concepts to a set of indicators, the conceptual levels between the concepts that refer to the same set of indicators and the integration into hypotheses between the concepts, which becomes the theory.

(para. 53)

The constant comparative method is true to its name and takes the researcher from data and conceptual fragments to a final unified theory. It also guarantees the 'groundedness' of an emerging theory through ensuring that properties of theoretical categories arise only through comparison of incidents in the data (or

between conceptual products that have originated from incident comparisons), and hence that each aspect of the theory has earned its inclusion.

### *Open Coding*

I began analysing the data through open coding. This is a substantive coding process that involves going over the data, identifying incidents and appending codes that conceptually reflect the content of an incident (Glaser, 1978, 1992, 1998, 2001). Though painstaking, line-by-line coding has been recommended to encourage 'full theoretical coverage' (Glaser, 1978), whereby the researcher is encouraged to carefully pore over the data and generate numerous codes as they go, which may often be for the same incident. This way the researcher is said to be 'running the data open' (Glaser, 1978). For example, (depending on the data) an incident could be coded as 'restraining oneself' as well as 'avoiding involvement'.

Early into my analyses, I took line-by-line coding rather literally, and quickly found that assigning a code to each sentence of my data was not the most useful way of coding. For instance, I found that in some transcripts, some interviewees appeared to say very little in a sentence, or that what was being said was taking place over a couple of sentences. Conversely, sometimes a code appeared relevant to one part of a sentence and another code to another part. So the density of codes tended to vary and thus I sought a more flexible approach to coding. Remembering that Glaser often worked with interview session notes and not transcripts helped me to identify this. In his coding advice, Glaser was almost certainly not advocating the coding of all sentences within a transcript. Rather, the suggestion of coding he made in his 1978 text was in regard to coding the recommended session notes that a researcher was encouraged to make during or after interviews and the field notes that could be made in other situations. By their nature, this would make the notes more selective, concise, and non-repetitious, and so such a process of coding all sentences makes more sense.

With this in mind, I kept to line-by-line coding in the sense that I considered each line of the data, but determined that any portion of data could be considered to be a single incident. This enabled me to code half sentences, multiple sentences together, or entire paragraphs (examples of my open coding are given in Appendix

E). However, I was conscious to ensure that my unit of analysis did not enlarge so as to become too much of a conceptual impression (Glaser, 1998). This 'overview approach' runs the risk of losing the precision of what is going on and instead incorporating a professional opinion of the data (Glaser, 1978). Therefore, although I kept analysing each line of my data, I only (and always) coded where one single thing could be said to be occurring in the data, which kept incidents focal, and coding plentiful and consistent. It is notable that the language around coding advocated more recently by Glaser has begun to emphasise coding 'incidents' and less about sentence coding, further inferring compatibility with my interpretation (Glaser, 2001).

In this initial open coding, I sometimes had recourse to use in-vivo codes with the data. In-vivo involve the participants' own language, and I found it useful to include such terms to better familiarise myself with accounts of prosthesis use and to retain meaning in my coding. As interviews and analyses progressed, I was able to better understand the meaning imbued in these terms by the participants and felt more comfortable using my own.

Despite the strategy of coding incidents appearing to initially work well, a single transcript generated over 50 apparently unconnected codes and led to an unmanageable amount over multiple transcripts. After some deliberation, I realised that I had not been conceptualising nor coding according to the Grounded Theory principle of constant comparison well enough. Since coding in Grounded Theory is the pursuit of patterns via comparative analysis, I had instead provided quite descriptive labels to each incident without considering them at a more conceptual level, particularly in regard to each other, from which to discern fewer codes that can span multiple incidents. This is a common pitfall in Grounded Theory analyses, particularly for the researcher new to the methodology (Higgins, 2006; Holton, 2010; Philbin, 2009). There was also an element of 'conceptual foppery' (Glaser, 2002a) where I had attempted to code but with comparison lacking, leading to the same issue. Returning to the open coding, I aimed to better invoke comparison and to consider incidents using the three important questions in Grounded Theory

coding that would help improve fostering conceptualisation. Glaser (1998) defined these as:

- 1) What is this a study of?
- 2) What category does this incident indicate?
- 3) What property of what category does this incident indicate?

Asking these questions when coding helps to encourage consideration of the individual incident as well as in comparison to other data and keeps coding at a conceptual level (Glaser, 1998). However, Holton's (2010) explanation was of some comfort to my former efforts:

As a grounded theorist develops her conceptual coding skills, she can more readily dispense with the initial descriptive codes and employ conceptual-level coding from the outset of the open coding process. This takes skill in conceptualisation as well as a ready arsenal of conceptual labels; both are developed over time and with continued practice. (p. 26)

In a way then, my first forays became practice at conceptualisation which I sought to improve upon. With the above guidance, I was able to move forward and backward across the data and my initial coding, comparing incidents and codes and adjusting and forming new ones where relevant. I often returned to refine codes given to patterns of incidents as I progressed through the transcripts and soon found I was managing a much more reasonable quantity of codes. This enabled a clearer view of the emerging categories and consequently clearer directions for theoretical sampling. However, before discussion of theoretical sampling, consideration must be given to the important process of 'theoretical memoing', where much of the work is done in composing a Grounded Theory.

### *Theoretical Memos*

When conceptualising a pattern, theoretical memos are written. These memos are said to be the 'theorising write-up of ideas about codes and their relationships as they strike the analyst' (Glaser, 1978, p. 83). They are the spaces for discussion of the possible linkages of incidents or codes and for postulating how a theory may

develop, and potential leads for theoretical sampling (Glaser, 1998). In short, they keep track of the emerging theory.

Glaser referred to memos as a 'moment capture of an idea' (Glaser, 1998), written at any time, and he advocates the freedom to construct these however the researcher sees fit. Initially, Glaser recommended they normally accomplish at least one of five goals: (1) helping to raise the data to a conceptualisation level; (2) developing the properties of each category which begins to define it operationally; (3) presenting hypotheses about connections between categories and/or their properties; (4) beginning to integrate these connections with clusters of other categories to generate the theory; (5) beginning to locate the emerging theory with other theories with more or less relevance (Glaser, 1978). However, he later suggested that formalising memo requirements could 'stifle emergence' (Glaser, 1998, p. 179) and these guidelines may instead be interpreted as common useful purposes of memos, but that memos may take any form in service analyses toward the emerging theory (Glaser, 2014).

In practice, I found it useful to focus my early memos on the naming and describing of a pattern, trying to justify this with reference back to the data and to the contributing code(s). An example of an early memo like this can be found in Appendix F, along with some more mature memos. As analyses progressed, these memos began to be re-writes of earlier memos, refining my writing of patterns and their relationships to others. 'Sorting', a process of comparison and consolidation of memos, then helps to refine the structure of a theory. Memoing was also an integral part of the final write-up, as they reflected maturing analyses and the shape of the developing theory.

### *Theoretical Sampling*

As the constant comparison processes of analyses in a Grounded Theory study are engaged, concepts and their properties emerge through coding and writing about these patterns through theoretical memoing. Once a pattern has been conceptualised, indications are made about a concept, but what is gleaned from the data may only inform a partial understanding of the concept. Theoretical sampling is therefore employed to seek out data to further elaborate concept

dimensions. It is important to clarify that theoretical sampling is not a search for 'negative cases' but instead for variation in a pattern and to understand what accounts for this. According to Glaser (1998), 'it is the "where next" in collecting data, the "for what" according to the codes" and the "why" from the analysis in memos' (p. 157).

During analyses, I sought to theoretically sample incidents in new and existing data to help explore concepts. Like other patterns, 'just normal' was therefore theoretically sampled for, but following the conceptualisation and identification of this as the core category of the theory, theoretical sampling was delimited to identifying the variability of only the concepts involved in the theory. As these concepts account for the core category of the theory, then in a sense, theoretical sampling for any of these was always part of a search for variation on 'just normal'. For example, a pattern that began life as 'protective aversion' had been conceptualised to account for incidents where individuals did not do certain things in order to protect their ongoing ability to use their prosthesis. After identifying this, theoretical sampling led me to determine protective aversion occurring in different forms that could be conceptualised as distinct concepts within a concept of protective aversion. In doing this, I also came across incidents where protective aversion did not occur, and persons using a prosthesis would press on with an activity even in the knowledge that there was a high likelihood of detrimental consequences. This enabled me to conceptualise a further related pattern of non-avoiding, and accounting for the difference between the two drew me closer to my core category through understanding what motivated these acts. Similarly, when the core category was established, I theoretically sampled for *black-spotting*, an evolved version of protective aversion, and which I had re-conceptualised as how persons identify situated threats to their ability to continue to be *just normal*. I therefore sought to explore the variability in how persons respond to these identified threats in order to keep *just normal*. As an account of *black-spotting*, I had established *protective avoidance*, and what later became known as *vigilant risk-reducing*, but it was through theoretical sampling that I identified the further distinct responding to situated threats that was conceptualised as *fail-safing* (these

are further individually explained and the relationships between these explored in chapter six). After no more variation became apparent while theoretical sampling for incidents concerning *black-spotting*, I felt I had a good understanding of the concept, and thus a part of how persons overall manage being *just normal*.

Theoretical sampling was therefore a process which was continually engaged throughout the analytical period. Whenever I conceptualised a pattern, this was from comparison of incidents that I understood was a pattern of something occurring, but like in the *black-spotting* example I was aware that I may only have understood part of how this pattern varied. Thus I sought to inquire further as to how persons resolved being *just normal*, exploring each pattern within the theory in order to try to gain a fuller account as to how persons manage the concern.

A process of theoretical sampling therefore is repeatedly employed until the cessation of further unique properties of a theoretical category. This is the point of so-called 'theoretical saturation' when no further variability in the theoretical categories appears present in theoretically sampled data (this is further explored in the section below on theoretical saturation/completeness).

### *Theoretical Coding*

It is said that the least understood aspect of Grounded Theory methodology is theoretical coding (Glaser, 2005; Hernandez, 2009). However, theoretical codes are the essential integrating elements of an emerging substantive theory and so deserve thoughtful consideration. These codes model relations between patterns and concepts, giving shape to the theory, whether that of a process, a typology, a continuum, or an 'amplifying causal loop', etc. (Glaser, 1978). They can be any form of proposition that suggest how the substantive codes that are derived from the data may fit together, thus providing the form of the final theory.

Glaser (1978, 2005) often discusses theoretical codes in terms of 'coding families' such as the oft used 'Six C's, comprising 'context', 'condition', 'cause', 'consequence', 'covariance' and 'contingency'. Considering such families stimulate further ways of thinking about the form of the emerging theory – for instance, if

analyses indicate that a cause may be relevant between patterns, considering the other five 'c's' may indicate further thought for the development of the theory.

Glaser (1998) said about theoretical codes that 'they are emergent and weave the fractured story turned into concepts back to an organised whole theory' (p. 163). A further claim of another quality of Grounded Theory being emergent should not come as a surprise at this stage, but Glaser drew attention to this to encourage that persons should not automatically draw upon ways of relating concepts that may be regularly employed in the literature in the substantive area, instead considering those which are best fitting – those which have 'earned relevance', as indicated by worked analyses with the data.

To assist in this emergence and considered fit, reading outside of a substantive area is encouraged, as this will help to develop sensitivity to potentially useful theoretical codes that can help draw the theory together (Glaser, 2005). In fact, a Grounded Theory researcher is recommended to have a wealth of theoretical codes from which to draw upon (Glaser, 1978), and so this can be problematic for an early researcher such as myself. Accordingly then, in accompaniment to analyses of the data, I read theoretical works not directly related to the area that were informed by my conceptual writing and of general interest. For instance, when I began to conceptualise around notions of normality and self-appraisals, this prompted me to read more deeply in the theoretical literature on self and other relations such as that discussed in Symbolic Interactionism (Blumer, 1986; Mead, 2009). So too with decision-making literatures when I was conceptualising how individuals chose whether to change their prosthesis or to stay with the limb they had. Considering the way that self-relations and decision-making were modelled in the literature appeared relevant and helped me to think about my own analyses, spawning many further memos, though I ultimately did not explicitly draw upon this structuring.

Despite the importance of theoretical codes, Glaser (2005) notes that a grounded theory is not flawed if it does not appear to utilise any. Many Grounded Theory studies do not appear to explicitly invoke theoretical codes, yet their usage is implicit and unavoidable as a theory necessarily consists of relationships between

concepts in some form. A researcher not noting the use of such codes may simply not have been aware of the codes they themselves were employing during the development of their theory. So though theoretical codes are an integral aspect of a grounded theory, their explicit identification is less important, but contemplating these may facilitate developing a theory if it provides useful considerations for further thoughts on modelling and for theoretical sampling.

In this study, I did not identify the theoretical coding of the theory until much later on in analyses, yet this was helpful in developing the theory. The final form of the theory is that of a core concept which has three 'modes'. That is, the core category takes three distinct, yet related dynamic forms. This is somewhat distinct from a typology in the sense that types may reflect the varying forms of something, whereas modes may do this but also reflect the manner of the action involved. To think of this a different way, there can be types of bicycle (e.g., road, mountain, fixed-gear, folding, tandem) and modes of cycling (e.g., leisurely, competitively, for fitness), and modes in this way indicate different kinds of cycling and where the purpose is important to consider. The difference between types and modes may be modest, but considering the phenomenon through a dynamic arrangement which varies, as a modal arrangement foregrounds, helped me to develop the theory by stimulating thinking about the nature of the differing modes, and so this helped me to refine those I had identified and to consider whether there were other modes of the core category, and how these might relate to each other. Considering 'modes' also facilitated capturing something of the action involved in the resolving of the concern when naming the theoretical categories, and this is important in a grounded theory and further addressed in chapter 10 (on the section on the 'fit' of the theory). I am not aware of a theoretical code of 'modality' being mentioned in Grounded Theory methodology, and so other Grounded Theory researchers developing their own theories may find it useful to glean this from this work or to study other models of modalities.

#### *A Core Category and Selective Coding*

During analyses (Glaser, 1998, contends this can come earlier or later), a core category is 'run into' (Glaser, 1998, p. 138). Up until this moment, concepts may

have been developed that may appear linked or separate, but the core category is identified as the pervading and organising concept that sits at the centre of a theory and accounts for the action within other categories. It helps to integrate identified concepts and is the key latent pattern of action that speaks to a main concern of the participants. In addition, Glaser (1978) stated that a core must relate meaningfully and clearly to other categories and have 'grabbing' implications for formal theory. To help this emerge, Glaser and Holton (2004) later recommended three sensitising questions to consider when working with the data:

- 1) What is actually happening in the data?
- 2) What is the main concern being faced by the participants?
- 3) What accounts for the continual resolving of this concern?

At this point it is important to note that a core category may be one of a number within a substantive area. That is, individuals likely have multiple significant concerns and likewise there are multiple core categories. However, a theory must contend with a single core category (Glaser, 1978), even if multiple theories can be derived from the same data. A case in point is Glaser and Strauss' original grounded theories, the first of which involved 'awareness contexts' as the core (Glaser & Strauss, 1965) and the second 'dying trajectories' (Glaser & Strauss, 1968), both of which were developed from the same data.

In this study, I contended with a number of possible core categories, memoing about these and their relations to other concepts. These were emergent 'possibilities' that I necessarily worked with for periods during analyses, testing their fit and whether they would 'pattern out'. Of course, all were ultimately rejected until one was determined to fulfil Glaser's (1978) core category criteria, accounting for the variation across and within identified concepts, and had best fit with the emergent main concern. I was aware that a prolonged period could be required to identify an appropriate core, having been cautioned by Glaser (1998) that 'it takes many misses to get to core and relevances' (p. 182).

Some grounded theories contain core categories that appear to link to a concern more closely than others. That is to say, some theories contain core categories that

more or less express a conceptual concern through the core itself. For instance, 'solutioning' in mathematical students quite plainly indicates a concern of coming across situations that require solutions, and 'moral reckoning' as a core action of nurses is a giveaway of a concern of needing to manage issues of a moral nature, as was the case in Nathaniel's (2006) grounded theory. In other grounded theories, a concern may become more apparent once the detail in the core and thus the constituent sub-core categories and their properties are expressed (e.g., "offsetting the affective filter", in Chametzky, 2013; or "mutual intacting", in N. Elliott, 2010). It is therefore arguable that there may be some cases where analyses do not prompt a need to distinguish a concern from a core category, particularly if forcing doing so for the sake of coming up with differing terms is detrimental in expressing both the concern and resolution. To take this study as an example - persons that use prostheses express a conceptual main concern about being just normal (explained further in Chapter 5). This is a significant concern that preoccupies prosthesis users, and was discovered to be resolved via diffuse modes of action that enable a person to live just normally. It is almost redundant to state then, that a concern of being just normal is resolved by actions effected to ensure a person can be this way. Therefore, though somewhat against tradition, but in-line with Grounded Theory principles, a concern and core category of participants in this study was considered to relate to living just normally: They were concerned about being just normal, and in resolving the varied ways in which this concern is brought about, they are implicated in various modes of actions to live just normally.

Once identified, the core category then helps to refine existing concepts as they are reconceptualised with regards to this pattern (concepts are reconceptualised into categories of the emerging theory). In this study, early on I identified patterns of participants comparing themselves to others in different ways, and so I memoed about these, but these patterns were then returned to and reconsidered when the core category of 'just normal' was determined to account for these comparisons and enlightened the purpose of doing so. This can be observed in the first sample memo in Appendix F, which was later re-conceptualised in the third sample memo.

When a core category has been recognised, open coding ends and selective coding begins. This entails limiting data collection and coding to only that which is relevant to the emerging conceptual framework (the core and categories that relate to the core) (Holton, 2010). Selective coding helps to delimit the scope of analyses by focusing theoretical sampling to just seeking variation in terms of the core category and thus the concepts within the theory (see Appendix G). This continues until the process of constant comparison yields no further properties or elaborations of the categories, and so theoretical saturation is said to have occurred (Glaser, 1978).

### *Theoretical Saturation and Theoretical Completeness*

When analyses of data from theoretical sampling determine no further variations of a particular theoretical category, it is said to be 'saturated' (Glaser, 2001; Glaser & Strauss, 1967). This is a proposal that has been criticised by some, and Dey (1999) in particular has taken issue with the idea of saturation, claiming that a notion of saturating categories implies a kind of comprehensive analysis which is at odds with a methodology that delimits and does not seek to code all data. Dey's issue is that saturation is a subjective claim on the part of the researcher and instead that researchers should consider a 'theoretical sufficiency' (p. 257) towards categories. However, Dey misunderstands the methodology as analyses towards a theory that is intended to reflect action in a substantive area will always need to be delimited at some stage. Instead, Grounded Theory promotes starting out with openness, working through early analyses to develop a range of concepts, before elaborating and refining those that recur, and in regard to a core category. Theoretical sampling enables those elaborations but also is a process that indicates cessation when significant conceptual variation appears to have been captured. Importantly, this occurs with the proviso that an emergent theory should be modifiable and so open to further variation that could at some point arise. As Glaser stated, a grounded theory is 'as good as far as it goes' (Glaser, 2003, p. 147), and by this, Glaser is suggesting that if the concepts and thus the theory have utility – if they have workability and resonance – then this is the sought after state that theoretical saturation relates to, rather than any implications that it is comprehensive of all

data that could be encountered and that it is a 'know everything' theory (Glaser & Strauss, 1967, p. 73).

In this study, theoretical saturation was judged present when no further evidence of variation within the core category could be determined in theoretically sampled data – both new data and the data already collected that was analysed for further variation. As the theory revolved around the core category, saturating this meant the saturation of the sub-core categories too. When this occurred, the theory was deemed 'theoretically complete'.

### *Conclusion*

This chapter reflects a commitment to the methodologies of Grounded Theory upon application. The basic principles of freedom and openness, emergence and flexibility helped to develop the theory that was systematically derived from the accounts of prosthesis users. It has been through extended immersion in the Grounded Theory methodology literature and the actual application of the method processes that I fully recognised that a credible theory of how prosthesis users process and manage a core concern could only be produced through thoughtful consideration of each part of the Grounded Theory methodological package.

## Chapter 5: The Emergent Theory - 'Just Normal'

### Introduction

In this chapter, the main theoretical contribution of the thesis is presented and defined. More specifically, the main concern and resolving core category that analyses helped to 'emerge' are discussed in detail. This discussion gives an understanding of the overall theory and sets the stage for further exploration of the particular components that make up the theory, which are then explored in the subsequent analysis chapters.

### Introducing the Concern

A main concern of the prosthesis users involved in this study is whether they were 'just normal' – this is a concern that persons are able to be and live in a way they perceive is right, such as it being fair and sufficient, and that this is how things generally will be for them. The 'just' naming of this concept accounts for qualities of 'reasonableness' and 'good-enoughness', and also foregrounds how such a way of being is not viewed by persons as an excess or that it must necessarily be an optimal, but rather a standard of how things at least *ought* or *should* be for that person. The 'normal' of *just normal* pertains to the state of being that a just-ness defines. It is the way in which things should typically be for a particular person, or the day-to-day regularity of the way in which that person lives.

When persons have *just normal* concerns, these relate to things about themselves and their experiences in the world that need to be of a right and reasonable nature. The particular areas for a particular individual that can be *just normal* or not *just normal* are therefore potentially limitless (although they may be delimited through use a particular conceptual framework – i.e., through the WHO's ICF). For prosthesis users, areas of concern may commonly pertain to aspects of their prosthesis use or the relationship they may share with a prosthetist. A prosthesis can also enable a person to live *just normally*. Consider an individual with lower-limb absence who believes that they should be able to get about without the need for crutches. They may perceive it as only right that they are able to walk about

largely like others, and that this is informed by them having some conception of prostheses that indicates that this is a possibility. They may therefore see it as *just normal* to possess a prosthesis in order to be able to get about in this way. To another, having a prosthesis that enables walking may similarly be viewed as necessary, but they might view an ability to run as also a requirement of being *just normal*. For this person, to gain a prosthesis that can only afford walking would not be 'good enough' because it is insufficient to only be able to walk and unfair not to be able to run if they perceive it possible to do so. So what it means to be *just normal* can vary between people, and between situations, and there are many dimensions of *just normal* for prosthesis users that go beyond mobility.

A concern of *just normal* manifests clearly at times when it is threatened or violated. One way this can be observed is when users of prostheses petition authorities, insurers or third-party providers to sanction payment of a particular prosthesis or part of a prosthesis, and when their petitions are denied. Such a limb, or part of a limb, may be determined by the individual to be the means to live *just normally*, in that the particular person perceives that a particular prosthesis can provide a sufficient level of enablement and that it would not be right to have less. But when financiers appear unwilling to sanction more than what one interviewed individual referred to as 'the cheapest of the cheap', then to accept a lesser solution instead could be to live in a way that is not *just normal* because of its insufficiency. For example, Alan, a lower-limb prosthesis user, spoke to me about his frustrations with his health authority who financed the prostheses he used. He had been refused a prosthesis of his choosing, instead being offered what he saw was a much poorer solution:

They wanted to give me the same leg as they would give an 80 year old that doesn't use the leg quite often. Well I use my leg for 15 hours a day! That's completely different to someone that might only use it for an hour or two and take it off!

Alan's frustrations lay in being told to use a leg that he felt was not suitable for him. He was aware of different prosthetic options; he asserted 'the technology is there'

and yet being recommended to use one that he perceived was suited to older, less-active individuals, and thus one that could only support such a lifestyle, was not right because this was not how Alan lived and felt he ought to be able to keep living. Alan used his leg for 15 hours a day and this was something he felt he should be able to keep up. The recommended leg would not even meet this standard. In addition, knowing that there were various types of prosthetic legs out there and that different legs suited different people, Alan was angered by being recommended the leg of an older person. To be treated as if prosthesis users were a homogenous group where 'one basic size fits all', when he knew this was not the case, was an injustice. His circumstances were 'completely different' and he felt this necessitated a completely different prosthesis. Thus the recommended leg might help an older person to live *just normally*, and Alan identified that 'it might be alright for them', but it would not do for him. If Alan had accepted this prosthesis, he would have been unable to live in such a way that he felt he ought to be able to because of the limitations in this limb, and knowing that there were alternatives that he could be using would not be right; in sum he would not be living *just normally*.

To give another example in the same context, consider Alison's account. Alison is a 50-year old lower-limb prosthesis user who has used prostheses for her entire adult life. One of her legs was amputated as a teenager and as part of her rehabilitation she was fitted with a prosthesis that she has replaced every couple of years when it comes to the end of its usable lifetime. At one time, her insurance provider that was financing her limb started to request a proof of necessity each time a replacement was needed, which Alison found was at odds with what she felt was reasonable. She described this:

It's a little bit demeaning to have to go and... say [the insurer], when I need a new limb for years and they'd want a consultant's note to say, oh she needs a new limb. Now I eventually tried to negotiate with [the insurer]. You know, *come on*. It's not going to grow back. You can see I'm only looking for one every three or four years, and I'm not trying to abuse anything. And eventually I got a note from

them saying, 'look, okay, we'll abandon that.' And that's why I stayed with [them], no matter what way the prices go.

Alison perceived that being asked for proof of the need of a replacement limb each time she needed one was not right. She suspected they did not understand how prostheses worked – 'It's not going to grow back... I'm only looking for one every three or four years' – and in addition did not trust that Alison's need was genuine – 'I'm not trying to abuse anything'. To be asked for proof each time was to have her integrity challenged, as if she was thought to be trying to take advantage of the system. So to keep up this process each time she needed a new limb financed would be to perpetuate a process that Alison saw was not right, and so motivated her to do something about it.

In her account, Alison was compelled to act through a concern that evoked the fairness of a way of living that she felt the actions of her insurer called into question. *Just normal* in this way pertains to the judged appropriateness of a way of being that entails meeting conceptions of fairness and justice. However, being *just normal* is also about living in ways that are sufficient and 'good enough', and where a moral judgement may not be so apparent. To be sure, if something about a person falls beneath a level of what they consider it 'ought' to be, then any expectation to continue with this insufficiency is therefore unfair, and likewise if something is perceived as unfair it is because it falls beneath the standards of what is perceived to be sufficient. So these aspects are intrinsically linked in conceptions of *just normal*, but at times one may be more salient than another.

Alan's earlier account further illustrates the dynamic between sufficiency and fairness, as there was insufficiency in the limb that was recommended to him, and unfairness that he was being treated as if individuals with limb difference were all the same. However, Alison's account illustrates how a just-fairness element can be more prominent and become the driver of action. It may therefore be useful to also illustrate the way in which a just-'good enoughness' component is foregrounded in a concern about being *just normal*. For instance, Roy is a 41-year old lower-limb prosthesis user who has attended a limb-fitting centre for many years. He described the different prosthetists he had been assigned to over the years, but

how moving between was something that could not always work out well. He explained:

If you get used to a person, just say... I work with Dan, he's fantastic. I work with Megan: absolutely brilliant. I could be with one person for one year and then all of a sudden I'm with a new person. ...It pisses me off big time. Now the limb fitters I've had, I've been very very lucky, except for one. I had a bit of a bad experience with him. I won't mention his name, but he's not there anymore. He's gone, thank Christ. He hadn't got a clue. He made the leg too tight: I couldn't breathe. He made it too loose: it was falling off. And I just told him to get lost. You're not making the limbs any more. So I had to get Dan to make it, and Dan took over my case.

As Roy describes, although he would periodically be assigned to a new prosthetist, this would often work out, and he considered this some good fortune. The prosthetists he had worked with could get him up and walking each time with little delay and he was happy with the outcome of his consultations. However, Roy's luck ran out when he was assigned a prosthetist who he felt was not up to task. Roy had described his difficulties earlier in scheduling and attending consultations, so to be kept there for longer than he was used to while the prosthetist tried and tried to zero in on an appropriate fitting, at a cost to Roy's time and patience, was not acceptable to him. Roy knew what consultations could be like, so to endure something he deemed well below this was something he felt he should not put up with. This individual did not meet Roy's standards of what it was to be a competent prosthetist and so Roy dismissed him. Working with someone who could get him up and going in a timely fashion was *just normal* for Roy, and he acted to regain this.

An issue of sufficiency is also foregrounded in Lorna's account. Lorna is a 51-year old bi-lateral lower-limb prosthesis user. She described the progress that had been made at recent limb-fitting consultations, but why she had stopped attending these.

The last time that I've been meeting them [prosthetists] -it's a huge leap forward- they've given me a silicone sock on the left one, which is just the straight down one with the bit on the end. It has helped, but I'd still like more. What I would really love is if they would make moulded ends in the socket, when I put in my legs, so it's like shooting your leg into a boot. If it's got silicone on the ground down there, that would be fantastic. Beautiful, gorgeous, and very very comfortable. The whole business. ...And what they've done the last time now is they've kind of chiselled out a little bit where my bone [in the residual limb] goes... you'll be grand for a couple of hours, but then eventually when my weight will settle in it, it'll go further and further. So I need it to be softer and softer at the end, but at the minute I'm stopping... I'd say been back and forth [attending consultations] about eight times now, with these particular ones. And I wouldn't be finished. Well I am finished now because I've kind of given it up for a while, it's like ok, I can't do this anymore. But I will go back and keep at it. But then you don't want to be permanently at the door, like 'Hi! It's me! [laughs] I'm still not right! I'm still not right! I'm still not right...'

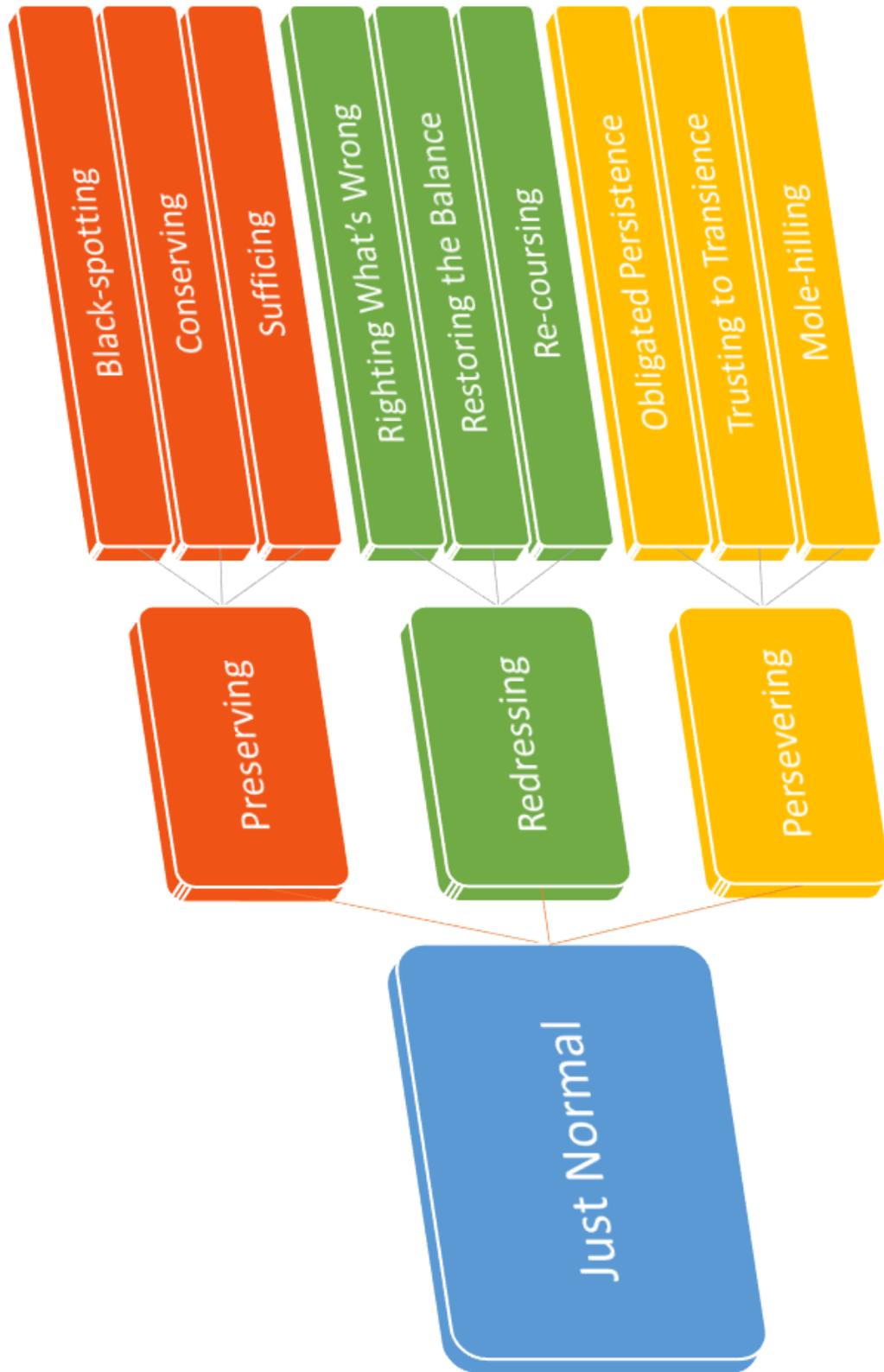
Lorna felt that she had been making progress with adjustments to her prostheses, but had 'given it up' temporarily despite still experiencing problems with her prostheses. She had stopped because she 'couldn't do' the back and forth of modifications and going home to test these for a while before returning for further modifications. She also did not want to feel that she was pestering her prosthetist, with whom she shared a good relationship and felt that this was necessary for the consultations to work. Keeping going back made Lorna 'feel a nuisance', testing the patience of the staff there. So she had stopped attending consultations despite there still being things that she would 'really love' to have. However, Lorna later described how she could do 'everything I need', that she didn't feel 'disabled in any way' because of her prostheses. The limbs she used, despite their imperfections, enabled her to live in a way that she considered good enough. In this way, her

prostheses were sufficient and with them she could get by – she realised there were ways the limbs could probably be improved further and this was something she would ‘go back and keep at’, but for now they ‘work fine for me, grand for me’ – they would ‘just about’ do.

As these accounts illustrate, *just normal* is a prevailing concern, and so persons act to manage this concern, such action constituting the core category of the theory. However, through analyses, three modes of resolving this concern were determined. In one mode, persons are aware of threats to being *just normal* and act on these in order to remain this way. This is conceptualised as *preserving* and accounts for the varied ways in which persons ensure their ability to continue *just normally*. *Redressing* is the second mode and entails bringing about and bringing back *just normal* when this is perceived not to be occurring. The third mode of *just normal* is *persevering*, accounting for the ways in which persons keep *just normal* and resolve difficulties within a *just normal* state of being. Together, these three sub-core categories express and account for the variation within how persons live *just normally*.

Over the page, a diagram is given to illustrate the *just normal* and its relationship with the constituent categories of *preserving*, *redressing*, and *persevering*, and also the concepts that constitute these. The next three analysis chapters are dedicated to exploring each of these categories in turn.

Figure 4. Diagrammatic representation of the theory of 'just normal'



## Chapter 6: Preserving (Being 'Just Normal')

### Introduction

In this chapter, a category of actions is conceptualised around efforts to ensure an individual stays *just normal*. This is when persons consider themselves to be *just normal*, but are aware of potential threats as a consequence of being a user of prostheses, and which threaten their ability to keep this way. Consequently, individuals act to protect their *just normal* status, and they do so in a variety of ways, as threats manifest themselves in a variety of forms. Without this proactivity, individuals could quickly find their ability to live *just normally* disrupted. In this chapter, this category of *preserving* being *just normal* is accounted for through patterns of *black-spotting*, *conserving*, and *sufficing*. These are now each discussed at length.

### Black-spotting

In using prostheses about daily life, individuals can encounter situations that are risky to them as users of artificial limbs due to a particular limitation of their limb. Engaging these situations runs the risk of an adverse outcome which threatens their living *just normally*. In a sense, this is analogous to when areas of roads are identified as black spots because they possess features that pose a particularly high threat to the safety of road users. For instance, areas of roads with tight bends are sometimes designated as black spots because there is an elevated risk of motorists being involved in road-traffic collisions due to this unusual road condition. Through the recognition of such hazardous areas, the notion is that road users can act accordingly to avoid unwelcome incidents. A similar pattern is found in prosthesis use, where there are specific situations where the limitations of a prosthetic are most strongly foregrounded. This term was repurposed then, to convey how prosthesis users engage in identifying and responding appropriately to prosthesis-specific black spots: they are involved in *black-spotting* in order to reduce the likelihood of an unwelcome outcome.

Whereas motoring black spots are confined to specific geographical areas, the scope of black spots for prosthesis users varies, and may refer to specific activities such as walking on a prosthesis in icy conditions where agility may be particularly tested, or more broadly, such as being out in public locations, where unwanted attention may be drawn to an individual's physical difference. In keeping with the motoring analogy, Neil, a 57-year old upper-limb prosthesis user, gave an account of how he identifies driving with his prosthesis as a black spot.

My view of the prosthesis is 'ok, what else can I try? What else can I do? What shouldn't I do?' [laughs]

What kinds of things shouldn't you do?

