The Transformed Consumer: collective practices and identity work in an emotional community

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This thesis is dedicated to Ninian Dunnett
and Chuck Koval; great men both.

Table of Contents

Chapter One: Introduction

Chapter Two: A Review of the Literature

Chapter Three: Research Design

Chapter Four: Presentation of the Findings

Chapter Five: Conclusions, Contributions and Reflections

List of Tables

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"If there is to be a community in the world of individuals, it can only be (and needs to be) a community woven together from sharing and mutual care; a community of concern and responsibility for the equal right to be human and the equal ability to act on that right." (Bauman 2001: 149-150).

Abstract

This interpretive consumer research study interrogates the idea that people turn to consumption as a means of self-determination. Proceeding from the understanding that the consumer enacts the development of their identity within the marketplace, it takes as its subject those in transition. Its context is a support group community of people brought together by an illness - multiple myeloma. Here, through a phenomenological approach designed to explore the lived experience of illness, the thesis discovers community to be the enabling context for the consumer's negotiation of both selfhood and the market. Conclusions are drawn about the incremental, complex nature of identity work, and the collective practices that empower it. It is found that the marketplace requires significant mediation, but that the social resources of the community can equip the consumer to navigate its challenges. This transformation is manifested in the newly-diagnosed patient's journey from dislocation and passivity to the empowered status of 'skilled consumer'. The importance of the often-overlooked emotional texture of exchange within consumption communities is highlighted. In conclusion, it is offered that this study extends the concept of communities of practice into the field of consumption.

Chapter One

Introduction

Summary

This chapter opens the thesis, offering discussion of the context, rationale and aims of the study at hand. Section 1.1 provides an introduction; 1.2 goes on to discuss the concept of consumption communities, introducing the notion of "emotional community" and highlighting the frequent neglect of caring and sharing social exchange in the study of collective consumption; 1.3 describes the wider social setting for the study, focusing particularly on the changing landscape of healthcare; 1.4 makes some observations on the research context; 1.5 and 1.6 draw the chapter to a close with a review of the aims and objectives of the study and an outline of the structure of the thesis.

1.1 Introduction

Michel Foucault (1988) uses the word *technology* to describe physical and material practices with transformative functions. As he asserts, *technologies of the self* act in resistance to technologies of domination, enabling individuals "to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality." (ibid: 18)

This thesis appropriates the area of marketing discourse known as Consumer Culture Theory (Arnould and Thompson 2005) to unpack the technology – in short, the practices – through which consumers transform themselves in a market context. In order to develop its conclusions about the nature of identity work taking place in the marketplace, it focuses its attention on a site where selfhood has fallen under intense pressure. Within a community framed by the condition of serious illness – and in a healthcare setting which has undergone (and is still undergoing) a significant process of "marketisation" - it discovers patients using the technology of communal resources to effect identity transition, transforming themselves into 'skilled consumers'. In summary, this study is presented as an investigation of an under-researched aspect of communal consumption – the sharing of social support resources in order to realise agency in market interactions.

1.2 The marketplace and (emotional) community

In the years since Gainer and Fischer (1994: 178) described the phenomenon of community as being 'curiously neglected' within the discipline of marketing, a rich stream of study on the subject has emerged (Fischer et al 1996; Cova 1997; Holt 1995; Kozinets 2002; Muniz and O'Guinn 2001; Schouten and McAlexander 1995). These studies move the research focus from the individual to the 'communal nature of human existence and meaning' (Thomson and Holt 1996: 204). After Maffesoli (1996), they look to the *linking* value of consumables rather than the material, and argue that community can be fostered through shared consumption (Cova 1997; Muniz and O'Guinn 2001). Fischer et al (1996) show that the linking bond may be

an experience, an idea or a thing that people have in common. As Schouten and McAlexander (1995) put it: 'consumption activities, product categories, or even brands may serve as the basis for interaction and social cohesion' (ibid: 43). Such work shows that sense of community and communitas can be created and fostered through consumption, and that people can relate meaningfully to others through shared consumption practices (Arnould and Price 1993, Shouten and McAlexander 1995; Muniz and O'Guinn 2001).

Critiquing the extant literature, though, Kates (2002b) has argued that consumer research has been overly preoccupied with understanding communities linked by brand, hobby or activity. Mindful of Kates' (2002b) work in the gay community, the study at hand focuses on 'a much more pervasive, permanent, but dynamic phenomenon' (ibid: 383) – the condition of illness. Consumption communities that provide a safe place for self-transformation – like Schouten and McAlexander's biker subculture of consumption (1995) - take on a more profound role in life-threatening circumstances. This study proceeds from the belief that a community dealing with issues of diminishing health and mortality may more clearly manifest the mechanisms of social exchange – fundamentally, sharing and caring – and thus help broaden our limited understanding of the ties that bind individuals. Its research pursues what Maffesoli (1996) terms the 'social link,' or sociality.

Wuthnow (1994) points to the role that small groups can play in reducing the harmful effects of, for example, the decline of traditional community. He argues for small groups as what Foucault (1988) would call a *technology*: while not stemming

the tide of societal change, Maffesoli says, small groups are helping people adapt to and cope with these changes:

> "Small groups provide a way of transcending our most self-centred interests, they temper individualism and our culturally induced desire to be totally independent of one another." (Wuthnow, 1994: 22)

The particular collective observed can be found, like Muniz and O'Guinn's (2001) brand communities, in the marketplace, and it is here that much of its members' adapting and coping is directed. As a caring community it also has much in common with Kozinets' (2002) 'caring and sharing', anti-market, Burning Man community. It is a non-geographic community of self-help, bringing cancer patients and their loved ones together at support group meetings. Together, the members of the community find ways of negotiating, not just the disease and its symptoms, but issues of identity and transformation, and concomitantly, the various market interactions they must enter into post-diagnosis.

Maffesoli (1996) has rejected the preoccupation with the decline of community and the 'withdrawal into self' (ibid: 9), presenting in contradiction a case for the decline of *individualism*, citing what he calls 'emotional community'. A Weberian concept, emotional community 'makes clear that the link between shared emotion and open communal relationships leads to this multiplicity of groups which manage, at the end of the day, to form rather solid social arrangements.' (Weber 1978: 452-56).

Consumer research has been slow to relate this social cohesion to behaviour in the marketplace. Fischer et al's (ibid) observation that 'emotional support, social

companionship and supportive resources' are 'believed to be at the heart of communities' (ibid: 180) signals an under-explored emotional undercurrent to many communal consumption activities. Yet communities that provide social support are, with notable exceptions - Adelman (1992), Kates (2002a) and Kozinets (2002) - absent from the discussion of consumption communities. The study at hand seeks to address the paucity.

Such communities can be seen to create wider social benefits beyond those experienced by individual members, too. Kozinets (2002) suggests that 'commercially influenced forms of community should be seen not merely as parasitic co-optations (Holt 2002), hybridized communal market forms (Muniz and O'Guinn 2001), or symbiotic unions (Schouten and McAlexander 1995). They should also be conceptualized as a corrective, or at least ameliorative, response to two effects of market logics, namely, its tendency to weaken social ties and to reduce or homogenize self-expression.' (ibid: 34). This study embraces that conceptual aim.

Further, it seeks to assert that community can be a technology which enables the consumer to make most effective use of the marketplace. The support groups under study are discursively positioned as receptacles of first-hand market information, with much of the exchange within the group being concerned with navigating the healthcare, pharmaceutical and health insurance industries. Crucially this culture of information-exchange fosters a sense of belonging. The group provides a safe space for members to '*forge new meanings and incorporate these meanings into changing self-conceptions'* (Kates 2002a: 636). Carrying out this arduous business of identity

work with communal support, informants make a journey from patient to agent that empowers them with the self-confidence and ability to negotiate and manipulate the market. In transforming themselves, in short, they are transforming the market.

1.3 A note on research context

Because of reasons of access and of understanding, the study at hand has methodologically necessitated a kind of researcher-embedding in a culture likely to be unfamiliar to outsiders. This presents certain challenges to the reader, and attempts have been made in a variety of ways to contextualise and explain the site and its inhabitants. Appendix One gives information about the symptoms, treatment and understanding of the disease suffered by informants: the cancer multiple myeloma. In addition there is background description of the support groups under investigation. Appendix Two consists of brief, largely anecdotal biographies of the key informants.

1.4 Social Context – the changing healthcare landscape

From the 1980s onwards there has been a recognised paradigm shift in the provision of healthcare services within the British healthcare system (Laing and Hogg 2002). The NHS has undergone a series of reforms which emphasize that service provision should be oriented around the user rather than the producer. This change of focus has come as a result of the transplantation of commercial marketing management technology, theory and language into the management of public-sector services:

"Central to breaking this producer dominance has been the idea that service users should be viewed as consumers, enjoying the same rights in respect of public-sector services as individuals enjoy in respect of private-sector organizations." (Laing and Hogg 2002: 174).

The overall aim of these reforms has been, of course, to provide better, more responsive services to users. This process has been called one of empowerment (Newholm et al 2006). Such consumer empowerment is defined by Wathieu et al (2002) as 'letting consumers take control of variables that are conventionally pre-determined by marketers' (Wathieu et al in Cova and Pace 2006: 1090). A central variable in this context is choice. Saren (2007) elucidates:

"One espoused value underpinning the concept of marketing is the belief in choice: the right of consumers to have the freedom to choose from a selection of options in what they buy, from where and from whom." (ibid: 6).

This conceptualisation of the patient as 'consumer' of a healthcare system, however, remains contentious. It has met with resistance from some researchers and medical professionals, largely due to its perceived role in eroding the traditional power balance of the service encounter:

"Instead of passivity and obedience, the newly-empowered consumer-patient will be able to demand specific treatments within strict time limits, and may

even select which clinicians may perform these, after consulting the relevant medical information, clinical practice guidelines, Patients Charter clauses and hospital league tables" (Keaney 1999: 698)

Henwood et al (2003) concur that the growth of consumerism in healthcare puts new pressures on practitioners. Indeed, in the last twenty years the professional/consumer relationship has undergone 'unprecedented change' (Laing et al 2005: 514). The traditional dominance of the service professional has been challenged (Laing and Hogg 2002) and as a result the consumer/professional relationship can be seen as being in flux (Laing et al 2005). Further, Laing et al argue that access to information on the internet - as well as from other patients - means that consumers are increasingly able to challenge the 'traditional power structure in professional relationships' (ibid: 514). Services which were once characterised by an 'information asymmetry' (Hogg et al 2003: 476) - in that the professional held specialised knowledge which the user did not - are experiencing a shift in the balance of knowledge; and as a result, the discourse of power (Department of Health 2001; Thompson 2003). This blurring of traditional roles brings to mind Firat and Schultz's (1997) conception of the 'effacement' of the role of consumer and producer, which they see as a feature of the postmodern marketing process (ibid: 636).

In this context it seems likely that support groups (which have become increasingly common, established and influential in US healthcare) will be of growing value to UK consumers negotiating the difficulties and responsibilities of healthcare consumerism. Indeed the proliferation of 'health consumer groups' in the United

Kingdom has been labelled a 'new social movement' by Allsop et al (2004:737). More recently, Downey and Caterall (2007) pinpoint the importance of support groups both to consumer well-being and to consumer research itself:

> "Current social and economic issues concerning the care of the elderly, disabled and chronically ill suggest that communities of care and care support structures may be an important area for future consumer research." (ibid: 179).

Certainly the increasing "marketisation" of healthcare brings to mind the question posed by Arnould and Thompson (2005):

> "[H]ow does the emergence of consumption as a dominant human practice reconfigure cultural blueprints for action and interpretation and vice versa?" (ibid: 873)

1.5 Aims and Objectives

This study aims to contribute to the field of consumer research by exploring the collective practices which serve to mediate structure and provide meaning for the rebuilding of consumer self-identity. As such this study will analyse how *a particular manifestation* of consumer culture is constituted, sustained, transformed and shaped by broader cultural forces, with the overall aim ***to penetrate the***

complexity of the simply-stated idea that consumers turn to consumption as a means of self-determination. Following this aim, the objectives of this study are:

- to contextualise the phenomenon of consumer identity transition;

- to explore the experiences, processes and structures underlying the production of collective culture;

- to investigate the co-creation of social resources within this context;

- to identify and illuminate the collective and co-productive practices through which consumers negotiate a sense of self;

- to identify the social situations, roles and relationships that foster the construction of these practices.

1.6 Structure of the thesis

The thesis is structured as follows: Chapter One introduces themes and areas of interest and attempts to contextualise the study. Chapter Two further contextualises the study with reference to the particular body of consumer research literature that coalesces around notions of community and identity. The need for the study at hand is highlighted, and research questions are developed. Chapter Three outlines the key decisions made in the composition of the research design. A phenomenological approach was adopted; the rationale for this is explained. Chapter Four presents the findings of the empirical study, attempting to represent the lived experience of informants. Chapter Five draws the thesis to a close by offering conclusions and reflecting on its contribution to consumer research and to marketing management.

The chapter ends by outlining signposts for further research arising from this project.

Chapter Two

A Review of the Literature

Summary

This chapter presents a review of literature deemed to be both relevant and helpful to the exploration of the topic at hand; that of collective identity reconstruction. Section 2.2 discusses the relationship between consumption and identity; 2.3 explores issues of identity loss and reconstruction; 2.4 draws attention to the link between identity and narrative, highlighting the shaping power of cultural discourses; 2.5 draws on the consumption communities literature to build an understanding of such collectives. Section 2.6 presents the research questions arising from this review and draws the chapter to a close with some concluding remarks.

2.1 Introduction

This review will explore the extant consumer research literature to develop an understanding of current knowledge and debate on issues of identity and community in relation to the market, and from them to develop the focus and direction of its research. It will consider the consumer as identity-seeker, and assess the tensions between the consumer and the market in shaping identity. It will investigate the processes of identity loss and reconstruction, proposing that chronic illness may tend to create separation from the known self and a prolonged liminoid state (Turner 1969). It will examine the dynamic between the personal and cultural discourses that compete for influence in (re)shaping the consumer's identity, and consider the

social structures, cultural context and practices of the communities that act as an enabling resource for this individual reconstruction work. Finally it will frame the terms of its forthcoming research and identify key areas and issues to pursue.

In doing so it employs Schouten's (1991) definition of self-concept as 'the cognitive and affective understanding of who and what we are' (ibid: 412), and follows Belk's (1988) practice (highlighted by Ahuvia, 2005), of using terms such as identity, self-identity, and sense of self interchangeably to denote how a person subjectively recognises who he or she is.

2.2 Consumption and Identity

2.2.1 The Consumer as Identity Seeker

> *[C]onsumer culture denotes a social arrangement in which the relations between lived culture and social resources, and between meaningful ways of life and the symbolic and material resources on which they depend, are mediated through markets.* (Arnould and Thompson 2005: 869).

It is understood that the function of material culture is not solely the satisfaction of need; it also enables the creation and reinforcement of social structures, in-group hierarchies and social statuses – such as in instances of gift-giving (Mauss 1966), or conspicuous consumption (Veblen 1899). Consumer goods can foster collective consumption, where brands become a nexus for community, belonging and shared identity (Muniz and O'Guinn 2001). As Levy (1959) puts it; '[p]eople buy things

not only for what they can do, but also for what they mean.' (ibid: 118). As 'way-stations of meaning' (McCracken 1986: 71), consumer goods are able to carry and communicate cultural meanings (Levy, 1959; McCracken 1986). In this way, products can be chosen to fit with consumers' sense of self:

> '[M]odern goods are recognized as essentially psychological things which are symbolic of personal attributes and goals and of social patterns and strivings.' (Levy 1959: 119)

Belk (1988), in his seminal paper on the extended self, takes the notion of symbolic consumption further, arguing that consumers do more than display their status or identity through the products and brands of material culture; instead we create an 'extended self' by appropriating and incorporating objects and symbols into our identity. He condenses this theory into the notion that 'we are what we have' describing this as 'the most basic and powerful fact of consumer behaviour' (ibid: 139).

With this in mind, Arnould and Thompson's influential paper on Consumer Culture Theory (2005) goes so far as to assert that 'the marketplace has become a preeminent source of mythic and symbolic resources through which people… construct narratives of identity' (ibid: 871). The study at hand aims to establish a point of perspective on this claim, interrogating mythical and symbolic dimensions to consumption within an empirical site where identity is observed to be overtly in motion.

Certainly, the extant literature depicts a material world where consumers seek to forge their own identities and meanings through interactions and exchanges (Holt 2002; Kozinets 2002; Thompson 2003). Goulding et al concur:

"Consumption…becomes a means through which individuals can creatively construct and express the multitude of identities that are open to them." (Goulding et al, 2002: 265)

As Arnould and Thompson (2005) highlight, the consumer can be viewed as both identity-seeker and identity maker. This view of consumption – as a creative, expressive act – suggests that the consumer is free to play with symbols, to make them their own and display them as they wish in a form of 'identity performance' (Murray 2002: 428).

2.2.2 The structuring influence of the marketplace

From the 1920s onwards, as Holt (2002) describes, marketers drew on pseudo-scientific management theories, behaviourism and clinical psychology and 'began to methodically drive home linkages between product attributes and a package of desirable personal characteristics that together was declared to constitute the modern good life' (ibid: 80).

Holt cites the influential ideas of Horkheimer and Adorno ([1944] 1996), who argued that the power to choose between slightly differentiated commodities provided people with identities that deflected them from seeking more power in

society. As Holt puts it (ibid: 71): '[m]arket segmentation is inherently a technology of domination.'

Several authors have questioned whether consumers can ever be truly emancipated from the structuring influence of the marketplace (Firat and Venkatesh 1995; Holt 2002; Kozinets 2002; Thompson 2004). Arnould and Thompson (2005) point out that consumer culture theorists find the market providing certain kinds of 'consumer positions that consumers can choose to inhabit' (ibid: 871).

Firat and Venkatesh (1995) describe this structuring influence as the 'totalizing logic' of the marketplace, where marketers enforce consumers' definitions of the world, even to the point of controlling their ontology, and their construction of social reality. In a postmodern world, the authors maintain, consumption practices have replaced other ways of organising society – so called metanarratives - such as religion, gender and class. Consumers, uprooted in the absence of the rigid categorisations of metanarratives, find alternative contexts in which to construct and express their identity (ibid). Goulding et al elucidate:

> "As the traditional institutions that formally provided the basis of identity disintegrate, consumption as a means of constructing and expressing identity becomes ever more dominant." (Goulding et al, 2002: 264)

After Bauman (1988) Saren (2007), in a critique of the theory of self-creation through consumption, notes that 'freedom is now defined as consumer choice through which the individuals are able to invent and create their own self-identity.

People are free to use consumer goods to 'become' any of their 'possible selves'; they are able to *create* their own perceived self by *identifying with* the objects and symbols of their consumption.' (ibid: 2 [emphasis author's own]). We are reminded of Bauman's view of the limitations and relational nature of freedom: freedom makes sense only as an opposition to some past or present condition (Bauman 1988:7).