Grab onto the steering wheel of the car when driving. There's no flexibility... there's almost zero flexibility to the wrist. That's the only real drawback. [For] the functionality for the hand, you're trading off flexibility in the wrist. It far outweighs it as far as I'm concerned though. You can't turn the wheel far- you may not be able to turn the wheel far enough to avoid an accident. And you can't release it fast enough, if you have to make a turn quickly. The response time is just not fast enough. It makes it more of a hazard driving...

With his prosthesis, Neil is enabled to live as a two-handed individual, but limitations in his dexterity mean that he cannot react as quickly or dynamically with his particular prosthesis compared to a biological hand, and this puts him at risk in situations where this is important. The danger of not being able to respond adequately means that Neil therefore identifies the entire activity of driving with his prosthesis as hazardous, because of the threat to his *just normal* living if he were to be involved in an incident.

Black spots may be identified through experience or perceptions of risky encounters. Neil had received indications from others about the unsuitability of his prosthesis for driving, but it was in testing it out on a short trip that the risk was fully realised. Mel, a lower-limb prosthesis user, instead imagines a variety of circumstances that are potential *just normal* black spots. For one, she considers

black spots that may result in damage to her limb, deprecating her enablement, such as taking her prosthesis to the beach where she perceives sand could easily get stuck in the joints. If this was to happen, Mel's prosthesis would function less well, or break entirely, and this would impact her mobility; an integral aspect of Mel's *just normal* living.

Black spots may also be identified through a particular experience that is projected to other situations, as Mel also provided an example of. For instance, she perceives that lifting young children up, as is sometimes practice in her job working in a nursery, is similarly something to think twice about because of the danger of falling with them if she fell because of her prosthesis. Mel experienced falls in other situations before, and so considers her impaired stability and her ability to regain her balance with the limb as aspects that make managing children in this way particularly risky. Not only does she risk injuring the child or herself if she were to fall, but this could also have wider implications for her retaining a role that expects the safe care of children. For Mel, looking after and working with children is something she has always done, something she feels she can and should keep doing, and thus such situations that threaten her *just normal* way of living like this are areas to be wary of – she is conscious of her stability and so is engaged in *black-spotting* accordingly.

*Black-spotting* enables individuals to manage threatening situations in various ways in order to stay *just normal*. Two ways of doing this, as similarly may be observed in motoring, are through avoiding the black spot, or engaging it differently. The choice of action is contingent on how a person perceives it is *just normal* to manage the situation, but both manage the threat. For instance, a black spot may be identified and avoided if avoidance does not compromise an ability to live *just normally*. This was what Neil did when he recognised driving with his prosthetic hand was hazardous. However, if engagement with an activity is instead important to being *just normal*, or rather that a lack of engagement is problematic, individuals will engage the black spot but with a particular approach to ensure the threat is managed. For example, while still wary of falls, Mel would 'lock' her prosthetic leg into a fixed position to reduce her risk of falling, and this gave her the confidence to

pick up the children she worked with. These acts of *preserving* are part of *black-spotting*, as persons are conscious of hazards to staying *just normal* and act in *just normal* ways following their identification. These particular courses of managing *black-spotting* are explained in individual discussions below.

### *Protective Avoidance*

One way that black spots are managed is through a pattern of avoidance. This occurs when situations are identified that present a threat to *just normal* living, and where this is unaffected by avoiding the black spot. A lack of engagement thus protects an ongoing ability to live *just normally*, and importantly, avoiding also does not compromise this.

Rob is a prosthesis user who gives an account of *protective avoidance*. He is a 34-year old sports coach who uses two lower-limb prostheses. Rob described how he used to enjoy playing football with his friends on a regular basis until one of his feet broke during a game. Despite being fitted with limbs intended to cater to an active lifestyle, Rob's prostheses could not survive the barrage of forces they were subject to while playing football and suffered damage that rendered one of them unusable. Since he and his prostheses were restored to full-working order again, Rob said how he had '*eased off*' from playing altogether because of the elevated risk of damaging his prostheses. In damaging a limb to the extent that it becomes unusable, as Rob perceived playing football risked, Rob loses his best means of getting about, albeit temporarily. He described the impact of losing this aspect of his enablement if he was to continue to play.

I'd be in a spot of bother to be perfectly honest with you. If two of them broke, you'd be in serious trouble. Even down to- I couldn't get in and out to work. If you think about it logically, I don't have a wheelchair. I haven't been in a wheelchair since I was in hospital, which was the mid '80s. So how do you get around? You're really stuck. The parts come from the States and all sorts of stuff, so it's not exactly ring up [the prosthetist] and it'll be here tomorrow. They're the kind of issues. They're at the back of your mind. It's the

worst case scenario. I certainly don't think about it every day, but it is a real [worse] case scenario if something happens.

Rob described himself as an '*active enough*' person, a person able to '*get in and out of work*', and moreover someone that can just '*get around*': '*I'm not out doing energetic things all the times, but I'm in here, in there, everywhere - the shops and all that.*' This is Rob's *just normal* mode of being, but with one of his prostheses out of action, he would struggle to live this way; as he says himself, he would be stuck. '*Imagine that [it's] a reasonably good day and you can't do anything. So it's certainly not up my street to be like that now.*' This loss of activity and capability and fundamentally being restricted is the threat that Rob referred to as prompting '*the fear factor: The bravado goes out the window.*' So to prevent this, Rob protects his enablement through avoiding black spots that present an elevated threat. This preservation comes at the price of avoiding activities he would otherwise engage in, like football. However, Rob says about football that he just played socially, '*just for a bit of craic, just for a bit of fitness*'. So through picking up other activities he perceived had a lower risk of damage but could enable him to keep socialising and keep fit, the loss of football was not at odds with what he perceived as *just normal*.

Rob's account is an illustration of the common focus for *protective avoidance* where situations are avoided that could otherwise lead to the loss of prosthetic enablement. This was why Mel avoided going to the beach with her prosthesis, and why others variously avoided excessive forces on their limb, or situations where there was a risk of water damage to electronic parts, or other ways in which function could be deprecated. Others *protectively avoided* black-spots where other facets of their *just normal* living were threatened. For instance, Julie, a 36-year old lower-limb prosthesis user, described her experiences in dating.

2011 was one of the worst years of my life for many reasons... and let's not forget dating. One time I was with a guy and I let it slip I had a fake leg and you could just see it in his face. Like he didn't even try to hide his disgust. He made these lame excuses and just got up and

left me there! That was a blind date a friend had set up. I've forgiven her now! ...Some guys just freak out when they realise. It's just a leg!

There was one guy who tried to ignore it but I could tell it was really bothering him. You just get this feeling and I could tell. He was making a real effort not to look at it or talk about it and then after that night he never contacted me again. ... It made me feel so bad. Like less than a person.

Being made to feel this way was not something Julie felt she should have to put up with. In everyday life, because others would not often know or realise her limb difference, they treated her ordinarily. But going out on dates, Julie had revealed her limb difference, and this often led to situations where she was made to feel bad.

I know some people can be fine but there are definitely some that can't handle it and it's not fair on me. They just make me feel like a freak and I'm not a freak.

Julie considered herself different due to her limb difference, but this was far from the disparaging extreme of a '*freak*' that dating situations often made her feel like. To be treated this way was just not fair, and so she decided to cut this out of her life in order to protect herself from such harm.

That was that time [dating]. It really got to me. I was in a dark place. I had this leg and I stupidly naively thought I would be ok but other people couldn't handle it. So I decided no more and I stopped dating altogether. I just don't go in for it any more. I have these friends who are always trying to set me up but I just keep playing it down. I've got my friends to go out with. I'm quite happy!

To keep *just normal*, Julie chose to avoid dating. This was not an easy decision, but after being downtrodden time and time again, and recognising the emotional toll it was taking on her, she began to avoid putting herself forward for dates and evaded being set up by her friends. This meant that she avoided situations where she was

made to feel abnormal and bad about herself, and though she lost this social aspect about her life, she reminded that she still had her friends to go out with, and did so, and so sustained this quality and kept herself *just normal*.

As Rob and Julie's stories illustrate, persons will preserve their *just normality* by *black-spotting* and then by avoiding putting themselves in risky situations that are identified. This is one way that black spots can be managed. However, there are conditions when a black spot must be engaged, and so different acts of *preserving* are employed.

### *Vigilant Risk-Reducing*

While black spots may be avoided, sometimes individuals knowingly engage with them anyway. This variation occurs when engagement with the situation is important to the extent that to avoid it would not be *just normal*. Given that 'preserving' may often be associated with conservative, risk-averse activity, the apparently contradictory notion of potentially jeopardising the thing that is sought to be preserved is therefore interesting. However, in these cases of engaging black spots, being *just normal* means engaging the situation in some way and so this is preserved through engaging but also through addressing the threats of the situation. Two forms of engaging black-spots are identified here, the first of which is identified as a process of adapting one's conduct to reduce the likelihood of an adverse outcome. This is termed *vigilant risk-reducing*.

An example of this is given by Pat. Pat is a 62-year old retired lower-limb prosthesis user who described difficulties in getting around where he lives out in the countryside. His particular prosthesis has limited flexion, which means that walking over uneven ground can easily cause him to lose his balance and fall, and this has caused injuries in the past that has resulted in days of pain and forced rest while he recuperates.

[I'm] very aware – when you're on tilted surfaces. Very aware if you're on an uneven surface. ... The hoof marks in the ground I'm constantly avoiding because it's going to do me – it's going to catch me if I'm not looking. ... You just know the consequences if you

stand on one, or on the side of one – you’re going to go. And I have gone over the top. ... The worst is because the ankle doesn’t bend, and when you fall you tend to give everything a yank and then you have two or three days of pain, suffering. You just have to endure it. So I’m careful. I’m much more confident in things that I used to do, but I can spot a lethal situation, whereas [my wife] wouldn’t. She probably does now, but other people wouldn’t.

Pat continues to do the things he did prior to his limb loss, including going for walks around his home and maintaining his land in the country, because these activities are important to him – they are what he has always done and how he likes to spend time with his wife. Doing these things requires him to be able to take on any surface - *‘I’m talking about all terrain’* - and so if he were to try to do so without consideration of his limited ankle flexion in these situations, he would likely fall. Hoof marks and other surface anomalies will *‘do him’* and he will be in pain and unable to do anything for days. Instead, Pat *black-spots* about the areas he goes and intends to go and when he needs to walk on uneven ground, he does so with a heightened vigilance, attending to the ground and to his walking more than he would otherwise: *‘It just requires a bit more thought.’* He is vigilant in such potentially risky situations by committing more attention to managing the limitations of his prosthetic agility and so catering for difficulties using the limb on this terrain. In doing so, Pat does not entirely insulate himself from danger, but he does diminish the risk of falling to a level that he feels is acceptable. In this way, his *vigilant risk-reducing* keeps him from a perceived inevitability of injury and retains his ability to keep engaging in the activities that are important to him.

Pat’s example is illustrative of one of the ways that prosthesis users *black-spot* and then engage these situations differently due to undesirable outcomes that they perceive themselves to be at greater risk of because of their limb difference. Their vigilance through greater care and attention while in the situation reduces the risk of falling foul of the black spot and keeps these situations as viable possibilities, which can be a requirement of a person’s being *just normal*. In his autobiography, Richard Riley, a lower-limb prosthesis user, gives another illustration of *vigilant risk-*

*reducing*. He described how he minimised the risk of danger of falling when using bathrooms by developing a specific limb for the purpose.

What do you do when you travel? If you are staying at a hotel or motel, they will often have handicapped accessible rooms that have extra large showers to accommodate a wheelchair and even some rails to hold onto. What do you do if the place you are staying doesn't have an accessible room or you are staying with relatives or friends? For me, the answer has been to have a shower leg. A shower leg is a simple prosthesis that is designed to receive minimal damage when it gets wet. I have made many shower limbs, using either an existing socket or a new one fabricated specifically for this function. I like to have a pelite (soft white foam) insert inside so that it can be worn with no sock or liner if necessary. I use a SAFE II waterproof foot (Foresee Orthopedic Products, Oakdale, CA) that gives good traction on slick surfaces. Sometimes I even melt a tread pattern onto the bottom with a hot knife and this gives the best traction. I use a suspension sleeve that is as waterproof as possible, and I find that if I hang the leg upside down after use, the suspension sleeve dries rapidly. The shower leg allows an amputee to stand in the shower, freeing up both hands. What a concept! For the first time since I had become an amputee, I was able to wash my hair with both hands. This may not sound important but if you are an amputee this frees you to be able to travel anywhere secure in the knowledge that you will be able to negotiate any bathroom with a minimum of danger. (Riley, 2005, p. 138)

For many prosthesis users, bathrooms present a risk of getting water into limbs that should not get wet, and for lower-limb prosthesis users that must therefore remove limbs in order to shower there is a consequent danger of falling. Having a substitute shower limb is a way of ensuring enablement is protected (and thus preserving being *just normal*) by avoiding the need to bring a non-waterproof limb into these environments, reducing the risk of falling by improving stability. For

Richard, ensuring he had his 'shower leg' with him at these times gave him the freedom and peace of mind to be able to travel, knowing that he could more safely use bathrooms other than his own.

A further, distinct form of *vigilant risk-reducing* to preserve being *just normal* is camouflaging the use of a prosthesis. As Julie's account of dating indicated, others can react in hurtful ways when they notice an individual's limb difference. Even prosthesis users that described enjoying '*showing off*' limbs said that the tendency to be stared at or treated differently because of their limb difference was unwelcome. Mark gives an account of this. Although apparently willing to talk to me, Mark, a lower-limb prosthesis user, complained about having to deal with the repetitive curiosity of others about his prosthesis use: '*...it's part asking the questions and you're going [groans] another after another question... it's painful, and duh duh-duh duh-duh, you know, that kind of way?*' He also gave a striking example of the change in a behaviour of a colleague who discovered his prosthesis use:

I was working all summer one place in Boston doing all kinds of everything, and suddenly this guy I worked with finds out I've a fake leg and he goes, "Oh, no, here - let me go up the ladder." "Dude - I've been doing this for the last 3 months - *excuse me?!?*" You know what I mean? It's really quite interesting that people misunderstand...: "*now [that I know,] you must not do this.*"

For Mark, the attention drawn to his prosthesis and being treated differently all of a sudden when others discovered his limb difference is understandably unwelcome. He finds it unfair that his limb should become a focal point of others' perception of him, and unfair when he detects that others attempting to block him from particular activities, regardless of any good-natured intentions. However, a prosthesis can go some way to disguising an individual's limb difference as most tend to at least provide the basic outline of an absent limb, and this can be further improved by using covering clothing or by cosmetic coverings that more accurately mimic biological limbs, and to the extent that limb difference may be apparent at

first glance. Alison, a lower-limb prosthesis user, said about public encounters that she felt *'old enough and bold enough to handle whatever'*, but still preferred to conceal her prosthesis use from others. She tended to wear covering clothing over her prosthesis, minimising the chance of discovery. This meant she did not present as an individual with limb difference and so could expect ongoing ordinary treatment: *'People wouldn't treat me any differently. But I think it's probably easy not to treat me differently because I know I look like any 50 year old looks and I move well and all that sort of thing.'* When others familiar to her discovered her limb absence, she felt that many tended to see her in a different light, associated with disability and inability: *'they kind of say, "My god, and you've always done everything!" Which I have!'* Alison found this frustrating because she perceived that others would then tend to see her in an unable light, regardless of her prior behaviour. So, *black-spotting* encounters with naïve others, Alison would reduce the risk of being discovered by camouflaging her limb difference, and then being vigilant in these situations to ensure her disguise would remain intact. In a blog post, Kate Sawford, a 31-year old lower-limb prosthesis user, also described her reasons for camouflaging in public, and explained the particular ways she was vigilant about avoiding discovery:

Today, I continue to choose pants over shorts, mostly. I suppose this is because I want some control over my first impression on people. My gait is good enough that unless a person pays close attention, my artificial leg goes undetected. There are other things that I do. Without thinking. Almost. When I sit with people on a couch, I will sit to their left so my 'real leg' is closest to them. And I will often walk just behind people if I'm concerned about appearing awkward, such as when walking on uneven or sloping ground. There are people I have known for years who don't know about my leg, and in some instances they have found out only because I've told them. We all do it: We form associations with the people that we know according to particular characteristics. These characteristics can be physical or associated with personality. We describe people to

others according to these characteristics. And I suspect most of us have had the thought 'I don't want to be known as the [blank] girl.' I am comfortable with my artificial leg, but I am uncomfortable with the idea of being described according to it. I'm happy to be 'the tall girl', or 'the blue-eyed girl'. Just not 'the-one legged girl'. And I'll take pretty much anything over 'the disabled girl'. (Sawford, 2013)

Kate reduced the risk of detection by being careful about the way she dressed and how she acted and positioned herself relative to others. This was a particularly risky black-spot that she had identified, perceiving that any unwanted associations could be enduring. However, these were situations with others that she wanted to experience – avoiding socialising was not an option, and so she kept vigilant, monitoring the positioning of herself and others in order to maintain what she described as her 'sleight of hand'.

Similarly, Peter Thomas, a lower-limb prosthesis user whose account is recorded in Sabolich and Sabolich's collected short autobiographies, remarked of his own camouflaging that '*I can think of no greater compliment than when an old friend seriously asks me if my new shoes are too tight or if my feet are cold.*' (Thomas, 2001, p. 131). Others mistaking Peter's prosthesis for a biological limb was a sign that he was getting on well in his presentation as someone with two legs and so he could expect to be more likely to be treated ordinarily. This was something he sought to maintain, rather than the '*disabled friend or family member*' (p. 131).

So, actions that lower the risk of black spots disrupting being *just normal*, such as watching one's step, remembering to pack a shower leg, or being careful about positioning relative to others, enable an individual to keep in ways that are important to them. *Vigilant risk-reducing* does not provide immunity from risky situations identified through *black-spotting*, but it does diminish the chance of a bad outcome to a level such that persons perceive they can engage the situation and stay *just normal*.

### *Fail-safing*

For persons using prostheses that seek to preserve their being *just normal*, black spots may be identified that can be neither avoided nor have the risk of the situation reduced. For such black spots, a person may not have the means to diminish the risk or they may be unable to do so if doing so means compromising a sense of *just normal*, similar to how avoiding it might. In other words, despite their hazardous nature, it is *just normal* that these situations are 'done normally'. In these cases, a third form of managing black spots is to instead address the impact of the outcome itself. This is a process of *fail-safing*, the result of which means persons can engage black spots and even if the unwanted outcome were to occur, they have the means of staying *just normal*.

For example, Mark, a 46-year old lower-limb prosthesis user, described how he goes ahead with activities such as hiking up mountains despite knowing that the conditions are particularly testing for his limb. He uses prostheses intended to be suited to his pursuits, yet he has suffered numerous breakages in the past to the point that he considers it an inevitability of engaging such activities. However, to avoid such pursuits or to do them at a lesser intensity is for Mark to concede an inability to hike 'properly' or to hike at a standard that he feels he should be able to meet. So hiking, and hiking 'normally' is a part of Mark's being *just normal* and he keeps at this. But being stuck on a mountain if his prosthesis breaks is something Mark recognises he must manage. To do this, he ensures he has a means of managing any breakdown if one were to occur. Mark's rucksack is laden with tools, duct tape and other bits that allow him to perform quick repairs that will get him home and so avoid him being stranded or needing to call for assistance. He can then get by for long enough to get home to perform proper repairs himself, or perform intermediary fixes while he waits for an appointment with his prosthetist. While Mark does not see this as an ideal state of affairs, he recognises that the limbs he uses have a tendency to break while hiking and during other activities he values, and so rather than not doing these or doing them at a lesser level, he gets on with them, ensuring he has the means to address breakdowns, should they

occur, thereby retaining these activities as viable pursuits, and so *preserving* being *just normal*.

So black spots that may need to be engaged and for which it is not permissible or possible to address risk, can instead be managed by having a means to deal with the impact of the undesirable outcome. This process of *fail-safing* can require an element of planning to ensure the means to protect against the outcome are to hand, such as Mark having his supplies to deal with breakage. Others suggested how they would variously take 'back-up' limbs to black spots which posed a threat to their prosthesis so they had something to fall back on, should something go wrong with their primary limb. Mel, a lower-limb prosthesis user, had attempted to *fail-safe* in her preparations for a holiday, after identifying this as a potential black spot, but ended up *vigilantly risk-reducing* when she was not able to gain the means to do so:

I'm supposed to go on holiday and I kind of said "do I bring the expensive leg with me or do I just bring the other one?" -Just if something happened to it. Because I looked into kind of getting leg insurance but nowhere really does it [laughs]. I think there's places in England now, but you kind of have to give them every little thing that's in the leg, components and all. I wouldn't have a clue, you'd have to get onto Germany [where it the limb was manufactured], so I just said "I'll just be careful for the moment!"

To give another illustration of *fail-safing*, consider Lisa's account. Lisa Brewer is a 44-year old lower-limb prosthesis user, living in the US, who keeps a blog about her experiences with limb difference. In one post, she disclosed her decision to get a firearm.

People ask me all the time if I can run with my prosthesis. It is not a running leg and was not meant for the impact of running, so I always say, "not really....I kind of look like a deranged penguin when I try – a fast, awkward waddle" and then I laugh. Recently, I started to really think about it. I am a 45-year-old, below the knee amputee with a

degenerative bone condition in both legs AND deathly severe asthma.....I literally could not run if my life depended on it. That is NOT ok with me. Unfortunately, our world is changing. Criminals are getting bolder and life is getting more dangerous. I am a very trusting person and believe in giving people the benefit of the doubt, but that doesn't mean I am naïve. I am a little, female, amputee who drives a vehicle that is frequently targeted in parking lots. If I am walking to my car, especially if I am in shorts, I am a prime candidate to victimize. However, if someone chooses to attack me, I will not sit by and idly take it. I will fight back and change that attackers mind as to what "easy prey" is. (Brewer, 2013d)

Lisa had come to identify situations where she felt she was at a higher risk of becoming a victim of crime, exacerbated by her limb difference. But she concluded there was little she could do to avoid being targeted, lest she never venture out alone or avoid parking lots entirely – neither viable options for her staying *just normal*. So to have a means of dealing with this, in this case to give herself the ability to 'fight back', she applied for a concealed weapon permit. Lisa had never considered carrying a gun before, but believing she was likely to be targeted in these kinds of environments prompted her to take action:

What concerns me is being here for my daughter's wedding.....my son's college graduation....Lauren's high school graduation....my first grandchild and the list goes on. I have chosen to protect myself in a way that suits me. ... I am able to defend myself against verbal and mental attacks just fine. As a matter-of-fact, I just did so today. I will never be a victim in those arenas, but when it comes to a physical victim, I was vulnerable and that was not ok to me, so I did something about it.

So in Lisa's case, while she remained appearing 'vulnerable', if she found herself targeted, she considered that a gun could keep her safe, thwarting any attacks. A similar example of managing unwanted public confrontations is given in Sabolich

and Sabolich's collected autobiographical accounts by Holley Howard (2001), a lower-limb prosthesis user. After losing her leg and being fitted with her prosthesis, Holley found herself encountering unwanted remarks and curious stares of others that made her feel bad about herself. Going out in public had become a black spot for Holley, yet feeling unable to stop this from occurring, Holley recounted how she then determined to respond:

As long as I feel good about myself and my appearance, I've fought the battle and won... I've had my share of stares from John Q. Public, but I've found the best thing to do is stare right back at people until they realise I do feel their stares and don't appreciate them. If I hold my head in shame, then they have won. (p. 226)

This became Holley's prepared response to counteract being made to feel bad, and enabled Holley to come out on top of the situation. Other individuals interviewed in this study also described having *fail-safe* quips to respond to undesirable stares, comments or questions about their limb difference. This was something also found across the discussion forums, where it is common to encounter threads about sharing favourite ways of responding to public naivety or ignorance in order to withstand the frustrating or disparaging effect they can have on an individual.

In summary of *black-spotting*, the identification of these risky situations is necessary for persons to then act appropriately toward them in order to continue to live *just normally*. Such acts of *preserving* can variously entail the (*protective*) *avoidance* of black spots, engagement that involves *vigilantly risk-reducing*, or *fail-safing* that is intended to ameliorate or counter the impact of a potential adverse outcome. The choice of *black-spotting* response is that which is most accessible and dependent on how an individual perceives it would be *just normal* for them to manage the given situation.

### Conserving

In many of the interviews conducted in this study, individuals made a point to state that they could do more or less anything they wanted to, and that no activity was

beyond them. This was often also a strong message in the autobiographies. However, while there are indications that prosthesis users can do anything, doing everything can be problematic. This is where a different, distinct form of *preserving* being *just normal* can be identified, as persons manage the limits they find themselves living within as prosthesis users. For instance, compared to a biological limb, using a prosthesis may mean tasks can take longer to complete and may be more fatiguing when there is a need to carry the weight of a limb or if there is discomfort when using the limb. Other aspects of prosthesis use such as the maintenance of a limb can mean additional time and effort is required. These elements mean that an individual may find time and energies disappearing faster than expected, and so they must cater for this in order to keep up their ability to do the things important to their living *just normally*. These depleting qualities can include the time a person has to do particular activities, or their energy levels before fatigue. Or it might be an individual's tolerance before discomfort caused by a prosthesis means they can use it no longer. Or it may be the power or the lifespan of the limb itself. Thus there are a variety of exhaustible qualities that individuals must manage if they are to ensure that *just normal* living is not disrupted by premature exhaustion. The various ways that persons consequently *preserve* to avoid this is through acts of *conserving*.

The limits of time and energy can be particularly salient for individuals with acquired limb absence, who may have a routine they are trying to keep up since gaining a prosthesis. In her autobiography, Lenor Madruga, a lower-limb prosthesis user, described the mismatch between her intentions and her ability to do everything, which she had done prior to her limb loss.

By the end of that year I was ready for a physical breakdown. I was worn out. I realised that if I wanted to continue doing the things that really mattered to me, I would have to rearrange my priorities. I would have to do only the important things; not do anything and everything... (Madruga, 2000, p. 171)

With her prosthesis, Lenor was capable of individual activities, but doing 'everything' together wore her out. Trying to live in the same way as she did prior to her limb loss was too exhausting for her, building to a point of breakdown. Other interviewees finding themselves fatigued to such an extent described needing an extended period of time to recover while energies returned or incurred injuries abated. Trying to do things in the same way as before or just in the way that one might assume they would after gaining a prosthesis can consequently lead to an overall reduction in ability if time is then needed to recuperate following fatigue. Lenor came close to this, and realised the long-term problems if she kept on as she was. Others described being confined to bed or forced to remain in the house while they recovered from fatigue or pain. Such 'overdoing it' can consequently lead to an inability to be *just normal*. However, as Lenor illustrates, one way to keep *just normal* and also keep from exhaustion is to give consideration to how time and efforts are being invested. Lenor considered what she spent her time doing, determining to cut back on the things that were not essential in order to ensure she could keep up the activities that were. In this way, she *conserved* her energies to keep up what was important to her, and so she kept *just normal*.

Alison gives another example of this. Alison is a 50-year old lower-limb prosthesis user who has used prostheses since her mid-teens. Because of this, she does not struggle with trying to keep up with a prior bodily-intact lifestyle in the same way that Lenor describes. However, Alison is faced with similar issues in trying to live *just normally*. She gave one example of this:

I have two dogs. If I take the two dogs for a long walk, that's fine and then I might do the same the next night and I might do the same the next night. But after four nights I might feel that little thing [residual limb wound] beginning to open up again and I'd be thinking, oh, bloody hell, I'm not doing that again, because it's more important for me that I get in and out of work, that I'm able to look after my kids ... that I'm able to sort of do the things I absolutely have to do.

When she uses her prosthesis for extended periods, Alison finds that the skin on her residual limb breaks down and can cause her considerable pain. She is forced to take time to recover while she heals and this can stop her from getting on with other things important to her *just normal* living. To be unable to get in and out of work and to be unable to look after her children is not a way that Alison desires to be. Having tried with limited success to address this problem over the years with various different prosthetists and prosthetic solutions, Alison recognises that she can only do so much on her prosthesis before pain sets in, and instead manages by similarly prioritising her activities. She enjoys walking her dogs, but when there are things she '*absolutely*' must do, like being able to look after her children and get in and out of work, Alison *conserves* by relegating lesser activities, doing them less frequently, or only when they will not threaten her ability to live *just normally*.

The mismatch between a level of assumed possible activity and what is actually possible may arise from what individuals expect to be able to do with their prosthetic enablement, and this may be a recurrent issue if changing between prosthetic solutions and not knowing what a new prosthesis will be like. Lenor and Alison illustrate the ways in which prosthesis users may *conserve* in response to detecting warning signs of impending exhaustion in order to ensure they can keep *just normal*. Activities of lesser importance are not necessarily ruled out, as to do so may be to violate staying *just normal*, but instead may fall lower on a priority scale, where they may be undertaken less frequently or at times when persons judge undertaking them will not pose a threat to being just normal.

Other strategies of spacing-out activities, punctuating days or activities with rest breaks, and being more efficient with one's movements were also given as ways in which individuals *conserved* energies in order to do the things important to them.

I have to get up a bit earlier, going to work and stuff as well, just making sure the leg goes on right, because there'd be bits like massaging it beforehand, physio, and whatever. But that's just the extra little bit of time. Getting ready. Going out now isn't too bad now, but I'd be very tired after getting ready, so I kind of do it in

stages. I'd get up and have my wash, my hair and whatever, then kind of I take a break, put the leg on, then take another break. *So it doesn't tire you too much?* Yeah, because then I'd be no use when I get out. (Mel, lower-limb prosthesis user)

There's only so much I can do in a day before my stump becomes sore. It's even worse if your stump is sore when you put it on in the morning. I find you can do more if you take rest breaks because pressure doesn't get the chance to create a sore or an angry red area of skin. My friends don't consider that once a sore has developed it will only get worse if you wear your prosthesis. So the idea is not to let one develop. So I do some of the housework then sit and rest a while. If I am walking round a shopping mall I stop and sit for a while. It can be annoying but in the long I can get more done. (Carl, 49, lower-limb prosthesis user)

If I wanted to go dancing with my husband on a Saturday night, I would relax that day and not sap my energy with grocery shopping or general house cleaning. I learned to shop the day before and maybe clean the house the day after so that I could be rested for the dance. If I want to do some baking, I do it in the morning because I'm rested. (Madruga, 2000, p. 171)

While I'm at the kitchen sink standing and waiting for the cookies to bake, I organise dinner. I clean the upstairs rooms of the house just after I've finished with my morning bath and dressing. Then, I'm prepared to go downstairs for the rest of the day. (p. 171)

Illustrating a further form of conserving, Rob, a lower-limb prosthesis user, said when he noticed he was starting to get tired while out during the day, this would prompt him to give greater consideration to the route between where he was and where he needed to get to next that resulted in the least energy expenditure. This kind of more considered path-finding meant that he wasn't '*wrecked*' or

'knackered' when he arrived and could still do the things he needed to do in a state he felt he should be able to do them in.

In addition to this, prosthesis users may need to be mindful of the energy level of a prosthesis itself. A growing number of prostheses, upper and lower, incorporate electrical power sources to provide and assist function, such as the popular Ottobock C-Leg and Touch Bionics i-limb hand. Myoelectric prostheses in particular are electrically powered limbs that run off the charge of a battery. Neil, a 57-year old upper-limb prosthesis user, spoke of his concern about his myoelectric prosthesis running out of power. He would use his prosthesis for a full day and was worried that if he kept using it into the evening, the battery could deplete entirely, rendering it unusable. He gave a light-hearted example of what could happen if this were to occur:

Sometimes I'll stop at a grocery store on the way home to pick up items and you know, I'll talk to the wife and she'll say 'oh by the way – on your way pick up something' and by that time I will have had the prosthesis on close to 12 hours and my big concern is I'm going to come home with the grocery cart one night because the battery died when I was grabbing hold of the bar! [laughs] Kind of a comedic image, but you've got to think about it, you know! If the battery died while I'm holding it, how do I get out – I'm stuck.

Neil's example conveys a more serious concern of getting stuck, or needing a limb to work when it has run out of power to do so, and this was echoed by a number of other prosthesis users. To contend with this, he is mindful of his exertion with his prosthesis relative to his expected activity. So, if he is expecting to use it later into the day on a single charge, *conserves* charge through using it less frequently or at a lower intensity to ensure there is enough power to use it later on. If he uses it more intensely during the day and finds he has need of it later, he will be mindful of the reduced level of charge. This ensures he does not risk full depletion and if he finds himself requiring use of the limb at these times, he will have sufficient power to get by.

In a similar way, Rob, a lower-limb prosthesis user explained the '*shelf life*' of his legs and how this could vary depending on what he did with them.

These are two years old next month in November and I know they're starting to come to the end of their shelf life. Before that I had a set of legs that had to last four years because I had other issues, I had to fight to get back on it [medical finance scheme], then I actually lost my job, that's how I got back on it. I was able to fit it in that window. But those type of legs, I really wore them to their last dying soles of it. To be honest, it's not out of really being a real conservative, I had no chance in that regard, I just couldn't afford to buy new legs. The reality is they did last me that long but I'm also very careful with the legs. They're literally-they're more important than your mobile phone. You wouldn't come in and throw your phone down on the ground. You do take care of them. ... The way I describe it to people that ask me or my mates, how long do they last for, and I say well it depends how active you are. So if you've got a brand new top dog pair and you wear them all the time, and you're really active in them, they wear down. If you buy a brand new car but it ages five or six, seven years in one year, all of a sudden you're driving something that's not road worthy. And that's the equivalent. If your runners wore down to a certain level, you could have all sorts of issues with your feet and so on like that and then they're no use to you. That's the same with the legs.

Because Rob was limited to getting new prostheses at particular times, and he noted that this did not necessarily match the lifespan of the limbs to keep him *just normal*, he was conservative with them in order to make them last. Rob treated his limbs with care, but he also avoided activities that would wear them down more quickly. He was keen to avoid deprecating his limbs to the extent that he was forced to use something 'not road worthy', causing him problems in his comfort, fit and what he could do with them.

So in order to keep *just normal*, persons must be mindful to avoid exhausting the means to keep this way, conserving depletable qualities, such as their time, effort, or tolerance to discomfort, or the power or lifespan of their limbs. Doing so ensures enough remains to keep *just normal* before these can be renewed. *Conserving* may involve the rescheduling or prioritising of activities, or becoming more efficient with travel or the way activities are conducted. Running out can be a particular threat to individuals new to prostheses or to a new prosthetic solution, where they may be less knowledgeable about the demands or the limits to their prosthetic enablement and how these can be best managed.

### Sufficing

There are times when a person may be presented with, or prompted to consider, changes to their circumstances, and which have implications for the way they live *just normally*. In prosthesis use, the change may be about whether features to an individual's prosthetic enablement could be improved upon. So individuals could return to limb-fitting centres to seek new limbs, to seek adjustments to current limbs, or they may even try a different prosthetist that they hope can provide a better solution. There can also be a tendency to perceive that the more modern the technology, the more benefits the user will receive, and so individuals may perceive newer prostheses as superior and seek these. However, despite a perceived potential for improvement, when persons live *just normally* with a prosthesis, there can be a tendency to avoid change because of the threats to remaining *just normal* that changes can result in. Change is not guaranteed to be wholly satisfactory, and even if one aspect of enablement is improved upon, another may turn out to be worse, and run the risk of leaving an individual in an overall poorer condition. This, then, is another context for *preserving* being *just normal*, and thus in response to potential change, individuals *suffice*.

Mark, a 46-year old lower-limb prosthesis user, described his *sufficing* when he explained his reasons for deciding not to seek changes to his limb.

I've seen there are things that you can attach to nerve endings or whatever to make it do this or that, and I'm kinda going, you know,

I've had it [the prosthesis] for how long, and if I start doing that, mmm might be better... mmm might not be either! And sometimes I might have to re-learn how to walk again... Ack! Do I really want to??

Mark had described seeing the latest in prosthetic limbs being demonstrated online and so knew that there were newer limbs out there that could potentially improve aspects of his enablement. However, he had been using the same kind of limb for a long time, working with his prosthetist to ensure he had the best setup for doing the things important to him. A new type of prosthesis was stepping into the unknown, and moreover an unknown where all manner of difficulties could arise, and which could potentially leave him worse off overall. So Mark considered these new possibilities but ultimately rejected them, *sufficing* with what he had in order to *preserve* being *just normal*.

To illustrate further, Natasha, a 43-year old lower-limb prosthesis user, explained her rationale for preferring to avoid seeking changes to the socket of her prosthesis.

I just think that when you've got comfort, I think it's a good idea to keep it as close and comfortable for the person and maybe make small changes, not make these big drastic changes that might upset - because you're walking on it all day and it's such a crutch and you're so reliant on it, you know.

Natasha's prosthesis enabled her to get around and do what she needed to do, but a big problem for her had been ensuring comfort. Over a number of consultations Natasha had eventually secured a solution that afforded a satisfactory level of comfort when she used her prosthesis, and she was reluctant to do anything to undo this. If she sought to try to improve anything else, this could risk discomfort which would limit how much time she could spend on the limb, and so limit what she was capable of. Similar to this, Carl, a 49-year old lower-limb prosthesis user, described how he would rather stay with what he had than risk trying something else.