2.2.3 The dynamic between consumer and marketplace

For Holt (2002), the relationship between consumer and market is a 'dialectic'. The consumer is free to be creative with marketer-generated materials and to resist the meanings and identities handed forth (Holt 2002; Kozinets 2002; Thompson 2004). Coining the phrase 'reflexively defiant consumer' Ozanne and Murray (1995) explain how resistance to this system is possible if a consumer reflects critically on the structuring effects of the marketing code to see the simple use value of a product. Resistance and activism are important to 'identity play' (Arnould and Thompson 2005: 874), as consumers define themselves in distinction to corporate capitalism and the marketplace (Holt 2002; Kozinets 2002; Kozinets and Handelman 2004; Thompson 2004).

Yet, while as Holt (2002) states, postmodern consumers 'strive to deflect the perceived paternalism of companies', brands have become more commercially successful than ever by matching the consumer's sophistication, using irony, association with attractive cultural epicentres like urban black culture, product placement and other devices to suggest authenticity. Crucially, they are presenting

themselves to the brand-aware consumer 'not as cultural blueprints but as cultural resources, as useful ingredients to produce the self as one chooses.' (ibid: 83). The market, in other words, has geared itself to deliver a sense of emancipation while continuing to exert its influence and make its profits.

The debate about the power of the marketplace to shape consumers' identities has been contested for many decades. For Firat and Venkatesh (1995) '[t]he postmodern consumer attempts to restructure his/her identities in the face of overpowering market forces' (ibid: 255). The authors go on to suggest that future research should look at the 'extent to which consumers, rather than producers, marketers or "the market", control their own reality' (ibid: 260):

> "The consumer needs to be studied as a participant in an ongoing, never-ending process of construction that includes a multiplicity of moments where things (most importantly as symbols) are consumed, produced, signified, represented, allocated, distributed, and circulated." (Firat and Venkatesh 1995: 259)

This study responds to the invitation to further explore the consumer as self-constituting entity. Its subjects are people whose identity has come under intense and unexpected pressure through illness, and who find themselves searching for an ameliorative identity position.

2.3 Identity Loss and (Re)construction

2.3.1 Life events and loss of identity

One becomes aware that 'belonging' and 'identity' are not cut in rock, that they are not secured by a lifelong guarantee, that they are eminently negotiable and revocable; and that one's own decisions, the steps one takes, the way one acts – and the determination to stick by all that – are crucial factors of both. (Bauman 2004: 11)

As Bauman (2004) asserts, identity is not set in stone; it is revocable. It can be altered, without consent, by outside forces and life circumstance, or intentionally and reflexively worked on as a 'project of the self' (Giddens 1991). The identities-studies strand of consumer research largely focuses on the latter area, in which – as noted above – the consumer is viewed as identity seeker. However consumer researchers (after Belk 1988) have also looked at particular instances where identity loss is experienced. This body of literature – which is largely concerned with life and role transition - is of particular relevance to the study at hand, where outside forces (the diagnosis of a serious illness) occasion an unforeseen transition that profoundly alters one's sense of self.

When healthy individuals are confronted with serious illness and death it can create a disruption of self-concept, a fissure from the familiar self:

> "The onset of illness, especially if severe, constitutes a threat to the integrity of the body and self-identity, and requires a status change from well person to patient." (Lupton, 1994: 79)

Consumer researchers have explored disruptive events such as terminal illness (Adelman 1992); job loss (Roberts 1991); relocation (Mehta and Belk 1991; Penaloza 1994) and death (Adelman 1992; Price, Arnould and Curasi 2000; Bonsu and Belk 2003) in order to understand the role that possessions (and in the case of Penaloza 1994, branded goods) play in the negotiation of transition. Among other conclusions, it is found that the marketplace offers tools for the rebuilding of the self. Brands and special possessions play a part in easing life transitions through their active function in the maintenance of sense of self (Belk 1988; Mehta and Belk 1991; Penaloza 1994). As this literature reveals, consumers use possessions, branded goods and services (such as elective plastic surgery) in an effort to manage or alter their self-concept (Belk 1988; Schouten 1991; Schouten and McAlexander 1995). Indeed Belk (1988) follows the logic of the extended self to find a loss or lessening of identity occasioned by involuntary loss of possessions. Goffman (1961), writing on institutionalization, notes that the removal of possessions aids the construction of a standardised identity. Citing examples where bodies are standardised with prison uniforms or military haircuts, Belk (1988) describes how this elimination of uniqueness may erode a person's sense of self.

It is from Belk's (1988) thesis that we can begin to understand the emotional consequences of a break from the known self. As Belk notes, a period of grieving or mourning ensues after the loss of possessions – 'what is lost…may be a part of the

self' (ibid: 142). Similarly, Frank (1993) argues that illness fosters a profound sense of loss, as sufferers grieve for that which is lost; their former "healthy" self.

The study of the lived experience of illness, in summary, offers the researcher a particular opportunity to develop insight into consumption processes – in this case the negotiation of role and identity transition – through observing the pivotal movement at a period of substantial change in an individual's life (Frank 1993; Pavia and Mason 2004; Wong and King 2008).

2.3.2 Identity (re)construction

Authors such as Schouten (1991) and Fischer and Gainer (1993) have approached the problem of framing identity (re)construction by employing van Genneps's (1960) theory of rites of passage. For Schouten (1991) this expands the current understanding of the self-concept by facilitating an examination of role transition in consumers whose life is in flux - more specifically, consumers (and potential future consumers) of elective plastic surgery. Fischer and Gainer (1993) seek to understand transition by applying the theory to motherhood and the ritual of baby showers.

Van Gennep (1960) deconstructs life passages into three phases with attendant rituals:

1. Separation, which constitutes a disengagement from a former state, role or status.

2. Transition, which constitutes a liminal phase in which one passes from one role or state into another.

3. Reincorporation, where an individual takes on a new role or state (and/or reunion with an existing group or integration into a new group).

Van Gennep's (1960) analysis of primal cultures conceptualises liminality as a collective experience of status change where rituals generate experiences of communitas. Turner (1969, 1974) reconceptualises van Gennep's framework for a modern, secular world in which few supportive rites of passage remain and individuals experience an isolated form of liminality – or liminoid state.

Turner (1969) notes that those in a liminoid state are 'reduced or ground down to a uniform condition to be fashioned anew and endowed with additional powers to enable them to cope with their new station in life' (ibid: 95). These 'threshold people', become homogenised (ibid: 95). This view of the objectifying and homogenising force of separation and liminality is consonant with patients' experiences of the standardising power of the medical encounter (Frank 1995). Becoming a medical 'case' can erode an individual's uniqueness, thus reducing the sense of self, as Belk (1988) observes.

In such circumstances consumers may construct 'self-imposed personal rite[s] of passage' with activities and symbols made available to them in the marketplace (Schouten 1991: 421; Mehta and Belk 1991). Rook (1985) notes that ritual is pervasive in consumer culture, from grooming rituals to 'rites of passage' events such as graduation and marriage (ibid: 254). Central to Schouten's (1991)

conceptualisation of identities in transition is the notion of identity play and 'possible selves'. He holds that liminal people engage in 'identity play' where they formulate and evaluate possible selves in a bid to create new roles for themselves (Schouten 1991: 421; [after Turner 1974]).

2.3.2.1 Chronic illness and the 'liminal consumer'

As recognised by Pavia and Mason (2004), consumers diagnosed with serious illness enter a kind of 'limbo' where they are neither dying nor - the full ramifications of their illness being unknown to them - cured. For the purposes of this study this transitional phase is understood as a liminoid state: a period of ambiguity, nonstatus and unfixed identity, Turner (1969). As Schouten notes:

> 'When a person loses or rejects an important aspect of self, separation occurs and liminality sets in.' (Schouten 1991: 421)

Exploring consumption practices in those whose future is threatened due to diagnosis with breast cancer, Pavia and Mason (2004) recognise (yet do not explore in terms of self-identity) that the period of 'limbo' experienced by patients after diagnosis and initial treatment is fertile ground for consumer researchers:

> "The period of sustained uncertainty after a life-threatening event is a rich field for consumer research. A prolonged time of limbo provides a setting in which changes over time can be assessed, and it allows time for sustainable changes in consumer behaviour to emerge." (ibid: 441)

Diagnosis engenders a separation from the known self and alienation from familiar life roles. Yet as Lupton (1994) describes, this period of ambiguity does not have a fixed term; patients may never achieve the stability of reincorporation and move beyond a liminoid state.

Pavia and Mason's (2004) conceptualisation of the lived experience of breast cancer privileges what Wong and King (2008) describe as a linear model of illness, which supports the culturally dominant restitution narrative:

> "These types of illnesses [cancer] have an acute stress-filled phase in which the person chooses among treatment options and then undergoes treatment."
> (Pavia and Mason, 2004: 441)

This linear model dictates that the ill avail themselves of the technology of bio-medicine in order to eradicate their illness and therefore return to a position of normalcy. But for Frank (1995), for whom the seeking of medical care is the central moment in modernist illness experience, the acceptance of the framing discourse of biomedicine is also a moment of 'narrative surrender' (ibid: 6). Frank embraces the idea of a postmodern negotiation of illness:

> "The postmodern experience of illness begins when ill people recognise that more is involved in their experiences than the medical story can tell."
> (ibid: 6)

This postmodern self-conceptualisation is consistent with the pathology of many chronic conditions – including multiple myeloma - where one may never be "cured", but may experience periods of wellness as well as illness.

Schouten (1991) supports the notion that liminoid states offer a window into a fruitful period of identity construction to the consumer researcher:

> "Role transitions are crucial times in determining the direction and quality of consumers' lives, but little is yet known about the consumption behaviours of liminal people." (Schouten 1991: 421)

The study at hand seeks to address the paucity, offering up the concept of liminality (Turner 1969) as a way of understanding the experience of those who suffer a crisis-induced separation from the known self.

2.4 Identity and Narrative

2.4.1 The narrative construction of identity

Post Belk (1988), consumer research has increasingly looked at the complexities and challenges of identity construction. Characteristically identity is viewed as being structured in terms of narrative (Fournier 1998; Giddens 1991; Thompson 1996, 1997; Thompson and Tambyah 1999). This means that we understand ourselves not just in terms of physical attributes (I am blonde), personal values (I admire honesty) or national affiliations (I am Scottish), for example, but also in terms of the stories we attach to them. Such stories are pieced together, and become

our life story. This narrative allows us to make sense of who we are, our past selves and who we may become in the future (Ahuvia 2005; Fournier 1998). This is not simply an individuated process; from the consumption communities literature we learn that identity can be discursively negotiated through the circulation of (brand) stories in a collective (Muniz and O'Guinn 2001).

Central to the study at hand is the notion that illness can act as catalyst for transition through the separation from the known self. As Frank (1995) puts it:

"Serious illness is a loss of the "destination and map" that had previously guided the ill person's life" (ibid: 1)

Diagnosis sets in motion a search for understanding, for social and cultural resources that give shape and meaning to newly emergent identities. Frank (1993, 1995) maintains that the ill – or 'wounded' as he terms them – understand their ill selves, and ultimately reconstruct their identities, through the shaping and sharing of illness narratives. As Thompson (1997) notes, narratives of personal identity are contextualised within a background of cultural meanings and belief systems. This cultural background provides 'social categories, common sense beliefs, folk knowledge, and interpretive frames of reference from which personalized meanings and conceptions of self-identity are constituted' (ibid: 440). Such cultural discourses are seen to act as a shaping force on narratives of identity.

2.4.2 Deconstructing cultural discourses

Arguing that those diagnosed with serious illness undertake identity reconstruction through the stories they tell about their experiences, Frank (1993, 1995) pinpoints three general types of illness narratives: the restitution story, the chaos story, and the quest story.

> "Illness becomes a *circulation of stories,* professional and lay, but not all stories are equal. The story of illness that trumps all others in the modern period is the medical narrative." (Frank 1995: 5 [emphasis added])

2.4.2.1 The Restitution story and its limitations

The restitution story is the most prevalent type of illness narrative in North America, Britain and Australia (Lupton 1994; Wong and King 2008), and is consistent with the dominance of technology (including biomedicine) in these cultures. It emphasises taking control to become well. Its basic story line is: "Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again" (Frank 1995: 77).

Building on the work of Thompson (cf 2003; 2004; 2005), Wong and King (2008) explore the cultural discourses surrounding the lived experience of breast cancer. They propose that the restitution narrative, as identified by Frank (1993, 1995), has become the dominant sociocultural norm shaping illness experience in Western societies. As such, their study extends understanding of motivations for risk taking behaviour by viewing breast cancer patients' treatment decisions as the 'embodiment of culturally reinforced illness narratives and metaphors' (ibid: 580). The authors define biomedicine as 'Western, technology-based, interventionist

medicine' and describe how individual health decisions reflect its 'culturally endorsed meaning systems' (ibid: 590). They expand Frank's (1995) framework of illness narratives from an interpersonal level to view the structuring power of illness narratives on a broader sociocultural plane.

Concurring with Ehrenreich's (2001) observation that the restitution narrative requires implacable optimism, Wong and King (2008) suggest that its framing discourse imagines the individual patient's body as resilient and reconstructable. Within the breast cancer community, narratives that build on restitution stories and discourses of control and certainty through biomedicine are promoted both by medical institutions and dominant survivor groups (Lupton 2003: 11). 'Winning the battle with cancer' (the "pink ribbon" approach) is linked to early detection and aggressive treatment. The biomedical model of cancer prescribes the "slash" (surgically removing the cells), "burn" (killing the cells with radiation), and "poison" (through chemotherapy) technique as its primary treatment method (Love 2005; Stabiner 1997 cited by Wong and King, ibid: 583).

Wong and King (2008) observe, though, that restitution stories actually come under considerable strain when exposed to a more complex reality. Indeed, the restitution narrative is far from perfectly applicable to *any* kind of cancer, because cancer is a disease in which risks of recurrence and metastasis are always present. Barbara Ehrenreich, following a diagnosis of breast cancer, writes with passion of the discord between her own cancer experience and the relentlessly positive framing discourses of the 'pink ribbon movement'. She sees this movement as an all-pervading cultural force:

"Culture" is too weak a word to describe all this. What has grown up around breast cancer in just the last fifteen years more nearly resembles a cult – or, given that it numbers more than two million women, their families, and friends – perhaps we should say a full-fledged religion. (2001: 50)

The norm of restitution encourages patients to feel a personal responsibility for their health or illness - a responsibility that extends even to include detecting the onset of disease. And, as Wong and King (2008) argue, the framing discourse further encourages the over-consumption of radical treatment options such as mastectomy. They report that a recent survey showed only 74% of women diagnosed with early-stage breast cancer chose a lumpectomy over the more radical surgery of mastectomy, though 82% had been so advised by their doctors (ibid: 579). In their interviews with breast cancer patients, Charles et al. (1998) found their informants would undergo everything possible in terms of treatment to allay any guilty feelings that they could have done more. Several informants in Wong and King's study similarly chose the most aggressive treatments because of this imperative of personal responsibility.

Exploring 'the emergent defiance against restitution and the adoption of narratives that are more consonant with the lived experience of breast cancer', Wong and King (2008) report that feminists such as Ehrenreich (2001) have found the restitution story's promotion of normative femininities and technocentric treatments oppressive to women (ibid: 580). Some breast cancer patients who do not share its cultural assumptions, like the Buddhist Asian-American "Ivy" in Wong and King's study,

have gone on to reject the imperatives of the narrative altogether (against medical advice, "Ivy" terminated her chemotherapy treatment and breast reconstruction early).

Whatever alternative discourses may more beneficially align with the individual survivor's experience of living with cancer, the prevalent rhetoric relating to the condition is still grounded in the restitution story. Wong and King's (2008) study makes a persuasive call for 'alternative discourses within an expanded composition of illness narratives' (ibid: 591).

2.4.2.2 Alternative discourses

Frank's chaos story contrasts with the restitution story, emphasising lack of control, lack of successful treatment, physical decline and other problems. Wong and King (2008), considering resistance to the restitution story, describe the radical alternative discourse promoted by the breast cancer activist community. Here is an organisation that mobilises anger against institutions of biomedicine and the healthcare system, countering the prevalent narrative with representations of breast cancer that include women living with the disease, and dying from it (ibid: 591).

Ultimately Wong and King (2008) advise that in order to help breast cancer patients receive the information that will allow them to make accurate risk assessments about their condition and treatment, alternative ideologies that are more consonant with the 'realities' of breast cancer should be privileged. Here the study at hand diverges from the authors' views, which would seem to disavow the embodied, subjective nature of illness and the value of personal experience. Indeed beyond looking at the breast cancer social movement, Wong and King can be seen to

neglect the *collective* nature of the lived experience of cancer. As this study proposes to demonstrate, the illness experience is often shared with fellow patients in settings such as self-help groups, where understandings of what it is to be a patient are forged *alongside* fellow patients (Kates 2002a).

Certainly the (dominant) restitution narrative can not be accessed by most of the myeloma patients who are this study's informants - who have been diagnosed with a terminal illness. But in considering the discursive resources available to them for identity reconstruction, we must give weight to Frank's quest story, which provides a positive alternative to patients who may not make a complete recovery. The quest story is consonant with the lived experience of chronic, incurable illness, such as myeloma. It accommodates the notion of living with cancer or illness, and the discourse it frames is a story of negotiating a new self and new ways of being. Quest stories often construct illness as opportunity, and those who adopt this framing discourse tend to emphasise positive life changes due to the illness, such as becoming involved in patient advocacy and other life-enhancing adjustments. As Frank puts it:

> "Quest stories meet suffering head on; they accept illness and seek to use it. Illness is the occasion of a journey that becomes a quest. What is quested for may never be wholly clear, but the quest is defined by the ill person's belief that something is to be gained through the experience." (1995: 115)

Unlike the restitution story, the quest story does not depict the illness as transitory, but recognises the moral duty of sharing the illness experience. As will become

evident from an assessment of community as the context for identity reconstruction in the literature, the sharing of stories can be a vital factor in personal empowerment.