I don't know that I will ever be completely happy about my setup. I think I will always find something I want improved... [But] it took me a lot of effort to get this setup and it is working reasonably well. It [is] a real hassle just to get it in alignment. If anything changes I may end up with a gait that will cause back pain and my health will really suffer. When my back is hurting it's so hard to achieve things. So I am kind of happy just to leave things as they are.

Having invested a lot of time and effort trying to get a satisfactory prosthetic solution, Carl was reluctant to try anything to threaten this progress. While there could be further improvements, the risk of the unknown was too much for him to gamble with, and he lamented not being able to know more about alternatives: *'I realize there may be problems with the kind of foot I want... I wish there was a shop where you could just go and try new components and feet.'* *Sufficing* instead keeps Carl away from the potential of being in pain and unable to achieve things as a poor outcome of change may result in. He felt his health was on the line in risking change, and to end up with poor health was not living *just normally*. So as Carl says, although he wasn't completely happy with his setup, he was 'kind of happy' to leave things as they were because of the threat of something worse, and in doing so he *preserves* his being *just normal*. Part of *sufficing* then, is recognising that while change could lead to improvements, if a person can live in a way they see as reasonable and 'good enough' with a prosthesis, then change is to be avoided because of the jeopardy to this '*crutch*' for *just normal* living.

However, Carl also identified a further motivation to *suffice*. In discussing how he felt that his current setup would be one to suffice with, he described: *'In the end I kind of settled for a foot I could live with.'* So Carl had a foot he could abide, and a setup that worked 'reasonably well'. Change then, was not a necessity. This illustrates another dimension of *sufficing*, that if a prosthetic solution helps to support a person to be *just normal*, then things are already 'good enough' and persons need not change. A prosthetic solution therefore may not be optimal, and indeed there may be some issues about it, but if it enables a person to live *just normally*, to change is to unnecessarily risk this.

To illustrate *sufficing* in a different way, Ann, a lower-limb prosthesis user, and long-time user of a prosthetics and amputee forum, gave her reasons for sticking with what she had:

What I find is that if the prostheses are comfortable and letting me do what I want to do, I really don't want any changes made ... now whether this is just because I am a bit set in my ways or perhaps because I've had too many new prosthetists wanting to try out new innovations on me and them not working, I don't know ... but usually what I see is people just really wanting their prostheses to allow them to get on with the everyday things in life without too many problems... (Ann, 2013)

The way Ann saw it, if a person could get about and do regular things comfortably, then they were living *just normally* and this was the prosthesis fulfilling its objective. Ann's solution enabled her to do this, and so she had grounds for *sufficing* rather than seeking or consenting to changes. Furthermore, she had experienced 'innovations' that had been 'tried out' on her in the past, and the experimental nature and mixed outcomes of these caused her to be cautious about change. So unlike Carl, who had invested a lot of effort to build up to his level of sufficiency and who had *sufficed* to avoid jeopardising his progress, Ann's *sufficing* was informed by her experience of ideas working and not working. This prompted her to stick with what she found could do the job, thus *preserving* her being *just normal*.

Ann's account also hints at a further property of *sufficing*; that as well as not seeking improvements, it also includes a resistance to change when this is recommended by others. Commonly, this will be from professionals involved in the selection, tailoring and fitting of a prosthesis, and who an individual may periodically return to for maintenance and replacing their prosthesis. A prosthetist may believe there is a more appropriate solution for the individual, but if an individual believes that their solution is good enough, they may resist any recommendations or suggestions. So there are potential grounds for difficulties in

the relationship between person and professional if there is not a shared understanding of what the person requires to live *just normally*, and thus an understanding of what is sufficient for them. Additionally, a professional may consider that the person may not know about potential options for change, and this may prompt discussion. On this basis, suggestions for improving prosthetic enablement can result in tension between prosthesis users and their prosthetists. Natasha provides an account of this happening to her when she was recommended to switch away from a solution she felt was working well.

...they [the prosthetists] probably see me coming in with this really old fashioned thing and think well we can bring this girl into the new world, we'll improve her life so much and she'll be like, thanking us, and that's exactly their intentions: good and honourable. It's just that I think if I hadn't had the [current solution], I'd be bringing them chocolates and flowers!

When Natasha was recommended to accept a new prosthesis, she described feeling pressure to do so. Mike, an upper-limb prosthesis user, had described a similar situation as involving the 'intimidation factor': *'They come in their lab coats – they're a doctor, you know, they should know more than you. ... Sometimes there's a little bit of an intimidation factor that I don't even think the prosthetist realises.'* Yet Natasha felt her life didn't need improving by the prosthesis and that adjusting her 'crutch' was risking too much. She didn't need or desire being 'brought into the new world', particularly knowing that a new limb could lead to an inability for her to live *just normally* if it turned out to be worse. In the end, feeling the pressure of the recommendation and being unable to articulate what was sufficient about her limb that meant she needn't gain a better one, Natasha consented to being fitted with the new prosthesis. However, while she accepted the recommendations of her prosthetist and gained the new leg, in private, she continued to suffice with her old limb. Natasha speculated that had she not had her good-enough present limb, she may have been more accepting of the new leg.

In the same vein, a recent online article by lower-limb prosthesis user, Emily Rapp, gives a similar account of *sufficing*:

I was a true cyborg, a half-robot, as I gradually gained access to the kind of advanced technology that was totally out of financial reach for me even 10 years ago. I now have about seven legs — all paid for, in part, by insurance — with a range of sockets, abilities, knees, hydraulic systems and general prosthetic superpowers. *I only wear one.* I call this favorite leg my “Harvard leg,” which is so named because while I was a student at Harvard, I had a stellar insurance plan that paid in full for every piece of “durable medical equipment” I accumulated. This leg, made in 1998 by my best prosthetist, Bill, is still my favorite. I like its shape, its fit, the way the heel strikes the floor. The leg has survived two blown-out knees, four foot replacements and a few “repaints.” It has carried a baby, been too big or too small, depending on varying periods of diet and exercise, biked thousands of miles (in a spin room) and done a lot of downward-facing dog poses in yoga. It’s not the most technologically advanced, so I find myself weirdly aligned, at 38, with the Vietnam veterans I knew as a child — guys who didn’t want new legs, and who were happy with the old wooden contraptions because “they work just fine.” (Rapp, 2012)

Emily’s favourite leg was the leg she liked for its shape, fit and the way ‘the heel strikes the floor’, indicating that despite her other limbs being more technologically advanced, they did not match up on these dimensions. Because of this, and because she had been using her favourite leg for so many years, overall the other legs fell short and so despite ‘accumulating’ new limbs over the years, Emily would only use this one. This ‘old contraption’ worked ‘just fine’, keeping her *just normal*, and so Emily *preserved* this through continuing to *suffice* with this prosthesis instead of moving to the more modern alternatives.

Zane, a lower-limb prosthesis user, spoke of *sufficing* for comfort, rather than also moving with technological developments:

At the amputee conferences there's -my god there's over a dozen exhibitors of different prosthetic companies and you know it's just overwhelming. And then because it's such a technologically driven society here in North America and everyone thinks technology solves every problem. I'm sure for a lot of prosthetic consumers they have this idea that if I get the best quote unquote "leg" my life is going to be a whole lot better, but in terms of what I need... I mean I tried [a particular new prosthesis]: I didn't like it... as I said before the most important thing is comfort so I'm willing to stick with what I've got.

From Zane's account, as well as Natasha's and Emily's, it is clear that individuals have particular requirements in a prosthesis that trump a quality of modernity. In fact, this can be a point of pride in indicating that the 'old reliable' still enables just as well or better than the latest technological advances in prosthetics, particularly when newer technology is often associated with being better.

Thus when prosthesis consider themselves to be *just normal* with aspects of their prosthesis use, they will *suffice* rather than seek or consent to changes. Change, in order to improve one's circumstances, can be too risky because of the threat of ending up in poorer circumstances, and which would consequently not be *just normal* to endure. Even when improvements may be recommended by others, individuals will be inclined to *suffice* if change is related to risk and redundancy. In this way, rather than an endless pursuit of seeking better and better levels of enablement and optimising one's own prosthetic solution, when an individual is able to live *just normally*, they will *suffice* in order to *preserve* this.

## Summary

It is a common desire to be *just normal*, and when threats to this are perceived, they will be acted upon in various ways in order that persons *preserve* being this

way. At the beginning of this chapter, *black-spotting* was discussed as a process of identifying situated threats to a person's ability to live *just normally*. Individuals respond to identified black spots through *protective avoidance*, *vigilant risk-reducing*, and *fail-safing*. The form of response is determined by the fit between a course of action and how an individual perceives it is *just normal* to manage the situation.

*Conserving*, the second form of *preserving* being *just normal*, pertains to the need to be mindful of limited resources or tolerances that prosthesis users may have and which are involved in living *just normally*. Becoming more efficient, economising, prioritising and other strategies that *conserve* resources or extend tolerances are employed to ensure that individuals are able to do the things important to being *just normal* instead of encountering exhaustion.

In the closing of this chapter, *sufficing* was explored to account for the way in which individuals *preserve* their *just normal* status by avoiding change to their prosthetic enablement. Change, when a person is already *just normal*, is redundant, and worse, can risk a poorer outcome and so the possibility of losing one's *just normality*.

These patterns account for the various salient ways in which prosthesis users *preserve* their *just normal* way of being, managing dangers to this as they are perceived. However, as was mentioned in the discussion on *black-spotting*, threats must be recognised in order to manage or pre-empt them, and so persons may find themselves at first encountering difficulties before they identify them as something to be managed and to be mindful of their occurring again. Experiencing something it is judged not right - or not *just normal* - to experience can therefore lead to acts to rectify this and so regain a sense of being *just normal*. Such acts of getting back to *just normal* are explored in the next chapter in a discussion of *redressing*.

## Chapter 7: Redressing (to 'Just Normal')

### Introduction

Persons desire, need, and feel they should be able, to be *just normal*, and so if they perceive that they are not *just normal*, they will be motivated to change this. This chapter explores actions that are characterised by efforts to change one's circumstances in order to be *just normal* when this is judged not to be the case. These are acts of *redressing*.

In *redressing*, persons may suddenly find themselves faced with things that are not 'right' in the sense that they are violations of what they consider *just normal*, prompting change to what *is* right. This is further clarified in a discussion of *righting what's wrong*. *Redressing* may also involve the correcting of things that have strayed to a point where they are discovered to have fallen 'out of keeping' with how they ought to be, and so persons are implicated here in *restoring the balance*. Finally, persons may seek *redress*, but attempts at change may not always be successful, and so *re-coursing* is a process of altering the approach of *redress* yet toward the same goal. Together, these give an account of the salient patterns of *redressing* as persons strive to live *just normally*.

### Righting What's Wrong

Persons may encounter things that go against what they perceive to be *just normal* for them; things that are at odds with what they perceive is fair or sufficient to live with, and as such must be rectified in order for the individual to live in a way that they see is right. So, individuals make efforts to change things that are not right to things that are right, and right in the sense that they are aligned with how they perceive things ought to be for them. This is a process of *righting what's wrong* in order to *redress* the way a person lives, and there are varying ways that prosthesis users go about *righting what's wrong*.

Consider Paul Martin's account. In his autobiography, Paul described his experiences with his first limb in the months following the amputation of his leg. After resolving to demonstrate that his acquired limb absence was not going to

hold him back, he decided to get a prosthesis as part of getting ‘back into the pack’ and living without limits (Martin, 2002, p. 79). With this leg, Paul attempted some of the sports he had done prior to his accident, but found that this leg was incapable of enabling him enough for these pursuits. So Paul sought a leg that was capable of getting him back into sports. His second limb could better cater for the activities he tried, and for a time this appeared to work out for him. However, after some further tests, he determined that though he could take part in some sports, running was still beyond him:

I could play hockey and I could ski, but I still couldn’t run. The foot absorbed too much energy and the suspension system worked insufficiently, which was the biggest problem. Duct tape or nor duct tape, I could only take a dozen strides or so before the leg would loosen and “piston”. Pistoning results from insufficient suspension where the residual limb slides in and out of the socket during each stride. The induced rubbing and abrasion leads to discomfort, blisters and miserable pain when repeatedly bearing full body weight. (p. 82)

Despite some problems when playing hockey and when skiing, Paul could still take part in these activities, and so this was good enough for him. However, the pistoning problem that led to discomfort when running was too much to bear, but Paul was not prepared to give up on this. Prior to losing his leg, Paul was not a big runner, but when he discovered that he was incapable of running at a level he felt he should be able to, he was motivated to do something about this because it did not fit with the mantra he had developed for himself. To be limited in this way, even though some other sports remained open, was a violation of what he perceived was his ‘right’ way of being. This was the wrong that Paul sought to right by finding a limb that could help him to run. So Paul had cause for *redress* when he found his second limb struggled with sports, but he sought *redress* again when he discovered he could not run. This was further illustrated in a conversation between Paul and his prosthetist, when the prosthetist told him while fitting the new leg that he would have him running marathons within a couple of years. In response,

Paul said '*I laughed. I had no intention or desire to go that distance.*' (p. 84). For Paul, despite going for a leg capable of running, this was not because he intended to be a marathon runner, or even a 'runner', but merely to *right the wrong* of having this door shut to him.

Paul's account illustrates the way in which prosthesis users may discover aspects about their enablement which are lacking and in violation of what it is for them to live *just normally*. When faced with such discoveries, contacting a prosthetist to see if changes can be made is often the first port of call when trying to right the situation. Paul also illustrates that having the potential to be able to do something can be the focus for *redress*, that perceiving restrictions or barriers can also be seen as wrongs to right, even if the individual does not have immediate plans to act on these. Part of living *just normally* then, can be about having this agency, even if some options are unlikely to be chosen.

Emily Rapp presents an account of *righting what's wrong* in a different way. Emily was born with proximal femoral focal deficiency in her left leg, and has used prostheses for most of her life. A significant proportion of Emily's autobiography from which this account is taken concerns Emily's desire to be 'normal', and which she considers is in conflict with her limb difference. As she described starting to accept that limb difference would be with her for life, she describes resolving instead to 'pass in able-bodied society', ensuring she appeared 'as normal as possible' and so would be treated accordingly (Rapp, 2007, p. 135). The main way in which such 'passing' was achieved was by using a prosthesis that could afford an appearance as close to normal as possible. However, around the time Emily went to university, her bodily anxiety began to increase as she perceived that her body was coming under greater scrutiny with her peers and with potential partners. She started to feel unable to 'pass', and described this on the way to a social gathering.

I felt sure I was about to be exposed for who and what I was, although I had no words at that moment to explain what this meant to me. What I knew for sure was that I felt entirely alone in this car with my new friends, headed for a crowd of yet more people. ... I

knew I'd never be able to compete in the strange, secret world I was about to enter with these girls. I would never be able to play by the same rules. Maybe I would always be running from boys instead of sauntering up to them with naïve confidence tinged with nervousness as my friends did. I knew, as we sped through the abandoned gas stations and warehouses on the edges of town, that someday someone was going to want to see this leg, with a miniskirt, without any skirt, with the leg off. I felt a horrible, hollow feeling deep in my chest. (pp. 141-142)

Passing required appearing as ordinary as possible, and as much as Emily tried to perfect other aspects of her appearance, she kept coming back to the prosthesis itself.

I felt so helpless in my difference that I was utterly disgusted by it. You're pathetic, I told myself. If I had only one leg, the least I could do was make it perfect. How hard could that be? I had trained as a skier and developed strong, lean muscles. I had gotten lazy; if I wanted to fit in, I needed to try harder. If I couldn't have two real legs, I would alter the rest of my body to suit my desires. Back to the calorie books first thing tomorrow, I thought. Back to doing my homework days ahead of time. Back to the long workouts that left me exhausted. Now what to do about the problem in this moment? What to do about the leg? (p. 140)

However, Emily did not know what to do about her leg. She had sought to right things by going to her prosthetist for help, but the outcome was never satisfactory. However, around this time, Emily met Samantha, a lower-limb prosthesis user also born with PFFD. Samantha did not appear to have to make as much effort to 'pass', coming across physically and romantically untroubled, impressing Emily, and Emily thought this due to her prostheses, which she saw as superior to her own. Samantha looked and appeared to live well, and these were qualities Emily badly wanted for herself.

I was amazed by her “gear,” as she called it, and remembered the way I had mythologized the Texas leg, as if possessing it would change my life. I remembered pressuring Vince [Emily’s prosthetist] and challenging him when the leg didn’t fit right. Now here it was—strap-free and leaning against the wall in my new friend’s closet. (p. 155)

With the ‘mythological’ limb now an obtainable reality, Emily suddenly saw a real means of passing. Seeing Samantha’s prosthesis also drew Emily’s attention to the particular deficiencies of her own leg, which then became harder to live with knowing there was an alternative.

None of her legs used the detestable waist strap that had plagued me for years and given me rashes, sores, and other headaches; it frayed and smelled bad and created weird bumps in my butt and hips when I walked. Next to Samantha, in my clunky wooden limb, I felt like a dilapidated robot. Samantha’s legs were built on advanced technology, not on outdated models that had been developed for war veterans decades before. She moved well and with confidence and was not afraid to wear shorts or skirts. (p. 155)

Samantha was living in a way that Emily not only desired, but now needed to be in order to be *just normal*. To persevere with her ‘clunky’ limb, when she knew that there were prostheses out there that could better help her to pass in the way she felt she should be able to was not right. So Emily contacted a prosthetist in her quest for redress.

“This is what I want,” I said, showing Dr. Elliot Samantha’s instructions. “This. I need a man who can make this.” My pulse raced. Please, I thought. Please. “Okay, Peanut,” he said. “We can do that.” I burst into tears. Finally, after years of hoping, it seemed that transformation would be that simple. The secret, festering hope I’d harboured that my life could change dramatically had not been unfounded after all ... I was ready to ditch my wooden leg as quickly

as possible. I wanted a state-of-the-art prosthesis and an updated body that was beautiful and mobile and, of course, as *normal* as it could be. Yes, I admired Samantha's athleticism, but what I really wanted was to be pretty and real looking enough in order to pass more effectively. (p. 157)

Emily sought to right her situation by seeking the 'state-of-the-art' prosthesis. Her current leg, deemed an insufficient means to help her pass, and unfair to be lumbered with when she was aware of legs that could help her pass, was the wrong that she sought to address when she put her request to Dr. Elliot. Shortly after getting this new prosthesis, Emily described returning to university.

The fall of my sophomore year, I walked onto campus bursting with confidence and prepared to experience a corresponding renaissance in my love life. With this new leg, I believed I could compete in the dating game just like everybody else. I couldn't wait. (p. 158)

*Redressing* involved Emily and Paul approaching their prosthetists to try to improve their enablement, and while Emily was initially unsuccessful, perceiving that she had done all she could meant that while she continued to struggle with her appearance, her actions were *just normal*. Persons will be bound to pursue *redress* if they perceive the option and need to do so, and even if unsuccessful, doing so means they have acted *just normally*. Paul and Emily's accounts also illustrate the way that *redress* need not necessarily be contingent on knowledge of particular solutions, but is about engaging the pathways perceived to potentially lead to being *just normal*, in this case contacting those who may have this knowledge.

Later in Emily's account, when she became aware of the prosthesis she saw could bring her closer to the 'normal as possible' appearance that she felt compelled to strive for, living with her current leg ceased to be *just normal*. In light of new possibilities, persons may therefore reassess their *just normality* and if their present status is judged to be not good enough or not right when compared to what they could have, then redressing involves seeking this in order to be *just normal*.

Emily and Paul were convinced that there were definite wrongs about their prostheses which required righting through replacement. Both approached prosthetists and were able to gain limbs that enabled them to live *just normally*, and in the same way alterations may be sought or recommended without the need for an entirely new limb that also enable a person to live *just normally*. However, a further variation on *righting what's wrong* occurs when persons approach gatekeepers (prosthetists or financiers) to improvements they perceive they ought to have to find that they are denied this. Being attached to these can then become the dominant wrong that prosthesis users are required to right.

For example, Natasha is a 43 year-old lower-limb prosthesis user who has used prostheses for many years. She travels internationally and has lived in a number of countries around the world. Natasha currently has a leg that she had made at her limb-fitting centre that she is happy with, but she described a time before this at a different centre that she returned to when she started to experience significant discomfort with her prosthesis.

I broke down in tears a couple of times in the [limb fitting centre] because I was so broken up because I'd been [abroad] and come back and they [limb fitting centre] were kind of making out that me being [abroad] I'd kind of exacerbated myself, by climbing hills and that type of thing, but you're meant to be able to do that – they told me that I shouldn't run the marathon. I'd run – not run it, walked the marathon – and that because I was getting older, that it's degenerating.

Natasha had returned from abroad to her limb fitting centre to find a way to address the problems she was having with her prosthesis, only to find it was the opinion of her prosthetist that she had brought the problems on herself. When she was told that her pains were from her doing too much, rather than a fault with the limb, and that she should therefore refrain from such activities, she did not take this well. To be able to exert herself, like when climbing hills and taking part in marathons, was something Natasha felt she should be possible – *'you're meant to*

*be able to do that* – these were things she saw as necessary for being *just normal*, and to instead be made to feel that these were excesses troubled her. Natasha felt that the staff were indicating that the prosthesis prescription was right, and that her actions were wrong, and so the solution to her difficulties should involve cutting back and leaving more *‘strenuous’* activities behind. But because Natasha says she *‘knew herself’* and knew what she was *‘meant’* to be able to do, she rejected this judgement on the basis that it was unfair to suggest she limit herself in such a way. Natasha stuck with her belief that the limb was deficient, and this was the wrong requiring righting. But being with a prosthetist who did not see things this way and would not support changes to the limb then became the foremost wrong she was compelled to right. In the end, at personal expense, Natasha went elsewhere in her search of *redress*, and was vindicated when she found a centre that could provide her with a limb that could cater for her lifestyle in this way. *‘I went there and they built me a perfect leg and I still have it.’*

Natasha felt that living in such a level of discomfort because of her prosthesis was wrong, and then that being told that a woman of her circumstances should not do the things she did that brought about the discomfort was also wrong. This kind of conflict can arise between the parties involved in helping an individual gain a limb if individuals are active with their prostheses and therefore cause an elevated rate of wear and tear on a limb. Mark, a 46-year old lower-limb prosthesis user, described a number of run-ins throughout his prosthesis-using lifetime that related to this:

I used to get a *‘side-lock guarantee’*. Which means as soon as I hit the side-lock, the guarantee was over because I would destroy things [laughs]. Because I would *do things*, you know. That was when I was a kid with the insurance companies... But this whole, *‘you should take the elevator, lift, instead of walking up stairs because that’s too hard on the leg’* was, you know, *‘you have to get it fixed too often’* and that was the insurance – I was getting something through the State of Massachusetts, you know, and through there they just went, *‘we’re paying out an awful lot for your legs and stuff, maybe you should stop, um, hiking, or stop going up*

stairs'. And I just went, 'yeah ok, I will. Yeah sure, right! See ya, goodbye!' [laughs].

Like Natasha, for Mark, being told to avoid ordinary activities because of his difference provoked a sense of injustice that even as a child, meant that he would flagrantly ignore it. As an adult, Mark recognises where the providers are coming from with their advice, but still sees it as wrong to bend himself to prosthesis or provider, and rather that these should bend to him. He recognised that a prosthetist provided a service to him, that he was paying for this, and he indicated how he had become more forthright in consultations, and stated that a limb '*should take it. If it doesn't, fix it.*' So whenever Mark's limb couldn't take it, he sought to gain replacements or modifications that could take it, and when he encountered providers of the mind that he ought to curb his activity as a solution to avoiding damage or breakage, he would go elsewhere.

In some ways, Natasha and Mark's accounts are similar to Mike's. Mike is a 50 year old upper-limb user who described his past experiences with prostheses and prosthetists, involving the need to *right what's wrong*:

My prosthetist right now is probably the best one that I've had. You know, I've had some that they give the socket to me, I go home, I take out a jig saw, cut it up and paste it, oh yeah I've done that. I've literally cut sockets up and re-did them. *Why would you do that?* Well, the thing is, by going to – you know the prosthetist I'm talking about was out in California- it was five or six prosthetists back. I thought he would be pretty good. I went to him, he built me a socket, I got it, and after wearing it for a week I was starting to have issues. I went back to him and he made a couple of minor changes and was basically like, 'That's how it's going to be'. And so basically I made modifications to it that made it last about another six months, broke the thing and went to a different prosthetist.

Mike refused to accept that his prosthetists' professional opinion was right. He considered 'how it's going to be' did not have to be the case because of prior

experience without these issues, and so he knew that this wasn't how it could be. 'Cutting up' his sockets and then going elsewhere were Mike's demonstrations of trying to *right what's wrong* as the prosthesis in its previous form was not good enough, and sticking with a prosthetist that would only willing or capable to provide this level of service was similarly not good enough. However, Mike expressed his concern that others who lacked this experience of knowing how things could be might not be able to judge such outcomes of consultations as wrong.

Somebody who say, that was their first prosthetist, that's the experience they're going to get. And if they are uncomfortable with the socket, there's a good chance they may never wear a prosthetic again. Imagine if the first time you went and tried shoes on, you were supposed to get a size four shoe, let's say, and they put you in a size two, and they say, 'well that's how shoes are going to feel.' You'd most likely spend the rest of your life running round barefoot.

Mike was able to judge issues with his prosthesis as wrong through his experience of prosthesis use without these. This gave him his yardstick from which he could make such assessments of good-enoughness, and from which came his concern for others about not being able to do so, and so being unable to identify wrongs requiring righting. Yet consider Zane's account. Zane is a lower-limb prosthesis user who also recounted difficulties he had with a prosthetist he once saw. While using his prosthesis, Zane discovered that when he went to kneel on the floor, the way that his prosthesis bent meant that the height difference between his left and right side left him unbalanced. Zane queried this with his prosthetist, and like Mike was similarly given a response that did not sit well with him:

I said to him 'you know when I sit on my knees, well, there's more space between the knee and the ground on the artificial leg than there is on the real leg', and he just said to me 'well, that's just the way it is'.

Similarly, rather than accepting this, Zane went elsewhere:

I spoke to another prosthetist and it turns out that there's a knee cap that you can put on the leg so that you're more level if you're on your knees. So he didn't know that; I had to go to another prosthetist to get that information.

Zane went elsewhere, and yet he did not have a yardstick with which to judge whether accepting being told about 'the way it is' was *just normal*. However, Zane had stated earlier that a good prosthetist to him meant that they would be '*receptive to my problem and can address it*'. So being told that he should just live with the issue instead of indications that the prosthetist was prepared to try to help him overcome it, or at least being receptive enough to explain why it was not possible to rectify, were indications to Zane that sticking with this prosthetist was not *just normal*. So Zane was motivated to go elsewhere because this professional had become a potential barrier to his living *just normally*. And like Natasha, he was similarly vindicated when going elsewhere resulted in a solution to his problem.

So there are various ways in which prosthesis users may perceive barriers to their ability to be *just normal* and to live in a way that is sufficient and fair. To continue to live with these violates a sense of being *just normal* and therefore constitute the wrongs that persons right in their *redressing*. Persons may *right what's wrong* through going to a prosthetist or financier, where individuals may have alternative limbs or components in mind, or they may approach providers as a patient may typically approach a doctor – with a description of the problem in the hope that the professional will call on their expertise to identify a solution to right the issue instead. However, if the outcome of this approach conflicts with how an individual feels they should be able to live, such as professionals appearing either unwilling or unable to help them *right what's wrong*, and persons perceive the possibility of otherwise achieving this, then this becomes the focus for *righting what's wrong*, as persons will go elsewhere to seek a provider that can provide a *just normal* solution.

Before concluding, an extract from Kevin Garrison's autobiography illustrates a further way that prosthesis users *right what's wrong*. Kevin, a lower-limb prosthesis user, described the difficulties he had had with his early prostheses. When he was

fitted with his first limb, Kevin recounts that it appeared to fit fine when he was testing it at the prosthetist's, but soon after he got home it began to cause him intense discomfort whenever he walked on it. After speaking to the prosthetist who fitted him with this limb, Kevin was directed to someone more local to where he lived in order to address this. The local prosthetist fitted Kevin with a new limb, and while this alleviated some of the discomfort, this limb had a host of other problems which only further frustrated Kevin. He concluded that receiving a limb so poor in other regards was evidence that some prosthetists were not as skilled as others, and that a prosthesis was only as good as the person making it. However, Kevin felt that he had exhausted his options; there was no one else he was able to go to for the right limb, and yet he perceived having one made was possible. This became the impetus for Kevin to embark on a career as a prosthetist himself. He explained the particular grievances he had with one of his prostheses that motivated his career choice.

I had two reasons for wanting to do this. First, I wanted to learn how to make artificial limbs that didn't make noise on quiet romantic nights while hurting your hip as you struggled to walk and scraping the bone every time you tried to remove it. Second, and probably most important, I wanted to learn how to make a *perfect one* for myself, one that made walking a pleasure, as it should be- not a nightmare! (Garrison, 2011, p. 66)

After living with breakage and discomfort for some time, and considering that walking *should* be a pleasure, and that it *should not* be a nightmare, as was his experience, the last straw for Kevin was having a date nearly ruined by his prosthesis. He felt it was wrong to keep with what he viewed as substandard limbs, and resolved to do something about this. So Kevin's course of *righting what's wrong* was signing himself up for a career in developing prostheses in order that he could learn how to develop the right prostheses to help himself and others to live *just normally*.

Pursuing a career as a prosthetist in order to gain the means to live *just normally* may appear somewhat of an extreme course of *redress*, but Kevin is not alone in doing so. In addition, Mike exemplifies cases of individuals modifying their prostheses themselves when they felt a prosthetist was unwilling or incapable of doing so. For these individuals, where professional assistance for righting wrongs is not possible, this can involve persons taking matters more directly into their own hands.

Furthermore, as the beginning of Emily's account illustrates, *redress* may be sought, but if this is unsuccessful and the person perceives this outcome to be reasonable and that there are no alternatives – that it is in fact 'the way of things' – then despite dissatisfaction, if a person's way of being aligns with the best of possible options, then this is *just normal*. Thus it is the instances of issues that violate what is perceived to be *just normal* that prompt *righting what's wrong*, but acting upon these is contingent on perceiving that *redressing* is achievable.

In summary, persons are implicated in acts of *righting what's wrong* that transform a way of being that is not *just normal* into one that is. Where professional assistance is required, if this person is unable or unwilling to facilitate this, they too may become a focus for *righting what's wrong*. In the next section, a distinct pattern of actions accounts for ways in which *redressing* is instead about things that are suddenly realised to have strayed from what is *just normal*, and where *redressing* lies in the 'getting back' to *just normal*.

### Restoring the Balance

In the previous section, persons identified violations of what they perceive is involved in living *just normally* and sought to address these, thereby *righting what's wrong*. These were things that persons found they were without, or were prevented from getting, or ways they were treated by others, and were things that motivated such righting. However, persons are also implicated in actions of a restorative nature, where they may discover things that have deteriorated and are in fact out of keeping with what they consider is *just normal*. Discovering this

prompts rectifying actions, recovering or tempering things accordingly to re-establish a *just normal* status. These are efforts of *restoring the balance*.

Mel is a lower-limb prosthesis user in her early thirties who gives an illustration of *restoring the balance*. Mel underwent the amputation of her leg a few years prior to our conversation, and described how her confidence and mood were extremely low because of the loss of her leg. When she got her first prosthesis, this did not improve things in the way that she had hoped it would. A combination of limited flexion, difficulties in usage, and a lack of trust in the leg to perform as required had led to falls and injury, and this had further reduced her morale. At one point, Mel described a time of having '*no confidence*' when she could not even bring herself to go out in public.

I refused to go into town on nights out or into the likes of a cinema or busy shopping centre in fear of someone hitting off me and kicking the [leg] from under me accidentally or causing me to lose my balance.

To live with such diminished confidence coupled with a largely absent social life was not *just normal* for Mel. She had hoped that her prosthesis would help to *restore the balance* but this had only eroded her confidence further. Mel therefore sought a different prosthesis, perceiving that a better limb would give her an improved level of dexterity that would in turn help her confidence to improve and get her back up and running. When she received the leg, Mel recalled that early on, she did lose her balance a number of times, but was able to use the features of the new leg to '*catch*' herself and prevent injury. She described how this helped her morale to '*return very quickly*' and the broader implications of this:

Personally, I felt much better in myself. I started doing a lot more everyday things. Even simple things like hoovering, going up and down stairs seemed easier. I was going out more places as I knew now I could catch myself if I did lose balance or someone accidentally knocked me. I wasn't constantly watching the prosthesis to see if I could take the next step. I was walking so much better that

several people didn't realise I had an artificial leg. And I was starting to dance again in pubs/clubs...hooray!

Mel's confidence and her socialising began to improve as she was able to do more with her leg and without fear that she would fall. She began to monitor the limb less and her anxiety towards using it began to diminish. In this way, obtaining the leg and training herself to use it was how Mel restored both her confidence and her socialising, and restored them in such a way that they returned to a threshold of what she felt acceptable, at which she could once again be *just normal*.

For a time, this worked out for Mel, but she then described more recent periods where she began to have other difficulties with her prosthesis.

Wearing the silicone liner on my stump constantly did cause me a few issues with dry skin and friction burns. This was down to me using the stump/hip a lot more now and not a stiff leg. At one stage the scald/burn was very sore or raw that it caused pain with every step I took and so I began to limp. People would then ask if I had hurt my leg etc and I would have to explain why I was limping. My confidence began to drop a little...

I was walking using a stick/crutch when going shopping or on long trips. I was going out but was sitting a lot and not up dancing as normal. I then began to refuse invites out as this soon became unbearable and I was paranoid re the way I was walking.

At these points, Mel found herself again living in a way that was not right. Her mood had dropped again and she described having more 'bad days' than normal. This was not the balance of what she considered reasonable - it was not within how she felt she should live, and so she sought to attend to root problems once more. In the first instance, she received adjustments to her limb and some treatment creams, and soon after the issue cleared up and '*everything was grand*'. When the issue arose again, Mel returned to her specialist to discover she had an infected lymph node, which she subsequently had removed, enabling her to return to '*full form*'.

Zane gives a further illustration of the way that things slip out of keeping from what persons perceive is *just normal*. Zane is a lower-limb prosthesis user who has used prostheses for many years and has been involved in a number of support organisations for individuals with limb difference. When discussing comfort in prosthesis use, Zane described how he expected a level of discomfort, but it was when this reached a particular intensity that this was problematic for him.

I experience varying degrees of discomfort almost every day. The question becomes is it something that I can handle or is it something completely unacceptable that is interfering with my day-to-day mobility.

For Zane, living with a prosthesis involved a particular level of discomfort that he experienced and in this way it was *just normal*. When this varied to the extent that it interfered with his ability to get about and became unmanageable, then this became intolerable and he sought to *redress* this, bringing it back to a tolerable level. Zane described how he would go about doing this.

There are numerous times where I am not comfortable and will make an appointment to meet with the prosthetist and no doubt the culprit can be seen right on the stump as there is skin breakdown caused by weight gain. ... Sometimes a new socket would be required to be made. Other times, the prosthetist can cut away or flame down the periphery of the socket so it doesn't dig in to the skin.

So there were a number of ways Zane's discomfort could be reduced once more and his mobility restored. As he describes, often the prosthetist or he himself could identify that the issue was weight gain, leading to an increase in mass in his residual limb that meant his socket no longer fit as well and caused these problems. As a number of individuals described, residual limb management was something to continually cater for, and when issues became apparent that persons attributed to changes in residual limb health or mass, then they would act to bring things back to what they perceived was normal.

*Restoring the balance* then, is to do with a normalising of an individual's circumstances back to what is *just normal* for them. However, Zane also indicated that a large number of trips to the prosthetist could also tip the balance of what was *just normal*, as it would not be right for him to be in and out of the consultation room to such an extent. So through improving his diet and his fitness, Zane could bring the level of discomfort as well as the number of consultation trips to a level that he saw was reasonable.

A further example is that of Luke, a 30-year old upper-limb prosthesis user. Luke had been using the prosthesis he had been fitted with for some time and was happy with how life with an artificial limb was working out. He described how he would tend to wear his limb from early in the day until late at night, involving it in a large proportion of his daily living and with only a minor amount of discomfort. However, at one time, Luke started to find that he could only wear it for a period before increasing discomfort forced him to remove it. The level of pain he had started to experience was intolerable, but removing the hand to alleviate this meant that Luke was suddenly unable to perform many of the tasks he needed his prosthesis for. So in the run up to his consultation to address this, Luke described being trapped between experiencing unbearable discomfort and diminished ability, neither of which was acceptable to him. The period of tolerable prosthetic usage had begun shrinking further and so Luke returned to his prosthetist to try to restore the balance of comfort and ability. Upon analysis, Luke's prosthetist told him that the muscle mass in his residual limb had grown through using his residual limb inside the prosthesis, and which had deprecated the fit of his socket, resulting in discomfort from tightness and sweating. His prosthetist performed a 'relief cut' in the socket, giving Luke's residual limb some 'breathing room' and which consequently brought Luke back to the level of usage and comfort he was used to.

A number of factors can conspire to complicate the use of a prosthesis and prevent this from being *just normal*. Zane and Luke give examples of the mass of a residual limb varying and causing complications with the fit of a socket, while others described sockets 'naturally wearing out' and losing fit over time, and one who developed a neuroma that would be antagonised by contact with a socket. For

each, persons may experience increasing discomfort and decreasing ability that corresponds to the development of the issue, neither of which is *just normal*. So whether replacing a socket, managing a residual limb, or otherwise, the *redressing* action of tackling the underlying issue is thus intended to *restore the balance* of bringing discomfort down and activity back up to what is considered *just normal*.

Thus *restoring the balance* constitutes a distinct pattern from *righting what's wrong*, though both are concerned with getting to being *just normal*. For *righting what's wrong*, outright violations of what is considered *just normal* are determined by the individual, such as obstructions or the absence of important things, whereas *restoring the balance* concerns individuals identifying the deterioration of things and realising this progression, and where they must act to prevent further decline and to get back to where they once were.

### Re-coursing

In the accounts given up until now in this chapter, it is impetus to change and the point at which this was achieved that have largely been foregrounded, as persons *redress* through *righting wrongs* and *restoring the balance*. The focus of these accounts means that the struggles of effecting change and failed attempts at *redress* are not always apparent. In this section, a pattern is elaborated that illustrates the different ways in which persons reconsider and reconfigure their approaches to *redress* when efforts fall short, and so how persons *re-course* in further efforts to succeed in being *just normal*.

One way *re-coursing* is observed is when persons seeking *redress* contend with being denied what they perceive is required to live *just normally*. In the context of prosthesis use, those with the power to sanction limbs may elect not to, and so when efforts to *redress* are denied by such gatekeepers, persons may *re-course* in their approach to try to overcome them through different means. Paul Martin, the lower-limb prosthesis user who gave an account earlier in this chapter, gives a related account of *re-coursing* in his autobiography.

...I knew I had found someone who could build the leg I so desperately wanted. Now I faced the challenge of convincing my insurance company that I needed an athletic prosthetic leg to return me to the fitness level I had enjoyed before the accident. This task required patience and determination. (Martin, 2002, p. 82)

Third-party financiers may be unwilling or unable to facilitate a request for a prosthesis or part of a prosthesis, and so approaches to getting what is required may need to be rethought. Like many others, Paul anticipated this would be an uphill struggle and kept at his efforts to convince his insurers. He sought to adapt his approach by reframing his case with more and more supplementary materials to support his application, but unfortunately, these efforts also failed. *'My attempts, properly backed by formal letters from medical doctors and certified prosthetists, were shot down again and again. Another leg, the insurers claimed, was not medically necessary. I became very discouraged.'* (p. 82). At this time, Paul judged that he would not be able to obtain the limb he needed this way.

Alan is a lower-limb prosthesis user who presents a similar account to Paul. Alan described how he had had numerous applications to his health authority rejected when he asked them to sanction payment of a prosthesis he sought. Like Paul's insurers, the health authority indicated that the prosthesis Alan requested was too expensive and the cost was an excess compared to simpler models. When Alan's case was rejected, like Paul, he re-applied and re-applied, each time re-writing letters and providing more and more 'evidence' of the need for this particular limb in order to improve his chances of success. Eventually, Alan was successful in his 'battle' with the authorities, and he considers that he now knows the level of what is required to effect change if he required another prosthesis in the future. In this way, both Alan and Paul *re-coursed* by 'ramping up' their efforts at *redress* until this was achieved or it became apparent that no amount of escalating this course of action would be successful.

Returning to Paul's case, when Paul was unable to get his limb sanctioned, he still perceived the possibility of getting this limb, and this led him to appealing to his prosthetist directly. Paul's prosthetist took pity on his case and set about creating

the limb, assuring Paul that *'one way or another he would get the under-writers to pay'* (p. 83). So in Paul's account, *redress* constituted Paul's quest for an athletic prosthesis, and when his initial attempt failed, and subsequent *re-coursing* through 'ramping up' was also met with failure, he sought to *re-course* through a complete change of approach, appealing instead to his prosthetist.

Rob, a 34-year old bi-lateral lower-limb user, gives a different kind of *re-coursing* in his account. Rob described being fitted with a new socket that was supposed to give him a 'firm but comfortable' fit, but after using it for a time he felt that this was way off the acceptable level of comfort that he was used to. *'I felt that it actually felt that it was pulling, pulling you rather than anything else. This one I have fits snug, the other one just felt like it was pulling me out. I just was not comfortable.'* So Rob returned to his prosthetist a number of times to fix this, but efforts at modification were unsuccessful and Rob was left with an ill-fitting limb. After a number of further attempts, Rob and his prosthetist agreed to give up on this socket, and instead to try something completely different. Rob described his uncertainty towards this shift, but he was confident in the judgement and ability of his prosthetist: *'I was kinda going, oh well, I'll give it a try...'* When Rob tried the new socket, he found it gave him the fit he sought, but he was aware that this had been a calculated risk. *'...I wasn't really into it but it just worked out phenomenally well. Again, it's just the way it goes. Some work for you, some don't.'* Similarly to the previous illustrations then, Rob had kept at the attempts to improve the fit of his socket, but he too reached a point where he determined that pursuing this course of improvement was unlikely to work out, and *re-coursed* to trying a different kind of socket.

We might also return to Emily Rapp, the lower-limb prosthesis user involved earlier in this chapter, in order to further illustrate *re-coursing*. Earlier, Emily had described feeling 'transformed' and 'reborn' after she obtained her new prosthesis; a limb that would enable her to 'pass' in everyday social life and to enjoy social occasions at university without fear that she would be perceived or treated abnormally because of limb difference. With her new leg, she matched up to her friend Samantha who used a similar prosthesis and appeared carefree, and so Emily was

confident that her efforts at *redress* had been successful. She perceived things to be *just normal*, yet soon after, at a party she was at, Emily overheard a conversation about her that caused her spirits to plunge:

As I was about to walk down the stairs and out the door, I heard a conversation to my left in the hallway that led to the bathroom. "I've got a bone to pick with you," said the man I'd been sitting with. "What, dude? I'm totally wasted. What are you talking about?" I stood motionless at the top of the stairs. "About that girl. She's got a wooden leg, man. What the hell? I thought you said you'd seen her before." I didn't wait to hear any more. I walked home quickly through the sharp, fragrant air of a Minnesota fall. ... I could not repeat the words that had confirmed my greatest fears. I wanted to tell Liz; I wanted her to say, He's wrong, he's a jerk, it will never happen again, even though I wouldn't have believed her. "Yeah?" she asked. I shook my head. "Mmmm," I said. Liz squeezed my hand and didn't make me continue. I began to cry. She didn't say, "Don't do that" or "stop crying," she just held my hand and never asked me to explain. For a decade, I'd been pinning the advent of my new life on the acquisition of an improved prosthesis, but I knew now I would not be prancing around or going on romantic dates as I had imagined. Boys were not going to start ringing me up or chasing me down to blurt out expressions of admiration. I feared—even believed—that the encounter at the party had been an accurate glimpse of my future. (Rapp, 2007, pp. 160–161)

Emily had sought to live as ordinarily as possible, to be 'chased' and sought after as she had imagined she might be with this limb, but continuing to be hurt by others despite her new prosthesis indicated to Emily that no kind of limb was going to transform her in the way she desired. Her limb difference continued to prevent her living in a way she felt 'right', and she now saw this would continue no matter how advanced the prosthesis was that she was using. This drove Emily to *re-course*, as she strove to find a solution elsewhere:

I wanted to live and thrive, only what kind of life was I really having now, willingly trapped in outdated social mores and my own self-hatred? How could I make it a good one? How could I be a good person with all this rage inside me? I agonised over this. The task of making choices that would lead to a good and right life versus an immoral or unsatisfying one-what I began to think of as a “crippled” life-drove me to declare a religion major that year. As an early reader of the Bible and a lover of its stories, I gravitated to these old-what we call “classical”-texts. Perhaps there were more elements of truth in those time-honored books, those ancient words, and maybe I would find some answers there. (pp. 163-164)

The way Emily recalled being ‘willingly trapped’ and full of ‘self-hatred’ hints at the direction of her *re-coursing*. When improved prostheses failed to help her live in a ‘good’ and ‘right’ way, she sought solutions through immersion in religious studies. And to an extent Emily found what she sought:

...I felt elated and terrified. In the book were detailed analyses of biblical texts and sociological studies explaining the emotional impact of feeling on the edge of the world or being viewed as a lesser person because of the shape and limits of your body. I read bleak statistics and stories of hope. [Nancy] Eiesland envisions God as disabled, as the body that is broken at each Eucharistic celebration. Her “bones and braces” embodiment challenges the notion that there is one normative standard for correct bodies and focuses instead on the “mixed blessing” of the unconventional—or crippled—body. “The disabled God makes possible a renewal of hope for people with disabilities and others who care. This symbol points not to a utopian vision of hope as the erasure of all human contingency, historically or eternally, for that would be to erase our bodies, our lives. Rather, it is a liberatory realism that maintains a clear recognition of the limits of our bodies and an acceptance of the truth of being human.” These words made a “difficult but ordinary”

life possible and permissible; a life that required no healing touch, nor miraculous transformation, in order to be complete or worthwhile. (pp. 164-165)

So in seeking to be *just normal*, individuals may determine that a particular course of *redressing* is not able to achieve this. They realise they are 'going the wrong way' about things, such that they need a change of approach in order to succeed. Paul stopped appealing to his insurance group and appealed instead to his prosthetist, Rob tried a different limb when adjustments to his socket were not working out, and Emily sought a way to re-considering her circumstances when she felt prostheses could not do this for her. Each changed their approach when they deemed that their original attempts at change were not working out.

In addition to this, persons may not know of ways to *redress* other than what they may have already tried, and so they may seek out similar others that may be able to indicate possibilities for *re-coursing*. This can be a 'last chance' at *redress*, where individuals may appeal to others to know whether anything can be done or whether their situation is unchangeable and to get on with it. In online discussion forums, threads of this nature are often started with questions about 'what to do' about particular problems. Two of these opening posts are given below:

I am a below knee bi lateral amputee. I wear silicone sheaths on both legs, the only down side is that where the sheaths end I get a terrible itching. I have tried everything I can think of to stop it, if anyone has had a similar problem and been able to solve it please could you let me know before I scratch my skin off. (Kastley3, 2011)

My insurance is no longer contracted with my leg man and he has taken another job in the same field but not seeing patients. I decided I needed to find someone else nearby. Last year I had a socket made here. What a fiasco this has been! This leg man proceeded to do his own thing saying the way I had had a socket made was 'old school.' I told him the new socket he made was uncomfortable and was making my knee swell, he said it wasn't

fitting because I had gained weight...not true. I could not wear the socket at all. He would not listen to me and I felt like I was talking to the wall I said screw it and never went back to him. The socket he made sits in my closet. In January of this year I decided to try someone else with the recommendation of a doctor friend of mine. This leg man has been working on a new socket for six months and am still without a new one. I have never heard of this, but he has sent it off to be computer sized three times now. Two weeks ago I brought the test socket home to try out. It is still uncomfortable and hits me wrong at the knee and needs more work. I have been putting off going back because I am frustrated and don't know what to do from here. ...Does anyone have any suggestions on what my options might be? (Impala, 2012)

These posts illustrate the way that persons may seek direction from similar others. By setting out their situation, they seek answers from other members of the community who they perceive may have had similar issues, and resolved them successfully. Responses to these questions tended to be supportive, with some offering possible solutions that variously entailed trying new ideas or escalating a course of address that had been attempted, as was the case in this example:

...Your own description of the conversation appears to make it sound more like you said something along the lines of, "That spot still hurts," and then you waited for the "professional" to make a decision for you. Granted, in an ideal world that's what would happen...but you've already found out that your "team" is not functioning as a team, that, in fact, they seem to be trying to just "pass the buck" and hope that someone else will be the one to find an answer or make a decision. Given that fact, it's up to you to be the one to press the question, demand an answer, and make your own decision. I can tell you from personal experience that, if you're trying to be detached from what's going on with your foot, it's not going to help your situation. I went a full year with a completely

snapped tendon in my right foot, while doctors kept telling me that "feet take a long time to heal" ... It wasn't until I got mad enough to stick my foot in my doctor's face, wiggle it weakly and ineffectively, and say "that's my FULL range of motion after a year, and it's STILL painful, and I'm STILL walking with a cane. If you can't figure it out, please refer me to someone who CAN." And so he did...[But] If I hadn't pushed the point, I have a feeling I'd STILL be shuffling about with a torn tendon. (CherylM, 2011)

In sum, prosthesis users have cause for *redress* when they determine that they are not living *just normally*, yet not all attempts to *redress* are successful. When attempts do not pan out as desired, individuals may *re-course* to a different approach that they perceive could be successful. Re-coursing may include escalating approaches, changing the channel of approach, or seeking suggestions from similar others who may be judged to be more experienced and to potentially have overcome a particular difficulty.

### Summary

Acts of *redressing* are intended to enable an individual to be *just normal* when they perceive themselves not to be. *Righting what's wrong* contends with the way that persons encounter violations of and obstacles to living *just normally*, and act to rectify or overcome these. *Restoring the balance* concerns persons acting on perceptions that particular things have fallen out of keeping with what is *just normal*, exceeding or falling below what is considered right, and so how persons seek to re-establish the right levels of things. *Re-coursing* accounts for acts of giving up on particular approaches to redress when these are perceived to be ineffective and engaging alternatives, as persons alter their approach to a way they believe can help them to be *just normal*.

## Chapter 8: Persevering (with living 'Just Normally')

### Introduction

In the previous chapters on *preserving* and *redressing*, individuals were said to engage in acts that keep them *just normal* and also in efforts to bring about a *just normality* when this was deemed not to be the case. While a way of living that is perceived to be just is sought, this is a way that is reasonable, and 'about right', and so not necessarily perfect; rather it is *just normal*, and 'good enough', and so this leaves scope for accompanying difficulties that persons must contend with.

In this chapter then, a category of actions is discussed that pertain to *persevering*, or the way that persons keep on with being *just normal*. *Obligated persistence* explores the way in which persons are compelled to live *just normally*, and despite issues they may encounter. *Trusting to transience* involves persons foregrounding 'an end in sight' to particular problems, and this enables them to grit through these. *Mole-hilling* concludes this section by exploring the ways in which persons equate or contrast difficulties to those that may be experienced by others, and in doing so, rationalise the occurrence of problems. This makes an individual's circumstances seem more ordinary, and so difficulties that much more tolerable and permissible. These categories account for the ways in which persons *persevere* with living *just normally*, managing difficulties of a *just normal* nature.

### Obligated Persistence

In this section, discussion focuses on the differing ways that persons consider what it means to live *just normally* and do so. *Just normal* is argued to be an important way of being to persons such that they are compelled to keep themselves in ways fitting with their conception of this. An ongoing obligation to keep living and doing particular things that keep a person *just normal* is termed *obligated persistence*. This pattern is perhaps most salient when persons are considered to be *persevering* even in the face of difficulties. If these difficulties are judged to be of a *just normal* nature, then persons may not have cause for *redressing*, as these difficulties are seen as a part and parcel of living *just normally*. Instead, *obligated persistence*

captures the way that persons consider that these are things they ought to get on with, as they keep at their *persevering* with living *just normally*.

For instance, in the context of prosthesis use, living *just normally* may be perceived to be contingent on the use of a prosthesis because of a particular function that the limb facilitates, and so which would not be possible without. However, the use of a prosthesis can therefore become a binding experience, since discontinuing use is to discontinue being *just normal*. This can be problematic if issues arise or accompany the use of the limb which would otherwise prompt cessation. If it is perceived that little can be done to alleviate an issue aside from non-use, then individuals must keep going with the difficulty. The prosthesis as a device that enables can therefore also be something that persons may find themselves obliged to persist with. This is a form of *obligated persistence*.

To introduce this pattern of *obligated persistence*, Neil's account is first drawn upon in order to explore a compulsion to gain a prosthesis and which then continued as an ongoing obligation to persist with. Neil, a 57-year old upper-limb prosthesis user, described how he had undergone the amputation of his hand, and following his discharge from hospital had largely adapted to life as a one-handed individual.

I had pretty much accepted the limitations and gone on with life. I wasn't, um, I wasn't stuck at that point. I found ways around, and solutions to, most of my daily issues that came up. ... I had found solutions that were workable to most of the problems I was having.

For Neil, the loss of his hand had caused initial upheaval in his life, but as he explains, after a time, he had '*gone on*' and '*wasn't stuck*'. In this way, Neil indicates a kind of living *just normally* and his persevering with '*daily issues*' within this. However, in his work as an attorney, Neil described discovering some tasks which he could no longer manage well, bordering on the unmanageable. Amongst other activities, multitasking, such as when he was on the phone and when he was required to present and discuss evidence in court, were somewhat possible but awkward with just his right hand and his residual left limb. While Neil accepted

difficulties and differences in how he went about other aspects of his life, not being able to perform as effectively as he felt he should at work was not right. Neil had learned of a prosthesis that he felt could address this, and that would enable him to function in his job at a level he was content with. So Neil sought this prosthesis, and in doing so he is implicated in *righting what's wrong*.

However, for Neil, the prosthesis was 'an all-or-nothing' that meant that if he used it at work, he felt he needed to involve it in other aspects of his life, and he foresaw a slow process of learning how to use the limb in tasks of his daily living, and doing things slowly and slower than he might with one hand as he learned to live again as a two-handed individual. He described his reticence in '*going back down that road again*' and '*re-visiting a lot of problems*' about going through a process of adaptation to get used to two-handed living, but despite these perceived issues, '*the big clincher*', as he described it, was in being able to get back to being an attorney like he was before, and this is what drove him to get his prosthesis and then to persist with difficulties in early and in ongoing usage.

Neil's account illustrates the way that when individuals with limb absence perceive that a prosthesis can enable them to live *just normally*, then to be without is to therefore live in a way that is not *just normal*, and so not 'right', compelling usage. In this way, persons may be engaging in *redress* when they gain a prosthesis in order to live *just normally*. However, *redressing* can turn to *perseverance*, as an obligation to become *just normal* becomes an obligation to stay *just normal*, and this ongoing persistence is the focus for the main part of this section.

In her autobiography, Emily Rapp, a lower-limb prosthesis user, gives an illustration of *obligated persistence* in her account of the difficulties she experienced while managing her prosthesis in sexual encounters. Emily felt that she did not require the limb for any physical aspect of sex and suspected that problems with the movement of her limb and the discomfort it caused would be troubling. Added to this, a friend who also used lower-limb prostheses had told her how much better the experience would be without it. However, any inclination to remove the limb was overruled by what Emily considered this would mean:

To remove the leg in front of a man was unthinkable; the very thought of it sickened me. I had no sense of myself as a desirable, sexual woman as an amputee. The only activities I did habitually without the leg were skiing, showering, and sleeping – and even these were tinged with shame. The person I wanted others to see – the person I wanted to be – had two legs. The only way for me to have sex – this whole body experience – and remain psychologically safe was with the leg on. When it was attached, I felt like a complete person; when it was removed, I felt monstrous and deformed.  
(Rapp, 2007, p. 172)

For Emily, *just normal* meant being bodily-whole, and moreover, as physically ‘normal’ as possible. Being without the limb went completely against this, and she perceived herself to be ‘deformed’ and to be perceived this way by others. Practicality prompted removing the leg in situations where things were getting intimate, but the thought of allowing herself to become ‘monstrous’ was not only undesirable, it was ‘unthinkable’. Keeping the leg on was something Emily felt she must do despite how awkward or painful this became because she needed to stay *just normal* in this way. Furthermore, the actual act of removing her prosthesis in front of her partner was something that conflicted with her idea of what was acceptable:

The body in two pieces was an image of violence, not of sexuality; it was what detectives came to examine after some terrible crime. I thought of the legs that arrived from the prosthetist in “body bags.”  
... No matter how hard I tried to pass as an able-bodied woman, the act of removing a leg was not normal – it never would be. (p. 162)

So because Emily felt complete with her prosthesis, and that this was a *just normal* way to be, she was obligated to keep wearing the limb whenever possible, persisting in this way despite the difficulties it posed for her and her partner.

Appearing as ‘ordinary’ through the use of a prosthesis is a common obligation for prosthesis users, and while Emily sought to keep this way as much as possible,

others may only do so for specific occasions. Chuck, an upper-limb user in his late twenties, uses his myoelectric prosthesis because he wanted to appear to have two hands. In part of the discussion, he described how he would even wear his prosthesis on occasions when it had broken, and so despite it being inoperable. At these times he would be able to get by better without the limb, and in fact when it was completely broken it hampered two-handed tasks where he would otherwise use his residual limb, yet in particular situations he was compelled to keep going with it. He explained:

I keep wearing it [the myoelectric]. I guess most for the mental aspect of it. I try to get onto them [the prosthetist] and get it back here as quickly as I can, because it's the only one I have besides the hook and I'm not wearing a hook. ... I have a hook as well but I'm not wearing it... we're too far technically advanced for me to be wearing a hook. The hook was sufficient back in the [American] Civil War era but it's not alright now.

*What do you mean by the mental aspect?*

Like more of the, I guess, ...stereotypes -people assuming you wear it and I'm gonna look at you, but when you don't wear it- [like] I might- the first thing they're gonna say is that it's gone.

Chuck did not mind others taking note of his limb difference provided this had a positive outcome. Wearing his myoelectric limb, if others were drawn to this, Chuck said they tended to be *'amazed by it, just like I was the first time I seen it'*. But without the limb, or even with his 'hook' prosthesis, Chuck felt that others would judge him more negatively, perceiving that people would think of him as 'disabled', and so treat him as if he was deficient in some manner. So because Chuck perceived that his myoelectric could avoid this, keeping him 'normal' in this way, he was compelled to persist wearing it when out in public, even when it had broken, rather than going without or falling back on his hook prosthesis, in order to keep *just normal*.

In addition, Chuck lamented how often his prosthesis would keep breaking, which led to a frustrating amount of trips back to the prosthetist, taking up most of his day trying to fix broken motors, displaced sensors, and ripped covers among other problems. This was something that had plagued Chuck throughout his prosthesis use, and at the time of speaking to him his limb had stopped working again. Yet despite his frustration, Chuck was bound to persevere, keeping using and breaking the limb because he needed it to keep in ways he felt imperative. And despite his hook prosthesis being a more reliable alternative, he persisted with the troublesome myoelectric and this cycle of breaking and repairing because only the myoelectric could allow him to be *just normal*.

Mark, a 46-year old lower-limb prosthesis user, gives a similar account that further illustrates *obligated persistence*. As a prosthesis user who underwent the amputation of his leg in early childhood, Mark has used artificial limbs for most of his life. He does a lot of outdoor activities, among these skiing and hiking, but his prosthesis has broken numerous times in the course of these pursuits, and so often that despite trying different solutions designed to overcome these problems, the ongoing incidence of something going wrong has led Mark to consider it an inevitability of engaging these activities. Mark regularly finds himself back in consultations at his limb-fitting centre, trying to fix the latest issue with his limb, and despite expressing his frustration with this, he will not stop doing these things because they are part of how he feels he ought to be able to live. To avoid or engage in these activities in a different way would be fundamentally non-normal for Mark; these things were *'what I do'*. And so because of this, Mark had resigned himself to being in and out of consultations.

So it's broken, then you have to fix it. Ok, fine, that's the way it is.  
I'm not going to... -just because the leg doesn't work doesn't mean you shouldn't be able to do something. That's how it is. No, I don't worry about it.

Mark was adamant that he should not have to 'pander' to a prosthesis by not doing particular things, or doing them at a lesser intensity to avoid damaging the limbs.

He had grown up doing things like the other children he knew, being brought back to limb fitting centres with broken prostheses when they could not take what he was putting them through, and so this was 'how it is' for him. In this way, Mark's *obligated persistence* is in part, an obligation to himself and to keep up his way of being, but as an adult he also perceives that it is only fair that he ought to be able to keep going like this; so either he gives in or the prosthesis gives in, and the fair way of being is for him to keep at it, even if it means continually being in and out of consultations.

Individuals using prostheses may do so to enable them in ways that are variously related to appearance and physical function, but when this enables them to be *just normal*, then they are obligated to keep using their limb in these ways in order to stay *just normal*. When use is bound up with being *just normal*, the idea that persons choose to keep using a limb and that they could easily discontinue usage is in fact an illusion of choice, and instead individuals are compelled into persisting with ongoing usage because of what this affords.

This is something that troubled Alison, though she too found herself *persevering*. Alison, a 50-year old lower-limb prosthesis user, described how the combination of her particular prosthesis and covering clothing meant that others usually do not realise her limb difference. She values this ability to live *just normally* in this way because at times when she has revealed her limb difference to others, she felt that she is often treated differently, and in ways she linked to stereotypes of inability. So Alison appreciates her ability to be treated ordinarily in this way and so to stay *just normal*, but she also feels she should be more involved in activism to change the way others think about limb difference.

Sometimes I have this thing in my head; maybe... this is like stream of consciousness: Maybe I should come out more as an amputee, maybe to change people's perceptions of amputees... But the second you appear on crutches with no prosthesis they have an image of you and it's kind of a negative image. So it's fairly hard to.

Alison recognises that she is in a position to try to effect change by '*coming out*' and demonstrating her capability, challenging perceptions of limb difference. But in doing so, she feels she will invariably incur stigma and could result in permanent undesirable associations. If this occurred with those she is in recurrent contact with, and her '*coming out*' did not change their way of thinking about limb difference, then she would have lost her ability to be *just normal*. So instead, Alison is compelled to continue to '*play it safe*', persisting with her unrevealed prosthesis use.

As Alison's account illustrates, persons may be 'locked in' to their prosthesis use and in ways they live with their prosthesis if this enables them to be *just normal*, despite other costs attached to this. A further example from Emily Rapp illustrates the physical toll that prosthesis users may feel forced to pay as a result of being *just normal*. Emily, a lower-limb prosthesis user, described taking part in a trekking orienteering exercise for students coming to spend time in South Korea. This event was particularly difficult for Emily, but she found herself compelled to see it through:

I felt sweat pooling at the bottom of the silicone socket, making it slip and chafe against the small ankle bone on my stump (the residual limb), creating sores that would later itch and bleed. Still I walked on. I knew the torn skin would heal after a few days, and I would not lose. If I arrived last, I thought, I would be nothing but a cripple. By the time I reached the dorm, I was hobbling and in a great deal of pain, but making it back was the only thing that mattered to me. I was thrilled to be one of the first to arrive at the meeting point. I felt a rush of relief mixed with a kind of intoxicating pride. (Rapp, 2007, pp. 5–6)

While Emily could appear to be just like her peers with her prosthesis, extended use, particularly in environments like this, turned discomfort to pain, yet she forced herself to keep going for fear of what it would mean if she gave in to this: '*I was afraid that if I arrived at the dorm last, people would think it was because of my*

*disability, and they would either pity me or look down on me. Both thoughts were equally intolerable and made me almost physically ill.'* (p. 5) So Emily pressed on, through soreness and pain because she needed to keep *just normal*.

Emily's account also illustrates how the limitations of a prosthesis can mean that while facilitating being *just normal* in certain regards, persevering with a prosthesis can also be a secret struggle for the individual. Emily could meet with her peers and be thought of just as one of them, but the discomfort that plagued her from where her residual limb connects to the prosthesis meant that keeping this up involved sometimes needing to fight through pain and fatigue in order to do so. Furthermore, this was something she had to keep to herself, in order to stay *just normal*.

In her autobiography, Lenor Madruga, a lower-limb prosthesis user, gives a further illustration of *obligated persistence*. Like many individuals with acquired limb absence, after the loss of her leg Lenor expressed a desire to return to how she was prior to her loss. To this end she described gaining a prosthesis and making significant efforts to maintain the roles she had held and doing the tasks she had done previously, and in doing so, to an extent she felt she did get back to how she was. However, this was not easy going, and Christmas was a particularly testing time. Lenor had always been the one to make Christmas happen in her household, and so she felt it imperative to keep this going, for herself and for her family. With her prosthesis, Lenor could do the things she was able to do before, decorating, baking and crafting festive things, but each was more arduous as the leg was heavy and less flexible and she found herself tiring quickly from the exertion. Despite this, Lenor persevered because her prosthesis presented the possibility to keep Christmas going, even if it required that much more effort, and so this was something she had to keep at. Through fatigue, Lenor persisted with work required for the festivities and described the outcome of this.

My friends couldn't understand why it was so important for me to do all the things that I was accustomed to doing. ... I wanted to cook, entertain, and join in on all the holiday festivities as I did before. ... It

was difficult and very tiring to stand for the many hours it took to decorate the entire house, but I did it. I wanted the house to have the same holiday cheer that it had the year before. (Madruga, 2000, p. 150)

*Persevering* then, is in part understood through the different ways that individuals consider what it means to live *just normally* and keep going with this. This can be as fundamental as just wearing a limb, as much as possible or only for particular situations, or it may mean doing or not doing particular things with a prosthesis in order to perpetuate a *just normal* status. Furthermore, when difficulties arise that relate to this, and when persons perceive that there is either no cause for, or possibility of *redressive* action to deal with these, they are *persisted* with as persons persist with living *just normally*.

In this section, persons have been depicted as *persevering* in various ways, often in the face of difficulties, because of the compelling nature of being *just normal*. In other words, *just normal* obligates persistence. However, individuals using prostheses are also implicated in acts of facilitating *perseverance* that ensure that difficulties can be persisted with, and which are explained in the next sections of *trusting to transience* and *mole-hilling*.

### Trusting to Transience

Living *just normally* means living in ways that are right, reasonable, or 'good enough', but this leaves room for difficulties of a *just normal* nature that therefore must be reckoned with in an individual's *perseverance*. One way of managing these is through *trusting to transience*. For instance, the use of a prosthesis may enable a person to live *just normally*, but the limitations of artificial limbs mean that users often need to contend with accompanying issues. Some of these were illustrated in the accounts given in the previous section. One way that *persevering* is facilitated when such issues are encountered is when these are thought of as transitory. In doing so, individuals perceive that problems are just temporary and will eventually ease to a level that is more manageable, or they will disappear entirely. This facilitates a toleration of problems that could otherwise be at odds with living *just*

*normally*, as to only bear difficulties on a temporary basis, believing that things will improve, can make living with them acceptable. This process of *trusting to transience*, whereby persons focus on the temporariness of an issue, can enable persons to *persevere living just normally*, as they consider difficulties as just bad patches to get through.

A common context within which *trusting to transience* occurs is when changes to one's prosthetic situation take place. This may be when a prosthesis is first fitted, whether a first limb or changing to a new solution, or when adjustments have been performed on an existing solution. Whenever such change occurs, issues may be experienced in the use of the limb, and persons may *trust to transience* in order to manage living with these. Alan's account illustrates this. Alan is a lower-limb prosthesis user who set up a support group for individuals with limb absence, as he felt a meeting point was sorely needed in his part of the country. Over the course of the group's meetings, Alan described how he had come across a number of individuals who were struggling to get on with their prosthesis as well as those who had stopped wearing them entirely. He differentiated himself from this group by indicating how he focuses on issues going away, and he tries to encourage others to think this way too:

I know there are a lot of people that, you know, the slightest bit of pinching or things like that and it can affect them, I suppose, mentally. In big ways. And then they tend to [be like] 'oh, I'm not putting that leg onto me because it doesn't feel right'. But they're forgetting - it's like a new pair of shoes: you have to wear it in. It takes time for your stump to adjust to a new socket, a new shape, a new design. Even down to if you get a new knee, you're walking in a different way.

Alan tried to convey to other members of his group that he was no different in experiencing varying difficulties with a prosthesis, but his perseverance was due to his conviction that things would get easier over time. He considered that difficulties with discomfort, with unusual sensations, or the way walking felt awkward on a

new or adjusted prosthesis would be transitory, and this helped him to keep going. So when Alan encountered things that 'didn't feel right' he avoided 'being affected' by this and so was able to keep at his usage through considering that difficulties would generally be a matter of 'wearing in' before things would eventually feel 'right'. He considered that if he persevered he could expect things to get better, and reciprocally this helped him to keep going with the difficulties he experienced.

Alison, a 50-year old lower-limb prosthesis user, gave a similar account when she described moving from one prosthesis to another:

There is a break-in period without a doubt. And you're kind of adrift between the two of them for a little while. I would always kind of find – maybe just get on with it and persevere with the new one. And there would usually be maybe three or four days of maybe significant discomfort. But I'd find if you work through that you'd eventually get used to it, you know.

So Alison also experienced difficulties when there were changes to her prosthetic solution, and she similarly urged herself to persevere as she needed the new leg to get about – part of her living *just normally*. Alison was able to do this because she considered that the discomfort she experienced would last only a number of days before it began to fade. The sensations could remain, but her *persevering* meant that after a time it would stop 'figuring' as she got used to it. Alison suggested that this was a process that just took time, where after gaining a new limb, at night she would have 'a slight change' where she would start to 'adjust to the new one' such that every day when she woke she would be a little more accustomed to the sensations of the limb, good and bad. In this way, Alison could put up with the 'significant discomfort' because she trusted that it would be as transient as the time it took to get better acclimated to it.

So *trusting to transience* as illustrated through these accounts can be considered as a belief that unpleasantness will pass, and so that these are difficulties to just grit one's teeth and get through. However, as Alison and Alan indicate, the transience of issues may be facilitated by persisting with particular actions as things perceived

to be related to the issue are 'worn in', helping unpleasantness to pass. So a trust in the transience of problems fuels perseverance, and then persisting with particular actions as persons live *just normally* may in turn help the attenuation of issues. This may be encouraged by previous experience of difficulties. In Alison's example, she had used many prostheses before that she had gotten used to, and this encouraged her to believe that future prostheses would be the same. Alan also had some experience of prostheses, but it was his likening of prostheses to shoes that need to be 'broken in' that gave him faith that his difficulties were only a matter of breaking in.

Lorna provides a further illustration of *trusting to transience* where she similarly had no prior experience of the problem. Lorna is a 51-year old bilateral lower-limb prosthesis user who has used many different prostheses over the years, moving from what she referred to as her 'peg legs' to more advanced prostheses. Lorna enjoyed getting better limbs, as she felt that each technological improvement helped her out in various ways that little bit more. However, when she went for her latest consultation, she was surprised at the extent of the maintenance procedures she was told that she would need to do in order to cater for the latest limbs that were being recommended to her. These prostheses required regular and thorough sterilising before and after use, and this was much more than she was used to. When faced with this, she was at first anxious about how much effort was required:

[I didn't want to be] getting hysterical every morning getting up, thinking, 'Oh god I have ten things to do before I even dress myself, and I have nine things to do when I come home'. I just want simple. Easy. You know, because when I heard about the silicone sock first, and they would say, 'You'll have to take it off and you'll have to wash it every night and you'll have to clean it'. I thought, 'I'm not going to do any of that now!' You know, I just thought, 'No, no, no. It's not going to be hassle. If there's going to be hassle with it I don't want it. I want it simple.'

Lorna was on the verge of rejecting the proposed setup, despite her desire for better limbs. Having modern prostheses was part of being *just normal* for Lorna, but simplicity was the ‘big, big, huge thing’ and limbs that were ‘hassle’ went against this. In the end though, she convinced herself that if she persevered with the maintenance then what might be ‘hassle’ initially would eventually become routine and something she would not think about. So although Lorna knew that she would have to keep at these tasks, she saw that if she did so, she could get used to them being a part of her routine alongside the other necessary things she did, and that they would soon become little bother. *‘It’s like washing your teeth. ... No hassle with it at all.’*

A different kind of *trusting to transience* is illustrated by Chris, a 61-year old upper-limb prosthesis user. When Chris first started to use his prosthesis, he found it cumbersome having to recall the procedures to use the functions of the hand, and annoying to constantly visually monitor it to make sure it was doing what he wanted it to do. Usage was not entirely intuitive and many things with the prosthesis would take longer than without it. Chris became frustrated by this and with mistakes and dropping and breaking objects he was trying to manipulate with the hand. But Chris described ‘needing’ to have two hands, and in this way he was *obligated to persist* with the limb despite frustrations because living *just normally* for him involved having two hands. However, Chris felt that his usage would improve if he kept at it. He believed that with enough time and effort, he would find using the limb much quicker and easier and become more proficient with it overall. This was the ‘challenge’ that Chris described needing to tackle and to get through, and he similarly trusted that the period of slips, breakages and the frustration of laborious operation would be only transient.

Now I just go off and grab it [objects] because it’s there and I feel the weight, and that indicates to me that I’m at the point where I need to think – I make the decision to close the hand, and grab it... it’s not a long process to grasp the understanding of how to make the thing work, but it does take time to practice to make it happen. Then all of a sudden it just happens -all of a sudden now it becomes

a second-nature exercise. ... I just do it, as it would be if you were going to pick up a pencil, you just go and pick it up and don't think about it. You just say well I'm going to make these fingers move, pick that pencil up, and I'm going to drop it again, so you don't think about how to move the fingers, you just pick it up. And that's what I now do with the hand.