2.4.3 Discourses of power, and resistance

"[N]o identity position stands outside of discourses of power that channel thought and action in certain directions. Broadly defined social institutions – such as the family, religion, professional work, education, and medicine – all produce discourses through which social hierarchies and status distinctions are contracted and legitimated, and through which normative identity positions (i.e. how one is to be a father, mother, teacher, student, worker, manager, doctor or patient) are institutionalized. These institutions and concomitant social roles have been thoroughly interpenetrated by marketing discourses (via advertising, fashion, and mass media) and the capitalist lifestyle ideals that infuse all facets of consumer culture."
(Thompson 2004: 172)

If the above assertion is to be subscribed to, the consumer is never free from the cultural forces that shape 'thought and action'. Broadly speaking the work of Craig Thompson and his co-authors concerns the framing of our consumer experiences and identity by marketplace ideologies and cultural discourses:

"Personalized consumption meanings then express a co-constituting (or dialectical) relationship between the social conditions and identity issues

salient to a given consumer and a broader legacy of historically available frames of reference, rather than being purely subjective or idiosyncratic constructions." (Thompson 1997: 441)

After Foucault's (1984) idea of power and knowledge being embedded in the discursive practices of institutions, Thompson (2004) conceptualises the framing narratives that seek to channel consumers' identities and lifestyles in a particular ideological direction as *discourses of power*:

"Discourses of power can take many forms ranging from the nexus of discourses and cultural ideals that give rise to gender socialization to more specific discourses that define one's identity in a specific institutional setting, such as being a particular kind of patient (i.e. a diabetic, an asthmatic, etc.) in the medical system." (Thompson 2004: 170)

Culturally-oriented studies argue that consumption meanings are represented, comprehended and put into social use through narratives (Arnould and Price 1993; Thompson 1997; Thompson and Troester 2002). But these narratives can be confining. As has been shown by Thompson (2004) and Holt (2002) among others, consumer identity is fettered by marketplace ideologies and the shaping narratives they foster. Thompson and Haytko, for example (1997), explore how the fashion industry acts as a cultural production system that predisposes consumers to certain kinds of identity choices. Turning to the consumption stories of expatriots, Thompson and Tambyah (1999) use the context to analyse cosmopolitanism as a framing ideology:

"The post-structuralist view is that all knowledge claims, cultural representations, and identity positions are constituted in ideological systems; thus, ideologies organize the practices of everyday life and sustain a vast array of socioeconomic and cultural hierarchies." (ibid: 214)

When Thompson comes to examine the structuring influence of natural health marketplace mythologies (2004), he concludes that no consumer position is truly emancipated. Yet consumers may resist and pursue alternatives, and Thompson's oeuvre illuminates ways in which consumers work *within* the framing mechanisms of the marketplace to develop identity positions. Indeed his natural health adherents, as he describes them, are 'contesting a medical identity' (ibid: 170). The framing discourse of biomedicine – the restitution story – may dominate patients' lived experience of cancer (Pavia and Mason 2004; Wong and King 2008); still, many of them come to resist what Thompson calls 'the confining orthodoxy' (2003: 97, 2004: 170):

"Often survivors are faced with the realization that returning to the same life that was lived before is impossible because of the future risks that they face. This awareness can lead to an emergent defiance against restitution, which we later present in terms of abandoning treatment and body victimology." (Wong and King 2008: 582)

Thompson observes that the informants of his 2003 study pursue a compelling alternative to the framing narrative of mainstream medicine – whose technologies are construed as lacking 'regenerative capacities'. Instead these consumers carry out

their identity work in the natural health marketplace, where holistic healing practices are seen as being free from 'degenerative connotations' (ibid: 97).

Such studies suggest that medical consumers do not just reconstruct their identity, they *reclaim* it from the grip, not only of the illness itself, but of the strictures of the medico-administrative system. Partly these oppositional alignments are conditioned by the sort of deep-running social, cultural and historical forces Thompson would characterise as discourses of power:

> "From a cultural perspective, choice options are fundamentally embedded in meanings and narratives; hence consumer perceptions of choice situations are always constructed within a cultural frame of reference." (Thompson and Troester 2002: 568)

2.4.3.1 Shifting discourses of power

The discourses of power around medical treatment are shifting. Services which were once characterised by an 'information asymmetry' (Hogg et al 2003: 476) - in that the professional held specialised knowledge which the user did not - are experiencing a shift in the balance of knowledge; and as a result, the discourse of power. This blurring of traditional roles brings to mind Firat and Schultz's (1997) conception of the 'effacement' of the role of consumer and producer, which they see as a feature of the postmodern marketing process (ibid: 636).

The increasingly prevalent notion that the patient should be seen as an informed consumer has produced some change in the balance of power, too. The patient-as-consumer model has 'placed patients in a more powerful position ideologically with

respect to the system for it has heightened their right to choose' (O'Connor, 1995: 168, cited by Thompson 2003: 84).

Thompson (2005) observes that medical experts are now 'prophets of probability', advising individuals on the risks and potential outcomes attached to particular treatment options rather than giving definitive opinions (ibid: 236). This transfers the responsibility to the patient, who must choose his or her own treatment pathway. The notion of a consumerist approach to health care has received support from patient advocacy groups, public policy makers and from proponents of a market economy model (Lupton 1997). Yet the question arises: how do consumers negotiate such a responsibility? Thompson (2005) suggests that consumers cope by moving away from scientific and medical authorities - which are no longer regarded as sacrosanct - towards communities of fellow patients (such as self-help groups) where they can find the narratives that provide the best "fit" with their sense of self and desired outcome.

The context for Thompson's (2005) study, for example - the natural childbirth community - inverts the view that hospital is the safest place to give birth. Such a community encourages childbirth choices in a position directly opposed to mainstream medical advice. Lupton (1997) points out that the "consumerist" conceptualisation of the patient, which enables such choices, fits Giddens' (1991) notion of 'reflexive project of the self'; the practices that constitute the self are constantly reflected upon, and life in itself becomes an entrepreneurial project of self-improvement (ibid: 374). Thompson asserts that this issue warrants further investigation, arguing that 'the critical objective is to understand the new

configuration of power relationships that have emerged, the identity positions and identity practices they engender' (Thompson 2004: 173).

Thompson's (2003) discussion of consumers' desire to produce their own identity implicates a modern/post-modern clash in the erosion of traditional medical professional/patient roles and the attenuation of professional authority:

> "The patient as consumer desires to produce his/her own medico-administrative identity through interaction with physicians, nurses and technologies. This has contributed to the diminution of medical authority as well as increased expectations (and incidences of dissatisfaction) regarding the quality of service. Yet these post-modern currents inevitably collide with the more intractable modernist features of the medico-administrative system." (ibid: 103)

Considering his informants' engagement with the natural childbirth movement, Thompson (2005) likens the community's ideals to a Romantic utopia (in contrast to the modernist ethos of institutional medicine). His observation of their 'very significant identity work' leads him to conclude that identity work through consumption practices can take the little-explored form – to be further explored in the study at hand – of "an anti-institutional construction of self" (ibid: 246).

Indeed for Thompson, after Frank (1993, 1995), a patient's illness narrative – their personal discourse of power, perhaps – is the key instrument of patient empowerment in a confining medical marketplace:

> "[I]llness narratives are a means to more effectively take up the position of the postmodern consumer. These stories do not just narrate suffering. They also personalize illness experiences and offer a way to meaningfully interact with ascribed medico-administrative identities." (Thompson 2003: 103)

Thompson's concept of (institutionally ascribed) 'medico-administrative identity' is akin to Kates' (2002a) use of 'illness identity'. Yet while both authors recognise that making sense of a diagnosis and the subsequent altering of self-conception is a collaborative act, Kates sees the outcome as one of co-creation, rather than a product of consumer resistance:

> "Clients and professionals of AIDS CBOs are actively, creatively, critically (and, some might even agree, desperately) co-engaging in the project of the self, as they reflexively forge new meanings and incorporate these meanings into changing self-conceptions." (Kates 2002a: 636)

Kates' (2002a) study of an AIDS community looks at how professionals and non-professionals co-create an emergent sense of self in the face of illness and death. Kates, employing the work of Fish (1980), observes that people living (and working) with AIDS become part of an 'interpretive community' through a process of self-disclosure within a support organisation. In this community 'broadly similar' views are held about death, dying and grieving.

He characterises the healthcare service worker – traditionally the 'producer' to the patient's 'consumer' – as 'fellow traveller', echoing Firat and Shultz's (1997)

sentiments regarding the erosion of the boundaries that circumscribe the concepts of producer and consumer. The consumer-patient and producer-professional move outside the traditional boundaries of their positions, working together to create meaning and understanding:

> "[T]he role of the "service worker" is not that of the superior medical professional but that of the "fellow traveller" or "facilitator", who helps those suffering achieve a particular kind of psychological "closure" or a fulfilling understanding of life's final curtain." (Kates 2002a: 636)

Such positive accounts of service providers (ie medical professionals) in the context of identity construction are rare in the literature. Thompson and Troester's (2002) study of informants' relationships to their natural health practitioners invokes Price and Arnould's (1999) exploration of 'service provider friendships' predicated on instrumentality (helping clients attain their desired goals) and social bonding (providing clients with needed social and emotional support). Price and Arnould (1999) also suggest, though, that conventional commercial settings can pose a barrier to the expressive and communal dimensions of friendship, preventing revelatory self-disclosures, deepened emotional attachments, and strong feelings of personal loyalty. In their investigation of another *anti*-institutional medical context, Thompson and Troester (2002) point out that: 'the explicitly therapeutic nature of natural health service encounters, coupled with their holistic ethos of treating the whole person, almost demands revelatory disclosures on the part of clients. Accordingly, our participants frequently describe strong emotional connections to

their natural health practitioners and see them as having played an important and often transformative role in their lives' (ibid: 560-561).

Much like Thompson's (2004) natural health marketplace, which allows consumers to 'find social networks of practitioners and like-minded individuals who will support and reinforce their preferred conceptions' (2004: 171), the myeloma community, and in particular its support groups, present ways of living with illness through collective mediation – and indeed friendship. To explore this context in the literature, this review now turns to the subject of community within the area of study defined by Arnould and Thompson (2005) as Consumer Culture Theory.

2.5 Identity and Community

2.5.1 Introduction to consumer communities

> *Our neglect of non-individual level phenomena stems from the biases of our dominant perspective and theories. The goal of most consumer behaviour studies has only been to explain how individual cognition, perception of traits influence individual behaviour.* (Gainer and Fischer 1994: 137)

For some time now consumer researchers have sought to address the lacuna identified by Gainer and Fischer, turning their attention to the phenomenon of community. This stream of consumer research argues that consumption activities play a central role in the development and maintenance of community and in the fostering of a *sense* of community (cf Fischer et al 1996; Cova 1997; Holt 1995;

Muniz and O'Guinn 2001; Schouten and McAlexander 1995). These studies move the research focus from the individual to the 'communal nature of human existence and meaning' (Thomson and Holt 1996: 204) and respond to critiques concerning the erosion of traditional forms of solidarity and the growing individualism of consumer culture.

Influential articles, such as Arnould and Price's (1993) study of the extraordinary service encounter and Schouten and McAlexander's (1995) study of the Harley Davidson subculture of consumption, bring the concept of communal consumption to the fore, where it is recognised that 'consumption activities, product categories, or even brands may serve as the basis for interaction and social cohesion' (Schouten and McAlexander 1995: 43). Consumers – as described in the extant literature - identify themselves in terms of the activities, objects, relationships and experiences that give their life meaning (Arnould and Price 1993, Schouten and McAlexander 1995). This area of inquiry has subsequently enjoyed the attention of several authors; Holt 1995; Schouten and McAlexander 1995; Fischer et al 1996; Cova 1997; Kozinets, 2001, 2002; Muniz and O'Guinn, 2001, to name but a few - leading Cova and Pace (2006) to point out that 'analysts are no more questioning whether the concepts of community and and/or tribe might have a place in marketing thinking.' (ibid: 1088). Indeed for O'Guinn and Muniz (2005) the interplay between community and consumption is where we can *begin* to develop our understanding of 'how we live and why we consume as we do' (ibid: 253). They go on to propose that community should be a 'fundamental consumer behaviour term' (ibid: 253).

2.5.2 What is community?

The attempt to define "community" has no single answer:

> '[T]here is no clear and widely accepted definition of just what characteristic features of social interaction constitute the solidaristic relations typical of so-called communities.' (Scott and Marshall, 2005: 94)

A nebulous concept, 'community' is different things to different people - and as Bauman (2001) points out, it is a concept that is loaded with sometimes questionable nostalgia and emotion; indeed he describes it as a word with a *feel*. A sociologist may consider it to be a spatially bounded neighbourhood, something distinct from society. A philosopher may think of it in ideological terms - a form of utopia (Plato trans. Lee 1974). The cultural sociologist may think of it in terms of the search for belonging or an expression of communitas (Turner 1969). An anthropologist may use the term to describe a culturally bounded group (Mauss 1966). From a political standpoint, civic engagement and citizenship may be looked for (Putnam 2002). But what they all might agree on according to Delanty (2003: 2-3) – if it's not too far fetched to imagine such a gathering agreeing on anything - is that community concerns the search for belonging, solidarity and collective identities. Scott and Marshall (2005) concur:

> "The concept of community concerns a particularly constituted set of social relations based on something which the participants have in common – usually a common sense of identity" (ibid: 93)

Within the consumption community literature few researchers find it necessary to develop their own definitions of community; this may be due to the difficulties in pinning down the concept. Yet those who are concerned to prove or disprove the existence of marketplace communities have undertaken to do so. Fischer et al (1996), set out to define what is, and what is not community in their study on an online discussion group. They synthesise various theories and arrive at the following definition:

> "Groups linked by social relationships and a sense of belonging, or by common bonds and a sense of shared identity" (ibid: 181).

This definition acts as a guide as they attempt to answer the question 'what, if any, type of community can be formed through consumption?' (ibid: 178). Muniz and O'Guinn (2001) develop their own concept of three core components or 'markers' of community through a similar literature review process. These markers are 'a shared consciousness, rituals and traditions, and a sense of moral responsibility' (ibid: 412). These markers are employed by other authors, such as Kozinets (2002), to aid their exploration and identification of community.

2.5.3 The concept of community in consumer research

A vast array of terminology has been used to describe the groupings in which issues of community are explored in consumer research. The idea has been used both as a label to describe geographic and non-geographic groups, such as the AIDS community (Kates 2002a), the gay community, (Kates and Belk 2001), and the Mexican immigrant community (Penaloza 1994), and it has been used as a concept

to explore and understand collective forms of consumption. It has been used to make sense of the extraordinary service encounter (Arnould and Price 1993), therapeutic discourse and relationship marketing (Kates 2002a), collective expressions of identity (Belk and Costa 1998; Goulding et al 2002; Kates 2002b; Schouten and McAlexander 1995), consumer emancipation (Kozinets 2002), consumer empowerment (Hogg et al 2004), risk taking (Celsi et al 1993; Thompson 2005; Wong and King 2008), consumers' relationship with brands (McAlexander et al 2002; Muniz and O'Guinn 2001; Shouten and McAlexander 1995), consumption of the internet (Fischer et al 1996; Kozinets 1997; Tambyah 1996), consumption of popular culture (Kozinets 1997, 2001) and the movement and meaning of possessions (Adelman 1992).

The term 'subculture of consumption' is introduced by Schouten and McAlexander (1995) in their study of Harley Davidson riders. A subculture of consumption is 'a distinctive subgroup of society that self-selects on the basis of a shared commitment to a particular product class, brand or consumption activity' (Schouten and McAlexander, 1995: 43). This concept draws on the work of Hebdige (1979) in the area of subculture, co-opting the concept to the realm of consumer research. Kozinets' (2001) Star Trek fans are referred to as a subculture because of their contrast with the cultural background; the status of outsider is important in the creation of meaning, and fosters a sense of community and communitas. Thompson and Troester (2002), sensitive to the notions of marginality implicit in the term subculture, favour the term 'microculture' to describe the alternative healthcare interest groups they explore.

Friedman et al (1993) and McAlexander et al (2002) employ Boorstin's (1973) term 'consumption community', which is based on the notion that people look to communality of consumption behaviour when seeking feelings of community. Schouten and McAlexander's (1995) work has been extended by Muniz and O'Guinn (2001) through their identification of 'brand community'. Brand community is a specialised, non-geographic community, based on a structured set of social relationships among admirers of a brand. Muniz and O'Guinn argue that consumers build community through consumption of consumer brands. This body of work describes how community can be organised around commercial objects.

The study at hand is concerned with 'marketplace cultures' of community (Arnold and Thompson 2005:873), and in line with much of the consumption community literature adopts a cultural sociological stance; it will explore community largely in terms of identity and belonging. Over the past twenty years debates on community have shifted focus from community as a form of social interaction to a preoccupation with identity and meaning (Delanty, 2003). The concept of community has been freed of its spatial boundaries - due, in part, to Cohen's (1985) *The Symbolic Construction of Community* and Anderson's (1983) *Imagined Communities* - and can be understood as a symbolic structure rather than a social practice. Anderson showed that community is shaped by cognitive and symbolic structures that are not necessarily underpinned by 'lived' spaces and immediate forms of social intimacy (Delanty, 2003:3). Imagined communities allow members to possess a well-developed sense of connection to innumerable unmet fellow community members. Indeed, Muniz and O'Guinn (2001) note that 'many (perhaps most) contemporary communities must be imagined.' (ibid:413)

2.5.4 Community: paradise lost?

'Community' is nowadays another name for paradise lost – but one which we dearly hope to return, and so we feverishly seek the roads that may bring us there. (Bauman, 2001: 3)

It is against the backdrop of the perceived demise of community that consumer researchers conduct their studies. Much of the modern discourse of community is dominated by the idea of loss. In Tonnies' *Gemeinschaft und Gesellschaft* (1897), society and urban life are contrasted with community and traditional rural life, with the former ultimately implicated in the decline of the latter. Tonnies considers community to be *living* - gemeinschaft is organic and natural - while society is *mechanical* - gesellschaft is rational and sustained by relations of exchange. 'Gemeinschaft ties' to the family, guild and village are weakened as the impersonal, atomizing, mechanical ties of gesellschaft take hold. Capitalism and commercialisation – of, for example, traditional industries such as farming - are implicated in the perceived loss of community (Delanty, 2003: 15).

Muniz and O'Giunn (2001) describe the loss of community as the 'grand narrative of the modern period' (ibid: 413). Market capitalism and consumer culture are often implicated in this demise, leading O'Guinn and Muniz, (2005) to point out that community and consumption have long been theoretical bedfellows. In this analysis, the materialistic desires of the individual consumer are said to drive the loss of community:

'As the self-interested logics of the market have filtered into communal relations, they have been accused of increasingly undermining the realization of the caring, sharing, communal ideal.' (Kozinets, 2002: 22)

Putnam's (2002) celebrated essay *Bowling Alone* outlines the decline of communitarianism in modern US society. For Putnam, waning social capital and communitarian behaviour – as seen through declining associational membership and public trust - is a result of apathy, self-interest and disengagement from public life. Putnam charges individualism, mass media, participation in personal pursuits and consumption with causing a decline in participation in associations and civic society generally. Individualism, indeed, is a central issue in the debate about community. Maffesoli calls the discussion of the 'problem of individualism' an 'obligatory rite of passage for those wishing to build a knowledge of modernity' (1996: 9).