For Chris, *persevering* helped him to reach a point where 'it just happens' and the use of his prosthesis became 'a second-nature exercise'. He described how he would remind himself about the temporariness of problems he experienced: '*It's not the end-all, because you can't get it to work the first time. And it is something that you have to work with, to get it to work.*' He explained further:

[You've] just gotta be persistent with it. It's like doing anything, like going riding a bicycle. The first time you get on a bicycle you fall down. So you get back on again, you fall down again. Then all of sudden you're wobbling down the road and the next thing you know you're running round the neighbourhood doing wheelies and shit.

So Chris likened the mastery of his prosthesis to mastering other tasks that require some degree of perseverance, and in this way he perceived that using his limb was something that *could* be mastered, and that with effort it would only be a matter of time before this was the case. Difficulties that Chris experienced could be persevered with as he considered that they would eventually pass with time and effort. This marks a difference in *trusting to transience* when compared to Alan, Alison and Lorna's accounts. Whereas the former were focused on an unpleasantness passing, Chris could be said to be more focused on an expectation of things getting better. While there is some conceptual overlap between these, there is a distinction to be observed in the way that there can be a greater focus on getting toward something or getting away from something. However, when faced with an issue, both *trust in the transience* of an undesirable state with an emphasis on the belief that it will pass.

Joe LaBrie, a lower-limb prosthesis user, gives an account of *trusting to transience* that is similar to Chris'. Joe is a 36-year old prosthesis user who started a blog to document his experiences after the loss of one of his legs. In one post, Joe described the aftermath of his first attempt at serious exercise after gaining his prosthetic leg:

My hips are screaming out in pain. My back is frozen in place. My hamstrings are wound up tighter than I can ever remember. My calf (singular) feels like it is permanently in a locked position and I can't release it. But I just keep laughing... because I'm so happy. Happy because for the first time I know it is real. It is really going to happen. (LaBrie, 2013)

Joe's delight was in realising he was able to run with his prosthesis. He had wanted to be able to do this in order to get back to taking part in triathlons as he used to prior to losing his leg. However, running was slow and painful and he could only go for short periods of time before exhaustion. Joe recognised that his running wasn't 'real running', but he was convinced it would be one day. The difficulties he experienced when trying to run were not something he was prepared to put up with in the long-term, but he saw these as being present only for a matter of time.

...it will only be a matter of time before my body takes back over and I wear out my prosthetic. It's a tall proverbial mountain to climb. And I'm starting even lower on the mountain than the last time I tried. But I know I can climb this mountain. I have done it before and I will do it again.

The position Joe saw himself at was one of transition back to his athletic standard. His conviction that he would improve and that problems would abate sustained his perseverance through early periods of being 'sub-standard'. Joe had trusted that things would get better, and what he had achieved had validated his perseverance, further facilitating this.

...There is no longer any doubt in my mind. I can barely run more than .25 of a mile and I'm lucky if I can do 250 meters in the pool without drowning, but I will do a triathlon again. And soon!

As Chris and Joe's accounts illustrate, persons may foreground a point in time when they believe a satisfactory state will occur, giving them the drive to keep going through difficult periods. As Joe's account exemplifies, noting improvements along the way can encourage perseverance as it becomes apparent that progress can be made. Thus a trust that motivates initial perseverance is further spurred on by evidence of change, even while no guarantee of further change is given.

In summary, when individuals encounter difficulties when living *just normally*, such as when using a prosthesis, their *persevering* with this can be facilitated by believing in the impermanence of these problems. Persons may trust in the temporariness of difficulties and consider the proverbial light at the end of the tunnel, though they may similarly consider themselves to be moving away from the dark. This *trusting to transience* eases persevering as persons expect that difficulties will abate, though there is no guarantee that they will. Persons instead go on faith, and they may be encouraged by prior experiences of similar difficulties that may have passed. Finally, if indications of desirable change are received during *persevering*, this further encourages an individual to persevere with difficulties while living *just normally*.

### Mole-hilling

A further way that *persevering* is accounted for can be seen when individuals indicate to themselves that difficulties they may experience are more reasonable than they may first appear. Persons recognise that there are worse possible ways to be, that difficulties may be 'natural', or that they are akin to what others may experience at some time, each inferring that these issues are actually of a fair and tolerable, and so a *just normal*, nature. It is this reverse process of 'making mole-hills out of mountains' that facilitates *persevering* as persons normalise issues through these ways of reconsidering them. This flattening of their impact is an act of *mole-hilling*.

One way that prosthesis users are implicated in *mole-hilling* is through engaging in social comparisons that can indicate a different way of looking at one's circumstances. This can be observed in the case of Alison, a 50-year old lower-limb prosthesis user, when she described a particularly low point early in her prosthesis use. Alison described being down about the amputation of her leg and the difficulties in using her new limb, and recounted how she got herself out of this by comparing herself to those she perceived were worse-off.

I began to realise I really wasn't that bad. Things weren't really that bad...

*What made you think that things weren't that bad?*

I suppose looking at people who, well, certainly... say, people who had a brain injury. That was one thing. I kind of thought, 'I'm still in possession of my brain, so at least I have that.' And also I suppose looking at people that had been paralysed ...I never used a wheelchair, but I was on crutches...

When Alison was down she compared herself with others who had also lost something about themselves, also in accidents as she had, but in doing so, she foregrounded the difference between herself and those who had suffered perceptibly more extreme physical losses. Reflecting on her circumstances, things could have turned out to be much worse. This gave Alison a more positive perspective of her situation, reflecting about her acquired limb absence that, in fact, compared to what she could have lost, 'things weren't really that bad'. What Alison perceived was 'bad' about herself was suddenly made less extreme by noting what was worse for others, and she considered herself considerably closer to 'ok' than the 'actual bad' of what she considered paralysis or traumatic brain injury would be like. She elaborated on this:

I realised that, say for someone who had been paralysed, there was going to be this wheelchair, and ok, I knew I was always going to have the prosthesis, but like, it could be hidden, you know... I don't

think I even fully realised, we'll say, what being paralysed really involved. You know, I wouldn't have been aware of bladder issues, or bowel issues, so I just thought it was a case of not walking. And the fact that I was walking made me realise I was lucky.

Comparing to others worse-off reminded Alison that her situation could have been that much more severe, and that lacking more substantial injuries and retaining the functionality of her body that she did, as well as being enabled as she was through her prosthesis use, pointed to instead considering that she was 'lucky'. Thinking about more substantial losses prompted considering the implications of these losses, like not being able to walk, having a visible difference or issues with bodily functions, and so what these individuals would also find difficult and what Alison would not. For Alison then, managing her lot was comparatively easier, and this made her feel better about herself: *'Looking at [these] people, you kind of realised, actually, ok'*. Through this realisation, Alison felt that she could better get on with things, that she could *'pull myself together and get on, you know?'*

In this study, prosthesis users often made similar kinds of downwards comparisons to others perceived to be worse-off, the *mole-hilling* quality of which distinguishes them from such others in a way that makes the individual feel closer to 'ordinary' and their difficulties that much more possible to persevere with. Many prominent examples of this are found on amputee and prosthesis user forums, two of which are given here as further illustrations:

I have to live and go on I try to have a "normal" life as much as possible. It not easy to do when your life is a constant struggle. I try not to let my leg dictate my life. But daily struggles remind me all the time from taking a shower to doing my food shopping to holding down a part time job as a teaching assistant. I do have more tings [sic] in my life to be happy about my wonderful husband of 13 years, my home, my family and friends. And I always think it could be worse. PLJ [another forum user] is double amputee and I have full

respect for him I feel lucky to only be a LBK [lower, below-knee] and that it could indeed be much worse off. (Snowbear, 2008)

...sometimes we get that why me syndrome [sic] as I call it and forget that there is someone somewhere in worse off shape than we are. I am always amazed when I get stared at and the people (a lot of the time adults sometimes kids) that almost trip and fall because they stare at me and don't pay attention to where they are walking. Then I see someone in a chair with some kind of disability what their disability is unknown to me and sometimes I find myself staring at them. I know I stare at them and think it's funny when other stare at me. I do it because I wonder what's wrong with them and then I wonder are they happy with life as they are? Then I tell myself on those days when I have the why me (I don't have them as much as I did when I was in my younger years) I say hey life is not that bad. Not that I am proud that I have less of a disability but because I think this is easy compared to their life. (Brenda, 2005)

So when difficulties arise while living *just normally*, persons tend to compare to others worse-off in order to *mole-hill* these, comparatively flattening the issue by considering the circumstances of these others more carefully and so realising or reminding themselves that things 'are not that bad', paving an easier way to 'live and go on'. These others are considered because persons consider they are reasonably comparable to themselves on something shared by both, but on a continuum of severity they realise themselves as less badly-off; that they may be 'lucky' to 'only' have particular issues, or as Brenda put it, 'less of a disability'.

*Mole-hilling* comparisons can be made to known others or to a generalised other perceived to be bearing a particular greater hardship. When specific others are perceived to be persevering themselves, and so potentially living *just normally* in their own way, individuals contrasting themselves with these others confirm the facility of their own perseverance. In his short autobiographical account, Peter

Thomas, a bilateral lower-limb prosthesis user, gave an illustration of this as he described how he reappraised himself in contrast to ‘other disabilities’:

...I must say the loss of both my legs below the knees at age 10 was a relatively minor handicap when compared with other disabilities. I was young and adapted to my amputations rather quickly. I still had mobility in my knees, and my stumps (or paws, as my girlfriend calls them) were in good condition. When I think of the tremendous accomplishments of people who have lost their knees or arms, are paralyzed or blind, I realise I have it pretty easy. (Thomas, 2001, p. 130)

Reminding himself that great things are achieved by persons he perceived were worse-off had led Peter to conclude that difficulties he faced were that much more surmountable. This prompted Peter to consider that he was only limited by ‘attitude and determination, not by my physical situation’ (p. 129).

In her autobiography, Lauren Scruggs, an upper-limb prosthesis user, gives a comparable account of *mole-hilling*. Lauren had lost an arm and an eye in an aircraft accident but had recovered from her injuries and had been fitted with prostheses for both that she was involving in everyday life whenever she could. However, her arm was challenging to use and she worried about her appearance and if she could still pursue a career in fashion as she had always intended. In one part of her autobiography, Lauren described reacting to media coverage of her that appeared to portray a miraculous recovery, painting her as carefree and being ‘all smiles’. She knew that her *persevering*, trying to keep going as normal, was not as easy as this, and described how she had kept going despite difficulties.

All I’d done was try to keep moving forward—just like Casey, my friend from high school, had done. Her father had died and her brother had gotten sick, and there were huge moments of pain in her life when all she wanted to do was lie down and quit. But she didn’t crumble under the weight of all the hardship that hit her. I’d drawn strength from her example and from watching others who’d

gone through adversity. I'd developed my definition of everyday courage—Even when life hits you hard, you keep on going—then lived by that definition. (Scruggs, 2012, p. 114)

Lauren likened her hardships to that of Casey's, and this had helped her. She pictured herself alongside others in the same boat of adversity and looked to those doing well despite this. But before exploring Lauren's account further, consider it alongside that of Roy, a 41-year old lower-limb prosthesis user, who reflected on how he would talk himself or others out of being down about themselves.

At the end of the day, it's only a leg, it's only an arm, it's not your body down there. You're not paralysed, you're not deformed, you haven't got this mad disease... It's part of life, like if you have a car accident, cancer, or leukaemia. But I say, would you be happy if you had a deformity on your face or an artificial leg? Which would you prefer? Artificial leg, straight away.

For Roy, having an artificial leg was preferable compared to a facial disfigurement, paralysis, or disease, and so living with a prosthesis was not as bad as things could be. These were the comparisons Roy made to remind himself it was 'only' his leg that was the problem. Like Alison, Roy had also explained that a prosthesis could enable him in ways where persons with paralysis or other physical difficulties might be 'stuck', and so he also illustrates how considering those worse-off can help to draw out further issues others may experience, making their situation even less appealing, and by comparison making his appear better. This helped Roy to keep going with the difficulties in life with a prosthetic leg. But Roy also illustrates another way that persons *mole-hill*. When Roy likens having an artificial limb to a 'car accident' or having 'cancer or leukaemia' he likens his circumstances to others that are meant to be perceived as undesirable but circumstances that anyone might find themselves experiencing. For Roy, having limb difference was 'part of life' in a way that it was something he had encountered by chance, like 'the luck of the draw', and while undesirable, was something to be taken in his stride and gotten on with. This is like in Lauren's mantra about 'when life hits you hard', and

when she referred to herself and others going through 'adversity'. Both Roy and Lauren exemplify the way that persons can *mole-hill* difficulties by generalising them to unfavourable incidents but that can happen as a part of a life, and so a life that any could experience. For Roy, losing his leg and now using an artificial one was just 'something that happened' to him as if it could occur to anyone else, and so was just the way life had worked out and so was something he needed to *persevere* with: 'I have to just get on with it'. For Lauren, being 'hit hard' as she had been in the accident that had resulted in the loss of her hand and eye was like how life hit others hard and so a notion of being landed an 'everyday' difficulty allowed her to form her idea of 'everyday courage' that she relied on to keep going.

In a comparable illustration, Lisa Brewer, a lower-limb prosthesis user, gave an account of *mole-hilling* in one of her blog posts. This post had been published on the anniversary of the loss of her leg, and Lisa had taken time on her 'ampiversary' to reflect on how she was currently getting by:

Yes, I am still struggling with limb loss. I do not claim to be perfectly adjusted to it. I still get angry. I still cry. I still get very frustrated with shoes and shoe choices. I still suffer from phantom pain and my prosthesis being uncomfortable. I miss being able to stand in the shower with the water cascading over my head and neck. I don't think I will ever be able to walk out of a pool with my water leg squishing, without being a little embarrassed. I will never get used to having to remember to put my leg on (or at least grab crutches) before getting out of bed. However, all of these are normal struggles.....and we ALL have struggles. Amputees are no different.  
(Brewer, 2013c)

Lisa described her battle with limb loss and how she managed life without a biological limb and with an artificial limb, but after describing her struggles, she concluded that these were 'normal' struggles. So while she recognised that her particular hardships were unique to the loss of her leg, Lisa considered the normality of having struggles. In this way, Lisa implicates herself in a process of

*mole-hilling* in a way not dissimilar to that of the conceptualising that goes on in Grounded Theory methodology: although her difficulties differed from others in what they actually entailed, if considering them at a conceptual level she could consider them analogous to what other individuals with limb absence could experience, and at a higher conceptual level, they were 'difficulties' that we all experience. Doing so normalises her situation, as she saw herself more like others in this regard: that she and other 'amputees' 'are no different' from everyone else. In addition to this, Lisa also considered her responses to her difficulties as 'normal' responding, as she described in another post:

As you can see by my posts, I have bad days. Some days, getting up and out of bed is difficult. Some days, my biggest accomplishment is brushing my hair. It's ok to have bad days, as long as you bring yourself back from them quickly. (Brewer, 2013a)

Lisa elaborated on this in further correspondence:

If I just feel like I have had too much, I allow myself ONE DAY to feel completely and totally sorry for myself. I stay in bed, eat junk food, watch cheesy movies or nap, but I make sure to remind myself that tomorrow, I get up and put my big girl panties on and just go where life tells me. It's ok to feel sorry for yourself sometimes-baby yourself a little and then move on. (Brewer, personal communication, December 18, 2013).

So Lisa had days when things were 'too much', and these tended to result in slow days of doing little and of just looking after herself. But she asserted that 'it's ok to have bad days' and 'ok to feel sorry for yourself' and in this way she made these things 'ok' through considering them at such a broad level, making their occurrence that much more permissible. In her short autobiographical account, Laura McClure, a lower-limb prosthesis user, provides another illustration of this:

Yes, there are limitations, even though I choose not to focus on them. I don't have the same endurance I once did. I can't run as fast as I would with a real leg. Sometimes, I still get blisters, or lose my

balance. But I look at it from the perspective that everybody has bad days. Everyone sits down and cries once in a while. And that's okay. My bad days may be because something went wrong with my artificial leg ... or one too many people stared at me at the mall. (McClure, 2001, p. 77)

Like Lisa, Laura described living *just normally* with her prosthesis as being far from perfect. However, she also *mole-hilled* by invoking a perspective of ordinariness, considering that everyone experiences hardship at some point. Laura noted the specific things that she struggled with, but that everyone struggles with something at some time, and 'looking at it' this way helped her to get on with these difficulties.

A further way that individuals *mole-hill* when experiencing difficulties is through considering the cause of the difficulties and similarly seeing these as ordinary. For example, on his blog, Keiron McCammon, an upper-limb prosthesis user, described dealing with being stared at in public.

...I look odd, people will stare, it means nothing, it's just a natural reaction. Hell, when I catch myself in the mirror I stare, my body lacks symmetry, the human mind is used to symmetrical bodies. The question is, what does it mean to you when you catch someone glancing your way? Whatever you think they are thinking, I can guarantee you are wrong, you have no way of knowing what the other person thinks, so I prefer to believe they find me so incredibly attractive that they can't help but look my way. I just smile, be open to questions or just continue on my way. Forget the stories you tell yourself about what you think they are thinking, again it's bullshit. Generally I'm oblivious to it, but occasionally I'll catch someone and it makes me smile. (McCammon, 2009)

Keiron diffused the issue of being stared at by indicating that staring at unusual things is a 'natural reaction' -that 'people will stare'- and this is because of the novelty of what they are seeing. To further impress this he implicates himself doing

this too. While as Laura illustrates, being stared at can be trying, Keiron's *mole-hilling* allowed him to remove the negativity from the experience, because it 'means nothing'. Because of this and because 'you have no way of knowing what the other person thinks', Keiron instead chose to see staring as an indication of unavoidable attraction.

Roy echoed this idea of 'natural' responding, similarly indicating that this means staring should not be anything to be concerned about:

I know people will stare, that's just... -people will stare. It's part of nature. Everybody stares, if you have big ears, big eyes, bald head or whatever. Like 'oh look at your man, he's a rough one', you know. At the end of the day I'm from... -I'd say for the younger generation – I'm in my 40s – the younger generation, they shouldn't be worrying about it. That's how I came to see it anyway.

Interestingly, Leslie Pitt Schneider, a lower-limb prosthesis user, described managing living with staring as a child through the kind of comparative boosting described earlier in this section, but then as she grew up, how this *mole-hilling* turned to the kind of 'naturalising' that Roy and Keiron described.

While I recall my childhood with fond memories, it was not always easy. There were a lot of tears, a lot of frustration, and a lot of confusion as to why people stared at me. To me, I was Leslie. I was no different. I developed what, in retrospect, was probably a defense mechanism in being grateful that the only thing "wrong" with me was my leg, while thinking that people who stared had something "wrong" with their heads. It was hard for my younger self to understand what I know as an adult: People are curious. (Pitt Schneider, 2014)

Prosthesis users may also *mole-hill* difficulties in their prosthesis use by foregrounding the nature of artificial limbs. Chris, a 61-year old upper-limb prosthesis user, gave an account of this when he described what he felt enabled to do with his prosthesis and what he felt limited by:

You start learning what the limitations are and understanding what that means. -But you know, it's a machine. Things break. And that's what you have to understand. It's... It's hardware. It's a mechanical thing and those things have a tendency to break. And when I got it, you know, being in the beta group, it was brand new technology, and the chances were, because of what it is, it was going to break. And it did!

For Chris, highlighting the nature of his prosthesis as a mechanical device meant that he was able to attribute problems with the limb to problems a person would potentially encounter when using a mechanical device in general. So when Chris spoke of taking time to learn how to use the limb, as well as dealing with the limb going wrong or breaking, he could bear these difficulties better through reminding himself that these were normal possibilities of using such a device. This kind of rationalising of issues means that they can be better accepted when they occur because they are seen as fair and reasonable difficulties of the technology being used. For instance, persons may tolerate some discomfort if they consider that it is an artificial attachment to their body, and like Chris, considering the 'tendencies' of experimental or 'brand new technology' can help persons endure teething issues.

In summary, *mole-hilling* refers to ways of making issues more manageable by making an individual's situation seem more ordinary. This is achieved through processes such as the comparisons that distance persons from others seen to be worse-off, indicating a closer proximity to what is perceived as 'ok', or through considering how difficulties might be analogous to difficulties faced by others, whether others also living with limb difference or others more generally, and so impressing the normality of having problems. Furthermore, the cause of bad experiences may be probed or reconsidered to be thought of as due to 'normal' reasons, and therefore the outcomes reasonable to expect and to experience. Difficulties linked to limitations in a prosthesis may be *mole-hilled* by persons considering how artificial limbs, as technology, will invariably have limitations; that it is part of the nature of technology, just as persons may consider it part of the nature of others to respond to persons with limb difference in ways that may at

first appear unfair and not right. These processes help individuals to *persevere* with difficulties as they are normalised to make them appear more ordinary and thus more acceptable to *persevere* with.

## Summary

*Persevering* accounts for the way that individuals live *just normally*, keeping going with this through an *obligated persistence* to stay *just normal*, and manage difficulties as they occur through *trusting to transience* and *mole-hilling*. Persons therefore 'get on' with the way of being they see as right and reasonable, and manage issues deemed to be of a *just normal* nature in a variety of ways.

In particular, *obligated persistence* accounts for the way in which persons persist with actions that are linked to living *just normally*, and in the context of prosthesis use, this may involve persisting with a limb and persisting in particular ways with it, and despite difficulties in usage. *Trusting to transience* captures the process of facilitating persevering through persons believing that issues experienced will be temporary, and that things will improve. *Mole-hilling* is to view or reconsider one's situation in a way that portrays issues as being more reasonable to persevere with than they may first appear. This can occur through comparing to others to indicate that the individual is better off, or to foreground a normality of experiencing difficulties. In this way, persons distinguish and liken themselves in ways that make problems seem more benign than they initially seem, helping persons get along better with them.

Together, these concepts constitute the category of *persevering* and also conclude accounting for the varied ways in which *just normal* motivates action in prosthesis use. The remaining two chapters are now dedicated to exploring the value and relevance of these patterns, and to critically appraising the overall theory.

## Chapter 9: Exploring a Theory of ‘Just Normal’

### Introduction

Over the previous four chapters, the theory of *just normal* was presented and described to account for the varied ways that prosthesis users are troubled about being *just normal* and work to resolve this. The theoretical categories of *preserving* being just normal, *redressing* to just normal, and *persevering* with just normal were given as three modes of resolving this concern. These modes and their constituent concepts were discussed with reference to illustrative accounts, exploring and clarifying the elements of the theory.

To briefly recap: In *preserving*, persons are said to engage in actions of a pre-emptive and protective nature, addressing perceived threats to being *just normal* in order to stay this way. *Black-spotting* was given as one pattern of *preserving*, where situated threats to an individual’s ability to be *just normal* are identified and acted on accordingly. *Conserving* is another pattern where persons are mindful of the limited resources or tolerances they may have and which are required to live *just normally*, thus prompting careful investment and engagement with these. A third pattern is *sufficing*, in which individuals avoid or refuse change when this is deemed risky and redundant. In the second mode, *redressing* was described as when persons act to be *just normal* when they perceive themselves not to be. Within this, *righting what’s wrong* was a pattern described as persons responding to violations or obstacles to living *just normally*, rectifying or overcoming these. *Restoring the balance* instead related to judgements that things had gone awry and to the extent that they were not *just normal*, and so where persons acted to increase or reduce these things to bring them back to what was *just normal*. *Re-coursing* is the final pattern of *redressing* and accounts for when persons judge efforts of redress to be ineffective and when they resort to alter their approach. The third and final mode of *just normal* is *persevering*, where persons keep going with being *just normal*. *Obligated persistence* was given to account for persons persisting in particular ways and how they consider themselves compelled to stay this way, despite difficulties that may accompany this. *Trusting to transience* is a

further pattern of *persevering* where persons facilitate living with difficulties though considering that problems they experience will be temporary and that things will improve. Finally, *mole-hilling* is a pattern of ways of viewing one's situation such that issues can be seen as more reasonable to *persevere* with than they first appear. These three modes together with their constituent concepts comprise the theory of *just normal*.

The development of the theory achieves the aims of the study, which were to identify a main concern of individuals that use prostheses and to develop a theory that accounts for the way in which this concern is processed and managed. To my knowledge, this is the first study to develop a theory in the context of prosthesis use. This in itself is an important contribution to the research base, but the purpose of this chapter is to foreground the particular new insights that the theory provides and also how it enables new perspectives on existing works in the area. In doing so, the significance of this theoretical inquiry is foregrounded, and this goes partway toward establishing the worth of the theory.

In this chapter then, the theory of *just normal* is explored in a number of different ways. First, further consideration is given to the concept of *just normal* itself. The theory is then employed to account for the particular ways that a prosthesis is used, including how 'successful' use may be judged. The theory is next shown to provide further insights into coping and the use of self-regulation theory, as it has been used in the area and in consideration of the notion of regulating oneself. The prescription of a prosthesis and the appropriate matching of persons to technology is also explored, and the theory is shown to provide a means of further understanding this process and how it may change over time. These discussions illustrate the utility of the theory and how it provides a range of novel insights and potential for application and practice in the area of prosthesis use.

### The Concept of Just Normal

*Just normal* is the name of the core category and of the overall theory presented in this thesis, but further exploration of this concept is important for understanding the fresh insight this alone can bring to the field. Doing so involves discussion of

extant works that this concept speaks to, namely work that has involved discussions of normality.

For instance, towards the end of my analyses, I discovered a body of literature referring to things associated with normality in limb absence and prosthesis use. In the older part of this literature, work has been conducted that has involved the assessment of the impact of limb loss and prosthesis use on proclaimed 'normal' activities. For example, Williamson et al. (1994) and Williamson (1995) describe self-care, doing household chores, or visiting friends as 'normal' activities and explored these in an assessment of potential 'normal activity restriction' due to the absence of a limb. A discussion of 'normal activities' is reminiscent of 'activities of daily living' (ADL), a term that is widely used in healthcare research, often in reference to models (e.g., Beetz, Tenorth, Jain, & Bandouch, 2010; Roper, Logan, & Tierney, 2000) or specific measures of ADL (e.g., Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963; Maenner et al., 2013), and similarly is about understanding 'normal' things people 'normally' do. These have been invoked to understand how ADL may be affected by limb absence (e.g., Kegel, Carpenter, & Burgess, 1978; Weiss, Gorton, Read, & Neal, 1990) and prosthesis use (e.g., Kejlaa, 1993; Millstein, Heger, & Hunter, 1986). In addition, studies such as that conducted by Nissen and Newman (1992) discuss factors that influence a 'reintegration to normal living' post-limb loss, and through which Nissen and Newman use a scale for measuring reintegration, originally devised by Wood-Dauphinee and Williams (1987) to explore the rehabilitation of individuals with chronic diseases. So this early body of work is characterised by notions of a 'normal' person or 'normal' people who do 'normal' things, and can be used as a reference for what an individual should be encouraged to aim for, whether rehabilitating post-limb loss or coming to use a prosthesis with the aim of re-integrating or 're-enter[ing] normal life activities' (Fishman, 1959, p. 328).

The utility of this approach can be understood through considering the benefit of assessing how individuals are managing post-limb loss or post-prosthesis fitting, and so where support can be given where difficulties are identified. Similarly, the 'success' of those who do 'reintegrate' or are found to be capable of normal

activities can be recognised. However, there is obvious danger in assessing an individual and suggesting they have not 'reintegrated' or are not able to do 'normal things normally', with consequent inferences that they are not living normally or are 'not normal'. This raises the question about the usefulness of broader conceptions of normality, and indeed, many have questioned this, such as can be found in the disability studies literature (e.g., Abberley, 1993; Marks, 1999; Shakespeare, 2007). Despite this, recent investigations in the field of prosthesis use have found that being 'normal' is something which individuals with limb absence tend to have a strong desire for. For example, Ostler et al. (2014) found that their participants who had been referred for prosthetic services (n=8) were focused on how this might interact with them 'returning to normal', seeing this as the 'key factor', and that the 'issue of normality was important to all participants and was raised repeatedly throughout all of the interviews' (p. 4). Similarly in Gallagher and MacLachlan's (2001) interviews with prosthesis users (n=14), the researchers describe that the wish to appear and be normal was something that was 'reiterated over and over' in discussions (p. 90). It is evident that normality remains a significant concept within the area of limb difference and prosthesis use, though how it is understood may be less clear.

In this more recent literature in the field of prosthesis use, 'normal' can be observed in two interrelated forms. In one, there is a desire to be and do like others, and this was a central theme in Murray's (2009) study. Murray described individuals seeking artificial limbs and who wished to use these in ways that enabled them to be like 'everybody else'. Here, normal was the ability to act, be observed and be treated 'ordinarily'. Or, it was about feeling a sense of 'humanness' or living life 'like everybody does' (p. 579). This is a kind of normal where persons consider 'what people are like' and seek to be like this.

Consider as well a second form of normal that occurs in the literature: Where persons are found to be wanting to be 'like me' and what they have known is ordinary for them. This is evident in the limb loss literature, where persons experiencing upheaval due to the loss of a limb are said to want to 'get their life back', recovering, re-establishing, or reclaiming abilities, identities or ways of being

and finding their way back to where they once were (Murray, 2009, 2010; Norlyk et al., 2013; Ostler et al., 2014). In these cases, the function of a prosthesis can potentially help a person 'return to normal', or get back to how they had previously experienced things (Ostler et al., 2014). This can be irrespective of considerations of 'how people normally are' and rather that an individual's own routine, sense of self, and prior experiences are instead the focus of what is sought following the loss of a limb or the fitting of a prosthesis. So this normal is a kind of everyday regularity that has been experienced and which persons seek to bring about when it is judged to be displaced. Parallels with this may be observed in works employing temporal comparison theory (Albert, 1977), where persons are said to engage in intrapersonal comparisons in order to maintain and adjust for an enduring and coherent sense of self over time. In the prosthesis literature there is a sense that persons seek a kind of personal consistency in the same way, and which can be particularly salient when a limb is lost or a prosthesis fitted.

However, neither conception of normal appears to be universally applicable to those who use prosthetic limbs or are considering doing so. For example, Frank (1986) described individuals with congenital limb absence who rejected the use of prostheses, as they perceived this would be giving in to pressures to become 'normal'. Rejecting prostheses for these individuals was a protest against a perceived conflation of what is frequent with what is 'right' when considering the body. There are also accounts of persons who desire prostheses in order to be perceived and treated 'ordinarily', but then there are also those who 'show off their metal' and foreground their limb difference (e.g., Batty et al., 2014; Murray, 2010, p. 89; Murray & Forshaw, 2014). Furthermore, persons may seek to break a normal routine or get away from the familiar, and in the context of limb absence this may be involuntary, as persons may consider it impossible get back to normal (Ostler et al., 2014). A 'new normal' may then be experienced and persons may find this acceptable (Ostler et al., 2014; Senra et al., 2012).

So it is apparent that normal can be taken to mean different things by different people, and this is a potential means of understanding the desire for normalcy. Michael Warner (2000) has explored the concept of normal at length in his text *'the*

*trouble with normal*', where he interrogates the concept in the context of hetero- and homosexual identity. In particular, Warner suggests that problems in discussions of normality generally rest 'on a confusion between statistical norms and evaluative norms.' (p. 56). In the former, there is a normal that comes from understanding the most frequent or ordinary occurrence of something, and this can be distinguished from something judged according to a standard, or a criterion of value. These may interact, but it is difficult to discern to what extent individuals are considering one or the other when they refer to wanting to be normal.

This is where *just normal* presents a new way of thinking about these discussions and has the potential to account for apparently divergent behaviours. *Just normal* is about how persons consider they generally ought to be or be able to be, and thus is a multidimensional idea that can involve drawing on prior conceptions of oneself as well as how they feel a person in general should be. *Just normal* makes no distinction about what kind of normal is involved here, but instead that a person considers that there is an appropriate way for them to be and that this guides their actions to ensure an outward consistency with this. For instance, the individuals in Frank's (1986) study who rejected the idea of 'normal' bodies through avoiding the use of a prosthesis were interpreted as standing up for the acceptability of differing body types, challenging ideas of a bodily orthodoxy or the notion that a body minus a prosthesis is something to be 'fixed'<sup>4</sup>. If such an individual considered that it was wrong to support an idea of a normative body, and that avoiding the use of a prosthesis is fitting with this, then by doing so they keep consistent with what they consider is part of a right and reasonable way for them to be; a way that they consider is *just normal*. Similarly, Murray (2010) recounts those with their prostheses 'on display' who had described decisions to conceal limb difference as an 'inability to deal' with limb loss or absence or pressures to conform, or that such others were ashamed of their prosthesis use (p. 89) – by acting 'loud and proud' these individuals are therefore also acting in ways that they saw 'ought' to be the

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<sup>4</sup> An interesting parallel in assistive technology can be found in the deaf community where there is some resistance to hearing interventions (see Miziara, Miziara, Tsuji, & Bento, 2012).

way of things, just as those who wanted to conceal their limb difference were through their desire to be perceived and treated ordinarily.

*Just normal* therefore foregrounds the interesting interplay between perceptions of normality and appropriateness for oneself, and thus when persons consider how things ought to be for them. This concept therefore presents a unique way of considering a broad range of actions within prosthesis use and limb absence, each of which can be understood as an individual acting to ensure they can live in ways that they consider are right, reasonable, fair or sufficient, and they do so through acts of *preserving*, *redressing* and *persevering*. Where 'normal' and 'right' are individually limited ways of exploring prosthesis use, *just normal* goes further than both. Furthermore, as the previous three analysis chapters illustrate, being *just normal* is a concern not just restricted to the initial experience of limb loss or beginning prosthesis use. It is instead a prevailing and widespread concern that individuals continue to manage (through acts of *preserving*, *redressing* and *persevering*). To build on Albert Camus' observation presented in the opening of this thesis, some people expend tremendous energy being normal, but in particular, people expend tremendous energy being *just normal*. This is the new and important concept presented to the field of prosthesis use, and as the rest of this chapter and the next illustrate, the concept of *just normal* and the broader theory about how people go about managing this concern have significant implications for the field.

### Just Normal and the Use of a Prosthesis

One area that the theory of *just normal* provides insight into concerns the diversity of prosthesis use. In chapter two, reports of varying frequencies of prosthetic usage were discussed, where individuals use their prostheses to greater or lesser extents than others and some report non-use. An understanding of these varying frequencies of usage is limited and interpretations are complicated by methodological inconsistencies across studies (Callaghan et al., 2008; Raichle et al., 2008). However, some have reasoned that satisfaction may account for variable prosthesis use, where those who rate aspects or their overall prosthesis as more

satisfactory will tend to use their artificial limbs to a greater extent (e.g., Pruitt, Varni, Seid, & Setoguchi, 1997; Williamson et al., 1994, p. 261). However, evidence for this is weak at best. One study that explored this involved a sample of Australian individuals with upper-limb absence (n=70), where associations between various aspects of satisfaction and usage ranged from moderate to 'very low' (Davidson, 2002). Similarly, Dillingham, Pezzin, MacKenzie and Burgess (2001) surveyed upper and lower prosthesis users in the US (n=78), and determined an average 'high' rate of 80 hours per week that a prosthesis was used for, yet only 43% reported being satisfied with their limbs.

The link between satisfaction and prosthesis use is further troubled when considering some of the qualitative research that has been conducted in the field. In Murray's (2005) study of upper- and lower-limb prosthesis users (n=35), individuals were described as continuing to use their prostheses even when there were significant difficulties in doing so. Murray includes the account of one individual who endured significant pain while away on holiday with friends, ending up 'in a mess' from the friction of his socket when it began cutting into his groin, yet he kept going with the limb despite this. Similarly, in a study of upper-limb prosthesis users, Saradjian et al. (2008) described a number of their participants continuing to wear limbs despite problems, including one who described doing so despite it being 'very uncomfortable' (p. 878). Such patterns of usage despite difficulties were also evident in my own study, where individuals described problems with their prostheses that were often frustrating, yet this did not deter their usage. For example, lower-limb prosthesis user Emily Rapp described enduring pain and discomfort caused by the use of her prosthesis, but kept up using her limb whenever she possibly could. As she in particular illustrates, it is possible to be deeply unhappy with a prosthesis and yet continue to be a 'full-time user'.

It therefore appears there is limited value in employing satisfaction in order to account for the variable levels of prosthesis use, though other interpretations have been put forward that are more compelling. For instance, Murray (2005) discusses the importance of portraying a particular identity to particular groups, and which

may manifest as individuals allowing or not allowing themselves to be observed as a prosthesis user or a person with limb difference. Murray invokes the work of Radley (1993) and Kelly and Field (1996) who have suggested that persons are compelled to be seen as capable participants in social life, which the stigma of disability can undermine. Bodies are managed in various ways in order to present as 'competent', and one of the ways of doing so is to wear a prosthesis, as this enables a more visibly 'capable' appearance. This was given as a potential explanation for why the individual holidaying with his friends persevered with pain, as he stated that he 'wouldn't let this group of people see me without a leg' (p. 434). In another of Murray's accounts, one individual was happy to wear or to go without her prosthesis when at her local pub, but could not envisage going to a club without her limb. She considered the people at the club were a 'different type of people' to those who knew her at the pub, who knew her more for who she was. At the club she would not have this understanding, meaning she would be thought of differently and in a way she was keen to avoid. While she was still happy to go to clubs, doing so meant she needed her prosthesis, minimising her limb difference and so maintaining her 'competent' appearance to others. Saradjian et al. (2008) provide a similar interpretation of the accounts of the participants in their study, who were described as being 'socially dependent' on the use of a limb, and how this compelled some individuals to use their limbs despite significant problems in usage.