Beck and Beck-Gernsheim (2002) describe how the social trend towards individualisation has altered communities – they use the family as an example - from 'communities of need' into 'elective relationships' (ibid: 85). They maintain that we do not need each other in the same way that we may have when communities produced their own resources together. We can now choose to be part of communities, to opt in or opt-out, even from our immediate family. The individualisation of society, as they see it, means that 'human mutuality and community rest no longer on solidly established traditions, but, rather, on a paradoxical collectivity of reciprocal individualization.' (Beck and Beck-Gernsheim 2002: xxi).

Many writers, though, have described this collectivity in positive terms. Bellah et al (1996), in their study of voluntarism in the USA, argue that while individualism can undermine community, it does not destroy it. Indeed, community is alive and well, and accommodating individualism. Their study found that volunteers characterised the benefits of their work in personal terms, rather than broad communal benefits. Wuthnow (1991) recounted similar sentiments – such as a sense of personal fulfilment – in his study of altruism in American society.

2.5.4.1 Paradise regained?

Consumer researchers in general have rallied to counter the assumption that the market and consumption weaken community with a range of studies of communalities found in the marketplace (cf Cova 1997; Fischer et al 1996; Holt 1995; Muniz and O'Guinn 2001). Describing consumer communities, Arnould and Thompson (2005) explain how in the face of individualization consumers forge 'collective identifications and participate in rituals of solidarity' (ibid: 873). Shared 'sacred experience' (Belk et al 1989), such as skydiving (Celsi et al 1993), can facilitate the emergence of communitas and bind people together. Sense of community is also employed to explore service experience (Arnould and Price 1993). Here, communitas is described as a component of the 'extraordinary' service experience of white water river rafting, and community is seen to be created through the communitarian actions of service providers and service users.

Theoreticians such as Cova (1997) and Holt (1995) look to the linking value of consumables, rather than the material, and argue that community is fostered through shared consumption.

The concept is not a new one. Boorstin (1973), in his discussion of modern American society and politics, describes how immigration in the late 19th and early 20th century weakened community ties and left many individuals feeling painful separations from their local communities. He observed that to compensate for feelings of loss and alienation 'consumption communities' formed where communality of consumption behaviour generated feelings of community. Penaloza (1994) echoes this in her description of the ways in which the Mexican immigrant community employ brands in both the process of acculturation and to maintain links to their native culture. Delanty (2003) encapsulates the shift:

> "Contemporary communities are groupings that are more and more wilfully constructed: they are products of 'practices' rather than of 'structures'. Communities are created rather than reproduced." *(*ibid: 130)

2.5.4.2 The Time of the Tribes

Much of the consumer research into marketplace cultures and community builds on Maffesoli's (1996) ideas on neo-tribalism (cf Cova 1997; Goulding et al 2002). Maffesoli is concerned with the postmodern state, describing it as a condition where 'outlines are ill-defined: sex, appearance, lifestyles – even ideology – are increasingly qualified in terms ('trans', 'meta') that go beyond the logic of identity and/or binary logic.' (Maffesoli, 1996: 11). This is a state that Firat and Venkatesh (1995) have conceived as fragmented. Maffesoli rejects the communitarian preoccupation with the decline of community and the 'withdrawal into self' (ibid:

9). He presents in contradiction a case for the decline of individualism, citing what he calls 'emotional community':

"[W]e are witnessing the tendency for a rationalized 'social' to be replaced by an empathetic 'sociality', which is expressed by a succession of ambiences, feelings and emotions." (ibid: 11)

He considers that we have entered an 'empathetic period', marked by a lack of differentiation, a phenomenon which he calls 'neo-tribalism' (ibid: 11). Shields elucidates in his introduction to the 1996 translation of *The Time of the Tribes*:

"Unlike anthropological tribes, our contemporary social life is marked by membership in a multiplicity of overlapping groups in which the roles one plays become sources of identity which, like masks, provide temporary 'identifications'." (Shields, 1996: xii)

These collective identifications are fluid, shifting and temporary (Maffesoli 1996: 76). Tribes are communities of shared beliefs and feelings but not of shared obligation or moral responsibility; they are friendship groups, built on sociality rather than a common purpose or aim.

Maffesoli paints a picture of mass society in decline, in which this 'tribalization' leads to cultural fragmentation and the emergence of new forms of community. Cova (1997), after Maffesoli, asks if it is possible 'to push the boundaries of marketing beyond the individual level of analysis in order to increase our

understanding of consumer behaviour?' (ibid: 297). Following this aim, Cova (1997) emphasises the role of consumption in neo-tribalism, showing that tribes can be held together by everyday consumption practices. Cova (1997) explores the concept of neo-tribalism, centring on the idea of 'tribal marketing'. He highlights that the 'social link' has been overlooked in consumer research and suggests that the idea of tribalism can redress this with its rejection of the individualistic view of consumers. For Cova modern consumption focuses on the utilitarian value of products and services, while postmodernity represents the beginning of the end of individuality in the emergence of a 'desperate search for community' (ibid: 297). He defines a consumer tribe as 'a network of heterogeneous persons – in terms of age, sex, income, etc. – who are linked by a shared passion of emotion; a tribe is capable of collective action, its members are not simple consumers they are also advocates' (Cova and Cova 2002: 602). The idea of advocacy – the public support of a cause beyond oneself – suggests a further dimension to community practice for the study at hand to consider in the field.

2.5.4.3 Social benefits

Fischer et al (1996), argue that significant social benefits are provided by consumption communities, whether it be in terms of a form of escape, or refuge, some kind of safety, or simply the 'warmth' of forms of support, signalling an emotional undercurrent to many communal consumption activities. Holt (1995), in his analysis of baseball consumers, shows us that shared consumption can counter materialism - where the value is in experiences and interaction with other people rather than the consumption object itself. Schouten and McAlexander (1995) highlight that 'through consumption activities [consumers] form relationships that

allow them to share meaning and mutual support' (ibid: 59). And for Wuthnow (1994), arguing that small groups are a supportive context for people to adapt to and cope with societal changes, the value of community is self-evident:

"Small groups provide a way of transcending our most self-centred interests, they temper individualism and our culturally induced desire to be totally independent of one another." (Wuthnow, 1994:22)

Community can be hard to see, too. Fischer et al (1996), Kozinets (1997) and Tambyah (1996) identify 'virtual' and 'computer mediated' communities and argue that these online communities may provide the resources we seek, but do not find, from face-to-face communities. These resources include a sense of belonging, social support, and space for the reconstruction of the self (Kozinets 1997; Tambyah 1996).

2.5.5 The social construction of consumer communities

The structure and maintenance of consumer communities can be viewed as socially generated phenomena (cf Belk and Costa 1998; Kozinets 2002). Three primary areas of attention emerge from the extant literature's investigation of communities' social structure and boundaries.

2.5.5.1 Myths, ritual and rules

Shared ritual experiences such as river rafting (Arnould and Price 1993), skydiving (Celsi et al 1993) or burning the "Man" at the Burning Man festival (Kozinets

2002), have been found to create the communitas which binds people together. Celsi et al (1993) use communitas to explore group camaraderie, 'a shared ritualistic experience that transcends ordinary camaraderie' (ibid: 12). This communitas allows participants to transcend the quotidian and experience the sacred (Belk et al 1989). Like Belk and Costa's (1998) Mountain Men, Burning Man participants seek communitas by looking back to a more primitive time and enacting community through a shared social construction (Kozinets 2002). This social construction involves the co-creation of community space and time, myths, traditions, rituals and rules.

In these, and in wider contexts, shared myths, traditions and rituals can be seen to function as social glue. Exploring the case of the Goth, Goulding et al (2005) highlight that myths are the 'encoded embodiment' of group values. They provide history, context and continuity, and allow new community members to become embedded through participation in rituals and the gathering of specialist knowledge (ibid: 6). Myths are passed on through storytelling, and this storytelling is in itself a means of creating and maintaining community. Within brand communities stories about experiences with the brand invest that brand with meaning and link community members to one another. This sharing of stories is a form of exchange behaviour that reinforces consciousness of kind (Muniz and O'Guinn 2001). The consciousness of kind created through shared myths and traditions (Muniz and O'Guinn 2001) provides a platform for civic engagement (Kozinets' 2002), and social support (Schouten and McAlexander 1995).

2.5.5.2 Commitment manifested through authenticity and participation

A sense of 'passionate community' is fostered through the construction of a shared history, mythical identities and rules concerning "authenticity" (Belk and Costa 1998). These shared rules are linked to issues of inclusion and exclusion. For example, the key criterion for inclusion in the Mountain Man community is "authenticity" – accommodation, dress and behaviour must conform to the archetype of the historic mountain man or woman (Belk and Costa 1998). Within the biker subculture, Schouten and McAlexander (1995) found social structures based on commitment to style, ideology, knowledge, experience and authenticity. For "Burners" at Burning Man (Kozinets 2002), participation is the central issue. All those attending the festival are expected to give something of themselves to the community's gift economy – through performance, art works or their dress. Spectators, in the traditional sense, are not permitted at the event, and anyone identified as such can be vilified and even ejected. Participation is a crucial contribution to the community, characterised as a form of gift-giving, and rewards the participant with a stamp of authenticity as a community member (Kozinets 2002). As Belk et al (1989) point out, such gifts can acquire 'sacred status,' imbued as they are with deeply-held cultural values. Sharing these values, through gift-giving, reinforces social integration (ibid: 18).

Muniz and O'Guinn (2001) found that within brand communities "legitimacy" functioned in much the same way as "participation" at Burning Man (Kozinets 2002) and "authenticity" within the mountain man and Biker cultures (Belk and Costa 1998; Schouten and McAlexander 1995). Legitimacy is based on knowledge of the brand - and of the brand community - and an appreciation of its history.

Becoming embedded in these communities requires a high investment of self and time, and may involve self-transformation and a degree of sacrifice. For example Star Trek fans accept and embrace the social stigma attached to the fan community in order to become part of it (Kozinets 2001). Authenticity can be seen as a display of commitment to the community, with the most "committed" members serving as opinion leaders (Schouten and McAlexander 1995).

2.5.5.3 Resistance

Subcultural studies understand the confines of subculture to be sites of struggle. Clarke et al (1976) argue that a challenge to authority characterised class relations in the position adopted by skinheads (Clarke et al. 1976), Teddy boys (Jefferson, 1976) and mods (Hebdige, 1979) towards elite powers in modern society. Like these subcultural sites, which inspired much of the investigation of collective consumption (cf Schouten and McAlexander's (1995) conceptualisation of subcultures of consumption), consumption communities deliberately set themselves apart from the 'outside world' and appear to require something to push against: to resist. There is a tension between these communities and the perceived anonymity and atomisation of the modern world around them, Kozinets argues (2002). This contrast with the cultural background or 'outside world' creates meaning and a sense of community within these groupings (Belk and Costa 1998). The Burning Man community sets itself up in contrast to the market by banning and discursively demonising commercial exchange (Kozinets 2002). Indeed, friction with the market appears to be one of the key creators of communitas within the collective. Burning Man attempts to create an internal antidote to the dominance of the market, creating its own alternative system of exchange through a gift economy.

Brand communities differ from subcultures of consumption in that they embrace the parent culture or 'outside world'. Yet the idea of resistance and opposition is also key to their ethos. They are defined in 'contradistinction' to one another. An important aspect of the Apple brand community, for example, is its opposition to and avoidance of the dominant Microsoft brand (Muniz and O'Guinn 2001). The idea of threat (of discontinuation of product or support, for example) is also important to both maintenance and boundary definition within brand communities, and leads to a kind of civic engagement through campaigning to help the brand under threat.

Crowther and Cooper (2002) present an interesting case of resistance and community-building in their study of itinerant "career" ecoprotestors. They found that the presence of a shared enemy (motorway planners, for example) fostered community between two disparate groups - the ecoprotestors and the residents of the threatened rural area. More than this common enemy, the presence of the ecoprotesors seemed to heighten the sense of community – a "blitz spirit" - among residents of the threatened neighbourhood. The ecoprotestors provided a focus and leadership for the community, and thus encouraged forms of organisation and civic engagement from it. Maffesoli (1996) points out that a sense of the 'other' is necessary to define, form and maintain community. The outsider status of subcultures such as Goths, Star Trek fans and bikers are examples of this (Goulding et al 2005, Kozinets 2001, Schouten and McAlexander 1995). Both Goths and Trekkies are portrayed negatively in the media, constructing a marginalised persona and stigmatic boundaries within the communities (Kozinets 2001). Schouten and McAlexander (1995) found that a 'sense of brotherhood' was heightened by a

feeling of marginality within the biker persona. These communities are sites of resistance and "alternative" self-expression for the marginalised, those under threat, and those seeking escape or refuge.

2.5.6 Consumption community as the site for identity work

Belk's (1988) notion of the extended self takes into consideration various levels of affiliation: family, nation, community and group. People see such affiliations as part of the self. Taking the idea a step further, Delanty (2003) imagines the community as an instrument of personal empowerment:

> "Insofar as it can lead to empowerment, community can reinforce personalism, giving to the individual a stronger sense of identity." (ibid: 121-122)

The individual identity is shaped by a collective understanding. As Muniz and O'Guinn (2001: 413) put it: community is more than a place, it is 'a common understanding of a shared identity'. Indeed to Elliott and Wattanasuwan (1998) the development of individual self identity is inseparable from the development of collective social identity (ibid: 133).

Studies such as Celsi et al (1993); Belk and Costa (1998); Kozinets (2001) and Kates (2002) highlight how collective 'experiential consumption activities' encourage shared identifications (Arnould and Thompson 2005: 874). Such studies delineate the role of collective belief systems, in-group hierarchy, myth and ritual in group identity formation. Assessing the literature's investigation of community as a

context for personal development, we also find particular emphasis on issues of communitas and fellow-feeling; refuge or shelter from, for example, the stresses of the modern world; and space to develop one's personal identity work.

2.5.6.1 A Safe Space

Communities are bounded systems in which members claim to experience personal freedom and escapism (Kozinets 2001). Although this idea goes against Bauman's (2001) assertion that to experience true community one must relinquish personal freedom, it is evident from the literature that consumption communities provide important safe spaces for identity construction and self-transformation. The gay community is a site of liberation and safety, as well as resistance, for members (Kates and Belk 2001; Kates 2002b). Online communities also serve a liberating function in users' lives (Fischer at al, 1996). Goths find a safe place within their community, where diversity is tolerated and they can be themselves free of ridicule and prejudice (Goulding et al 2005). Consumers actively seek a sense of belonging and communitas from their consumption. This communitas offers refuge from, for example, market logics (Kozinets 2002), the pressures of the modern world (Belk and Costa 2001) and stigma and social exclusion (Kozinets 2001). Kozinets (2001) describes the Star Trek fandom subculture as functioning as a 'powerful utopian refuge' from the inequalities of modern life (ibid: 67). The perceived sanctuary and refuge offered by these communities, coupled with feelings of security, sponsors loyalty among members.

2.5.6.2 Self-transformation and transcendence

Individuals depict their identity through association with groups and communities where 'the idea of belonging is vital', (Crowther and Cooper 2002:345). This sense

of belonging brings with it a sense of self, or sense of a possible self, giving answers to the question "who am I?" Consumption communities provide space to explore this question and to enact the reconstruction of self. Belk et al (1989) predict that in an increasingly secularised Western world 'consumption may become a primary means of transcendent experience' (ibid: 13). Schouten and McAlexander (1995) describe the biker subculture of consumption as providing sanctuary in which to experience 'temporary self-transformation' (ibid: 50), where bike riding can be seen as a transcendental experience – physically leaving the mundane behind. They note that the identity construct of "biker" is viewed as a possible self for the neophyte rider. Transformation involves a journey through a status hierarchy, from novice or outsider (inexperienced), to neophyte, to fully embedded member (mastery). This journey is completed through a process of information and knowledge gathering, participation in community rituals and displays of 'authenticity' (Belk and Costa 1998; Kozinets 2001, 2002; Schouten and McAlexander 1995). Schouten and McAlexander (1995) postulate that through understanding the process of self-transformation, marketers can take an active role in socialising new community members and cultivating the commitment of current ones.

2.5.6.3 Communitas, rites of passage and liminality

Just as we have seen them employed in the delineation of individual identity transformation, the works of Turner (1969) and van Gennep (1960) on liminality, rites of passage and communitas have been used by various authors to explore community and consumption (Adelman 1992, Arnould and Price 1993, Belk and Costa, Celsi et al 1993, Goulding et al 2002, Goulding et al 2005, Kates and Belk 1998, Kozinets 1997, 2001, 2002, Tambyah 1996). Communitas is described as a feature of consumption communities – '[w]hen he gets here he's just a buckskinner'

(Belk and Costa 1998: 223). This levelling of participants is an element of communitas, described by Turner (1969). Members can exist in a liminal state within a community's protective confines and enjoy a sense of communitas. Communitas frees participants from their normal social roles and statuses - instead they engage in the camaraderie of status equality (Arnould and Price 1993, Celsi et al 1993). This is most likely to occur when an individual is in a "liminal" state – between two statuses.

> 'This spirit of communitas emerges from shared ritual experiences "which transcend those of status-striving, money-grubbing [sic], and self-serving" and act as "proofs that man does not live by bread alone"' (Turner [1972: 391-392] in Belk et al [1989: 7])

Tambyah (1996) identifies 'Net communitas' as arising from the enactment of a state of liminality during which net users engage in 'deeply symbolic processes related to the reconstruction of self' (ibid: 173). The anonymity offered by the internet enables users to enact a state of liminality.

> 'In primal cultures, liminality is a collective experience mediated by culturally prescribed rituals that gave individuals an experience of communitas or shared psychological support through major status passages' (van Gennep, 1960 in Tambyah, 1996: 173).

As well as providing the space and the supportive communitas to enable identity work, the community offers the discursive and ritual resources for negotiating

transition. In Thompson's (2004) terms this manifests an alternative 'discourse of power' to the prevalent narrative (for example, Wong and King 2008, the restitution narrative of biomedicine). The sharing of stories communicates and enacts group values, and communal rites of passage mediate the liminal states that are key to identity transformation.

2.6 Conclusion and Research Questions

From Muniz and O'Guinn's (2001) communities with 'a sense of moral responsibility' (ibid: 412) to Maffesoli's (1996) loosely-knit tribes with no shared obligations, it seems there are as many theories of consumption community as there are communities. This study seeks to suggest that community is not only the context but the vital resource that enables the reconstruction of identity.

It is evident from the consumer research literature that community and communitas can be experienced through consumption, and that people can relate to others through shared consumption practices (Arnould and Price 1993; Belk and Costa 1998; Celsi et al 1993; Holt 1995; Muniz and O'Guinn 2001; Schouten and McAlexander 1995). Consumption practices can create the social space of community and structure it through myths, rituals and exchange (Belk and Costa 1998). Consumers may experience community, communitas and even social support when shopping (Griffith 2003; McGrath et al 1993; Sherry 1990), when holidaying (Arnould and Price 1993; Belk and Costa 1998), and when undertaking hobbies (Celsi et al 1993; Schouten and McAlexander 1995). Within these communities members find sanctuary, refuge and a sense of belonging. They offer escapism and

space to undertake self-transformation (Belk and Costa 1998; Kozinets 2001; Schouten and McAlexander 1995).