Such interpretations indicate the utility of exploring the meaning behind prosthesis use in order to understand the extent to which a limb is used. This is where the theory of *just normal* is particularly insightful, as it provides an extensive understanding of prosthesis use and a means of interpreting what may prompt or affect the use of a limb. The theory can also work with existing interpretations such as that of Murray (2005) and Saradjian et al. (2008) but go further than these. For instance, in these studies a prosthesis was said to provide a social function, supporting presentation and an ability to engage in social activities important to the individual. The theory would indicate that a perceived *just normal* level of this social function may vary between individuals and between situations and so also

account for those who would allow themselves to be recognised as a prosthesis user in particular situations as well as those that would desire to avoid this whenever possible. However, the theory also has scope for other motives. For instance, the WHO's ICF (2011) could be considered to include social function as a part of its categories of body functions and structures, activity, and participation, but this indicates a need to also consider non-social functioning. For instance, individuals within this study described the importance of prosthesis use in managing particular tasks about their households, and how some would wear their limbs even when others were not around. Yet this was not universal and the theory of *just normal* considers that persons perceive a way of being, part of which may include social function or another kind of function, that is right, reasonable, fair or sufficient for them, and that a prosthesis will be used to the extent that it can support being these ways.

So persons may consider a *just normal* level of something such as social function that means they need to be a particular way or do particular things, and if a prosthesis enables or aids these endeavours then it must be used as long as is required to satisfy this function. The theory of *just normal* conceptualises a perseverance in usage toward such ends (despite difficulties) as *obligated persistence*. In *obligated persistence* persons are said to be compelled to keep going with things that keep them *just normal*, given that they consider this the right and reasonable way to be. So when persons go out of their way to conceal their prosthesis use, or they keep using a limb despite pain it causes them, they are persisting with these activities because of an obligation to keep in ways they see as right. *Obligated persistence* captures the variable extent of prosthesis use, despite potential issues in usage, as persons use their limbs to keep in ways they see as *just normal*. So when persons report using a prosthesis 'when needed' (NiMhurchadha et al., 2013; Østlie et al., 2012; Saradjian et al., 2008) or for 'specific purposes' (Davidson, 2002), these needs and purposes may be related to specific functions (i.e., social competence, facilitating task engagement) but that ultimately support an ability to be *just normal*. Thus even if a prosthesis is rarely used, the function that it supports when it is used may be integral to being able to be *just normal* and

so there is an imperative need to keep up this usage, no matter how infrequent. Motives for usage may also be diverse and subtle, where studies have identified that persons may require a prosthesis not just (or at all) for physical function, but to support a perceived body hexis (e.g., Hoffman, 2013; Vasluian et al., 2013). The extent to which a prosthesis is used is therefore importantly related to why it may be used, and can be usefully interpreted through the theory and considering what an individual conceives may be *just normal*.

Such an interpretation indicates the need for professionals to be receptive to persons that use prostheses to ensure they are able to express difficulties they might experience, given that the extent of their usage may not necessarily reflect their contentment with their limb. Researchers and other relevant professionals should be sensitive to the difference between a prosthesis that 'does the job' in a sense that it enables a person to be *just normal*, and a prosthesis that can be used without significant difficulties. Understanding the kinds of *obligated persistence* that an individual perseveres with, where there may be a 'need' to use a prosthesis in certain situations or in certain ways, despite the costs attached, means that addressing any difficulties has implications for improving an individual's situation. For individuals such as lower-limb prosthesis user Emily Rapp, who described persevering with the use of her limb despite pain and discomfort because 'it was normal and expected: part of living with a prosthesis' (Rapp, 2007, p. 5), any improvements to her prosthetic situation could only improve her everyday life. A skilled and receptive prosthetist who is aware of an individual's prosthetic circumstances, including the particular limb and why an individual considers it important to involve in their life, and who is on top of developments in technology, may be able to suggest improvements where relevant.

Furthermore, the use of a prosthesis may be affected by persons managing threats to their ability to live *just normally*. This is drawing on the *preserving* elements of the theory. For example, if a person considers the lifespan of their limb may be deprecated from 'overuse' of their limb, or through using the limb in particular ways or situations, then if they require their prosthesis to live *just normally* they may reduce their usage accordingly to ensure this can continue. Recall Rob, the

bilateral lower-limb prosthesis user who described ‘easing up’ and ‘taking care’ of his prostheses to ensure he could keep with limbs that were ‘road worthy’ during the years up until he could obtain new ones. The need to *preserve* his prostheses in order to *preserve* his ability to live *just normally* influenced the way he would use his limbs. These are patterns of *conserving* and *protective avoidance* that serve to *preserve* an individual’s ability to keep *just normal*, and are further important ways of accounting for variation in prosthesis usage.

Related to this discussion, there is an important point to be made about how the theory can inform what constitutes appropriate usage. For instance, while there is a general consensus that a prosthesis can be beneficial to persons with limb absence in a variety of ways, some studies extend this logic and consider greater usage as being better than lesser usage, and moreover, lesser usage as potentially problematic. Concerns are expressed about individuals who undergo the loss of a limb who may fail to ‘fully rehabilitate’ if they are only using their prosthesis infrequently, and similarly, there are concerns about wasted resources if prostheses are perceived to be ‘underutilised’ (Schaffalitzky et al., 2012). Consequently, researchers have indicated the need to address this ‘problem’ (e.g., Callaghan et al., 2008; Dillingham et al., 2001; Williamson et al., 1994).

Contrary to this, *just normal* indicates that variable levels of prosthesis usage should not necessarily be considered as better or worse unless indicated this way by the individual themselves. Persons may use a prosthesis in ways that help them to live *just normally* and also to the extent that they perceive it is *just normal* to do so. This may translate to some using a limb on a full-time basis, but for others, a prosthesis may only be required for particular activities, but yet which are just as critical for being *just normal*. As illustrated above, this may be just for the ability not to be noticed for one’s limb difference in public settings, and so when in non-public places a limb may not be required and persons may get on just fine without it (e.g., Murray, 2005, p. 433; Saradjian et al., 2008) – for these individuals it may actually be *just normal* not to use the limb in these settings.

It may be possible that those considering greater prosthetic usage as better may be following the WHO’s guidance that has defined rehabilitation as about achieving

and maintaining an individual's 'optimal functioning' in interactions with environments (World Health Organization, 2011, p. 96). If a prosthesis is viewed as a device which can afford or enhance function, then an extension of this is that greater usage means sustaining these greater levels of function, and similarly, that time being without a limb means being deficient of a particular function. This fits with the UN Convention on the Rights of Persons with Disabilities (United Nations, 2006) that calls for 'appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain their maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life' (p. 19). Persons should, of course, be afforded the provisions to enable their maximal function, or to reach their 'maximum potential', yet the Convention calls for an ability or capacity to attain these rather than encouraging that persons must actually achieve or take this up, and this is what may be overlooked by those considering greater prosthetic usage as better. As one of Saradjian et al.'s (2008) participants described about the use of their prosthesis: 'I'm not using it to its full capability I know, but I am using it to mine... for what I want...' (p. 877). This reflects the crux of *just normal*, and was echoed across the accounts in this study, where persons rarely sought the best of something, or to reach the peak of what they were capable of, but rather they sought what they felt was appropriate – what was right, reasonable, fair, sufficient or 'good enough' (though this includes scope for those who consider optimal and appropriate to be the same). To further illustrate, recall lower-limb prosthesis user Paul Martin, who fought to get a running leg, but laughed when his prosthetist told him he could have him running marathons with it. Paul wanted to be able to run and had described how important it was not to be 'limited' or have doors 'shut' to him, but he did not want to take running to his 'maximum' capacity – he just wanted to be able to run to an extent that he felt was *just normal*.

It is therefore important to recognise and respect the potentially varying levels of usage that persons may seek or report when researchers and rehabilitation professionals consider what a suitable frequency of prosthetic usage should be. According to the theory of *just normal*, persons should be afforded the capacity for

function that they consider is right and reasonable, fair and sufficient, but what they actually envisage is their right level of function is also important to identify and work with. This goes somewhat against a rhetoric of promoting prosthesis use as a means of enabling an individual's 'full participation' (e.g., Sinha et al., 2014, p. 116) and would instead be better expressed as a means of enabling function to an extent that the individual considers is sufficient and good enough – that a prosthesis can enable a person to live *just normally*.

Out of the outcomes identified in Schaffalitzky et al.'s (2011) interviews with prosthesis users and service providers (n=34), 'reaching his/her potential' was an outcome only identified by service providers, and is telling about the potential differences in attitudes that may be borne by users and professionals on this matter (Schaffalitzky et al., 2012, also later found that outcomes similar to this did not reach consensus in a Delphi study between professionals and prosthesis users). Concerns about an 'underutilisation' of technology or a failure to 'fully rehabilitate' can be addressed instead through probing an individual's understanding of their potential with a particular prosthesis, ensuring an awareness of their 'capacity' or their 'optimal function', and in doing so it may be possible to discover those who may seek change (those seeking to *redress*) and those who are content to keep going as they are (those who are content may already be living *just normally* and so may *suffice* in order to preserve themselves being this way).

This discussion also speaks to the body of literature on prosthetic 'outcomes' research. In this body of literature, researchers have sought and debated ways of assessing how a person is getting on in their prosthesis use. In other words, there are questions about how 'successful' prosthesis use may be quantified. Deathe, Miller and Speechley (2002) recommend that a consensus about outcomes should be reached in order to inform evidence-based practice, but this is currently far from the case. A systematic review of outcome measures conducted by Condie, Scott and Treweek (2006) documents the significant range of measures that have been involved in prosthetics assessment over the previous 10 years, from metrics of physical abilities to psychosocial scoring, but the researchers note that there is little agreement about which measures should be used and when. Research since has

sought to employ the framework of the WHO's ICF to assess and group existing outcomes (Hebert et al., 2009; W. Hill et al., 2009; Lindner et al., 2010) as well as a means to consider further outcomes (Stucki, Ewert, & Cieza, 2002). However, Wade and Halligan (2003) argue that the ICF framework is currently deficient since it does not consider changes over time, nor does it give enough emphasis to individual conceptions of their circumstances, conflating perspectives of the individual with 'external observers' that may well differ, as well as not doing enough to emphasise individual autonomy, and the researchers argue that much remains to be done in order to further distance interpretations of disability and rehabilitation from an implicitly deterministic bio-medical approach.

Thus there is currently a lack of agreement in terms of how to go about assessing successful prosthetic usage, but a desire to develop a means to do so. In one more recent exploration of outcomes, Schaffalitzky et al. (2012) used a Delphi method, involving prosthesis users and professionals (n=21), to determine what might constitute the most important outcomes in lower-limb prosthesis prescription and use. The researchers found 13 outcomes that reached consensus, and which involved assessing physical as well as psychosocial factors. NiMhurchadha et al., (2013) also performed a Delphi study with users and professionals for upper-limb prosthesis use (n=53), in order to gain consensus upon how to judge 'success'. An interesting finding in the study by NiMhurchadha et al. was that consensus was only reached on a small number of broad outcomes, including when a person 'wears a prosthesis for specific activities', 'wears prosthesis as often as they wish' and 'uses the prosthesis as intended'. More specific measures such as satisfaction with cosmetic appearance or use of the prosthesis to gain social acceptance were rejected by participants. This underscores the points raised earlier in this chapter that what persons consider *just normal* to be may vary significantly, and so consequently how a prosthesis may serve a *just normal* function may similarly differ significantly across individuals. NiMhurchadha et al. suggest that their findings indicate a means to develop subjective rehabilitation success measures upon which individualized goals and 'pertinent psychological and social outcomes' can be set and measured against (p. 1730). Subjective measures are fitting with

theory of *just normal*, as are individualised thresholds about what would be 'good enough' in such measures. Drawing on the beginning of this chapter, even a non-subjective measure of 'reintegration to normal living' may be useful with a given individual if they have indicated the importance of reintegrating to this shared understanding of normal living.

In order to gauge 'success', holistic discussions are recommended between the individual and the professional where the individual is able to outline their intentions for a prosthesis or to update professionals on how they are getting on with their limb in such regards. The professional should be able to use these discussions to discern how persons seek to live *just normally* and so how this can be best facilitated or how persons are getting on in view of this. The importance of such an individualistic approach to consultations was underscored in the interviews conducted during this study, where individuals expressed the importance of being able to paint a picture of themselves and their lives in consultations, and the importance of having a receptive prosthetist who was willing and able to understand this in order to shape consultations accordingly. In other words, individuals sought to be able to convey how they lived or desired to live *just normally* in order for outcomes of consultations to fit with this.

Therefore, the desire for researchers and professionals to gauge and monitor 'success' can interface with the individual's desire to have their needs fulfilled if consultations are approached with a *just normal* perspective. An ideal avenue for further research is thus an exploration of how this can be operationalised within the consultation environment, given resource and time constraints. In addition, professionals taking a *just normal* approach to consultations may be able to probe the ways that individuals may use *preserving* strategies, which individuals themselves may appear content with, but which can be evaluated by the professional to determine whether these can be improved or supported, or ways that threats that prompt *preserving* can be eliminated entirely. For instance, an individual who has found themselves exhausted while trying to use a prosthesis to do everything they felt they should be able to do may have found that taking breaks between activities is a way to ensure they have enough energy to get by and

get what they need to done. A prosthetist understanding what a person intends to do and perceiving why this is important may be able to identify how the individual is being fatigued and use their expertise to find ways to address this, which can be discussed with the individual as possibilities for improvement.

In summary of this section, the theory of *just normal* indicates the importance of understanding how and why a prosthesis may be used, and the theory provides a useful means of doing so. Persons will use their prostheses to varying extents in order to be *just normal*, and their usage may not reflect their satisfaction with the limb, but rather that they are doing so because they perceive it to be the right way for them to be. The theory indicates that there may be many things that persons consider are requisite for being *just normal*, such as a particular level of social function, and where a prosthesis can be considered to facilitate this, *obligated persistence* foregrounds the way that persons may be compelled to use their limbs to the extent that they can continue to be this way.

In addition to this, part of being *just normal* is also having the capacity for particular endeavours even if they are not taken up, meaning that individuals should know what is available to them and not feel precluded from potential options, even if they are ultimately not chosen. Fundamentally, it is important that persons are educated about what they can do with prosthetic technology, and learn about the various options available to them in order for a decision to be made about what might be the most appropriate technology, ensuring persons have the means to do what they feel they ought to be able to with a prosthesis, without necessarily encouraging them to always try to 'meet the best of their capacity' (Schaffalitzky et al., 2012, p. 2092). Where discussions have tried to determine the most suitable outcomes in prosthesis use, through agreeing which standardised measures should be involved in consultations or through trying to develop new measures, the theory of *just normal* instead presents an approach which emphasises the importance of attending to each person individually, exploring where their values lie and what they consider to be right, reasonable, fair or good enough, and thus enables identification of what to work towards or to try to maintain. A good measure of 'success' is surely to understand the aims and aspirations of an individual in order

to understand what they themselves consider would constitute (within the limits of prosthetic technology) a *just normal* success for them.

### Just Normal and Coping

Man has, as it were, become a kind of prosthetic god. When he puts on all his auxiliary organs he is truly magnificent; but those organs have not grown on to him and they still give him much trouble at times. (Freud, 1962, pp. 38–39)

Within the literature on limb absence there have been investigations of coping, and this is an area that can be extended through the theory of *just normal*. Most of this research has focused on individuals who have received amputations, where studies have employed coping perspectives in order to understand responses to the loss of a limb and how this may vary between individuals. For instance, Livneh et al. (2001) employed the COPE inventory (Carver, Scheier, & Weintraub, 1989) in order to explore coping in individuals with amputations (n=61), determining that coping strategies could be clustered into active/confrontive (e.g., positive reframing) vs. passive/avoidant (e.g., social withdrawal), pessimistic/fatalistic (e.g., disengagement) vs. optimistic/positivistic (e.g., planning), and social/emotional (e.g., venting) vs. cognitive (e.g., acceptance). Subsequent investigations have linked coping strategies associated with avoidance and disengagement to poorer psychosocial outcomes following limb loss, while task-orientated problem-solving approaches tend to lead to more favourable outcomes (Desmond, 2007; Desmond & MacLachlan, 2006).

Similarly, Dunn (1996) explored three forms of adaptive coping in persons adjusting to the amputation of a limb (n=138), specifically investigating the impact of positive meaning, dispositional optimism, and perceiving control over disability. Positive meaning was found to be associated with lower levels of depression, while dispositional optimism and perceiving greater control over disability were linked to lower levels of depression and higher levels of self-esteem. Oaksford et al. (2005) also explored positive coping strategies in a qualitative study with individuals who had lost a limb in the previous six months up until five years (n=12), and

determined that persons would tend to use strategies of support-seeking, escapism and cognitive appraisal soon after the loss of a limb, though for those with older amputations the use of these would tend to become more infrequent. 'Practical coping' (e.g., continued efforts at physical rehabilitation) was found to peak in usage around one year after an amputation before being used less often, and this was interpreted as individuals reaching greater adaptation to their circumstances, including their prosthesis use, meaning this strategy would be required less when persons came closer to reaching this. Also the researchers found that the use of humour as a means of coping was useful soon after the loss of a limb, but was then used less frequently until a year after the amputation whereby it would begin to be used more frequently again. As with previous studies exploring coping in this area, this study was cross-sectional in design, and with such a small sample then divided and contrasted by age, these findings must be interpreted with some caution. However, the suggestion that coping strategies may change over time as persons consider different strategies may be more useful at different times, or that some responses become less beneficial over time, is consistent with studies from other areas that have explored this (e.g., Fawzy et al., 1990; Snyder & Pulvers, 2001).

However, individuals with limb absence are somewhat unique in their ability to adopt a prosthesis as a potential means of managing stressors related to their condition (for example compared to chronic illness). Thus a prosthesis may be considered to facilitate coping, particularly following the loss of a limb. However, living with artificial limbs may in itself be a source of problems taking a variety of forms, and this may present an additional area for coping. The potential impact of infrequent issues related to a prosthesis is perhaps more clearly illustrated in a blog post from lower-limb prosthesis user Lisa Brewer, who described a time when her limb difference caused her significant difficulties, and how she later reflected on her response to this:

We decided we were going to decompress and hang out at the pool all day. I put on my water leg and was shocked to discover it was too small (I just got that one as well). I could barely get it on and it was painful to even walk. ... I got angry and frustrated and kept

saying things like, “I just don’t understand how this is possible!” and “What the heck happened? It fit when I got it...we even had to pad it a little!” Then it hit me like a ton of bricks! ... MY everyday liner just has a pin and the water one doesn’t. My problem was, I got a new, thinner liner for everyday use but never got a new one for the water leg. Because the water liner is thicker, it would not fit in the prosthesis. My frustration mounted, but I realized all I had to do was remove the pin from one of my everyday sockets (I have two), and use one for water and one for daily use. ... Michael tried, he really did, but none of the tools worked. My frustration was mounting, and Michael, bless his heart, was trying very hard to be patient with me. ... At this point, I was in full-fledged tantrum mode while tears rolled down my face. I kept saying things like “this is my f’ing life forevvvvvver! I hate this!” ... Later, as I laid by the pool, the REAL reason I freaked out hit me! It occurred to me that I never really think of myself as disabled. Heck, most of the time, I don’t think of myself as an amputee. I have done everything I have wanted to do with little to know [sic] problem. This was the first time in a long time that I realized that I am “disabled”. I was unable to go in the water with two legs unless it was fixed. I think, because I don’t feel disabled, it hits me hard when a disability moment happens. (Brewer, 2013b)

A prosthesis can be a device that enables but also can cause difficulties when limitations become salient. While Lisa’s post above illustrates how difficulties may arise from time to time, persons may also live with persistent difficulties, such as being fatigued from the weight of carrying a prosthesis, or enduring discomfort or pain in usage. Or, as Mathias and Harcourt (2014) indicate, prosthesis users may suffer ‘constant pressure’ from society related to their appearance or being discovered for their limb difference. Many of these kinds of difficulties and frustrations were described in the accounts included in this study. Some difficulties

may be addressed with differing models of limbs, but the nature of prostheses means difficulties may always be found in a limb that is artificial.

There is a dearth of studies exploring how persons live day-to-day with a prosthesis and manage such difficulties and limitations, but the theory of *just normal* provides a potential account of this. According to the theory, if issues are perceived as not *just normal* to persevere with, then persons will not do so, and they will act to *redress* the situation instead. In the context of difficulties with a particular limb, this could involve seeking modifications or an alternative to their current limb, or reducing usage. However, being *just normal* is a way of being that is about right, that is fair and sufficient or 'good enough', and so this leaves scope for a way of being that is not necessarily free of difficulties. These difficulties that do not merit *redressing* (or cannot be redressed) may therefore instead be viewed as part of living *just normally*; they are difficulties of a *just normal* nature, and so persons may endure these. This is managed in the theory through *persevering*, where persons are said to continue living *just normally* and do *just normal* things even when these are accompanied by difficulties because of the importance of being this way.

Part of an individual's *persevering* is accounted for through an *obligated persistence*, where persons are compelled to continue to be *just normal*, and this may involve doing particular things that incur difficulties, yet are necessary if the individual is to be this way. The earlier example from lower-limb prosthesis user Emily Rapp illustrates this, where Emily noted the discomfort caused by her prosthesis that she saw no means of *redressing*, but because she needed to use her limb to be *just normal*, she did so, accompanied by discomfort that she saw would be 'expected'. In a sense, some difficulties may be incurred through the use of a prosthesis because doing so may be considered a necessary part of being *just normal*. However, *trusting to transience* and *mole-hilling* are the two other concepts that account for *persevering* and which address the way that persons grapple with such *just normal* difficulties. In *trusting to transience*, individuals perceive that difficulties will be fleeting, and this helps persons endure their occurrence and to persist with activities that bring them about, such as the use of a limb that may lead to pain or discomfort. Persons do so expecting these problems

to abate, and so this perceived temporariness makes issues more permissible to endure. In *mole-hilling*, persons adopt strategies that normalise issues, making them seem less severe than they may initially appear. Thus persons may liken difficulties to 'the problems people have' or similarly they may consider particular groups that are more disadvantaged and that their own problems should therefore be more tolerable. These latter processes may have resonance with particular coping strategies already identified in the scholarly literature. For instance, downwards comparing is a well-known process identified by Wills (1981) that advances Social Comparison Theory (Festinger, 1954) through indicating that persons experiencing negative affect engage in comparisons with others considered to be worse-off in order to distance themselves from these others and raise self-regard. Downward comparisons have also been observed in the literature relating to limb loss (e.g., Rybarczyk, Nicholas, & Nyenhuis, 1997; Sjö Dahl et al., 2004). However, the theory of *just normal* delineates processes of managing difficulties as a means of *persevering* with living *just normally*, and so underscores the reasons for doing so differently to that in the literature. *Mole-hilling* may be considered a form of coping in order to manage a difficulty, but it is employed in order to ensure stressors are realised as *just normal* stressors. Thus both *mole-hilling* and *trusting to transience* are processes that help persons keep themselves going *just normally*, but it is the *just normalising* nature of these processes that is important to recognise and presents a novel understanding in the prosthesis use literature.

As indicated by the accounts within this study and the wider literature, prosthesis users may face difficulties relating to their limb absence as well as their prosthesis use. By exploring *persevering* within the theory of *just normal*, a basis for developing a better understanding of patterns of coping in prosthesis use may be established. *Persevering* indicates how persons keep going in ways they perceive are *just normal*, and in particular, processes such as *mole-hilling* account for the way in which persons may respond to difficulties. However, it is the *just normalising* and attenuating quality of these processes, where persons respond to difficulties in ways that frame these as *just normal* difficulties, and so allow them to keep this way, that may stimulate further investigation.

## Just Normal and Self-Regulation

A further way that a theory of *just normal* provides an important insight into prosthesis use is when considering the recent investigations that have invoked self-regulation theory in order to understand adjustment to limb loss (Coffey, Gallagher, & Desmond, 2014a, 2014b; Coffey, Gallagher, Desmond, et al., 2014a, 2014b; Dunne et al., 2014). The main tenet of self-regulation is that human behaviour is organised around the pursuit of goals which derive from core aspects of the self, and these goals exist in a hierarchical structure. Persons are said to self-regulate through assessing whether there is a discrepancy between a desired and a perceived state of being and act to close this gap if it is detected. The particular self-regulation framework employed in these investigations is the dual-process model of assimilative and accommodative processes (Carver & Scheier, 2000) which proposes two ways of addressing discrepancies. In an assimilative approach, known also as tenacious goal pursuit, efforts are made to modify a person's situation or behaviour to fit with goals and preferences, such as gaining knowledge or skills, or changes to a person's lifestyle, and this is said to enable an individual to maintain a sense of identity and purpose. When the assimilative approach is deemed ineffective, an accommodative approach, known also as flexible goal adjustment, is employed, in which goals and preferences are modified to what is considered possible given situational constraints. This approach is said to be useful when persons perceive insurmountable barriers between themselves and a particular goal (Carver & Scheier, 2000).

While the studies by Coffey and colleagues indicate how self-regulation can be a useful means of understanding adjustment to limb loss and provide an informative account of the variety of goals and ways that persons work towards these, it remains unclear what persons are actually self-regulating. Coffey et al. (2014b) specify that the physical and psychosocial disruption caused by the loss of a limb leads to a disturbance between an actual and a desired state of being, but beyond this, the goals persons are actually seeking to work towards, or back towards, are not entirely clarified.

The process of the selection of goals and what they may pertain to is a known criticism of self-regulation theory (Locke & Latham, 1990), yet the theory of *just normal* can potentially shed light on this and so provide a greater understanding of the regulation of the self in prosthesis use and beyond. For instance, as Carver and Scheier (2000) describe, self-regulation theory is about purposive processes, or '*the sense that self-corrective adjustments are taking place as needed to stay on track for the purpose being served*' (p. 3). The 'purpose', objective, or goal that persons are self-regulating themselves about is not further defined and in this way ensures that self-regulation theory has significant scope. However, Carver and Scheier describe that there is a hierarchy of purposes, from concrete goals to more and more abstract goals, the highest of which pertain to core values a person possesses: '*be goals*', or things about a sense of 'self' that persons regulate themselves around (Carver & Scheier, 2000, p. 49). *Just normal* was described to be an important 'be' state that prosthesis users are compelled to attain, and so there is potential overlap or fit with a core value/be goal as Carver and Scheier describe it. To use the parlance of self-regulation, persons can be said to be in a state of *just normal* or to be making corrective efforts to try to get back on track/become *just normal* (they would be implicated in *redressing* in order to be this way).

If being *just normal* is considered important to an individual, then it is a state or goal that will shape the decision to employ particular strategies toward more concrete or particular goals. According to the dual-process theory, persons will 'assimilate' or 'accommodate' toward concrete goals but these are in service of being *just normal* and depending on the viability and fit with these strategies and what is considered *just normal*. This is addressed through the *redressing* category of the theory, concerning the efforts an individual makes to try to live *just normally*. However, the theory of *just normal* goes further than just processes of closing a gap between perceived actual and desired states of being. For instance, *preserving* is a mode of *just normal* that establishes the way that persons anticipate the possibility of not being *just normal* and act on this in order to stay *just normal*. When *preserving*, persons are aware of the potential for losing an ability to live *just normally* and so they are proactive about ensuring this discrepancy does not occur

in the first place. Taking *black-spotting* as an example, persons identify particular situations which could lead to a loss of being *just normal*, and identify these through prior experience of this happening, or through predicting this as they consider how their engagement with the situation could play out. So the theory of *just normal* not only caters for managing discrepancies (*redressing*) but it also accounts for the way that individuals are aware of the potential for discrepancies occurring through particular means and proactively act to manage their occurrence. In this way, the theory of *just normal* goes beyond the focus of self-regulation, which is primarily concerned with the resolution of discrepancies. Its reactive nature does not take into account the pre-emptive actions that individuals also engage in seeking to stay in particular ways as the theory of *just normal* does.

A further important way that the theory of *just normal* can inform the way we think about how persons 'self-regulate' can be identified when considering the way that persons come to act on discrepancies in being *just normal*. Carver and Scheier (2000) have said that persons engage in self-regulation 'as needed', and yet there is no real definition about how this process occurs. When developing the theory of *just normal*, I identified that being *just normal* was an ongoing and pervasive concern that prosthesis users continually process, but this did not mean that persons were constantly consciously troubled by this or ceaselessly checking themselves to ensure they were *just normal*. Rather, *just normal* appeared to be more of a *latent concern*; something that emerged to conscious deliberation from time to time.

Crossley's (2006) work provides a comparable and useful way of explaining this through a different context. In his ethnographic analyses on motives for joining a gym, Crossley began with the traditional idea that persons are concerned about 'investing' in their bodies, but quickly determined that gym-goers, for the main part, were instead intent on doing this in order return to a 'former glory'. Individuals would tend to suggest they needed to lose a bit of weight, that they had 'let themselves go', or had ambitions of other aesthetic or health improving objectives that related to prior conceptions of themselves. An individual's decision to start going to a gym therefore related to a concern that their actual bodily-

condition had fallen out of alignment with their preferred self-image. So in doing something about this, there is some resonance with discussions of *just normal* and self-regulation. However, Crossley noted that persons were 'shocked' to have discovered things they had lost about themselves, whether it was catching a view of oneself in the mirror one day, discovering clothes had become too tight-fitting, or getting out of breath too quickly. In some ways then, these reasons for taking up gym-going implicate Crossley's participants in *restoring the balance*, where going to the gym was the means to reduce or increase particular things which had slipped out of keeping from what persons considered ought to be the case. However, the important point here is that Crossley determined that persons were not continually vigilant about their bodies, and that it was chance encounters that led to the discovery of a discrepancy between a desired and actual state. Clothes were not necessarily checked for their fit each time they were put on, and persons were not necessarily militantly watching their weight. Despite this, when prompted, individuals gave indications that an appropriate weight or the fit of clothes were important to them, but it was only when contextual factors provoked their particular consideration that the individuals realised their need to go to the gym to get back to what they felt was right for them.

In an earlier article, Crossley (2004) elaborates this discussion by discussing lifestyle as largely habitual or routinized, drawing on the work of Bourdieu, Giddens and Merleau-Ponty. In this perspective, the way people go about their lives is said to be generally without deep reflective thought, and habits and routines undertaken in such a way possess the flexibility and adaptability to cater to a changing world to ensure they can keep going without continual explicit steering. However, this also means that subtle and piecemeal changes can occur that may be invisible to the individual when the core elements of a routine remain present. Crossley referred to this as the 'creep factor' where 'bad habits' could then work their way into lifestyles when exceptions gradually become more prevalent, even the rule (p. 242). Thus even when persons have an awareness of their conduct in given instances, the greater pattern or trajectory of change may pass unnoticed until a

situational prompt indicates that at some point a threshold has been crossed and the magnitude of this change becomes apparent.

So this is somewhat analogous to the present theory, where *just normal* was not identified as an overt, omnipresent concern of prosthesis users, or in the terms of self-regulation, a *purpose* which was being continually monitored for any required self-corrective adjustments. Rather, it was a prevalent and important concern where things would come up which triggered a realisation about how a particular thing may not fit with an individual's conception of what is *just normal*. Persons identify outright violations of what they conceive to be *just normal* and they *right what's wrong*, and similarly they identify things that have strayed from what they ought to be and they *restore the balance*, but they do so when prompted. For instance, lower-limb prosthesis user Zane described that he would act to ensure his weight was managed (and so his residual limb mass managed) when it had strayed to the point where the discomfort in his socket had become so intense it would be hindering his ability to get about. Or how lower-limb prosthesis user Mel suddenly found herself not going out in public and socialising because of the incremental problems in her prosthesis use that had diminished her confidence and her mood over time. In this way persons manage being *just normal* but as it is stimulated through their being in the world.

This then indicates a way of thinking about how persons manage being in ways important to them that is different from what self-regulation theory implies – that persons do not devote themselves to an overt continual monitoring of a way of being, but that such checking is actually bound up with how persons conceive of particular states of being (e.g., *just normal*) and how they experience the world, which interacts with these conceptions. In other words, persons can be said to be concerned about being *just normal* and this will be prompted for explicit consideration as it is brought up by specific encounters that have implications for the individual and their perceptions of this. Chance encounters foreground discrepancies, bringing the concern back into what Crossley (2004) termed 'reflexive consciousness'. The 'regulation' of the self therefore seems to have less fit with what has been described to occur in prosthesis use, as persons do not

appear to be as self-obsessed or vigilantly checking themselves as the self-regulation literature intimates (e.g., Johnson, Pratt, & Wardle, 2012; Karoly, 1993; Zimmerman, 2005).

In sum, employing self-regulation theory can help to explore phenomena such as adjusting to limb loss and prosthesis use, but the theory of *just normal* goes further than this, enabling a richer understanding of how and why persons may go about managing themselves in view of desired ways of being. Where self-regulation emphasises reactive processes, *just normal* includes this through *redressing* but also indicates the importance of considering how persons stay in ways important to them, giving additional consideration to proactive *preserving* processes.

Prospective researchers considering the utility of self-regulation approaches may therefore consider the additional importance of this other aspect of managing valued ways of being. Finally, future researchers may also consider *just normal* as a means of distinguishing 'regulation' from persons responding to their experiences and interactions with the world.

### Just Normal and Matching Person to Technology

A further area that is informed by the theory of *just normal* concerns the process of matching of person to technology. Within the literature, there is concern about ensuring appropriate prosthetic prescription, specifically, that an individual seeking a prosthesis receives a limb that is right for them and that technology or funds are allocated suitably. Discussions have focussed on models of matching a person to the technology they will subsequently use, though these models are found under the broader area of assistive technology (AT) prescription.

A systematic literature review of AT prescription was undertaken by Bernd, Van der Pijl and De Witte (2009) and resulted in the discovery of three models that have specifically addressed the AT selection process. The first model, developed by Scherer (1998), is the model of Matching Person to Technology (MPT). According to the review, this is the most well-known model in the literature, and incorporates the user's perspectives and abilities, the attributes of the AT, and environmental conditions (Bernd et al., 2009). Taking these into account, along with the needs,

desires and goals of the individual, the MPT model indicates that appropriate AT can be matched to an individual if these factors are considered, that user expectations are met, and that the AT is easy and comfortable to use (Scherer, 2002). The second model, the Framework for Modelling the Selection of AT Devices, builds on the literature of AT outcomes that predict the use and non-use of AT (Scherer et al., 2007). This model emphasises an optimal match between person, AT, and environment in order to facilitate ongoing usage (Scherer, 2014; Scherer et al., 2007). The third model, the Human Activity Assistive Technology Model (HAATM; Cook & Hussey, 2002), gives particular consideration to the place of AT in an individual's life that the technology is meant to provide assistance with. Thus it foregrounds the particular person and the activity that the AT is meant to support, but also gives consideration to the context in which the activity will take place, and how these three areas may interact.

There is significant overlap between these models, and Scherer has said about the first two (though the same could be said of the HAATM) that they are a move from a previously 'people-centric' approach of determining the broader requirements of users in general, to a 'person-centred' approach, foregrounding the requirements of a particular individual when considering what might be the right technology (Scherer, 2014). It is suggested that invoking models such as these that match person to technology and also involve the person in the process will ensure the individual is satisfied with their AT and that this will therefore lead to long-term usage (e.g., Scherer, 2014; Scherer et al., 2007).

However, long-term usage is extrapolated from an initial match and means that there is less consideration given to how this may vary over time. The second of Bernd et al.'s identified models (Scherer et al., 2007) links to a model of AT outcomes (Fuhrer, Jutai, Scherer, & DeRuyter, 2003) and so does go some way towards exploring what goes on after an appropriate match has been made. However, this model of outcomes is adapted from models found in broader health sciences literature, and has been altered to suit AT usage, which is assumed to be retained in the short and long term if usage is deemed effective, efficient, satisfactory, and supports psychological functioning and subjective well-being.

Ongoing usage is also said to be moderated by factors linked to the domains of the ICF, concurrent interventions, comorbidities, continuing AT device services and costs.

A theory of *just normal* is largely complementary of these approaches as both emphasise an individualistic perspective where the particular and potentially nuanced requirements of each individual are important to attend to when considering a good match of prosthesis to person. However, *just normal* indicates that there is a need to consider the idea of matching more closely. For instance, an important feature of the theory is that what is actually *just normal* for an individual is continually liable to change. This potential for change is because an individual's judgement of what is and what is not *just normal* is informed by their conceptions of appropriateness, justice and fairness, and these are employed to assess something in reference to what is known more broadly about it. So if an individual's knowledge about something develops, then a judgement about whether a given instance is in fact *just normal* may also change. For example, we can only judge if something is fair if we know something about that thing such that we can distinguish what might be fair about it or what might be unfair. Knowledge of the judged thing may expand through a deepening understanding or through learning of further variation, and this has the potential for changing judgements about what is deemed actually *just normal*.