As Cova et al (2007) point out, tribes have a tendency to produce and 'twist' meanings and to 're-script' recognised roles (ibid: 4):

> "Active and enthusiastic in their consumption, sometimes in the extreme, tribes produce a range of identities, practices, rituals, meanings and even material culture itself. They re-script roles, twist meanings, and shout back to producers." (Cova, Kozinets and Shankar 2007: 4)

Studies such as Schouten and McAlexander (1995) and Muniz and O'Guinn (2001) show that consumption communities – such as subcultures of consumption or brand communities - can shape and re-create brand meanings. Brand communities perform an interpretive function; 'with brand meaning socially negotiated, rather than delivered unaltered and in toto from context to context, consumer to consumer.' (Muniz and O'Guinn 2001: 414).

This study postulates that the myeloma support group is analogous to the brand community – with illness, and specifically multiple myeloma as the undesired brand, which is subject to a communal and ultimately a personal (identity-transforming) re-interpretation through the mechanism of the group (Muniz and O'Guinn 2001).

Consumption communities that provide mutual support and a safe place for self-transformation take on a more urgent role in circumstance of serious illness. Kates' (2002a) study of an AIDS community shows how professionals and non-professionals co-create an emergent sense of self in the face of illness and death. Kates observes that people living (and working) with AIDS become part of an 'interpretive community' in which 'broadly similar' views are held about death, dying and grieving. Fischer et al (1996) found that strangers with a common bond, such as experience of an illness, share their stories of intense emotional experiences with unknown others. They observe that 'emotional support, social companionship and supportive resources' are 'believed to be at the heart of communities' (ibid: 180). Yet Kozinets (2002) highlights that this ideal of a caring community that provides social support is absent from the discussion of consumption communities.

This study seeks to emulate the notable exceptions to this omission, such as Kates (2002a), Kozinets (2002) and Fischer et al (1996). It will look for the markers by which consumer researchers have identified community (common bonds, a sense of belonging, a sense of identity and shared consciousness, rituals and traditions, group hierarchy, and a sense of moral responsibility (Muniz and O'Guinn 2001). Within this context attempts will be made to unravel the processes through which liminal consumers rebuild their self-concept under duress, looking initially for the first stages of identity transition in its informants: erosion of sense of self, and crisis of identity; and then examining the ways in which lived experience of illness is shaped, enacted and embodied. The study's research will seek illustrations of the individual investment of self in the group (comparable to the ideas of "legitimacy", "authenticity" and "participation") and attempt to assess the extent to which the

group manifests resistance to the wider medical marketplace. Considering informants' position with regard to illness narratives like the restitution and quest stories, it will explore the role of framing discourses and other cultural influences in the (re)construction of individual identity – and focus on the support systems, relationships, understandings and other collective practices that feed off these narratives. It will work to unravel the subtleties and complexities of group and identity dynamics and will assess what responsibilities the market's positioning of the patient as consumer gives to its informants, and to what effect. Findings will be situated in the context of consumption, relating informant consumers' personal development to what the market provides for them.

Kozinets (2002) proposes that 'commercially influenced forms of community should be seen not merely as parasitic co-optations (Holt 2002), hybridized communal market forms (Muniz and O'Guinn 2001), or symbiotic unions (Schouten and McAlexander 1995). They should also be conceptualized *as a corrective, or at least ameliorative*, response to two effects of market logics, namely, its tendency to weaken social ties and to reduce or homogenize self-expression.' (ibid: 34 [emphasis added]).

It may seem self-evident that communities are mechanisms for promoting concern for others beyond oneself, but the idea warrants further exploration. As we have seen, the consciousness of kind created through shared myths and traditions (Muniz and O'Guinn 2001) provides a platform for civic engagement (Kozinets 2002), and social support (Schouten and McAlexander 1995). The act of sharing – as for instance with the giving of gifts imbued with cultural values at Kozinets's (2002)

Burning Man festival – in itself reinforces social integration. Consumption communities may even facilitate the strengthening of ties within other collectives, such as family and geographic communities (McAlexander et al 2002). Even the members of Cova and Cova's (2002) postmodern tribes are 'not simple consumers they are also advocates,' their advocacy expressed on behalf of a common cause.

Consumer research exploring other-centred behaviour has been rare (Bendapudi and Singh 1996). On issues such as gift-giving, the emphasis has largely fallen on ideas of exchange (Sherry 1983), cost and equity (Rucker et al. 1991), personal utility (Strahilevitz 1994), power relations (Rugimbana et al. 2003), or sexual strategies and reciprocal altruism (Saad and Gill 2003).

Recently, though, the model of the self-interested individual has come under increasing challenge in several disciplines. In biology, the selfish gene theory (proposing that *genes*, not individuals, are the primary vehicles for the all-important evolutionary selection) and the group selection theory (which argues – Wilson and Dugatkin 1997 - that *groups* should also be considered as vehicles for selection) have asserted alternative views. Peressini (1993) has argued persuasively that the postulation of an inherently self-interested individual is far from self-evident.

In psychology, Batson and Shaw (1991) have made an influential argument that individuals can be motivated by empathetic concern for others. And the assumption of self-interest has come under increasing challenge from economists (Margolis 1982; Sen 1989; Sen 1994).

Within the field of consumer research, Belk and Coon (1993) have been unusual in their accommodation of this shift, asserting that the dominant economic and social exchange paradigms do not sufficiently account for the complexity of human behaviour. As Elliott has pointed out (2004), consumer research literature has been slow to embrace the social aspects of the self, and few attempts have been made (eg Bocock 1993; Slater 1997) to rise to the challenge of consumption's socio-culturally complex nature.

Observing that consumerism has been repeatedly associated with problems of alienation, anomie and oppression, Bajde (2006) attacks what Maffelosi terms 'the problem of individualism' head on: 'consumer research should not be inhibited by a full-out surrender to the established behaviour models, nor should the domain of consumption be narrowed solely to self-interested behaviour. Consumer researchers would do better by openly investigating consumers' experiences of other-centred behaviour, including the ways consumers attach meaning to that behaviour (eg, the process of negotiating "the self" and "the other".)' (ibid: 310)

In answering the call, this study seeks to avoid being waylaid by the (frequently protracted) conjecture about the fundamental nature of altruism. It does propose to explore, nevertheless, the possibility that the negotiation of "self" and "other" that individuals carry out in a consumption community is made not only desirable but necessary to the degree that the marketplace has failed to meet their needs for narratives which reflect their lived experience (Wong and King 2008). It argues, in other words, that community is not only a corrective to Kozinets' (after Firat and Venkatesh 1995) 'damaging market logics of weakened social ties and limited self-

expression' (2002: 34), but to the medical market's prescription of inadequate identity.

The idea of the medical market's shortcomings leads us back to Foucault (1975), and the idea of a "carceral" culture enforcing its social ordering in institutions like prisons, schools and hospitals. Foucault's argument carries to the specifics of the patient experience: "the examination, surrounded by all its documentary techniques, makes each individual a 'case'… an object for a branch of knowledge and a hold for a branch of power." (ibid: 191).

Referencing Foucault (1975), Thompson (2003) cites the extensive subsequent literature on the power structures and normalising discourses that operate within conventional medical settings (Foucault 1975; Illich 1976; Ehrenreigh and English, 1979; Armstrong 1983; Martin 1987; Turner 1987, 1992; Frank 1998a), as well as the numerous more recent studies demonstrating that medical patients are often subjected to an alienating barrage of diagnostic classifications, technological interventions, and autocratic (and at times dehumanising) social encounters (Semmes 1991; Frohock 1992; Frank 1995, 1998a; Schneirov and Geczik 1996; Turner 1997; Shohat 1998; Singleton 1998). In summary, Thompson declares that: 'a profound institutional gap exists between the medical institution as a consumer-oriented service and its enduring modernist function as an expert system that rationally optimises life by producing compliant, normalized patients.' (ibid: 103).

The following chapter will outline the methodological considerations central to the fulfilment of the above research objectives.

Chapter Three

Research Design

Summary

The purpose of this chapter is to outline the methodological considerations of the study at hand. The research questions arising from the review of the literature conducted in the previous chapter will be recorded here, along with the research objectives of the study (3.2). Decisions made by the researcher in the methodological arena will be elucidated. Phenomenology will be shown to be a suitable methodology for the purposes of addressing the research questions (3.7), and the research context will be described (3.4). The methods used for data collection and analysis will also be discussed in detail (3.8, 3.9).

3.1 Introduction

> "*Like other social sciences (psychology, sociology, anthropology and so on),* [consumer research] *aspires to some degree of rigor and empirical warrant (associated with the physical sciences) but also to some degree of understanding or "Verstehen" (associated with the humanities)."* (Holbrook and O'Shaughnessy 1988: 400)

This chapter will outline the research design which was employed in order to approach the desired '*verstehen*' or understanding of the phenomenon under examination. Denzin and Lincoln (1998) state that four basic questions structure research design:

"(a) How will the design connect to the paradigm being used? That is, how will empirical materials be informed by and interact with the paradigm in question? (b) Who or what will be studied? (c) What strategies of inquiry will be used? (d) What methods or research tools will be used for collecting and analysing empirical materials?" (ibid: xii).

The following chapter explores and endeavours to answer these questions.

As Crotty highlights, researchers bring their own assumptions or "baggage" to the research project:

"The long journey we are embarking upon arises out of an awareness on our part that, at every point in our research – in our observing, our interpreting, our reporting, and everything else we do as researchers – we inject a host of assumptions." (Crotty 1998: 7)

This baggage contains the researcher's world view, life experience, values, preferences and assumptions, among other things. As such we can view the wrangling of conceptual and philosophical issues regarding methodological practice as a merging of the requirements of the research project and the world view brought to it by the researcher. Denzin and Lincoln (1998) delineate this elegantly:

"Three interconnected, generic activities define the qualitative research process. They go by a variety of different labels, including *theory, method* and *analysis*, and *ontology, epistemology,* and *methodology*. Behind these

terms stands the personal biography of the gendered researcher, who speaks

from a particular class, racial, cultural, and ethnic community perspective."

(ibid: 23)

This chapter will stop short at providing details of the researcher's biography, but

will attempt a brief look inside the researcher's "baggage", as it were, in order to

unpack the rationale for the methodological choices made.

3.2 Statement of research objectives

This study aims to contribute to the field of consumer research by exploring the

collective practices which serve to mediate structure and provide meaning for the

rebuilding of consumer self-identity. It will analyse how *a particular manifestation*

of consumer culture is constituted, sustained, transformed and shaped by broader

cultural forces, with the overall aim ***to penetrate the complexity of the simply-***

stated idea that consumers turn to consumption as a means of self-determination.

Following this aim, the objectives of the study were:

- to contextualise the phenomenon of consumer identity transition;
- to explore the experiences, processes and structures underlying the production of collective culture;
- to investigate the co-creation of social resources within this context;
- to identify and illuminate the collective and co-productive practices through which consumers negotiate a sense of self;

- to identify the social situations, roles and relationships that foster the construction of these practices.

As such, particular research questions arising from the literature review are:

- What practices allow consumers to rebuild their self- concept?

- What markers of community (Muniz and O'Guinn 2001) can be identified in the myeloma community?

- What is the individual investment of self in the community?

- What is the role of framing discourses and other cultural influences in the (re)construction of individual identity?

- To what extent does the myeloma community manifest resistance to the wider medical marketplace?

- What responsibilities the market's positioning of the "patient as consumer" gives to patients, and to what effect?

3.3 Theoretical perspectives

"[A]ll scientific enterprises...are themselves grounded in interpretation."
Holbrook and O'Shaughnessy (1988: 401).

A review of the consumer research literature (see Chapter Two) leads us to discern that there is conceptual "space" for the study at hand. The selection of an appropriate research methodology to apply within this space is dependent upon the preconceptions held by the researcher about respondents' understandings of their social worlds, and crucially, how these can be represented. The aims of the study

call for an attempt to be made to explore and develop an *understanding* of the lived experience of cancer, with particular focus on collective practices. An interpretive approach has therefore been taken (Holbrook and O'Shaughnessy 1988; Spiggle 1994).

Crotty (1998) delineates four elements of social research, and advocates the setting-out of the research process in these terms: epistemology, theoretical perspective, methodology and methods. An example of this schema for the study at hand would be as follows:

1. Epistemology – Constructionism
2. Theoretical perspective – Interpretivism
3. Methodology – Phenomenological research
4. Methods – Interview

(Adapted from Crotty 1998: 4-6)

Hence, *interpretivism* can be described as the philosophical stance behind the methodological choices made herein (Crotty 1998). Spiggle (1994) describes interpretive research as the 'making sense of experience and behaviour, and seeing or understanding some phenomenon in its own terms, grasping its essence (e.g. interpreting a cultural form).' (ibid: 492).

The study at hand adopts the philosophical assumption that reality is 'constructed by the individuals involved in the research situation' (Creswell 1998: 79). Constructionist values dictate that 'meanings are constructed by human beings as they engage with the world they are interpreting.' (Crotty 1998: 43). From this

viewpoint meaning cannot be described as purely 'objective', nor can it be viewed simply as 'subjective'; rather, it is meeting of one's subjectivity with the objectivity of 'objects in the world' (Crotty 1998: 44).

3.3.1 Paradigms and positioning

"You need positioning, like a product in the market – the jails are full of people who didn't manage their positions."

D.B.C. Pierre, *Vernon God Little,* p34.

Interpretivism has a rich and lengthy history of application within consumer research. Empirical studies from authors such as Belk, Wallendorf and Sherry (1989), Hirschman (1986) and Thompson, Locander and Pollio (1990), have enriched the field and made it possible for others to tread the interpretivist path in their wake. However, the path has not been without its difficulties.

Interpretivism emerged largely as a reaction to positivism, positing an alternative way to understand 'human and social reality' (Crotty 1998: 66-67). The interpretivist approach - in contradistinction to the positivist - 'looks for culturally derived and historically situated interpretations of the social life-world' (Crotty 1998: 67). Hence, the situation arose where a dominant paradigm and its proponents were asked to make room for another way of doing things. Somewhat inevitably, critical debate ensued (Holbrook and O'Shaunnessy 1988). The point of contention centred on how we can represent what we know about reality, and was termed the 'crisis of representation' by some (Spiggle 1994: 491). This debate or 'crisis'

resulted in the fragmentation of scholarly communities (Spiggle 1994: 491), and this fragmentation had serious real-life consequences for some scholars. Hogg and Maclaran (2008) note that 'interpretivist researchers have encountered difficulties in convincing mainstream audiences that their findings are as much a contribution to knowledge as those of their colleagues working within more positivist-oriented disciplines.' (ibid: 130).

The heyday of the paradigm debate within consumer research has long since passed, however, leaving in its wake a broader notion of what it is to carry out consumer research (Brown 2003). Hogg and Maclaran (2007) elucidate:

> "Early in the history of consumer research the path towards qualitative research remained largely unvisited. Now it has become a very well-trodden path that itself diverges in a number of different directions" (ibid: 3).

Recognising the inheritance of the debate, Arnould and Thompson (2005) encourage researchers to move beyond the methodological "ghettoisation" of consumer research by imagining an academic brand: Consumer Culture Theory (CCT). This branding attempts to transcend the types of categorisations that have been prevalent in the past, and which have tended to marginalise so-called "qualitative" consumer research (ibid: 870). Whether or not this endeavour will leave further academic "ghettos" in its wake remains to be seen.

Rather than classify research based on the methodological choices made therein, Arnould and Thompson (2005) rightly propose that research should be thought of

(and if you follow them, branded) in terms of its focus and contribution to knowledge. Following their lead, this chapter will not enter into the now somewhat cooled debate on positivism versus interpretivism; rather it will state that this is an interpretive study which employs a phenomenological approach because that theoretical perspective is the most suitable for its purpose.

Arnould and Thompson (ibid) point out that a researcher's choice of perspective and methods is not based on an enthusiasm for a particular type of data, but rather on the research methods' fit with the aims of the project. This assertion, while largely consonant with this researcher's experience, perhaps overlooks the assumptions about the world that the researcher brings to the task. Within such "baggage" can also be found the preferences, skill-set and experiences that may have shaped the project well before its "aims" have materialised.

3.3.2 Contexts and Culture

Crotty describes the elaboration of the theoretical perspective as a 'statement of the assumptions brought to the research task' (Crotty, 1998: 7). The values that a phenomenological approach brings to the research project are contextualist. The notion of intentionality views individuals as 'beings-in-the-world'; as Crotty puts it, 'we cannot be described apart from our world, just as our world – always a human world – cannot be described apart from us.' (1998: 79). Denzin and Lincoln (1998) emphasise the situated nature of knowledge:

> "All knowledge is always local, situated in a local culture and embedded in organizational sites. This local culture embodies cultural stereotypes and

ideologies, including understandings about race, class, and gender" (ibid: xvii).

Thus the practices of any given culture can be seen as the source of personhood (Crotty 1998: 74). McCracken (1986) argues that culture can be viewed as a "lens" through which we see the world, one which gives our world meaning:

"[A] specific culture establishes its own special vision of the world, thus rendering the understandings and rules appropriate to one cultural context preposterously inappropriate in another. In sum, by investing the world with its own particular meaning, culture "constitutes" the world" (Ibid: 72).

Here we learn of the specific nature of culture. Similarly, Thompson (1997) tells us that cultural knowledge is not a monolithic and internally consistent system. Rather, he sees it as a 'heterogeneous network that offers a multitude of interpretive positions and endless opportunities for context-specific combinations, juxtapositions, and personalized transformations of established cultural meanings.' (ibid: 441).

Denzin and Lincoln (1998) cite Sartre (1981: ix) to illustrate that the person is 'summed up and for this reason universalized by his epoch, he in turn resumes it by reproducing himself in it as singularity,' allowing them to conclude that 'to study the particular is to study the general.' (ibid: xiv). It then follows that any case will hold traces of the universal (Denzin and Lincoln 1998). Such are the assumptions that the phenomenological tradition is built on.

We often assume that others experience and understand the world in the same way as ourselves:

> "We take our subjectivity for granted, overlooking its constitutive character, presuming that we *intersubjectively* share the same reality. Shultz points out that this intersubjectivity is an ongoing accomplishment, a set of understandings sustained from moment to moment by participants in interaction." (Holstein and Gubrium, 1998: 140, emphasis authors' own).

Phenomonlogical perspectives follow this rationale, asking that the researcher gain cognitive proximity to the subjective experience of the informant rather than impose meaning on them. The importance of the subjective point of view to social science is paramount to Schultz. Holstein and Gubrium (1998: 138) employ Schultz's (1964) argument that 'the social sciences should focus on the ways that the life world – that is, the experiential world every person *takes for granted* – is produced and experienced by *members*: "The safeguarding of the subjective point of view is the only but sufficient guarantee that the world of social reality will not be replaced by a fictional non-existing world constructed by the scientific observer." (ibid: 8)'.

3.4 The research context

For many years now the branch of consumer research now branded as Consumer Culture Theory (Arnould and Thompson 2005) has broadened both our notion of

what it is to study consumers, and our understandings of marketing as a discipline. From the banks of the Colorado river (Arnould and Price 1993) to the spectacle of Burning Man (Kozinets 2002), consumer researchers have moved beyond the quotidian in search of contexts which will aid our understanding of the way we consume. It is in this spirit that the study at hand is conceptualised.

The study looks at a consumption community which has at its heart an illness, rather than a brand or consumer good. Understandably this choice of empirical site requires justification. Like Kates' (2002) study of gay consumers, this project aims to explore issues of community, culture and consumption within a group of people who are linked to each other through circumstances over which they have no choice. This contrast with the prevailing interest in avocational collective activities (Belk and Costa 1998; Kozinets 2001, 2002; Schouten and McAlexander 1995 to name a few) was deliberate, as it was felt that looking at a "consumption community no one wants to belong to" might shed new light on notions of collective practice and identity work.

As stated above, the study is concerned with identity transition. The research aims, developed through a review of the extant literature, necessitate a context that provides access to those experiencing change: those whose self-concept is unfixed. Literature from the field of sociology - as well as notable consumer research studies such as Pavia and Mason (2004) and Wong and King (2008) - tells us that those who experience the diagnosis of serious illness experience a break from the known self (Frank 1995; Lupton 1994). Following the work of Thompson and his co-authors (2002, 2003, 2004), a diagnosis can be conceptualised as a confining form

of institutional identity (or in their terms a *medico-administrative identity*). Illness invariably *necessitates* interaction with the medical marketplace; and within this context, consumption – specifically, consumer decisions - becomes a high-stakes activity.

As issues surrounding the notion of community were to be explored, a context where patients met face-to-face outwith the medical setting was felt to be appropriate. Ultimately a suitable empirical site was identified; three myeloma support groups in a single state in the American Midwest were selected as a face-to-face instantiation of the wider myeloma community. Groups that deal with a single type of cancer were selected, as it was thought – in line with Fischer, Bristor and Gainer (1996) – that a feeling of 'we-ness' may be heightened by shared experience of similar symptoms.

It was felt that to undertake fieldwork in the USA rather than the UK would enhance the study by providing access to a culture with a rich history of self-help (Wuthnow 1994). This culture of self-help is evident in the American myeloma community (where an annual Myeloma Support Group Leaders' Retreat has been organised by the International Myeloma Foundation [IMF] since 2000), yet was just beginning to become established in the UK by 2005. In addition, gaining access to customers of a free-market healthcare system, where consumers are required to make economic decisions regarding their care, was seen to be advantageous. This decision also meant that the researcher was able to work with myeloma groups which, to all intents and purposes, were unfamiliar to her (and her to them). As outlined below, the researcher had been involved in setting up myeloma support

groups in the UK in her previous employment, and for this reason analytical distance may have proved difficult if fieldwork was undertaken within these groups.

3.4.1 Ethical considerations

The debilitating character of myeloma intensifies the sensitive nature of this exploration (Renzetti and Lee 1993). Sensitive research, according to Renzetti and Lee (1993: 4), is research which 'potentially poses a substantial threat to those who are or have been involved in it.' They further clarify that sensitive research 'intrudes into the private sphere or delves into some deeply personal experience. Research into such areas may threaten those studied through the levels of emotional stress they produce' (ibid: 6). While the study at hand's research context does not seem to raise issues of "intruding" or "threat" in the extreme way they manifested for Renzetti and Lee (ibid), its characterisation as 'sensitive research' is nevertheless pertinent to the execution of the research design, and acts as a helpful reflexive reminder for the researcher when considering her own conduct.

Issues of informant "vulnerability" are particularly significant to the undertaking of data collection, where the researcher interacts directly with the researched. With this in mind, the researcher worked closely with a gatekeeper (a member of the myeloma community and support group leader) to negotiate appropriate access to suitable informants. Permission for the research visit was sought from members of the '[State] Myeloma Support Group' through a notice in their monthly e-newsletter, several months in advance of the planned visit. Only those who expressed an interest in being interviewed were then contacted by the researcher.

After access was gained to the myeloma community and trust developed, snowball sampling was used to gain access to professionals involved in the care of myeloma patients, and purposeful sampling was used to access the patients themselves.

3.4.1.1 Reciprocity

Harrison et al (2001) discuss reciprocity in qualitative research, with particular focus on the interview situation. They maintain that judicious 'self-disclosure' on the part of the researcher engenders not just the gathering of good quality data, but also brings parity to the power imbalance between the researcher (seen to hold the power in the interview situation) and those researched (ibid: 323). This approach was adopted by the researcher, and I offered details about my life where appropriate. Participants were free to ask me questions, both in relation to the research project and in relation to more personal matters. Typical areas of interest among the informants included my family, my religious life/beliefs, and my thoughts on matters such as the British National Health Service (a matter of current political relevance in the USA). It should be noted that the phenomenological interview, with its conversational style and focus on the informant leading the discussion, also goes some way to balancing the inequality between the researcher and those researched (see section 3.8.2 for further discussion).

For those who feel the recruiting and interviewing of the so-called vulnerable for the purpose of consumer research is a dubious undertaking, the issue of "what's in it for the participant" is paramount. The concern is not without validity. Participants give so much to the research projects (and the careers) of researchers, yet seemingly

receive nothing in return (obviously this is in reference to projects without payment or incentive for participation).

Both Pavia and Mason (2004) and Fischer et al (2007) counter this argument with an interesting take on reciprocity (it should be noted that the participants they refer to are breast cancer patients (Pavia and Mason) and consumers of assisted reproductive technologies (Fischer et al):

> "Based on feedback, it [the interview] also benefited the informants themselves, thus making a step toward balancing the exchange between researcher and informant." (Pavia and Mason 2004:444)

> "Informants were not paid for participating, although some said helping others cope with infertility was compensation enough." (Fischer et al 2007: 427)

Volunteering, helping behaviour, "reaching out" to one another and caring are common practices within the myeloma community (see Chapter Four for further discussion). I would like to speculate that participants' motivation for taking part in this study were an instantiation of the myeloma community ethos and values. Without qualification, I am grateful to them for doing so.

The researcher's responsibilities go far beyond gratitude. The researcher must strive to be respectful to the informant long after the interview is finished. There is the matter of confidentiality, and crucially of accurate representation. It was felt by the

researcher that a phenomenological approach would on the whole allow the depiction of the informants' experience and life-world in their own language, using their own terms of reference. The methodology was therefore judged suitable to the task.

3.4.1.2 Ethical Approval

Ethical approval for the fieldwork component of this study was sought from the University of Stirling, Division of Marketing's subcommittee for research ethics. A written application outlining the proposed research design and methods, including a detailed description of the empirical site, was submitted. Ethical approval for the study was then granted. The researcher also undertook research training offered by Stirling Graduate Research School on a course entitled 'Research Ethics'. This process allowed the researcher the opportunity to reflect on the ethical considerations engendered by research with so-called vulnerable groups (Lee and Renzetti 1993), particularly with reference to issues of informant vulnerability (especially emotional vulnerability), safety and privacy. As is usual in sensitive research, informant names have been changed and key biographical information has been omitted or altered to preserve anonymity. Efforts have also been made to disguise the geographic location of the fieldwork to further protect the identity of the informants.

3.4.1.3 Contextualisation

Researcher sensitivity to issues and vulnerabilities particular to the myeloma community was enhanced by a period of contextualisation. In order to develop an appropriate research design for the study, a period of preliminary, exploratory

fieldwork was undertaken. Some months were spent in 'broad exploration' of the topic area (Wong and King 2008). This process of contextualisation – a component of the phenomenological tradition - incorporated reading cancer support materials and memoirs, attending conferences and events, and informal discussion with patients, carers and professionals (as per Pavia and Mason 2004). It should also be noted that the researcher has significant personal experience of the illness in question, having worked for a UK-based myeloma charity – The International Myeloma Foundation – in a patient-support role from 1999 to 2002. This work experience provided the researcher with extensive experience of communicating with those living with serious illness, as well as a broad knowledge of the character of the disease and its treatments. While in this employment the researcher also undertook British Association for Counselling & Psychotherapy-accredited training in counselling skills; the focus of this course was what is called "active listening," using discursive techniques such as paraphrasing and "reflecting back" in order to achieve (and confirm) understanding. These skills, coupled with the researcher's previous experience in interviewing those living with myeloma (interviews with 10 myeloma patients in California were conducted for a MSc Marketing dissertation in 2003), meant that the researcher was already experienced in and sensitised to many of the issues that affect members of the myeloma community.

3.5 Interpretive consumer research and the study of community

In order to make informed decisions regarding research design it was felt that a review of interpretivist studies conducted within relevant contexts might provide

methodological signposts. Therefore the techniques used by consumer researchers investigating the phenomenon of community were examined and then distilled in the table below. As outlined in Chapter Two, since the mid-Nineties the concept of community has frequently featured in the consumer research literature. Authors have used a variety of methods in order to explore issues of community and communitas with ethnographic techniques being the most commonly employed.

Table 1: A comparison of research methods employed in community/subcultural contexts

Paper	Context	Research design
Arnould and Price (1993)	River rafting trip on Colorado river – consumption of services	Participant observation, interview, focus groups, quantitative survey
Belk and Costa (1998)	Mountain men rendezvous, community of consumption	Participant observation, interviews at related/contrast events Formal/informal/depth interviews, photographs.
Celsi, Rose and Leigh (1993)	Skydiving subculture, high risk consumption	Ethnography, prior ethnography to gain access – 1 year of participant observation, comparative analysis, emergent design, use of skydiving media, photographs and interviews
Goulding, Shankar and Elliott (2002)	Weekend ravers subculture, UK	Two-stage methodology, phenomenological data gathered through participant observation, 2nd stage interviews were conducted, part to whole analysis.
Holt (1995)	Chicago Cubs baseball spectators	Observational case study, attended games over 2 baseball seasons, attempts were made by the researcher to distance himself from "normal" perspective of baseball supporter, used methodological strategy of Goffman, 3 part iterative analytical technique, constant comparison, coding, memoing.
Kates (2002b)	Urban Gay subculture	18 month ethnographic immersion, follow-up visits to geographic area, informal lifestyle data gathering, participation in groups/clubs, formal interviews, snowballing sample, iterative readings, creating categories.

Kozinets (2001)	Star Trek fans	20 month ethnography, different sites, participant –observation, boards/ committees. Analysis of web pages, email, newsgroups. Creation of research website, use of photographs, grounded theory, NUD*IST.
Kozinets 2002	Burning Man festival	Participant-observation, active in internet community, use of photographs, email, mass media, internet, participant-observation, videography, semi-structured interviews, photography, research website, constant comparative analytic techniques.
Muniz and O'Guinn (2001)	Brand communities – Apple, Saab, Broncos	Face-to-face interviews non/participant observation, analysis of web pages Snowballing/gatekeepers Iterative, manual analysis.
Penaloza (1994)	Mexican immigrants to USA	Critical ethnography, emergent design, purposively selected informants for variety and contrast, used snowballing, 23 individuals interviewed
Schouten and McAlexander (1995)	Harley Davidson Bikers	3 year full/part-time ethnographic immersion, informal interviews, photographs, Biker media, iterative 'puzzle building' (p47).

Critical review of the aforementioned studies encouraged the researcher to reject an ethnographic approach to the study on the basis that the technique largely focuses on interaction rather than subjective experience, traditionally privileging observation over the voice of the informant. With the exception of Kates (2002b) and Penaloza (1994), the studies outlined above feature avocational pursuits, meaning that participation was practical and possible. However this methodology was felt to be inappropriate for the research context at hand, as the researcher could not legitimately "join in" in the research situation (i.e. conduct participant observation). Adhering to the tenets of phenomenology, the experience and world view of the informant is seen as subjectively theirs, and cannot be adopted by the researcher. This was a particularly stark distinction in the study at hand, as the

researcher was relatively youthful and healthy while on the whole the informants, sadly, were not.

3.6 Interpretive consumer research and health(care)

Having discounted ethnographic techniques due to their unsuitability for the research context it was felt that a review of interpretivist studies within relevant contexts might provide methodological direction. In consumer research those dealing with illness, disability or healthcare concerns appear infrequently. The following provide notable exceptions: people living with AIDS (Adelman 1993; Kates 2002), users of an online Downs Syndrome community (Fischer et al 1996), breast cancer patients (Pavia and Mason, 2004; Wong and King, 2008), people undertaking infertility treatment (Fischer et al 2007) and the natural childbirth community (Thompson 2005). These studies are unpacked below with specific focus on their context and research design.

Table 2: A comparison of research methods employed in healthcare/illness contexts

Author/s	Context	Research Design
Adelman (1992)	Geographic community of persons living with AIDS	2.5 years volunteer work, Participant-observation, interviews, documentary film, interpretive analysis
Fischer, Bristor and Gainer (1996)	Online Down's Syndrome newsgroup	Hermeneutic examination Viewing newsgroup for 1 month, semiotic-structural analysis of texts. Researchers identified own preunderstanding about concept of community and communities to which they belonged.

Fischer, Otnes and Tuncay (2007)	Consumers of assisted reproductive technologies	One-to-one semi-structured depth interviews with 23 consumers (both male and female), snowball sampling, some interview conducted by speakerphone, "grand-tour" question employed (McCracken 1988), developed themes and patterns with issues of consumer goals and existing theory in mind.
Hogg, Laing and Newholm (2004)	Online communities of healthcare service users	Indepth interviews with 20 'posters' from health based websites (10 in UK 10 in US), face-to-face or online, interviewees were 'high involvement users', observation of online discussion forums, content and dynamic of forums was analysed.
Kates (2002)	People living with AIDS (PLWA), AIDS community, not-for-profit sector	Qualitative exploration, 20 interviews with PLWA, both professionals and non, narrative technique used, interviews lasted from 1hr-3hrs, data analysed by iterative, part to whole process, open coding used, tropes identified – metaphor.
Pavia and Mason (2004)	Breast cancer patients	Phenomenological interviewing, 13 depth interviews and two focus groups with 'breast cancer survivors', period of contextualisation; use of reading materials, memoirs, attending events and informal discussion with patients, carers and professionals, informants recruited through flyers at clinics, support groups, conferences and therapists.

Thompson and Troester (2002)	Natural health microculture	Phenomenological interviewing, 4 year project, attended natural health seminars, used therapies, consulted natural health media, purposive sampling used to select 32 natural health consumers (varying degrees of immersion in microculture), part to whole analysis.
Thompson (2005)	Natural childbirth community	Phenomenological interviews with 10 couples, part to whole analysis, iterative process.
Wong and King (2008)	Breast cancer patients	Hermeneutical approach, in-depth understanding of lived experiences desired – delve into thoughts, feelings and behaviours of informants, interviews with 12 participants – diverse sample in terms of occupation, education and marital status, visited breast cancer walks, hospitals, clinic and immersed themselves in breast cancer media.

With the exception of Adelman (1992) (which must represent a highly unusual case), the studies listed above provide the researcher with examples of techniques which are suitable to the task. These studies variously employ 'qualitative', hermeneutic and phenomenological techniques, and have acted as inspiration for the study at hand. Specifically the work of Pavia and Mason (2004) and Wong and King (2008), which both concern those living with breast cancer, have acted as exemplars for representations of the lived experience of illness. Both studies use a phenomenological perspective, representing the experiences of a single (or multiple) case/s in an instantiation of wider cultural norms or discourses. Wong and King

(2008) in particular make use of a hermeneutic technique to draw attention to the discourses – such as the restitution narrative – which shape consumers' understandings of risk. Pavia and Mason's (2004) phenomenological approach enables them to develop an understanding of the lived experience of coping with breast cancer, and the role this diagnosis plays in the informants' consumption practices.

3.7 Methodology: Phenomenology

"Existential-phenomenology seeks to describe experience as it emerges in some context(s) or, to use phenomenological terms, as it is "lived"."
(Thompson et al 1989: 135)

A review of the extant literature, coupled with mindfulness of the study's aims, reveals phenomenology to be a suitable methodology with which to proceed. As previously stated, the aim of the study is to generate insights based on informants' lived experiences of illness. A methodological stance which enables the researcher to get close to the subjective experience of the informant is felt to be crucial (Goulding 2002). This cognitive proximity allows the researcher to build up a picture of the 'life-world' of the informant (Thompson et al 1990: 346). As a 'descriptively oriented research approach' (Thompson et al 1990: 346), phenomenology engenders rich, thick (Geertz 1973) description of the emotional context of the experience of illness, as well as enabling examination of the community currencies and values, and the larger cultural discourses that shape

informants' experience. In this way, phenomenology is concerned with the 'experiential underpinnings of knowledge' (Holstein and Gubrium 1998: 138).

As Table 2 shows, phenomenology has a relatively rich history of application within the field of consumer research. It has been employed as a methodology for the exploration of compulsive shopping habits (O'Guinn and Faber 1989); self gift giving (Mick and Demoss 1990); the consumption experiences of married women (Thompson et al 1990); self-care practices (Thompson and Hirshman 1995); ideologies of fashion (Thompson and Haytko 1997); and rave culture and fragmented consumer identity (Goulding et al 2002). The review below deals largely with the work of its main proponent in the field, Craig Thompson. Thompson, Locander and Pollio first proffered existential phenomenology as an applicable methodology for consumer research in Thompson et al (1989). Since then phenomenology has been used in consumer research 'to develop an understanding of complex issues that may not be immediately implicit in surface responses' (Goulding 2002: 21-22).

At the foundation of this research strategy is a belief in the inseparability of experience and context – in the *situated* nature of experience:

> "Existential-phenomenology's world view is a *contextualist* view in which experience is seen as a pattern that emerges from a context. The ontology (nature of being) is in-the-world: experience and world are viewed as co-constituting." (Thompson et al 1989: 137, [emphasis authors' own])

As Crotty (1998) puts it, 'the object cannot be adequately described apart from the subject, nor can the subject be adequately described apart from the object. Thus, existential phenomenology bespeaks the relationship between people and the world. We are beings-in-the-world. Because of this we cannot be described apart from our world, just as our world – always a human world – cannot be described apart from us" (ibid: 79). For example, Thompson and Tambyah (1999) use a phenomenological approach to investigate cosmopolitanism among expatriates in Singapore. The strategy adopted 'assumes that a coconstituting, figure-ground relationship exists between consumption stories and a personalized, cultural understanding of one's existential position.' (ibid: 222-3)

3.7.1 Phenomenological Tenets

Following Thompson et al (1989), phenomenology can be viewed as a 'descriptive science' that focuses on an individual's 'life-world' (ibid: 136). At the heart of this type of research is the consumer *experience* as described in first-person narratives:

> "The research strategy is *holistic* and seeks to relate descriptions of specific experiences to each other and to the overall context of the life-world."
> (Thompson et al 1989: 136, [emphasis authors' own])

Thompson et al (1990) describe the three central concepts of existential phenomenology as intentionality, emergent dialogue and hermeneutic endeavour. 'Intentionality' dictates that 'lived experience may not always honor standard conceptual boundaries and, therefore, must be understood relative to the specific

life-world from which it emerges'. 'Emergent dialogue' describes the notion that course of interview is set by participants and the researcher does not approach the interview with a set of a priori questions. 'Hermeneutic endeavour' suggests that textual analysis consists of part-to-whole analysis. This is an iterative process in which interpretations are continuously revised. Common patterns, termed 'global themes', are identified (ibid: 347).