Persons may therefore desire or consent to be fitted with a particular prosthesis depending on their awareness of available options that they perceive are overall better or worse than others and therefore what would be *just normal* to have. So they may be fitted with a prosthesis that they consider is reasonable and good enough because they consider it so through reference to what they know about prosthetic options. This would make an initial matching of person to technology a *just normal* match. However, the literature actually informs us that persons are largely unknowledgeable about prosthetics when first coming to prosthesis use (Murray, 2013), but similarly, if there is nothing known to prompt considering that a particular prosthesis is not right or reasonable, fair or good enough, it may be tentatively considered to be *just normal*. However, if the individual was to then

gain indications about why a limb may be unfair or unreasonable to be expected to persevere with, such as experiencing particular difficulties in using the limb or learning of a limb they feel they should be using instead, then they may deem their current prosthesis use no longer *just normal*, considering alternative courses of action that would be *just normal* to switch to instead. *Persevering* may therefore turn to *redressing* as persons do something about a limb that is no longer 'good enough'. These particular courses of *redress* could be to try to gain a prosthesis that is good enough, to seek improvements to the limb they use, or to stop using the particular limb altogether.

Paul Martin, a lower-limb prosthesis user whose autobiographical account of his prosthetic rehabilitation was included in this study, provides a useful illustration of this. To briefly recap, Paul was fitted with a prosthesis after the loss of his leg, but when he discovered this leg was incapable of enabling him to participate in sports, he sought to *redress* this through seeking a leg that was capable. Similarly, when this second prosthesis appeared unable to facilitate running, Paul sought a leg that could do this. In each instance, Paul was motivated to seek a prosthesis in order to stay true to his conceptions of what it was to be *just normal* – he saw that being limited in his activities, or unable to participate in something was to be restricted by the loss of his leg, and this ran contrary to what he saw should be *just normal* for him. When there were prosthetic options that could enable him to overcome these difficulties and help him do what he saw was important, then it was not *just normal* to stick with what he had. However, at each fitting, Paul was not aware of the particular deficits of the prosthesis that he would later take issue with, and so each match at that time was a *just normal* one. But as he tried to use his prosthesis and discovered these issues, they impacted his judgement about whether it was actually right to keep going with the limb.

A different illustration is given by, Alan, another lower-limb prosthesis user who was also involved in this study. Alan described how he had been fitted with a particular prosthesis, but when he came into contact with another user who was using a more advanced limb, he sought to get this instead. Alan was not aware of the more advanced prosthesis at the time of his fitting, and his own prosthesis was

meant to be good enough for him in enabling him in doing what he wanted to do, but when he learned of the existence of this other limb, which he perceived could help him to get about more easily, which would not be as difficult to use, and which was being used by a person in a similar situation to him, he was motivated to try to get this other limb because these things meant persevering with his particular prosthesis was no longer *just normal*.

Thus if an individual gains information (such as through experience with their prosthesis or learning of alternative limbs) which indicates to them that to keep using their current prosthesis is not *just normal*, then this may be because what is *just normal* may have shifted to something else, whether indications of a need to alter their prosthetic solution in some way, or to non-use, and so persons have cause for *redressing* in light of this. In other words, a particular match of person to technology has been lost. This is not to suggest that this change occurs because of a change in a person's needs, desires or goals, because a prosthesis may be judged as good enough for supporting these at one time but then not at another without these necessarily changing (when new information informs this). Instead, what good enough, fair, right or reasonable mean may not have changed but what these actually look like may have.

So while extant models in this area are useful, a fuller understanding of the 'match between person and technology' should include that initial matches are not necessarily final. A 'technological solution' (Scherer, 2002) is instead only ever a temporarily sufficient solution for the person, and will continue to be sufficient until the individual receives indications that a more fitting solution is known. From the result of their study where men's aesthetic satisfaction was negatively correlated with time spent with a prosthesis (n=44), Murray and Fox (2002) inferred that the needs of users may change over time and that these could be monitored and addressed to avoid an overall decrease in prosthesis usage. Similarly, Biddiss et al. (2011) indicate some recognition of the need for potential renewal of a matching process when they note that bodily changes, particularly in growing children, may necessitate new limbs, and that needs will also change as a person ages, meaning that 'one single prosthesis purchase is NOT a lifetime

solution' (p. 221). However, the theory of *just normal* provides an understanding that goes further than changing needs and physical changes that might necessitate a new match, and does so by foregrounding that there is a need to be cognizant of a person's sense of what is *just normal*. This is sensitive to new information that informs whether particular things such as a given prosthesis are in fact still *just normal* to continue with. This is an important point to attend to, as it adds a further dimension to the matching process and provides a possible interpretation of those who may reduce or discontinue their usage with a particular prosthesis when there is no apparent change in their needs.

This discussion also draws attention to the importance of attending to the initial matching more closely, ensuring that persons have a good understanding of the options available to them. As noted earlier, Murray (2013) described how individuals experiencing limb loss tend to come to the realm of prosthetics with little knowledge about the area. As a novice, the experience of limb loss and then of prosthetic consultations is often daunting and individuals tend to feel unable to contribute to shared decision-making processes (Murray, 2013; Nielsen, 1991). Many are reliant on or strongly guided by their prosthetist, and Murray includes one poignant account of an individual recalling how they had 'nothing to go on' in early consultations and who was led to his matched technology by his prosthetist, 'going where ever they told me to' (p. 516). While prosthetists are often educated and trained in their field in order to identify and fit appropriate prostheses, there is still much room for problems to occur and Murray includes a number of mixed outcomes in illustration of this. In addition, Murray describes individuals that were often aware of their own unawareness, prompting them to actively seek confirmation of the 'normality of their experiences' (p. 516) through discussions with others online. One forum post I encountered during this study illustrates this particularly well:

I've been trying to live a normal life. Doing things like changing the tires on my car, which requires me to crawl around on the pavement and getting back up. I'm starting to feel as though maybe I need to baby the prosthetic leg. This is the temp one. One day I went in to

have it adjusted and it made a world of difference. I was able to wear it 13 hours that day. It felt so good and things were looking up. Next time I go to wear it I was back to it making my lower back hurt and I'm also experiencing pain in my left foot on the side. Just wasn't fitting good. That may have something to do with the weight and how my shoes get worn. That adjustment made a huge difference but it was nothing I knew about needing. He made it on his own noticing while I was walking. Meaning, not knowing what to expect with a prosthetic leg you don't know what's "normal" and what can be improved upon. I understand it's all a learning process but how often do you go back for adjustments and how much time is between them? I'm just a little frustrated. Seems like my prosthetic guy is only as good as my ability to tell him what I feel needs adjusted. By that I mean if I go and I can't explain what I think needs adjusted there isn't much he can do aside from his own observations. I'm stating I feel it's my fault. I just don't know how to explain yet what needs adjusted or how to know. I do know that it can feel awesome. It has once. I just hope I can find my way back there again. (Systematic Chaos, 2010)

This individual illustrates the frustration with not knowing more about prostheses, and in his searching to know more and learning as he goes along. This developing knowledge could then lead to reappraising a prosthesis (or a prosthetist) and could indicate to the individual whether it is right to keep going with this. So persons can be aware that their judgement may be particularly tentative or that knowing more about it may determine that something is not in fact *just normal*, and this may be concerning for the individual as they remain unsure about whether they should be *persevering* or *redressing*.

Furthermore, a search for some clarification may similarly be considered to be *righting what's wrong*, as persons consider it not to be *just normal* to be unsure about their experiences. To address this need, researchers have recommended improving the information available to individuals, the key benefit of which is that

individuals would then be better placed to participate in a shared decision-making process if they are better informed from the outset (Murray, 2013; Murray & Forshaw, 2013; Ostler et al., 2014). This is echoed by the UN Optional Protocol to the Convention on the Rights of Persons with Disabilities, which calls for the provision of 'accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, as well as other forms of assistance, support services and facilities' (United Nations, 2006, p. 6). Ensuring individuals have access to good sources of information about limb loss and prosthetics is not only important from an ethical standpoint, but if individuals tend to 'go along' in consultations and with what is recommended to them because they 'don't know', then having an improved knowledge from the outset facilitates a better ability to participate in in early consultations and so could help to ensure satisfaction and the longevity of a period during which an agreed solution will fit with what an individual conceives is *just normal*.

A final further consideration for an ongoing matching process comes from the *preserving* mode of the theory. Within this, *sufficing* foregrounds that when persons consider themselves able to live *just normally*, they will tend to avoid change as this constitutes a potential threat to their ability to be this way. So if an individual considers they are living *just normally* with a particular prosthesis, they may reject proposals from professionals for suggested improved matches and it is important to recognise and respect this. Even when an individual describes difficulties in their prosthesis use, they may consider these difficulties of a *just normal* nature and so change in order to address these could constitute a risk in pursuit of what is at best considered redundant. Recall Natasha, the lower-limb prosthesis user who described her prosthetist seeing her ageing prosthesis and who she perceived wanted to 'bring her into the new world'. Natasha was keen to avoid changes to her prosthesis because she considered herself so dependent on her limb to live *just normally*, where changes could risk losing this and where she could already get by with what she had. Persons will be more inclined to 'stick with what generally works', than risk losing this altogether or when change is not about helping them to become *just normal* when they perceive this is not the case. Thus

professionals should be mindful when informing individuals about potential improvements and anticipating a change in match between person and technology that persons may be willing to change and *redress* if this new information leads them to the belief that change would be *just normal*, but persons may also be inclined to *suffice* even when this means difficulties may remain.

In summary, when considering models that contend with AT prescription, the theory of *just normal* prompts additional consideration of an individual's knowledge of AT (in addition to features such as needs, desires and goals). An appropriate match between person and technology may be usefully modelled on a *just normal* match, and this takes account of such an awareness of the individual. This highlights the need to supply an individual with information about prostheses or to connect them with experienced others in order to ensure that persons are more informed and comfortable with the decisions agreed and that such decisions may be long-lived. These models would also therefore be helpfully expanded by taking into account that continued retention of AT such as a prosthesis is contingent upon a continued fit with what is considered to be *just normal*, and so which is continually liable to change as individuals become more knowledgeable about their prosthesis and available options. An open channel of communication between prosthetist and prosthesis user can enable the discussion of changing needs, desires and goals, as well as the changing nature of what persons may consider is *just normal* for them.

## Summary

The theory of *just normal* provides a range of fresh and important insights into areas associated with prosthesis use. As a concept, *just normal* foregrounds the importance of considering how users of artificial limbs are motivated to live in ways they perceive are in fact *just normal*, and how this can account for a range of behaviours. The theory also provides novel insights into a range of contexts within prosthesis use, including accounting for the variable usage of a prosthesis, managing difficulties in the use of a limb, and how some display or conceal their limb difference in different situations. The theory also provides implications for the

way consultations can be framed and how the match between person and technology might be ascertained and monitored.

As far as I am aware, *just normal* is the first theory of prosthesis use, and so provides a useful base to bring together much of the extant literature, extending many of the concepts that have been presented in the field. In each instance, the theory prompts new ways of thinking about the actions described. Collectively, the areas discussed within this chapter illustrate the utility of the theory and its breadth of applicability, and in doing so the significance of the theoretical product is foregrounded. In the following chapter, the theory is evaluated according to methodological criteria, and this helps to further draw out the significance of the theory. This chapter culminates in a discussion of the strengths and limitations of the overall project, and provides a number of useful avenues for further study, as indicated by the theory.

## Chapter 10: Judging a Theory of 'Just Normal'

In the previous chapter, the significance of *just normal* was explored through examining the theoretical product in a number of contexts related to prosthesis use. The new insights offered to these areas partly establishes the worth of the theory. This chapter continues this pursuit, but through assessment of the theory according to a number of evaluative criteria. These criteria are those accompanying the methodology of Grounded Theory itself – of 'workability', 'relevance', 'fit' and 'modifiability'.

As the theory is judged according to these criteria, this leads to discussions of the strengths and limitations of the work conducted thus far. These are summarised towards the end of the chapter, where avenues for further scholarly inquiry and recommendations for practice are also given.

### Evaluation of the Theory of Just Normal

Every Grounded Theory study should undergo evaluation according to the criteria of the methodology. This ensures that the theoretical product is credible through remaining faithful to the methodology, and as a means of demonstrating how it can be of value to both researchers and those in the researched area. In chapter three, an argument was made for the decision to employ Grounded Theory evaluative criteria rather than more generic qualitative research criteria. These criteria of the methodology are now explored individually.

#### *The 'Workability' of the Theory of Just Normal*

Workability means do the concepts and the way they are related into hypotheses sufficiently account for how the main concern of participants in a substantive area is continually resolved? (Glaser, 1998, p. 18)

An important measure of a good grounded theory is how well it reflects the way or ways a main concern in a substantive area is acted upon. This 'workability' element then, means doing a satisfactory job of conceptualising the potentially varied

patterns of action that resolve the concern. Through the processes of constant comparison, open coding, and theoretical memoing, I identified *just normal* as a main concern of prosthesis users, and selective coding, theoretical sampling, and further memoing helped to refine the categories of *preserving*, *redressing* and *persevering* that reflect the modes of managing this concern. These were the ways that I determined the concern is resolved, and when theoretical sampling yielded no apparent further variation in the resolving, and so no other distinct modes of resolving the concern were salient, this to me was an indication of a step toward the sufficiency Glaser (1998) speaks of.

In addition, the modes of *preserving*, *redressing*, and *persevering* have significant breadth. That is, they are each accounted for through multiple constituent concepts, such as *obligated persistence*, *trusting to transience*, and *mole-hilling* that account for *persevering*, and these give an indication of the scope of these three sub-core categories. When considered as a whole, the theory of *just normal* does a considerable job of detailing the variety of ways in which prosthesis users strive to be *just normal*. In this way, the theory enables an extensive understanding of how persons are concerned about being *just normal* and how they act on this, and so part of the workability of the theory is established.

Adding to this, the particular ways in which *just normal* manifested were reflected across the varied accounts of prosthesis users given in chapters five to eight. These illustrate a diversity of contexts that indicate the particular ways in which individuals are concerned about being *just normal* and do something about this, in different ways and in different situations. For instance, how lower-limb prosthesis user Alison sought to remind herself how things could be much worse, which then encouraged her to consider that her own circumstances were 'actually ok' (*mole-hilling*), or how lower-limb prosthesis user Julie began to avoid dating, keeping herself from further hurtful experiences (*protective avoidance*). In chapter nine, the categories from which these actions were conceptualised were seen again when *just normal* was offered as a means of interpreting a number of situations identified by the research literature, such as how a prosthesis might be used (e.g., to *protectively avoid* others discovering their limb difference and so perceiving them

differently) or when issues with the use of a prosthesis warrant change or when they are persisted with (persons seek *redress* or they *persevere* relevant to how the issue and options for response fit with their conception of being *just normal*). These interpretations indicate the explanatory power of *just normal*, further establishing the workability of the theory and also contributing towards the second criterion of 'relevance'.

### *The 'Relevance' of the Theory of Just Normal*

[Relevance] deals with the main concerns of the participants involved. To study something that interests no one really or just a few academics or funders is probably to focus on non-relevance or even trivia for the participants. Relevance, like good concepts, evoke instant grab. (Glaser, 1998, p. 18)

Grounded theory puts into relief... what people think they know already, virtually as they hear it. But they only know it casually as incidents, mostly with no methodological, conceptual pickup. This conceptual pickup is a natural, but waiting to happen for these people. ... The fact that people recognise bits and pieces of grounded theory methodology shows its naturalness and legitimises it through sensitive recognition. "Sounds right," I often hear. (Glaser, 1998, p. 62)

Building on workability, a good grounded theory must also be relevant. This is arguably the most crucial criterion in a Grounded Theory study, and means that concepts must relate to actions within a substantive area that manage a concern, therefore making them relevant to the individuals perpetuating them, and thus others who are also interested in this group (i.e., researchers or other relevant professionals). To this end, participants considering the theory should be able to relate to the work as it reflects the important actions they are engaged in. This is where the 'grab' of a theory comes from, and Glaser (1998) suggested this would then prompt participants to enthusiastically offer their own examples of stated processes as they identify with categories within the theory. Relevance, then,

entails the concepts of *just normal* having some resonance with prosthesis users, although there may be aspects that are not always immediately recognisable:

GT is generated from much data, of which many participants may be empirically unaware. GT is applicable to the participants as an explanation of the preponderance of their ongoing behaviour which is how they are resolving their main concern, which they may not be aware of conceptually, if at all. It is just what they do! GT is not their voice: it is a generated abstraction from their doings and their meanings that are taken as data for the conceptual generation.

(Glaser, 2002a, p. 5)

So *just normal*, or parts of *just normal*, may not have immediate resonance with an individual partly because of the mundanity of these actions that they might not have given a second thought to. For instance, persons may not recognise that they are *vigilantly risk-reducing* because they just do this as is needed without necessarily deliberating over this or consciously reflecting on the act. 'Grab' may also be hampered as a result of the conceptualising process, where how it is for one person is but one variation within a concept. Thus, lower-limb prosthesis user Pat may not immediately make the connection between *vigilant risk-reducing* and his being careful about terrain he walks on and how he is walking on these surfaces because of the difference between a more descriptive 'care when walking' and a more inclusive but abstract *vigilant risk-reducing*. This can be somewhat addressed in the naming of concepts, ensuring they bear a strong resemblance to the data in an evocative way, and in this way they can be more easily received by individuals:

The concepts themselves have grab for the participants. It gives them a conceptual handle which summarises many apparently disparate incidents which up that point were just descriptions. It does not offend them by telling them what they know. It empowers them to see the patterns involved with names for referring to them.

(Glaser, 1998, p. 55)

Accordingly then, the intention was that the naming of a concept such as *vigilant risk-reducing* would enable an individual such as Pat to recognise actions such as his particular attentiveness and concentration when walking on even surfaces as vigilance in order to reduce risk, and so he may then also perceive other situations where he may have similarly *vigilantly reduced risk*. This would then be the summarising intention of the concept, as individuals can then begin to see *vigilantly risk-reducing* in other walks of life, which previously may have been thought of as unconnected, but through this connection persons can understand their relation to being *just normal*.

The naming of parts of the theory of *just normal*, then, was an important task to attend to, where relevance was sought through resonance, and this was something I believe is imbued in the naming of each of the patterns within the theory. The naming of *just normal* itself was discussed in chapter five, with further discussion at the beginning of the previous chapter. From these discussion and the illustrative accounts across the analysis chapters it should be clear that 'normal' was partly chosen because of the strong desire many expressed about being or being able to be 'like everyone else'. This was something Murray (2005, 2009) also found was a prominent feature in prosthesis users' desires when living with a prosthesis. In the present study, many expressed a desire for a prosthesis to help them to look normal or to do normal things. This was what a prosthesis 'ought' to be able to do, or how persons felt they 'ought' to be, or be capable of, and which was just like anyone else should be afforded. This was how normal was connected to 'just'. Yet *just normal* was also named to account for individuals who sought to be normal in ways more about how they generally were, such as persons who lost limbs that sought to 'get back to normal' through a prosthesis (Dise-Lewis, 1989; Ostler et al., 2014), or persons who had limbs go wrong or sought to avoid situations where they might go wrong in order to keep or return to this familiar normalcy of functioning. For these individuals, normal was less about being like others and more about keeping like themselves. In this way, *just normal* is intended to be identifiable by persons in a range of ways, maximising its relevance, and so similarly to Pat potentially identifying with *vigilant risk-reducing* and so potentially also relating to

the underlying motivation behind this (to stay *just normal*), identifying with *just normal* means that individuals are then prompted to give consideration to this concept and so track the constituent concepts as they see how *just normal* can play out.

Relating to a resonant concept in this way means that individuals should also be able to perceive other possibilities – they can relate to patterns that vary and see how these vary for them in particular contexts, and so through understanding the variability of a pattern, what alternatives may exist. This is the conceptual empowerment that a relevant theory affords, which Glaser elaborated:

The analyst gives the knowledgeable person categories, which grab many indicators under one idea and denotes the underlying pattern. One idea can then handle much diversity in incidents. Once ideas can be seen as conceptual elements that vary under diverse conditions, action options are provided the man in the know.  
(Glaser, 1978, p. 13)

A relevant grounded theory then, should also extend beyond recognition of a person's own actions to enabling individuals to see their particular variation as one of a number, and so enhance awareness of possibilities. The theory of *just normal* does this by presenting a range of patterns in resolving a concern of being *just normal*. The way some individuals keep using prostheses in particular ways despite particular difficulties, whereas others do not, or the way in which persons stay with a particular prosthetist, while others do not, or variously shy away from particular activities or social situations while others embrace them, or embrace them in different ways, all indicate the different possibilities for action for an individual locating themselves within the theory and then recognising alternatives. Agency is afforded to the individual who was previously unaware of particular actions, such as hearing of successful *redressing* through *re-coursing* by intensifying one's petitions to gain a better prosthesis, or through other means. Or, they may learn of particular strategies through considering *mole-hilling* that enable them to live with difficulties that bit easier. Furthermore, a fundamental quality about *just normal* is

that persons judge the just normalness of something with regard to what they know about its variability, and so becoming more aware of different options therefore has implications for an appraisal of one's own situation. This was discussed in chapter nine, and for example, could be the difference between an individual struggling with a prosthesis that they require to do particular things, but then being able to do something about this if they were to hear of others seeking to address similar difficulties and so considering this a *just normal* path of action instead. This is not to suggest that prosthesis users act in particular ways because they are variously 'informed' or 'uninformed' but rather that persons do what they can with the information available to them. In this way *just normal* is a sympathetic theory but is also the basis for action through learning more about alternatives.

Discovering 'action options' is also particularly relevant given studies such as that of Murray and Forshaw (2013) who found that individuals were vocal about their lack of information and direction post-amputation and when living with a prosthesis. Prosthesis users in this study and in others (e.g., Murray, 2013; Ostler et al., 2014) indicated their uncertainty about particular actions or their experiences, suggesting that they were often unaware of what was 'normal', or as one individual put it, they were 'flying blind' and did not know enough to know what they ought to keep going with or what they should try to change. Studies stressing the importance of 'peer visitors' and support groups also indicate the importance of learning more about how things are or could be (Liu et al., 2010). A theory of *just normal* meets these demands, and thus prosthesis users, both new and experienced, may benefit from learning about the theory of *just normal* as it can prompt a deeper consideration of their own actions as well as inform them of the possibilities available to them, both of which may lead to beneficial change and for persons to become more confident in the just normalness of their prosthetic decision-making.

A further feature of a relevant grounded theory involves extending the appeal of a theory beyond those directly involved in the substantive area (e.g., see Glaser, 2004; Gynnild, 2014). Accordingly then, *just normal* is intended to also appeal to researchers and other relevant professionals. This is partly achieved by being relevant to prosthesis users, but there are also other ways the theory may appeal

to others. For instance, in chapter nine, *just normal* was put forward as a means of interpreting a range of situations identified in the literature concerning prosthesis use. Discussion of these indicated how *just normal* offers novel insights into areas that have already received some attention, such as how to manage the prescription of a new prosthesis and to consider how an appropriate match between person and technology may change over time, or how *redressing* has implications for conceptions of how persons self-monitor and self-regulate. *Just normal* is argued to provide new understandings by extending extant research and providing new interpretations of findings or processes. Furthermore, the theory and the constituent concepts of the theory do not have a forced or loose fit with the literature as it discusses prosthesis use, and so when studies describe activities of prosthesis users such as ‘maintaining leisure time activities’ after the loss of a limb, or ‘preventing further damage’, or engaging ‘downward comparisons’ (e.g., Dunne et al., 2014; Oaksford et al., 2005), it is clear to see how these fit and can be informed by the theory of *just normal* – how they may map on to concepts within the theory and so how a concern of being *just normal* may provide an underlying motive for these actions. The theory may therefore be attractive to researchers in a variety of ways.

Finally, the theory of *just normal* may also have relevance for researchers beyond the field of prosthesis use, and perhaps also to a wider public, through considering the concepts as they are presented and without reference to prosthesis use. This is a discussion better situated in the final criterion concerning the ‘modifiability’ of the theory. However, before this, the ‘fit’ of *just normal* is discussed.

#### *The ‘Fit’ of the Theory of Just Normal*

Data should not be forced or selected to fit pre-conceived or pre-existent categories or discarded in favor of keeping an extant theory intact. Our position is that the reality produced in research is more accurate than the theory whose categories do not fit, not the reverse. (Glaser, 1978, p. 4)

Fundamentally, the 'fit' of theoretical categories is how well they reflect what is going on in the worlds in which people live. This is helped by careful and competent application of methodological processes that foster the conceptualising of patterns in the data, but it is important to clarify that this occurs on an ongoing basis, such that conceptualising continues to occur where comparisons to further incidents and categories indicate a better way of framing what is perceived to be going on. Memoing, selective coding and theoretical sampling are involved in this comparative analysis and each help in the ongoing process of 'fitting' and 're-fitting' concepts to data.

How well the categories of *just normal* fit the data is difficult to convey, and to some degree the final judgement upon this is left to the reader to compare to their own experience of prosthesis use. However, in chapter four it was my intention to try to indicate how I went about the processes of the methodology in order to express how a good fit might be reached through extended critical discussion of the analytical processes. Yet an understanding does not necessarily equate to good application and so this is part of the reason for also including the appendices that illustrate some of the coding and memoing involved in this work, and importantly, that convey the development of some of the categories within the theory which underwent significant alterations when striving for a good fit. To include all my workings would be to provide this thesis several times over, as the 'writing up' of the final product was not so much a pulling together of 'findings' but a re-drafting of many mature memos, which themselves were re-drafts many preceding drafts, each refining and re-thinking the match of the work to the data. I would argue that the core process of Grounded Theory is constant comparison and the reflections on this process when writing about the comparisons at a conceptual level. These writings are continually sharpened as comparing goes on. Thus the work in the appendices may be considered one moment within analyses of working towards a good fit between my writing and the data, before which the fit was less good and after which the fit improved some more. By including this, I hope to give a sense of the methodology in action towards the final theory and a sense of how fitting and

refitting were constant companions throughout the development of the theory of *just normal*.

Within the naming of the categories within *just normal* I also aimed to convey a sense of the acts happening, such as in *obligated persistence*, where persons sometimes expressed a sense of trapped-ness or that they were helpless to do anything but keep going with a particular thing because they considered it *just normal*. Or how in *righting what's wrong*, where there were often strong 'righteous' responses to transgressions or violations of how things ought to be, and persons appeared crusader-like against perceived injustices. Or, in *mole-hilling*, which was conceived to express the opposite of persons making mountains out of mole-hills and thus how these acts appeared to have an attenuating or pacifying quality for the individual. It was my intention to provide names for patterns that captured the essence of the action they represented and therefore give an evocative sense of *just normal* occurring in various ways<sup>5</sup>. To further illustrate by contrast, consider the theoretical product developed by Oaksford et al. (2005), which was proposed as a grounded theory of coping following amputation. This model includes concepts such as 'coping' and subcategories of 'support seeking', 'humour', and 'cognitive appraisal' (p. 271). While no issue is taken with the assertion that these concepts come from the application of the methodology, there is not much sense of a life being lived through any of these concepts. They lack the 'imageric meaning' that Glaser (2002a) recommends, possess little grab and it is hard to believe that they have any immediate resonance with the individuals involved in their study. Instead, when giving names to patterns, if emphasis is given to trying to capture some of the lived action, concepts become more compelling on sight as well in their elaborations.

Throughout analyses, I did my best to work towards a good fit and continued to sharpen the fit of the categories through selective coding and theoretical sampling for further variation in the patterns of *just normal*. When it appeared that no more variation was being turned up by theoretical sampling, I reflected on the work as it

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<sup>5</sup> This is like the reverse of Green's (2003) 'poetical dictionary', where Green took everyday words and elaborated them in compelling exposition that captured something of the experience of the words (p. xx).

stood and felt that the theory and the constituent concepts worked well in expressing the variation in the data and how they worked with each other, and also that they had strong 'grab' and 'resonance' about them. At this point, I felt that a good fit had been achieved, and that *just normal* was also strong in its workability and in its relevance (these three criterion, to an extent, having implications for each other). However, there is a fourth and final criterion to consider in an evaluation of the theory.

#### *The 'Modifiability' of the Theory of Just Normal*

The theory is not being verified as in verification studies, and thus never right or wrong. ...it just gets modified by new data to compare it to. A conjectured theory tends to pre-empt the data by one saying the theory is correct and we should ignore the "bad" data which does not support it. Many grand theorists are given to this "poor data" pattern. New data never provides a disproof just an analytic challenge. (Glaser, 1998, pp. 18–19).

In his later writings (e.g., Glaser, 1998, 2003) Glaser was particularly cautious about the claims that could be made for a grounded theory. He asserted that the methodology was all about the development of meaningful and valuable theory in a substantive area, but that additional work would be required to test or to 'validate' a theory. Rather than 'findings', the result of a Grounded Theory is a set of interrelated conceptual hypotheses – a theory. So while careful adherence to the procedures of the methodology would ensure a theory grounded in the data, the actual verificational 'proving' of these hypotheses, i.e., confirming the 'empirical accuracy' of *just normal* or the features of *just normal* in the area of prosthesis use, is a direction for further research: 'That is all, the yield ... is just hypotheses!' (Glaser, 1992, p. 16).

This statement about the yield of the methodology speaks to those such as Dey (1999) who have suggested that what is written about Grounded Theory indicates that the methodology generates theory and also verifies it. It is true that Glaser and Strauss's (1967) original text does contain some ambiguous writing that is

indicative of the verification of a theory, and also true that Strauss did go on to develop his branch of Grounded Theory that emphasises verification/validation (see Charmaz, 2000; Walker & Myrick, 2006). However, this is something that Glaser has clearly addressed in many of his works since (e.g., Glaser, 1978, 1992) and made clear that this is not a part of a Grounded Theory study, though it is fine to do so afterward. Thus one immediate avenue for further inquiry is identified – the testing of the hypotheses of *just normal*.

It is possible to envisage testing these hypotheses, such as taking the patterns of *black-spotting* and assessing whether and to what extent prosthesis users might engage in *protective avoidance*, *risk-reducing engaging*, or *fail-safing* in order to *preserve* their ability to be *just normal*, and while going about the activities of their daily lives. Or in assessing what persons would be willing to live with in a prosthesis or prosthetist that prompt *sufficing*, how this may change over time and what may lead to these changes.

Following statements about verification, it is also important to recognise that *just normal* is a theory of prosthesis use in that it reflects the data of prosthesis users that the theory is grounded in, and so caution must be exercised when considering the ‘generalisability’ of the theory to prosthesis users at large. This is not to say that the theory bears no significance with this wider group, as indeed, the relevance of *just normal* to prosthesis users has been argued and in chapter nine the links to the literature and work involving other prosthesis users discussed at length.

Furthermore the breadth of data involved in this study – from the interviewed individuals across the world, the collected autobiographies, biographical accounts, and internet data that were sampled and theoretically sampled in pursuit of variation – give further indications of the broader relevance of *just normal*. Each of these champion the applicability of the theory to prosthesis users as a whole. However, it is ultimately up to further research (such as a large scale survey) to have the final say on this.

So there is confidence to be had that *just normal* and its interrelated conceptual hypotheses apply to prosthesis users broadly. However, a grounded theory is never ‘final’ in the sense that data could always emerge that could challenge the theory,

such as if surveying further prosthesis users and discovering patterns not in keeping with *just normal* as it is presently conceived. A theory should be able to withstand this and incorporate it as further variation on a pattern, and this is the key aspect of 'modifiability'. As astrophysicist Dave Goldberg (2014) put it, '*theories are malleable, but not infinitely so. ... Evolution has, itself, adapted a lot over the years, but not so much that it wouldn't still be recogniz[able].*' In this way, *just normal* can be adapted to further variation should this arise, and this can be managed through further conceptualisation and reconceptualization of the patterns.

To explain further, the period during analyses could be seen as a time when the theory was 'incomplete', but this was knowingly incomplete because I was still searching for and identifying variation within *just normal*, and so expecting further variation to arise in further data. As stated earlier, when no more variation was apparent, I became confident that theoretical completeness was established. However, such completeness does not indicate finality and that the theory of *just normal* will never undergo further development. For example, further investigations could reveal a fourth course of *black-spotting*, or a pattern pertaining to *black-spotting* that prompts a re-formulating of the entire concept. Involving this new variation would add to the scope and density of the theory, and so it is important to recognise that the emergent fit of theoretical categories is therefore good as far as the data goes:

Our strategy of comparative analysis for generating theory puts a high emphasis on *theory as process*; that is, theory as an ever-developing entity, not as a perfected product... To be sure, theory as process can be presented in publications as a momentary product, but it is written with the assumption that it is still developing. Theory as process, we believe, renders quite well with the reality of social interaction and its structural context. (Glaser & Strauss, 1967, p. 32)

In a practical sense, modifiability means ensuring it is possible to re-engage conceptualising, comparing new data to existing categories and reformulating where appropriate. This is the 'analytic challenge' that Glaser (1998) referred to,

prepared for by ensuring a theory is not tied to the data it has been developed from. Being 'readily modifiable' then, can be received as ensuring a good degree of conceptuality/abstractness in a category compared to something more descriptive or locked to a particular context, e.g., *obligated persistence* that can cater for a variety of things that persons are compelled to persist with, as opposed to 'persisting with prosthesis use and activities', which is less accommodating should something else that persons are required to persist with become salient.

This discussion of modifiability draws out some of the limitations of the study and in developing theory in general, but nonetheless should be balanced with recalling the strengths of the theory as outlined in the former part of this chapter and in chapter nine. Additionally, the idea of modifiability and the modification of a theory may stimulate further advances in broader scholarly inquiry. For instance, at the end of the discussion of the relevance of the theory, *just normal* was also suggested to have potential appeal to researchers and lay persons external to the area of prosthesis use. This can occur when theoretical categories can gain more widespread appeal than just in their original substantive area, whereby others can envisage their application elsewhere. A theory of *just normal*, while currently grounded in accounts of prosthesis use, has that quality about it. For example, when developing the category of *persevering*, I began to see examples of persevering occurring in all manner of contexts. Colleagues would complain of unreasonable workload burdens because they 'just had to get through it', or that it would 'be over soon', and that 'the end was in sight'. This appeared to keep the unreasonable reasonable as I considered them to be *trusting to transience*. Similarly, when I was later reading for stylistic ideas and read in David Karp's (2001) *The Burden of Sympathy*, that despite the degree of difficulties in caring for a family member with mental illness, even when persons felt unable to keep going, they also felt unable to stop because it was not right to do otherwise - they seemed *obligated to persist* with their caring.

Moreover, we are each arguably committed to living in ways that we perceive are *just normal*, acting through this and on this when there are problems. Niebuhr's well-known serenity prayer, occurring in various forms, goes as far as calling for

divine support to this end: *'Give me grace to accept with serenity/ the things that cannot be changed, /Courage to change the things/ which should be changed,/ and the Wisdom to distinguish /the one from the other.'* This opening verse about living day-to-day is strongly suggestive of *persevering* and *redressing* according to a way that things 'should' be, and that there is 'wisdom' in making this apparently *just normal* judgement. It becomes difficult not to see *just normal* as an account of behaviour in general and so possible to envisage the concepts of the theory having utility well beyond the area of prosthesis use. Glaser (2011b) pre-empted this by stating that researchers developing readily modifiable concepts would start to see them occurring everywhere, that it would lead to a 'core category fever', and that this could be taken as a sign of readiness for Formal Grounded Theory (see Glaser, 2007b, 2010; Glaser & Strauss, 1967):

Grounded theory is based on a third level conceptual perspective analysis. The first level is the data. The second level perspective is the conceptualisation of the data into categories and their properties. There are sub-levels exist within this level. The third level is the overall integration through sorting in a theory. A fourth level perspective is the formalisation of a substantive theory to a more general conceptual level by constantly comparing substantive theory articles, as I did in my reader: "Organisational Careers". Thus credentialising of nurses can be generalised to credentialising of professionals or even of all occupations. These are the basic levels. But, of course, the level of perspective can get higher and broader, as it gets more general. One can also conceptualise concepts. And there is always a perspective on a perspective, as all is data. (Glaser, 1998, p. 136)

So *just normal* is ready to be further abstracted from the area of prosthesis use, though doing so was beyond the scope and objectives of the present study. However, the potential application of *just normal* to areas beyond prosthesis use does appeal to further investigation. One step towards formal theory yet close to prosthesis use is to consider the theory of *just normal* with regards to those using

other forms of assistive technology (e.g., wheelchair users, hearing aids, forms of prostheses other than limb prostheses), or those with different forms of physical difference (e.g., paralysis, disfigurement). The extent or ways in which persons are concerned about being *just normal* in these areas would be interesting in itself but also for potentially drawing out differences between these areas and prosthesis use via constant comparison. As Glaser indicates, an understanding of potential differences and what may account for their variation can lead to further conceptualisations, and so toward broader theories, such as theories of assistive technology use, or of physical difference.