3.7.2 Moving from the emic to the etic

The existential phenomenological work of Thompson, Locander and Pollio (1989, 1990) draws on literature and theory in moderation while illuminating the subjects at hand. For example Thompson et al (1990) do not begin their paper with the traditional review of the literature; instead they outline the chosen methodology. Literature on the pertinent topic is employed sparingly, but is brought in 'briefly' (as the authors put it) to discuss their contribution to the conceptual area of impulse buying (ibid: 357). 'Free choice' – the concept under investigation - is not defined or explored through a body of literature; rather it is left to the experiences of the respondents – as recounted in the interview process – to give this term (and others) meaning. The authors "stay with" the informant, using their experiences and understandings to frame terminology, and the study as a whole is filtered through the researcher's interpretations of participants' individual experiences. As Goulding (2002) puts it:

> "Language is the central medium for transmitting meaning and as such
> provides a methodological orientation for a phenomenology of social life

which is concerned with the relation between language use and the objects of experience. The meaning of a word is taken to be what it references, corresponds with, or stands for in the real world" (ibid: 23)

Yet later studies by, for example, Thompson and Tambyah (1999) and Thompson and Troester (2002) are rich in contextualisation, social and historical detail, and employ various sets of literature and theory extensively. One could speculate that a *relaxation* in the adherence to the tenets set out in Thompson et al (1989) has occurred. There is a movement away from use of a strict existential phenomenology template (cf Thompson at al 1990) to studies where the methodological *tools* of phenomenology are employed (cf Thompson and Haytko 1997) and the analytical focus is on moving from emic description of individual experience to etic theory building. These differing approaches are evinced by Thompson et al's (1989) claim that existential phenomenology should adopt an 'emic' approach to interpretation - using informants' own terms and categories – and should attempt to stay at the level of 'lived experience' (ibid: 140). Yet by the time of Thompson and Haytko (1997), the outline of methodological procedures includes an attempt to make transparent (or justify) the progression from emic description to etic constructs in the analytical process:

> "[S]pecific personal experiences, social practices, or cultural texts are interpreted as sites where cultural traditions of meaning and social value systems are enacted, negotiated, and transformed." (ibid: 20)

"This mode of analysis assumes that the particular (or microlevel) case represents an instantiation of macrolevel cultural processes and structure." (ibid: 20)

Thompson and Haytko (1997) show how they have used existing consumer research theory to position research themes in relation to existing research on fashion. They describe their movement between the emic and etic, an oscillation between interview texts and theory that Geertz (1983) has termed "dialectical tacking." The interplay between interview texts, thematic interpretations and literature moves interpretation from the emic to the etic. It is this movement that the study at hand attempts to embrace. While it does aim to "let the informant speak for themselves" and make use of their language and descriptive terms, it has a broader aim of approaching an etic understanding of the phenomenon in question. Thus, as Chapter 4 displays, theory was brought to the informants' narratives when it was felt to be appropriate. Like Thompson's later work (see Appendix Three) this study employs the tools of phenomenology without adhering to the seemingly strict rules of existential phenomenology set out in Thompson et al (1989) and Thompson et al (1990).

In order to develop a fuller understanding of the processes and actions involved in conducting phenomenological research this chapter will provide a description of the sampling procedures, interview process, and procedures of analysis employed in this study. (Note: Appendix Three gives further details of the work of Craig Thompson and co-authors, in particular with regard to procedures of participant recruitment, number of participants and interview process.)

3.8 Methods for qualitative data collection

"[R]esearch that attempts to understand the meaning or nature of experience of persons with problems such as chronic illness, addiction, divorce, and the act of "coming out" lends itself to getting out into the field and finding out what people are doing and thinking." (Strauss and Corbin 1998:11)

In line with the advice of Strauss and Corbin (1998), and with the contextualist worldview of phenomenology in mind (Thompson et al 1989), fieldwork was seen as being central to this study. Processes of contextualisation and data collection were undertaken during an 18 week research visit to the Midwest of the U.S.A. between April and August 2006. Access to informants was negotiated through the leader of the '[State] Myeloma Support Group', with access to the larger myeloma community arranged through the cancer support organisation, the International Myeloma Foundation (IMF).

Living and researching within the fieldwork site allowed the researcher to further familiarise herself with the phenomenon under investigation by engaging in an all-important period of contextualisation (Pavia and Mason 2004; Thompson and Troester 2002). Thompson (1997) highlights the significance of this phase of the research process:

"The quality of the research findings is contingent upon the scope of the background knowledge that the researcher brings to bear and his or her

ability to forge insightful linkages between this background knowledge and the texts at hand." (Thompson 1997: 442)

The researcher was a non-participant observer of the monthly meetings of three support groups in addition to attending other community events such as the Annual IMF Support Group Leaders' Retreat in Scottsdale, Arizona, May 2006. In order to approach an understanding of the experience of illness the researcher engaged in informal conversation with those living with myeloma, and with the professionals who provide services to them: charity professionals, Consultant Haematologists, nursing staff and social workers, accessed through snowball sampling (see Appendix Seven for an extract from the fieldnotes.) The process of familiarisation with the myeloma community and the wider healthcare system was invaluable to the project, sensitising the researcher to the language and tropes used by community members (Kates 2002a) and to the previously-unfamiliar American healthcare system. This system - which differs radically from the NHS in Britain - is largely reliant on individuals having healthcare insurance, and as a result much of the life of the patient is spent in bureaucratic to-ing and fro-ing with such organisations. The complex science of the disease and its treatments were further demystified at this time, too. The process of familiarisation with the names and application of the various drug regimens, for example, proved invaluable to the researcher's comprehension of conversations with informants. As Wong and King (2008) explain, an understanding of the 'vernaculars and discourses' surrounding the disease and its detection and treatment (in their case Breast Cancer) is vital to building up a picture of the life-world of participants (ibid: 582). (See Section

3.4.1.3 for more details on the researcher's previous experience with the myeloma community.)

3.8.1 Sampling

Goulding asserts that the dictates of phenomenological research mean that 'participants are selected only if they have lived the experience under study' (Goulding, 2002: 23). As Goulding (2002) highlights, purposive sampling is invariably employed by phenomenological researchers because the aim of the study is to investigate a *particular experience* through the individual narratives of participants. The fundamental criteria for selection in this study were that the participant was diagnosed with myeloma, or was the carer of someone who had been, and that they were members of a support group or the wider myeloma community.

Following this rationale, purposive sampling was indeed used in this study. As outlined in section 3.4.1, the researcher worked with a gatekeeper to gain access to the myeloma community and its support groups. This gatekeeper was leader of one of the groups, and a myeloma patient himself. He circulated details of the research study (provided by the researcher) in the support group's monthly, state-wide e-newsletter, which he compiled. He also asked the group's permission for the researcher to attend meetings and interview those who wished to participate. Group members were able to reply to this request at a face-to-face group meeting or later by email to the group leader (this procedure was also adopted for two other support groups). Permissions to participate in the groups' meetings were granted before the fieldwork visit was organised. Once in the field, the researcher attended group

meetings. At her first attendance she introduced herself and the research project, and offered a supplementary information sheet to those who wished to know more or who wanted to take part. Interested individuals then contacted the researcher (by email or telephone), and only those who followed up in this way were invited to participate as informants in the study. Because of this method of recruitment, all of those who contacted the researcher were "suitable" informants (i.e. they had experience of the phenomenon under investigation).

Considering the goal of obtaining good quality data, Creswell (1998) suggests that phenomenological researchers need clear criteria in mind when attempting to locate suitable interviewees. Thompson and Troester (2002) outline that their choice of purposive sampling follows 'interpretivist research conventions,' and that their sampling sought 'variance on the extent of their immersion in the natural health microculture' (ibid: 554). In line with their study, participants in the study at hand were at different stages of immersion in the myeloma community, both in terms of the period of time since they had been diagnosed with myeloma and of the time they had been attending a support group. No particular efforts were made in seeking demographic variance (age, ethnic background etc.), as these aspects were not employed as variables in the study (and the disease itself creates boundaries of selection - the majority of sufferers are over 50, for example). However an attempt was made to select both male and female informants. It was left to participants to decide whether they were well enough to participate.

3.8.2 Interview

"[T]he stories consumers tell about their consumption experiences are a prime locus of discovery" (Thompson 1997: 439)

The aim of a phenomenological interview is to achieve an in-depth, first-person description of the participant's experience of a particular phenomenon (Thompson et al 1989), and therefore the goal of such an interview is to hold a conversation with the informant. This discourse should, ideally, be shaped largely by the informant, and the questions asked by the researcher should arise from their understanding of the particular discourse they are engaged in. The interviewer will not normally enter into the interview situation with a list of predetermined questions; rather, the conversation should flow in as natural a manner as possible. As Pavia and Mason point out below, the informant leads the conversation with *an interpretation* of the questions asked, and they are given conversational "space" to proceed with their contribution:

> "The informant led the discussion with her own interpretation of the question, and the interviewers followed her lead with the topics that emerged." (Pavia and Mason 2004: 444).

Twenty face-to-face, depth interviews (McCracken 1988) were conducted with 15 informants: myeloma patients and their spouses or family members - "carers", as they are known. Several informants were interviewed more than once to 'allow space for both the researcher and participant to reflect' (Shankar et al 2001: 444). The length of interviews ranged from 35 to 150 minutes. Informants all resided in

the same state in the American Midwest and were members of myeloma support groups. They were between 47 and 87 years old, in line with the epidemiology of the disease, and sixty percent of the informants were female (see Appendix Two for informants' biographical details).

On advice from the community gatekeeper, patients and carers were interviewed together if they wished to be. This seemed to make both feel more comfortable and relaxed, adding to the richness of the data. All informants were interviewed in a setting of their choice – their home, a local coffee shop, or their place of work.

The researcher attempted to put the participant at ease (and the researcher at theirs) by asking informants about their day, their home (if this was the setting), or their family, for example (Thompson and Haytko 1997). A brief outline of the study was given, and informants were advised that the data collected would remain confidential and would be anonymised when represented verbally or in print. In addition, each informant was asked if they would be comfortable if the conversation was recorded. All agreed to be recorded. At this time the researcher offered information about herself in reply to informants' questions. These largely concerned the following topics: which University I attended, how long I had been engaged in study, where I lived, how long I had been in their State, and was I enjoying my time in their State. I responded to anything they cared to ask (for example about my family background) in an effort to engender the conversational style required for the interview. As Harrison et al (2001) point out, such 'reciprocity' acts to empower the researched:

"Through judicious use of self-disclosure, interviews become conversations and richer data are possible." (ibid: 323)

The conversation was then brought by the researcher to an opening 'grand-tour' (McCracken 1988) question regarding the experience under investigation:

"The purpose of the opening question was to establish an understandable domain for beginning the dialogue, but the interviews focused on descriptions of specific consumer experiences." (Thompson et al 1990: 348)

The opening question generally took the form of "Tell me about how myeloma entered your life?" The collection of data in narrative form was felt to be important, as stories are a significant way in which experiences are made meaningful (Shankar et. al., 2001). Most informants began their narratives by describing their lives prior to diagnosis – jobs, family and hobbies, for example – and then moved on to explaining how the disease was first detected, how it was treated, how it had affected their life, and finally their disease status - how they were - at time of interview. The researcher made use of counselling skills training (see Section 3.4.1.3 for more discussion) and engaged in a process of "active" listening throughout this interview, using techniques such as paraphrasing and 'reflecting back' informants' words to confirm understanding. Probing questions were also employed in response to informants' revelations, to enable the conversation to explore particular areas in more depth. The following example elucidates:

Researcher: *You mentioned that the support group gave you a place to "belong"; could you tell a bit more about that?*

Probing questions were used to gain depth of understanding of a subject brought to the conversation by the informant. It was felt that this technique must be used judiciously and, for example, probing was not used to open conversation on topics which could be characterised as "sensitive" or "emotional". It was left to the informant to decide whether or not to bring this type of narrative to the conversation.

A digital voice recording device was employed; in addition field notes (written after the informant/researcher had left the interview situation) were also documented to capture discussion and note contextual observations. While interview style and technique evolved as the researcher became more experienced during the data-collection period, this format was adhered to throughout (see Appendix Four for an example of interview text).

3.9 Analysis

As Cherrier (2005) notes, phenomenological research methods tend to generate a large volume of data which must then be wrangled with by the researcher. This study was no different. Approximately 20 hours of recorded material were generated from the 20 interviews with 15 informants. Selected interviews were transcribed in the field and subjected to iterative readings, data analysis occurring simultaneously with data collection and data interpretation (Miles and Huberman

1994). This helped to build up an index of community terminology, language and tropes (cf Kates 2002a). Further data analysis was carried out on exiting the field. The contextual observations contained in the field notes were used 'to offer a sense of re-orientation during the analysis stage.' (Goulding et al 2002: 267)

Thompson et al (1989) describe giving a 'thematic description' of experience as the research goal of phenomenological projects (ibid: 137). Adhering strictly to the narratives of the participant, 'existential-phenomenological understanding is attained by describing lived experiences and the meanings that emerge from them.' (ibid: 139). The text of the interview is treated as an 'autonomous body of data' containing the respondent's reflections on their lived experiences (ibid: 140). The key analytical approaches are described below.

Hermeneutical circle

The term hermeneutical circle is used to describe the part-to-whole, whole-to-part analysis employed in phenomenological studies. This involves several (iterative) readings of each interview transcript (text) individually. The text is viewed as a whole, and an understanding of the experiences described within is sought through the process of relating 'passages of the transcript to its overall content' (Thompson et al 1990: 141). This intratextual stage is described by Thompson et al (1990) as the 'idiographic level' (the individual level):

> "In this process, earlier readings of a text inform later readings, and, reciprocally, later readings allow the researcher to recognize and explore patterns not noted in the initial analysis." (Thompson and Haytko 1997: 20)

The second level of part-to-whole analysis is intertextual, taking further texts and relating them to each other through the identification of common patterns and differences. These patterns are termed 'global themes' by Thompson et al (1990). Global themes emerge from readings of the texts, and must be "traceable":

> "Even at the level of global themes, the researcher should be able to point to specific passages in the transcripts that afford a clear statement of a theme." (ibid: 142)

Texts must be read several times at various stages in the interpretive process, and themes emerging in one text may affect the understanding of another text. The aim is that a holistic understanding develops over time. As per Thompson (1994), readings of the interview texts were informed by the consumer research literature.

This process of building up an 'experiential gestalt' (pattern of experience), as Thompson et al put it (1990: 346), requires intense reflection and time spent with the individual texts and data set as a whole, and can be prolonged. The researcher here acts as a kind of tool, reading and rereading texts to discern meaning:

> "Commonality is not an intrinsic property of texts that exist independently of an interpretive understanding. Rather, different situations must be seen as similar by an interpreter." (Thompson et al 1990: 347).

As Thompson (1997) states, in phenomenological hermeneutic interpretation, the part-to-whole process occurs in two phases; at individual (see Appendix Five for a worked example) and communal levels (see Appendix Six for a worked example).

Holbrook and O'Shaughnessy (1988: 400) highlight the intention of the relationship between researcher and text:

> "This dialogue between reader and text then proceeds through subsequent iterations of a circular process that, far from being vicious, tends toward its own correction in the direction of increasing validity."

A note on bracketing

Crotty (1998) states that the phenomenological researcher must attempt to bracket their pre-understandings in order to allow the phenomena to speak for themselves. Thompson et al (1989) describe the process:

> "When bracketing, the researcher relates to respondent reflections in a non-dogmatic fashion and attempts to grasp, rather than impose, meanings emerging from the dialogue." (ibid: 140)

Thompson et al (1989) suggest that this 'holding in abeyance' of preconceived notions allows the researcher to approach texts as an 'autonomous body of data'. Holstein and Gubrium (1998), after Shultz (1970), suggest that bracketing is a 'setting aside' of one's 'taken-for-granted orientation' to the life world (ibid: 139). Thus, the researcher can concentrate on the ways in which 'members of the life

world themselves interpretively produce the recognizable, intelligible forms they treat as real' (Holstein and Gubrium, 1998: 139). This laying aside of prevailing understandings presents a challenge to the researcher, particularly within the academic framework of the PhD, where time may have been spent working with theory and literature before entering the field. One might suggest, as do Hudson and Ozanne (1988), that absolute bracketing is near-impossible. While the researcher recognises that meaning can be suppressed by our received notions (Crotty 1998: 80), it can be argued – from a phenomenological perspective – that as 'beings in the world' whose 'life-world' is inseparable from us, we are never really free from preconceptions (Crotty 1998: 79). However, this problem can be viewed as a matter of *degree;* and while, perhaps, we as researchers cannot compartmentalise our innate preconceptions, we can at least attempt to bracket or lay aside those that relate to the phenomenon at hand. A procedure that can be invoked to approach the ideal of bracketing is the recording of one's preunderstandings of the phenomenon before entering the field (cf. Fischer et al 1996 and Fischer et al 2007). This exercise, which was conducted verbally in supervisory meetings prior to the fieldwork of the study at hand, enables the researcher to develop reflexive distance from personal viewpoints (Hogg and McLaren 2008) and can help to achieve analytical distance (Pavia and Mason 2004) when dealing with data.

Interpretive groups

Thompson et al (1989) describe using an 'interpretive group' of researchers and other individuals who come to the data in order to aid analysis. This method brings a broader perspective to the data – "new eyes", if you will – yet the group does not look for compromise on interpretations. Rather, agreement of the veracity of the

interpretation is sought. This procedure was undertaken by the researcher and her supervisory team of Prof. Douglas Brownlie and Dr Paul Hewer, and was seen to benefit the project immensely. The researcher, after spending some time undertaking the procedures described above, brought analytical materials outlining some global themes and audio files of data to present to the interpretive group. These were listened to and reviewed, and the ensuing discussion both enriched interpretation and provided the researcher with confirmation of the veracity of her interpretations. This form of meeting was employed three times during the analytical process. Another benefit of such an approach is that the use of interpretive groups can aid bracketing by 'conscientiously questioning the assumptions each member employs' (Thompson et al 1989: 140). In addition, Pavia and Mason (2004) describe using a similar technique to achieve analytical distance.