This concludes an assessment of *just normal*, though it is now useful to summarise the strengths and limitations of this study, and to draw together the implications for practice and avenues for future research.

### The Strengths and Limitations of the Study

The key strength of this project is the development of novel and relevant theory in the area of prosthesis use. This is the first theory to be produced specifically about the use of prostheses and contributes a deeper understanding of the use of artificial limbs.

A core concern of prosthesis users has been identified, against which the modes of resolving this concern have been presented. This concern enables an understanding of an important preoccupation of prosthesis users, and the resolving theory accounts for a broad range of action within the area. The theory is argued to resonate with prosthesis users as they identify with the categories of the theory and perceive how their own variation is captured within it. In doing so, individuals are also afforded 'action options', or recognition of other possibilities which may have implications for an appraisal of their own situation. Furthermore, discovering more about the patterns of prosthesis use addresses a critical information need that has been identified in the literature.

The theory is also of importance to researchers who are interested in learning more about prosthesis use, through understanding this main concern and the varied ways it is resolved. The theory also provides further insights into existing research

in the area, such as potential explanations for the extent to which a prosthesis is used, gained through a richer understanding of the purpose it serves. The theory can also provide an enhanced understanding of the goal structure that may motivate prosthesis users in rehabilitation, and has implications for considering how persons regulate themselves.

Through development of theory, considerations are prompted for the prescription of a prosthesis and the need to consider an individual's patterns of usage and how these may be judged by both the user and relevant professionals. Suggestions for the development of best practice in consultations and the direction of prosthetic technology development are also given. Directions for further inquiry are also foregrounded and these are summarised in the section below.

There are also some limitations to this study that must be considered. In particular, developing theory through analyses of data from a limited number of prosthesis users means that ultimately the applicability of the theory to prosthesis users in general remains to be verified. This is a caveat found in many forms of qualitative inquiry that use relatively small sample sizes, but the diversity of individuals involved in this study encourages that the theory is relevant to prosthesis users in general. A further verification study exploring the hypotheses of the study in a broader sample of prosthesis users could address questions of generalizability.

The limits of the methodology also invariably dictate how a theory will develop. For example, it could be speculated that sampling from prosthesis users who happened to be (or, in terms of the internet data, who appeared to happen to be) from Western societies and so where assistive technology is relatively accessible, led to the emerging concern of *just normal*, whereas those in areas where prostheses are harder to come by may have different main concerns. At the least, *just normal* may be of lesser relevance in these contexts, and this would be an interesting avenue for further study where more data can only help elaborate the theory and contribute to a developing understanding of global prosthesis use.

Furthermore, prosthesis users were sampled and theoretically sampled, as were autobiographies and internet data, but in each case these were people who

appeared to have something they wanted to say. Such sampling overlooks the individuals who specifically do not put themselves forward in such ways. For individuals experiencing depression or anxiety as the result of the loss of a limb, and so who may be more withdrawn and less willing to engage with research, *just normal* may also be less relevant. Further sampling from a clinical population therefore presents a possibility for additional exploration to see whether these individuals are similarly concerned about being *just normal*. However, it is difficult to envisage how those who do not wish to talk could (or ought to) be encouraged to do so.

Finally, *just normal* is a readily transferrable concept and theory, prepared for exploration in other areas and to be potentially expanded through further data that indicate variation beyond which was identified in the present study. *Just normal* appeals to the development of formal theory, and more locally there are indications that the theory may provide useful interpretations of those living with other physical differences or using other assistive technologies.

### Summary of Implications for Practice and Directions for Further Inquiry

Following the development of the theory of *just normal*, a number of recommendations for practice can also be made. Potentially the most salient of these is to add to the suggestions of others in recommending an individualised approach to prosthetic consultations, where persons can be encouraged and feel able to express their particular needs and desires in their prosthesis use. Doing so enables the professional to understand and be able to assess how a prosthesis can support individuals in doing what they consider is important and in ways that the individual considers reasonable.

Professionals must be able to gain a holistic picture of the individual in order to understand how a prosthesis can support an individual to be *just normal*. This involves learning about the specific functions a person may perceive a prosthesis is required to serve (e.g., wanting to run again, wanting to feed oneself with two hands) as well as how these may fit with more abstract or broader functions (e.g., remaining independent, being able to socialise). Going beyond the specific enables

professionals to evaluate how a person is getting on with these particular goals and if troubled, whether there may be alternatives befitting broader goals. Thus it is encouraged that professionals try to understand what persons may consider sufficient in prosthetic provision. Provided that individuals are knowledgeable about various prosthetic options and have an awareness of the potential that prostheses can enable, it is important that professionals work towards what individuals may consider is reasonable or 'good enough'. This is not to encourage outcomes of consultations that are merely tolerable or passable, but more that professionals consider that persons may not wish to 'optimise' themselves, to reach a 'maximum' potential, or to have the 'best' they can in a prosthesis (though some may do). Instead, a prosthesis that enables a person to be *just normal*, as the person conceives it, may constitute a useful individualised model for rehabilitation and ongoing prosthesis use.

In consultations, *just normal* foregrounds that what persons consider right and reasonable in a prosthesis and in consultations themselves may be subject to change based on a developing knowledge of both. Thus it is recommended that individuals be afforded information early on to an extent that decisions can be made about gaining particular prostheses or managing targets for prosthesis use in order for the persons to be more comfortable with these and to encourage that they are lasting. Furthermore, understanding that a good match between person and prosthesis is only as lasting as it continues to be seen as appropriate means that it is important to maintain an open dialogue between professional and client, where individuals are able to discuss possibilities for change when this appears warranted.

When considering the theory of *just normal* and the constituent theoretical categories, each inspire interesting opportunities for further research. For instance, the exploration of the hypotheses of the theory in a broader sample of prosthesis users may be informative, such as exploring what in particular may be most likely to prompt individuals to *suffice* with a particular prosthesis and what could persuade them to try different forms of limbs. Or, it may be of interest to discover

more about the forms of *black-spots* that prosthesis users identify, and the particular strategies they invoke to work around these.

The extent to which persons are willing to put up with particular limitations in a prosthesis would also be a further area of interest for future research. For instance, persons may *trust to transience* with issues that they deem are of a *just normal* nature, but how long this trust lasts before persons consider ‘enough is enough’ and they seek to *redress* the situation is something that would be important to explore, particularly if this impacts an individual’s perseverance with a prosthesis. Researchers (e.g., Coffey, O’Keeffe, Gallagher, Desmond, & Lombard-Vance, 2012; Sjöberg et al., 2014) have called for an increase in longitudinal studies in the area of limb loss because of the potential for change in psychosocial outcomes over time, and similarly here such study designs may provide insight into how individuals may engage in processes of *perseverance* and *redressing* differently over time, and what may contribute to this.

The non-use and abandonment of prostheses is an area for further research that could also be an insightful next step. The theory of *just normal* was developed to discover more about prosthesis use, given the sizeable number of persons using artificial limbs, but the literature has also identified a sizeable incidence of persons that stop using a prosthesis altogether, as well as those that never begin using one, and so non-use presents an additional interesting area to explore. The literature has also struggled to account for non-use, yet the theory of *just normal* could provide potential leads. While the theory was not developed from data from persons that could be considered ‘non-users’, it did involve individuals who had variously given up on prostheses before trying others, given up on them for a time, or persons who came to prostheses at later stages. Persons did so because of the fit with the use of the prosthesis and what they considered was involved in being *just normal*. An extension of this logic therefore presents a potentially useful means to explore non-use.

Finally, *just normal* is a concept that was developed over the course of this study that may inspire further work in itself. While the theory of *just normal* is presented as a contribution to the area of prosthesis use, and potentially to fields beyond, the

concept of *just normal* is also submitted to help stimulate further thought on the notion that people desire to live in ways that are generally right, reasonable, fair and good enough. Furthermore, throughout this thesis, 'the' theory of *just normal* is referred to, but perhaps it would be more fitting to refer to it as 'a' theory of *just normal*, in the same way that there are multiple theories of coping or identity development, each sharing these central concepts but being distinct in other ways. This may not be the only theory of *just normal* and further inquiry beginning with this idea or similarly conceptualising it through emergent analyses of data may develop theory that is distinct from what has been presented here.

### Concluding Remarks

This research presents the first theory of prosthesis use. It was developed using Grounded Theory methodology in order to better understand the substantial number of individuals using artificial limbs across the globe, and it does so through clarifying a prevailing concern of this group and delineating the varied ways that this concern is resolved. In the theory, persons are said to be concerned about being *just normal*, such as living in ways they consider are generally 'about right', fair, reasonable, and good enough. An in-depth conceptual account of the resolving of this concern was given through the three distinct modes of the theory: That individuals *preserve* their ability to be *just normal* when this is perceived to be threatened, they *redress* to *just normal* when this is judged to be lacking, and they *persevere* with living *just normally*, keeping going with this despite difficulties. The theory was discussed at length and each of these modes of resolution were accounted for through a number of constituent concepts, foregrounding the richness and explanatory power of the theory through the variety of processes described.

The theory enables a new way of considering how persons using prostheses live and perceive the need to live and draws out what may not be readily perceptible, being useful to both prosthesis users and professionals alike. It also offers an interpretation of a breadth of contexts in the area, such as accounting for how and why a prosthesis may be used, and has implications for other existing research and

for informing evidence-based practice through considering how to develop the consultation process and when matching person to technology. Finally, the theory of *just normal* indicates a variety of interesting avenues for further research in the field of prosthesis use, in broader topics of assistive technology use and disability, and potentially beyond.

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## Appendix A – Letter of Invitation to Participate in the Study

Ollscoil Chathair Bhaile Átha Cliath  
Dublin City University



Dear participant,

I am a researcher at Dublin City University conducting a study in prosthesis use. The aim of the study is to discover how individuals that use artificial limbs make the most of their prostheses. I believe that understanding those that are getting the most out of their prostheses can enhance the rehabilitation process for others that are adjusting to their own prosthesis and potentially aid the design of new prostheses. To this end, I wish to talk to a number of individuals about any successes or obstacles in their lives that they have encountered since obtaining their prosthesis. I also hope that this project allows those that take part to have their say on a range of topics, whether about their prosthesis or other related issues they believe are important.

I would like to invite you to take part in the research. This will simply involve a short interview/phone call interview lasting less than one hour where I would like to engage you in an informal discussion about the things most important to you in relation to your prosthesis. In particular, I would like to ask you a number of open-ended questions about the good and bad aspects of using your prosthesis, your lifestyle and how this is affected by the use of a prosthesis, and your main concerns with using your artificial limb. Any information you provide will be treated with the utmost confidentiality.

If you are interested in participating, I would be grateful if you could read the brief information sheet overleaf and complete the consent form. Please get in touch if you have any questions about the project.

I look forward to hearing from you soon. Thank you for your time,

Phil Jefferies

*PhD Researcher, School of Nursing & Human Sciences, Faculty of Science & Health, Dublin City University, Ireland*

Phone – 00353 (01) 7007582

Email – [Philip.jefferies@dcu.ie](mailto:Philip.jefferies@dcu.ie)

## Appendix B – Study Information and Consent Form



### **‘Aspects of prostheses and their relation to individuals and society’**

#### **Plain Language Statement**

##### **Investigators**

Mr. Phil Jefferies, School of Nursing, Dublin City University

Dr. Pamela Gallagher, School of Nursing, Dublin City University

Prof. Malcolm MacLachlan, School of Psychology, Trinity College Dublin

Dr. Mark Philbin, School of Nursing, Dublin City University

##### **Introduction**

You are being invited to take part in a research study. Before you decide to take part or not, it is important that you understand why the study is being done and what it will involve. Please read the following information carefully and discuss it with others, if you wish.

If you require further information, or would like to ask any questions, please contact Phil Jefferies (Tel: 00353-1-7007582 / E-mail: Philip.jefferies@dcu.ie).

##### **What is the purpose of the study?**

The aim of this research is to investigate the psychosocial aspects of complex prosthetics. It will explore your experience of using your prosthesis, the benefits and challenges of using your prosthesis and what you think about your prosthesis. This information is important as it will provide insights on future areas to focus upon in rehabilitation. Having a better understanding of these issues will be helpful in managing issues that arise while deciding on the most appropriate prosthesis. Therefore, it will also help inform the process by which the prosthesis prescribed is matched to the person’s needs. This is an important endeavour in getting the best use from the prosthesis, in facilitating independent living and participation in society, and enhancing quality of life.

**Why have I been invited?**

The study aims to investigate how people feel about their prosthetic limb. You have been asked to take part in this study as you have been prescribed a prosthesis.

**Do I have to take part?**

No, it is completely up to you whether you take part or not. If you decide to take part, you are free to withdraw from the study at *any* time without giving a reason. Your decision will not affect the standard of care you receive and you will not give up any benefits you had before entering the study.

**What will happen to me if I take part?**

You are being asked to take part in a study about your thoughts about your prosthesis. The actual study will consist of an interview, lasting about an hour. The interview will consist of a series of simple questions probing your thoughts and feelings towards your prosthesis and lifestyle with the prosthesis. This interview will be audio-taped. No one will listen to these tapes except the members of the research team listed above. If you are willing to take part, you are asked to sign and return a consent form indicating that you agree to take part and for the interview to be tape-recorded. When we receive your consent form, we will contact you to arrange a convenient time to meet.

**What are the possible risks of taking part?**

We do not anticipate any risks that are greater than those encountered in everyday life. However, if at any stage during the interview, you feel uncomfortable or distressed at any stage, you can withdraw without any consequences. In addition, the research team will support you in accessing suitable support systems, if required.

**What information will be held about me?**

If you agree to take part, all information collected will be kept strictly confidential within the limitations of the law in Ireland. Interview transcripts with all identifying information removed (e.g. names) will be stored for 5 years in a locked cabinet in DCU. Only the researchers named above will be able to access this information. Tapes of the interview discussions will be destroyed when the study is finished. Any information that will identify you in any way will be removed. Despite this, it is important to note that if you are using a prosthesis which is new and only used by a small number of people, it might be possible to identify you. The researcher, Mr. Phil Jefferies, will be responsible

for the safety and security of the data. The procedures for handling, processing, storage and destruction of your data will be compliant with the Data Protection Act (1998).

### **What will happen to the results of the study?**

The results of this study will form the basis for preparation of reports, academic publications, conference papers and other scientific publications.

### **What will happen if I don't want to carry on with the study?**

Your participation in this study is entirely voluntary. You are free to decline to take part or to withdraw from the study at any time without having to give an explanation. If you choose not to participate in the study, or to withdraw once entered, you will not be penalised. It will affect any care you receive and you will not give up any benefits you had before entering the study. Any participation you had in the study before your departure will be stricken from records and destroyed if you so wish. Participation in this study will in no way affect your legal rights.

### **Who is organising and funding the research?**

The research is organised by a research team from the School of Nursing & Human Sciences, Dublin City University, Ireland. It is funded by the Irish Research Council for Humanities and Social Sciences.

### **Complaints**

If you have any concerns about this study, please contact a member of the research team who will do their best to answer your questions:

Mr. Philip Jefferies (principal investigator): e-mail [Philip.jefferies@dcu.ie](mailto:Philip.jefferies@dcu.ie)

Dr. Pamela Gallagher (co-investigator): e-mail [Pamela.gallagher@dcu.ie](mailto:Pamela.gallagher@dcu.ie)

Prof. Malcolm MacLachlan (co-investigator): e-mail [Malcolm.maclachlan@tcd.ie](mailto:Malcolm.maclachlan@tcd.ie)

Dr. Mark Philbin (co-investigator): e-mail [Mark.philbin@dcu.ie](mailto:Mark.philbin@dcu.ie)

If you wish to discuss any concerns you may have with an independent source, please contact:

*The Secretary, Dublin City University Research Ethics Committee, c/o Office of the Vice-President for Research, Dublin City University, Dublin 9, Ireland. Tel 00353-1-7008000*

This research has been reviewed by the Dublin City University Ethics Committee.

You will be given a copy of the information sheet and a signed consent form to keep.

Thank you for taking the time to read this sheet.

If you have any queries regarding this study, please contact the researcher at the following:

Name: Philip Jefferies  
Address: School of Nursing & Human Sciences,  
Dublin City University  
Glasnevin  
Dublin 9  
Ireland  
Phone: 00353 (01) 7007582  
E-mail: [Philip.jefferies@dcu.ie](mailto:Philip.jefferies@dcu.ie)



**DUBLIN CITY UNIVERSITY**  
**Informed Consent Form**

**Title of Project:**

Aspects of prostheses and their relation to individuals and society

**Investigators**

Mr. Phil Jefferies, School of Nursing & Human Sciences, Dublin City University

Dr. Pamela Gallagher, School of Nursing & Human Sciences, Dublin City University

Prof. Malcolm MacLachlan, School of Psychology, Trinity College Dublin

Dr. Mark Philbin, School of Nursing & Human Sciences, Dublin City University

The aim of this research is to investigate the psychosocial aspects of complex prosthetics. It will explore your experience of using your prosthesis, the benefits and challenges of using your prosthesis and what you think about your prosthesis. This research is being funded by the Irish Research Council for Humanities and Social Sciences.

You will be asked to take part in an interview which will take about one hour. This interview will be audio-taped.

Participant – please complete the following (Circle Yes or No for each question)

*Have you read or had read to you the Plain Language Statement?*

*Yes/No*

*Do you understand the information provided?*

*Yes/No*

*Have you had an opportunity to ask questions and discuss this study?*

*Yes/No*

*Have you received satisfactory answers to all your questions?*

*Yes/No*

*Are you aware that your interview will be audiotaped?*

*Yes/No*

It is important to remember that you may withdraw from the Research Study at any point. There will be no penalty for withdrawing before all stages of the Research Study have been completed.

If you agree to take part, all information collected will be kept strictly confidential within the limitations of the law in Ireland. All information will have your name and address removed to protect confidentiality. Any information that will identify you in any way will also be removed. Despite this, it is important to note that if you are using a prosthesis which is new and only used by a small number of people, it might be possible to identify you. Tapes of the interview discussions will be destroyed when the study is finished.

**Signature:**

I have read and understood the information in this form. My questions and concerns have been answered by the researchers, and I have a copy of this consent form. Therefore, I consent to take part in this research project.

**Participant's Signature (please type if replying by email):**

\_\_\_\_\_

**Name in block capitals:** \_\_\_\_\_

**Email address:** \_\_\_\_\_

**Telephone number:** \_\_\_\_\_

**Date:** \_\_\_\_\_

## Appendix C – Sample Breakdown

### Interviewees:

Pseudonym	Gender	Age	Nature of limb absence	Bodily region (unilateral/ bilateral)	Date of amputation
Rob	M	34	Acquired	Lower (b)	1984-86
Sean	M	18	Congenital	Lower (b), Upper (u)	N/A
Alan	M	Unknown	Acquired	Lower (u)	2007
Alison	F	50	Acquired	Lower (u)	1976-77
Pat	M	62	Acquired	Lower (u)	2008
Roy	M	41	Acquired	Lower (u)	1985
Roger	M	44	Acquired	Lower (u)	2004
Zane	M	Unknown	Acquired	Lower (u)	Unknown
Mark	M	46	Congenital	Lower (u)	N/A
Mike	M	50	Acquired	Upper (u)	1982-83
Chris	M	6	Acquired	Upper (u)	2008
John	M	52	Unknown	Upper (u)	Unknown
Luke	M	30	Acquired	Upper (u)	Unknown
Mel	F	26-34	Acquired	Lower (u)	2009
Lorna	F	51	Congenital	Lower (b)	N/A
Jay	M	18	Acquired	Upper (u)	2006-07
Stephen	M	Unknown	Acquired	Upper (u)	Unknown
Neil	M	57	Acquired	Upper (u)	2003
Liam	M	Unknown	Acquired	Upper (u)	2010
Natasha	F	43	Congenital	Lower (u)	N/A
Chuck	M	Unknown	Acquired	Upper (u)	Unknown
Carl	M	49	Acquired	Lower (u)	2009
Jack	M	47	Unknown	Upper (u)	Unknown
Julie	F	36	Congenital	Lower (u)	N/A

## Autobiographies:

Author	Year	Gender	Title	Nature of limb absence	Bodily region (unilateral/bilateral)
Lenor Madruga	(2000)	F	One step at a time: A young woman's inspiring struggle to walk again	Acquired	Lower (u)
Lenor Madruga Chappell	(2000)	F	The next leg of my journey	Acquired	Lower (u)
Paul Martin	(2002)	M	One man's leg: A memoir	Acquired	Lower (u)
Paul Martin	(2010)	M	Drinking from my leg: Lessons from a blistered optimist	Acquired	Lower (u)
Richard Riley	(2005)	M	Living with a below-knee amputation: A unique insight from a prosthetist/amputee	Acquired	Lower (u)
Lauren Scruggs	(2012)	F	Still LoLo: A spinning propeller, a horrific accident, and a family's journey of hope	Acquired	Upper (u)
David Rozelle	(2005)	M	Back In action: An American soldier's story of courage, faith and fortitude	Acquired	Lower (u)
Scott Rigsby	(2009)	M	Unthinkable: The true story about the first double amputee to complete the world-famous Hawaiian Ironman Triathlon	Acquired	Lower (b)
Kevin Garrison	(2011)	M	It's just a matter of balance: You can't put a straight leg on a crooked man	Acquired	Lower (u)
Jamie Andrew	(2004)	M	Life and limb: The true story of tragedy and survival against the odds	Acquired	Upper (b), Lower (b)
Oscar Pistorius	(2012)	M	Blade runner: My story	Congenital	Lower (b)
Aron Ralston	(2005)	M	Between a rock and a hard place	Acquired	Upper (u)
Emily Rapp	(2007)	F	Poster child: A memoir	Congenital	Lower (u)
Sarah Reinersten	(2010)	F	In a single bound: Losing my leg, finding myself, and training for life	Acquired	Lower (u)
Ivy Gunter	(1993)	F	On the ragged edge of drop dead gorgeous	Acquired	Lower (u)

Becky Alexander	(2013)	F	One smile, one arm: Life experiences with one arm	Congenital	Upper (u)
Scott Sabolich & John Sabolich	(2001)	-	You're not alone: With the stories of 38 remarkable amputees who conquered the challenges of a lifetime	Various	Various

### Blogs:

Author	Gender	Address	Nature of limb absence	Bodily region (unilateral/bilateral)
Allie Frick	F	onearmchick.blogspot.ie	Acquired	Upper (u)
Becky Alexander	F	onesmileonearm.wordpress.com	Congenital	Upper (u)
Caitlin Pereiras	F	streamofcaitlinness.com	Congenital	Upper (u)
Dave McGill	M	limblogger.wordpress.com	Acquired	Lower (u)
Dwayne Fernandes	M	dwaynefernandes.com.au	Acquired	Lower (b)
Justin 'Glen' Pedua	M	lifeofawesomeness.blogspot.ie	Acquired	Lower (u)
Kate Sawford	F	shesgotlegs.me	Acquired	Lower (u)
Kieron McCammon	M	onehandedblogger.wordpress.com	Acquired	Upper (u)
Lindsey Erdody	F	lindseyerdody.wordpress.com	Acquired	Upper (u)
Lisa Brewer	F	lisaonalimb.com	Acquired	Lower (u)
Mark O'Leary	M	amputee-adventures.org	Acquired	Lower (u)
Paul Martin	M	onemansleg.com	Acquired	Lower (u)
Peggy Chenoweth	F	amputeemommy.blogspot.ie	Acquired	Lower (u)
Ross Turnbull	M	terminaldevice.wordpress.com	Congenital	Upper (u)
Suzanne - 'Trac'	F	bionicismom.blogspot.ie	Acquired	Lower (b)
Ty Wilson	M	activeamp.blogspot.ie	Acquired	Lower (u)

### Discussion Forums:

Name of site	Address
The amputee discussion & support forum	Amputees.proboards.com
Heather Mills forum	Heathermills.eu/forum
The amputee treatment center forum	Amputee-center.com/forum2
Amputee Coalition of America (Facebook group)	Facebook.com/amputeeusa

## Appendix D – Interview Guide

Brief explanation of the project aims (to investigate experiences of patients and their prosthetic devices).

Ice-breaker (question of minor importance for research but designed to encourage discussion):

Can you tell me a little about yourself, what your job is and how you came to be doing what you're doing?

1. How long have you had your prosthetic limb(s)?
2. What are you happiest about with your prosthesis?
  - a. What isn't so good?
  - b. What might you change?
  - c. Would you ever consider trading the device in for something better?
    - i. Why/Why not?
3. If you were to design yourself a new prosthetic limb, what would be the most important factors for you?
  - a. What would be the least important?
4. How does having the artificial limb make you feel? (prompt: How natural does it feel?)
5. How do others treat you with regard to the prosthesis? (prompt: Do they try to ignore it, or are they actively interested?)
  - a. What do others think about your prosthesis?
    - i. How does this make you feel?
6. How do you feel about the functionality of the device? (prompt: Does it do what you want it to do?)
7. How do you feel about the look of the device? (prompt: Does it feel/look right to you?)
8. Is there anything that you feel is no longer open to you, since gaining the prosthesis?
  - a. What are they and does this affect you?
9. Are you interested in the design or the workings of your prosthesis?
  - a. Do you take an active interest in the development of these devices?

## Appendix E – Open Coding Samples

Below are two examples of the open coding conducted during analyses. The first is an excerpt from an interview transcript which was hand-coded. The second is an excerpt from NVivo v10 where coding was typed. Because of such organisational features as being able to quickly view all incidents under a code, NVivo became the coding platform of choice.

You don't realise how much you bend your ankle.

P: Are there ankles that bend? *Realising - Things coming to light.*

Yes, at a price. That would be way over our range. *Being limited.*

P: So it's quite a source of contention with cost and medical cards and finance?

*In a minefield* It's a minefield. We have it here with the new prosthesis, and it's bog standard. They question everything. You don't just have a prosthesis, you have to get the money out to get the socks. *Being questioned Interrogated.*

*Being inhibited* During the day the stump will shrink so you can't do all these things. They want to know why. It's the same for everyone. *It's 'normal'*

*Being hassled* They question why I need waterproof – for getting me out of the shower. It's great. It allows me to shower normally. It was €22 and they questioned it. ...They question – this sort of hassle. I didn't ask for this. They rang me to know why I wanted it and I flipped. You know, I let them have it. Those annoying things. They just make my life easier, my wife's life easier *Being normal*

*Making life easier* because I can have a shower myself. If I have to go back to taking off this, crutches into the shower, there's always the fear of falling, all of that. €22 they kicking off. I told them to shove it. *Letting them have it. Setting straight.*

*Just wanting to go back* and they were *Going elsewhere?*

File Home Create External Data Analyze Query Explore Layout View Window

Navigation View Find Quick Coding Dock All Undock All Close All Docked Bookmarks Close

Annotations See Also Links Relationships Links

Node Node Matrix Node Matrix Report

Framework Matrix Classification Report

Previous Next

Color Scheme Visualization

Reference

Look for: Search In Nodes

Nodes

Name	Sources	References	Created On	Created By	Modified On	Modified By
Upgrading	9	13	07/12/2012 12:18	PJ	18/01/2013 17:25	PJ
Apprehension to prosthesis	2	2	11/12/2012 12:07	PJ	10/01/2013 15:07	PJ
Being upgraded (passive)	3	6	11/12/2012 11:51	PJ	12/12/2012 17:08	PJ
Desiring more	8	10	11/12/2012 11:46	PJ	07/01/2013 11:16	PJ
Forced upgrading-downgrading	1	2	11/12/2012 13:37	PJ	11/12/2012 15:38	PJ
Not going back	1	1	20/12/2012 21:34	PJ	20/12/2012 21:34	PJ
Sticking to what's working (see experimenting-sticking...)	4	4	19/12/2012 15:11	PJ	14/05/2013 15:37	PJ
Reaching the top	2	3	19/12/2012 15:12	PJ	07/01/2013 11:16	PJ
Vicarious learning	3	4	09/05/2013 12:50	PJ	21/05/2013 13:19	PJ

Interview 016 - 18.07.12 11:30

You keep going back. But you kind of have to explain every time. it's like it's hurting a little place [?] here and they say ok, great, and they take it away into a back room and they fix it in there and then they bring it back, and then you say ohh it's still hurting a little bit here [said nervously]. And I'm a wuss, I kind of [say] 'oh it's fine, it's fine, I'm grand' and I'm trying to think oh I'll go home now and I [inaudible—think it's going to be grand, and] it's not really. It's never—in the last couple of years, the last say, 20 years of [inaudible], I've always made compromises. Do you know what I mean? Because it's just remarking appointments and remarking appointments and fixing one tiny thing and fixing one tiny thing and I feel that you're taking up a huge amount of time of their particular time, you know, and you don't want to be doing that. You'd like to say to them—I'd be in to the guys since—I told them exactly where to shave off and bits to put on to me, and that doesn't happen now, which is—it just makes it kind of slower, really. Much slower, for them, for everybody, you know what I mean, that they're in and out and in and out between me and the workshop and I never see the workshop or the guys in it. Now there's no need for me really to, as things stand, but

Not being informed  
Not wanting to change prosthetist  
Frustration at distanced ad  
Frustration with appointment  
Compromising  
Being more involved  
Keeping going back  
Avoiding bothering prosthe  
Coding Density

Sources  
Nodes  
Classifications  
Collections  
Queries  
Reports  
Models  
Folders

## Appendix F – Theoretical Memo Examples

### Sample Memo 1:

#### *Making comparisons*

There are two forms of social comparisons individuals using prostheses engage in.

One form of comparison is the comparison to others that use prostheses in order to develop knowledge. This is to expanding one's knowledge of prostheses to be able to determine whether a current prosthesis is good or whether another might be better.

For example, 006 describes how he has to wear three stump socks. He does so for comfort and he says this eventually leads to sweating and eventual discomfort. However, he accompanied this by describing how he knows of a woman who only wears one stump sock, but he realises that this person only has to wear one because she is that much lighter and so she does not experience discomfort so easily from the weight of her body pressing down into the socket of her prosthesis. This comparison enables him to realise that although the number of stump socks are a pain from being uncomfortable, for a man of his stature they are necessary, and by comparison to a lighter woman, he can see how he proportionately needs to wear more. This gives a sense that three stump socks is reasonable, given his circumstances, even if it's not ideal because of the discomfort.

The second form of comparison is to others that is not limited to users of prostheses. The individual compares for reasons of self-esteem, engaging in kinds of upwards or downwards social comparisons. So some individuals use these comparisons as a way of saying they are lucky - at least they aren't as bad as this person with spinal injuries, or this person with more amputations than themselves. Others compare with 'high flyers' in the world of prostheses, like Oscar Pistorius or Heather Mills, which then link to discussions of positive possibilities. However, one individual remarked that this can be detrimental for him if he sees prosthesis-using athletes on TV because he didn't believe it would be possible for him to get to that same level. He tries to keep away from situations where he could encounter this.

So these patterns of comparing contain a number of property patterns of types of comparing – for evaluation and for self-esteem – and which may be useful to investigate individually. There are linkages here to memos on learning and developing knowledge with prostheses.

Extra note: Comparing to similar others appears to be extended by examples where the comparison is to what they see as a 'normal' prosthesis user. Persons compare themselves to this generalised individual in order to check how they are faring by comparison. For 020, he describes the importance of being told by his prosthetic team that he had picked up mastery quicker than most, and how this helped him keep going through a difficult rehabilitation period.

## Sample Memo 2:

### *Avoiding losing enablement*

Persons within this study are often implicated in avoiding particular things that could cause their enablement to suffer. A common example of this is activities where a prosthesis can be broken or rendered inoperable. One instance of this is Rob, who played football and broke one of his legs in doing so. After getting the leg repaired, which was costly in terms of his time and energies in not being able to do things and then attending consultations and going through the fixing and re-fitting procedures, he would avoid things like football because he didn't want to lose his legs and get stuck inside where he would get 'cabin fever'.

This has been discussed in previous memos but there are several incidents coming to light which appear to go against this. Roy is a 41-year old lower-limb prosthesis user who has had a number of different prosthetic limbs over the years since his limb loss. He uses an artificial limb to aid him in ambulation, but has periodically had limbs break during use. He recounted one particular instance:

*R: It was a nightmare. I was getting off the bus, I forget where I was, and the foot just went snap. And I looked at it...*

P: Had you been doing anything?

*R: I wasn't doing anything. No, I was coming off the pavement, just you know how you normally step off the pavement and it snapped down. The only thing is I had a pair of boots on – thick boots on, and I had my laces done up and the foot didn't come off, but it was hanging. It's like someone getting an amputation – having their leg cut off. ... They said Roy you were lucky you didn't walk any further - because I was in the middle of the road – coming off the middle of the road when this thing happened. And I'm thinking oh Jaysus...*

So naturally Roy went to get this sorted out and to try to stop it happening again. He did not avoid 'stepping off pavement'. He 'wasn't doing anything' and was just

doing what a person 'normally' does, so this potentially accounts for why he kept at it, rather than being like Rob and avoiding such situations.

Or Mark gives an example of his prosthesis breaking up hills and yet he does not stop doing this. He is aware that it may well continue to happen if he keeps going hill-walking but he insists on doing so because he feels he should be able to hike up hills and not be stopped just because of a prosthesis breaking.

This disparity appears to be accounted for by what an individual feels they should be able to do. Those that avoid particular things see themselves as having no choice or that it does not matter so much if they avoid these particular things that are hazardous to their enablement, and that it is better for them if they do, but Roy and Mark are intent on keeping doing what they feel is normal and right to do, and things would be worse if they did not. In this way they are also avoiding losing their enablement but in different ways.

### **Sample memo 3:**

#### *Comparing just normally*

Elaborating previous memos on comparing, persons engage in social comparisons for the purposes of keeping just normal. When difficulties occur or persist, they compare to those worse-off because this reminds them about how things could be, and therefore that their own hardships are more acceptable (are acceptable) to bear. This makes their situation more manageable and they are able to keep persevering this way.

Comparisons are also made to others that are like the individual in order to normalise their situation. Individuals refer to others 'like me' when describing issues they face, noting that they are not alone and that their particular troubles are being experienced by others too. There are numerous examples of this occurring between individuals with limb absence, but it also broadens out to others who experience disability as well as examples of persons pointing out that 'we all have difficulties'. Doing so puts into relief how difficulties may be commonplace and so that they are therefore relatively 'normal' difficulties, or difficulties of a just normal nature, and thus something to keep going with.

## Appendix G – Selective Coding Sample

Excerpts of selective coding within autobiographical and interview data. This selective coding – the coding for further variation within the core category of the theory – was performed within Microsoft Word, though other coding was generally done through NVivo.

Paddy opened up the world for me. She became my hero, my role model, on par with Michael Jordan. She was athletic, smart, beautiful, and not only could she run marathons, she had a husband, and an important job at the hospital. In meeting her, I finally saw that, yes, you can have a normal life as an amputee. She altered my perception of what I could and couldn't do, so when she introduced me to a Long Island-based physical therapist who said she could teach me how to run, I was ready.

With my job and family, I don't have a lot of extra time to research options. I try to be in contact with my prosthetist, but it is hard with just the busyness... [I try] to describe [to my prosthetist] what I do with word pictures. However, this is a challenge, because a prosthetist and a doctor don't do what I do so they don't understand. ... It is frustrating not knowing how to describe what you need and the pictures you have in your brain with what actually is developed... I use what I have and deal with frustration and pain because it isn't what I need but like I mentioned finding someone to develop exactly what I need is almost impossible.

The main thing was the sensors kept slipping. They [prosthetist] re-set them but whatever I did seemed to make them move so I couldn't use it. And they moved them and so I had to learn how to use it again. And somewhere along the line I dislodged the motors in the fingers too and they had to fix that too. ... A couple of times the battery ran out on me and I just thought, no more. It's supposed to be top of the line. The people at [limb-fitting centre] do an amazing job and my decision was no reflection on their work but I just sort of sat down and went, "if it's not one thing it's another and I'm spending half my time either broken or playing fix-up" ...the technology just isn't there yet. I decided to give the cable hand another go. I got a new one since as well. ...it might not look so pretty and it's not the most modern thing out there but it does the job and for me that's the main thing. We're still working on bits and it's not perfect but it's better. I just can't have something that doesn't work, or worse, that works when you're at [limb fitting centre] but the moment you get home it breaks!

- Phil**  
Revealing
- Phil**  
Discovering normal possibilities
- Phil**  
Altering perceptions
- Phil**  
Realising what can be done and then doing it
- Phil**  
Circumstances are reasonable because of reasonable commitments – just-ifying
- Phil**  
Trying different ways to get change
- Phil**  
Persevering – I use what I have and deal with [it]
- Phil**  
No options but to go on
- Phil**  
Fixing. Repeated repairing.
- Phil**  
Reaching breaking point – no longer tolerable.
- Phil**  
Not just normal so not doing it.
- Phil**  
Redressing by reverting.
- Phil**  
'Good enoughness'
- Phil**  
Persevering despite issues
- Phil**  
Knowing what is not just normal