Symbolic Metaphor

Thompson et al (1994) seek out symbolic metaphors in order to deconstruct and interpret participant narratives:

> "A key aspect of our interpretive logic was the identification of a symbolic metaphor in each text: that is, an exemplary image or event that conveyed a nexus of assumptions, concerns, values, and meanings that systematically emerged throughout the interview dialogue." (ibid: 435)

The application of symbolic metaphor 'highlights and summarizes patterns of meaning that have been derived from the interview texts.' (ibid: 435). This form of coding was employed by the researcher along with coding which utilised key words

118

or experiences (the informants' own) in order to record emergent themes and approach the identification of broader, global themes (see Appendix Six for an example of the application of symbolic metaphor).

3.10 Conclusion

This chapter has attempted to explicate the decisions made by the researcher in developing a suitable research design for the study. Phenomenology was identified as an appropriate methodology, due to its fit with the research aims and its suitability for the research context. Examples of other consumer research studies that investigate the experience of illness or the consumption of healthcare (such as Fischer et al 2007; Pavia and Mason 2004 and Wong and King 2008) inspired this decision, and remain useful models. This choice of methodology enabled the researcher to approach an understanding of the lived experience of serious illness, and to deconstruct the phenomenon of identity transition described by the study's informants. The methods used to do this were fieldwork involving a period of contextualisation, depth interviews with 15 informants, and part-to-whole phenomenological analysis.

The following chapter presents the research findings arising from the investigative process outlined above. In line with the aims of the study, it is hoped that the voice of the informant can be heard in this presentation.

Chapter Four

Presentation of the Findings

Chapter Summary

This chapter presents the main findings arising from fieldwork and interviews with multiple myeloma patients and their carers who were members of support groups. The chapter is split into three sections; 4.2 looks at the transition of identity precipitated by the myeloma patient's medical diagnosis. 4.3 describes the collective practices that enable the individual patient's identity reconstruction work in the context of the support group. 4.4 evidences their return to the medical marketplace as skilled consumers.

4.1 Introduction

The findings of this study present what are considered by the researcher to be the key stories from the field. This chapter attempts to depict the 'lived experience' (Thompson et al 1989) of those living with multiple myeloma and experiencing identity transition. In doing so it links idiographic meanings derived from interview transcripts to broader cultural processes and structures surrounding the experience of healthcare consumption (Arnould and Thompson 2005). In accordance with phenomenological traditions, the data in this section are presented in longer excerpts and vignettes, "treading lightly" to allow the informants space to speak for themselves (cf Pavia and Mason 2004). Brief biographies of informants can be found in Appendix Two. Section 4.2 provides the emotional context for the study,

describing the experience of diagnosis and the ways in which it triggers a separation from the known self and an ensuing period of transition. 4.3 describes the identity-shaping practices fostered by the myeloma community, highlighting the tensions consumers experience within the medical marketplace (with particular regard to the ascribed role of "patient"). 4.4 describes the ways in which community members employ new-found expertise and knowledge to navigate the medical marketplace and exercise the identity of "agent" or "patient expert".

4.2 Identity in transition

This section considers the self in movement, observing how informants experience a destabilisation of identity upon diagnosis with multiple myeloma. Dislocated from their previous, "healthy" selves (and the practices that sustained them), the new patients find themselves stigmatised, disempowered and fearful. Institutional medicine is often found to be inadequate in response, providing poor information and tending to view the patient in a confining and inflexible role that we term (after Thompson) the *medico-administrative identity*. Caught between this ill-fitting new identity and the person they used to be, the myeloma patient is in an unfixed, liminal state. It is in this transitional condition that they can begin to evaluate the possibilities for a new self.

4.2.1 Separation: the loss of the self

> *A transition of identity begins with separation from some role, relationship or other key component of the extended self.* (Schouten, 1991: 421).

As an entry point into the research findings Turner's ([1969] 1997) working of van Gennep's stages of transition - separation, liminal and reincorporation (Ibid: 94-95) – will be applied (after Schouten [1991]), to the "transition narratives" with which informants describe what happened to them when they became ill. This analysis highlights the breakdown of identity and the role transition that can occur after diagnosis.

By its nature, diagnosis is the redefining of oneself by somebody who claims to know more about us than we do ourselves. Immediately the ill person is in the grip of outside forces – not only represented by the "experts" of institutional medicine, but also by the unknowable, unseen changes an insidious disease can make within the patient's own body. Daniel struggles with the idea of a new self, with a different body – one which contains the alien cancer. His words echo Sontag's (2002: 14) disturbing description of cancer as 'a demonic pregnancy':

> **Daniel:** And that's, in fact I was talking with my wife last night about it, I said, you know, I don't know what's happening inside my body. [The disease is in] there - and it's just weird to be dealing with something like that.

In social terms, as Lupton (1994) asserts, the onset of illness '*requires* a status change from well person to patient' (ibid: 79, emphasis added). Thompson (1997) has delineated the 'social categories, common sense beliefs, folk knowledge, and

interpretive frames of reference from which personalized meanings and conceptions of self-identity are constituted' (ibid: 440), and it is clear that much of this *requirement* is culturally conditioned in a way that is beyond the individual's control. The ill person finds themselves confronting stigmatisation.

> **Colin:** Cancer is a stigma still for some people. And if they're younger, to some extent people are worried about their jobs.

Goffman's (1963) seminal work on stigma describes our (those who are not stigmatised) reaction to those who are stigmatised in powerful terms:

"By definition, of course, we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances." (ibid:15).

Sontag (2002) too has perceived cancer – as understood through its attendant metaphors – as stigmatising. She describes how cancer has been characterised as a shameful disease; a metaphor for evil. In Goffman's words stigma represents a 'danger' to others, and at the very least, confrontation with those who have cancer reminds us 'normals' (to use Goffman's term) of the fragility of life and the horror of disease (ibid: 15). This stigmatisation has implications beyond social exclusion, Henry (2005) has observed the ways in which economic, social and cultural capital can affect the empowerment (or disempowerment) of consumers. Henry (2005) states that such perceived empowerment or disempowerment shapes self-concept and in turn affects consumption practices.

The myeloma patient's marginalisation is further exacerbated by the particularities of an uncommon illness. Both the language and concepts of the patient's medical condition are alien to those around them. The effect is one of isolation.

> **Julie:** There isn't anybody else you can talk to. You know, none of your friends have any idea; they're concerned, but they don't have any idea about the research on thalidomide, or second-generation thalidomide with revlamid plus dex or, you know, harvesting stem cells.

This is a change in circumstances that can impact heavily even on the most secure and intimate relationships.

> **Jill:** You know, we both [her husband and herself] had been healthy for so long. And all of a sudden there's an elephant in the living room.

In many ways, then, diagnosis creates a fissure from the known self. Arriving at moments of urgent medical crisis – as it often does – it can assume the form of high drama in the ill person's subsequent narrative. The dialectic of that drama is invariably predicated on the "before" and "after" that pivot on the crucial moment of redefinition. Julie's previous, healthy life is still vivid in her story, even as she describes its erasure:

> **Julie:** Like most of us, you think you're invincible. I had my own law practice, me and three men, with my name at the top (as it should be!), big name in town, big reputation, big practice, you know, working fifty, sixty hour weeks. And by August of 2001 I was feeling worse and worse, and I could barely walk the flight of stairs to my office. And I did some blood tests, I was waiting for the results, and I was at the courthouse with two lawyers and clients, and my husband walked into the room and put his hands

on my shoulders and said: "You have to call your doctor, this is an emergency," and walked me right out of the room. So I went to the next room, called my doctor, and he said: "I want you in the hospital right now, you're in terminal kidney failure."

Julie's diagnosis with multiple myeloma followed swiftly. Perhaps we can observe in her words, too, some of what Frank (1993) has characterised as the ill person's 'profound sense of loss'. Her tone is bright, but Julie's story finds her grieving for her past self.

Whatever the symptoms and discomforts that have led them to this point - and many informants remained undiagnosed for considerable periods - the *moment* of diagnosis of multiple myeloma almost invariably remains a watershed in their lives. It is the point in the multiple myeloma sufferer's story that comes to symbolise the *separation* from their previous, healthy state: the loss of self.

> **Daniel:** I'd never been sick in my life before, I mean *nothing*. I didn't care what it was (laughs), I hadn't been in hospital for a darn thing. So I mean all of a sudden I was jolted from being a very healthy and active person – I'd never smoked, I do very little drinking – and all of a sudden I'm thrown into this intense situation. It was quite an eye-opener for me.

Informants describe an abrupt dislocation from the familiar, healthy state to a new and unfixed state. Daniel describes himself as being 'jolted' from a healthy and active lifestyle, a way of being that consciously avoided the vices commonly believed to cause some cancers, almost as if there was an injustice in what happened to him. Jill, like Daniel, emphasises the foreignness and strangeness of her new state, pinpointing the insidious discomfort of the 'elephant in the room'.

As we have seen, Frank (1993:41) suggests that serious illness can cause this ending of self-recognition. Succumbing to what Lupton (1994: 79) terms the 'threat to the integrity of the body and self-identity' this study's informants typically express a post-diagnosis dislocation of self comparable to Frank's (1995) idea of the 'loss of destination and map' - and in equally powerful metaphor:

> **Colin:** Once we got [the support group] started, we really found that people – they were just lost. They were like: "I've got this disease, and I'm hanging out here on a far limb on a cliff, and I don't know if I twist or I turn or I fall."

The sense of disempowerment is acute. In Colin's account, the emotional impact of the experience is so overwhelming that sufferers are almost paralysed, afraid to take the slightest action for fear of fatal consequences. Diagnosis with incurable cancer brings the sufferer an abrupt confrontation with their own mortality:

> **Kate:** I hired and fired [my doctor] on the same day (laughs)! [When he had diagnosed me] he was very strange; he told me that he had never seen somebody, anyone, so angry in his entire life. And I looked and him and I said *I don't believe you*. You tell people every day that they are going to die, and you don't see anger?

In a (Western) culture that is not noted for its negotiation of finality (Lupton 1994), this sudden new relationship with death is almost overwhelming, carrying with it further emotional and social pressures and disempowerment. The known self is terminated, and it seems as if life, too, may imminently end.

As well as detrimentally affecting an ill person's bodily self, the overt physical realities of an illness are often in themselves disabling enough to disrupt any previous pattern of living. Multiple myeloma patients experience a myriad of debilitating – and sometimes life-threatening - symptoms which make leading their everyday lives impossible. Pain is not the least of these.

> **Colin:** I knew something was wrong in late fall and early winter of '97; I was getting shooting pains all the way through me, and went through a lot of physical exams, but the doctors couldn't find anything. And we were on a ski trip in Norway, I was taking about twenty to twenty-five Advil a day at that point - and so I took my Advil, I took some Tylenol, got up to the top and went to ski off the chairlift, and collapsed in the snow. And [I was] just in tears. I was in so much pain, I couldn't stand it.

The insidious effects of physical symptoms subvert every aspect of a seriously ill person's life. As their abilities become limited, the everyday practices on which their identity is built – from holidays to working life - are chipped away. Rosalind, a nun, describes the impact of her diagnosis and its implications:

> **Rosalind:** I was working as a pastor in a priestless parish, and I was told the day after surgery: "You can't go back to work, and you have multiple myeloma." Well the myeloma didn't bother me too much – it was the not going back to work, that really hit me.

Newly-diagnosed patients frequently communicate the loss of a secure, familiar environment. This loss could include being unable to continue in one's job or course of studies, having to leave one's home to be nearer relatives, accommodating the substantial financial pressures illness can bring, or simply adjusting to diminished capabilities. Not untypically among informants, Jean and her husband are moving to

a condominium, downsizing from the family home where they brought up their children because it has become "too much to take care of." She describes the process of packing and getting ready to move as one of dispossession:

> **Jean:** [There are] days when I'm really tired working on all the stuff that we've collected over all the years we've lived here. It's a big chore to sort through stuff because - do I really want to part with all this? And then, when you know there isn't going to be room for it, you have to be…[tough]

We can conclude that the ill lose more than their health. They are removed from familiar surroundings and all-important roles in work, home and society. There is also a loss of possessions (one's health being among them) which Belk (1988) with his assertion that 'we are what we have' (ibid: 139) equates with loss of self. Beyond changing one's life, identification of oneself with a serious illness works a fundamental change in self-concept (Lupton 1994).

4.2.2 The medico-administrative identity

To those whose previous, healthy selves have been subverted by serious illness, there is a new role available. Diagnosis acts as a labelling of the individual in which they become characterised by their disease: "breast cancer patient" or "myeloma patient". What we have seen defined by Thompson (2003) as the *medico-administrative identity* is supplied alongside the ill person's medical care, and its assimilation is rarely a happy experience in the accounts of informants. Frank (1995) elucidates:

"Becoming a victim of medicine is a recurring theme in illness stories. The incompetence of individual physicians is sometimes an issue, but more often physicians are understood as fronting a bureaucratic administrative system that colonizes the body by making it into its "case". (Frank 1995: 172)

Frank's eloquence on the standardising power of the medical encounter brings to mind Turner's ([1969] 1997: 95) description of the liminoid identity as 'reduced or ground down to a uniform condition'. The ill person may be characterised as a patient in the realms of work and social interaction, but nowhere is that identity enforced as it is in institutional medicine, which seems to *require* that each "patient" accepts a highly-circumscribed and standardised role.

Unable – through the patient's incurability and the often unfamiliar complexities of their condition – to tell myeloma sufferers they will be "fixed", medical professionals have no recourse to the comforts of the restitution narrative that is the dominant illness story in the technology-dominated biomedical institutions of the West (Lupton 1994; Wong and King 2008). Instead, what is often starkly dispensed is a classic expression of Frank's (1995) chaos narrative: a story about lack of successful treatment, physical decline and loss of control.

Kate: You know the physicians are not always tactful, I know they'd always like to be - but my diagnosis was (pauses) "You have multiple myeloma and you are going to die". And this is my present doctor, and I love him dearly, I can't believe that he even… but I mean he believed I was going to die. He's a very straightforward man, and that's what multiple myeloma was.

It cannot be surprising that patients who are supplied with this sort of definition of who they are and what is happening to them, having been painfully robbed of their

previous identities, should succumb to the new characterisation. Many of this study's informants retain their own chaos stories as bitter souvenirs of the grim time before they engaged in the work of positive identity reconstruction.

> **Kate:** I just kinda gritted my teeth and did my chemo and watched the counts go down and… It was after the first falling out of remission that I really lost it. I became very, very angry – yeah no wonder, I'm getting angry just thinking about it! They didn't catch that I was… At one point they were not treating the cancer, they were just treating the pain, and that's when I almost died. I mean literally, literally, literally, they gave me the last sacraments and were planning the funeral! … After I'd almost totally wiped out, I was like a hundred pounds, I mean I was frail and sick and I don't remember any of that, I was in the hospital for a long time. I was delusional and emotional.

The medico-administrative identity is generally viewed as being negative and disempowering by informants, reflecting limitations in perspective, flexibility and responsiveness that are endemic in institutional medicine. Post-diagnosis patients do not simply have to negotiate a new knowledge of themselves and a new institutional landscape of doctor's surgeries, clinics and hospitals; they are also trying to build an understanding of multiple myeloma and its treatments. When communicating with medical professionals, though, informants describe encountering a vocabulary of unfamiliar language and alien concepts that typically finds them struggling for understanding and meaning.

> **Julie:** The doctor said: "You have bone marrow cancer. And it's got a name. It's called multiple myeloma." Well I had to get him to spell it three times… Well he explained it to me, and the process of going through chemo, and

then harvesting the stem cells, and going in for the transplant. And by the time he was through, I thought he was talking about Star Wars.

Many informants are expansive on the subject of the *lack* of information, explanation and interpretation offered about their condition by medical professionals. Even at the level of fundamental practical knowledge, institutional medicine can be grievously inadequate at helping the newly-diagnosed patient to answer their most urgent questions about what they *are*, and what they might expect to *be*.

> **Jill:** I guess it's just the fact that here I have something I know nothing about. It was just kind of a lonesome, alone feeling. (Pauses) That's the thing that bothered me more than anything: I'm by myself, and I don't know anything about this disease.

Jill speaks of feeling 'by herself' despite the fact that she is receiving attention from medical professionals on a regular basis. But as Ehrenreich tells us, even the physical act of medical intervention itself has a tendency to objectify:

> "The endless exams, the bone scan to check for metastases, the high-tech heart test to see if I'm strong enough to withstand chemotherapy – all these blur the line between self-hood and thing-hood anyway, organic and inorganic, me and it." (Ehrenreich, 2001: 45)

In some way Ehrenreich feels she takes on the inorganic qualities of some of the treatments and procedures she endures, becoming less human through their consumption. The self is eroded away, and her sense of personhood is lost in the blur between self and other.

We have learned from Thompson (2004) and Holt (2002) among others, how consumer identity is fettered by marketplace ideologies and the confining narratives they foster, and Firat and Venkatesh's (1995) description of this structuring influence as 'totalizing logic' finds a subjective echo in the personal accounts of those who have experienced institutional medicine at its most objectifying:

> **Jill:** I got so frustrated, because [my doctor] would never tell me what was coming next. I found out I was having a stem cell transplant from one of the nurses.

> **Researcher:** How did that feel?

> **Jill:** It was just kinda like, oh that's what's happening. And then I tried to find out *when* this was happening, and [the doctor said] "I haven't talked to the insurance people yet". Wait a minute! We've been doing this all summer - *why* haven't you talked to them? (laughs). There were just stupid things like this that really *really* upset me… I just kept getting more and more frustrated. Somehow after you've been to a doctor for three years and seen him every other month… I just really felt peeved, because I thought he should know what my name was. And not Ms [surname], oh I hate that! So, and to never know what the test results were, bothered me… And I wanted to be treated as a person, not as something that he had to work with, you know, "my job is to take care of this object and this one and this one" and never let me know what comes next. That was so frustrating… I was an object that was being treated. I had no clue if I was getting better. You know, what should I be doing?

Jill feels dehumanised by the doctor who can't even use her name, or inform her about (and involve her in) her treatment decisions. She feels a need to act on her own behalf and expresses her anger at her objectification, and above all her

powerlessness to act. There is no more acute manifestation of identity unresolved than the asking of the question: "What should I be doing?" Lupton has observed (1997: 379) that '[d]ependency is a central feature of the illness experience and the medical encounter, and serves to work against the full taking up of a consumer approach.' In these terms, institutional medicine's tendency to acculturate its consumers with little more than a passive role could be interpreted as a grievous inadequacy in the medical marketplace.

4.2.3 Liminality

> *Liminal entities are neither here nor there; they are betwixt and between* (Turner [1969] 1997:94).

The lack of control, fear, frustration and loneliness expressed in Jill's narratives (above) can be seen as an expression of her liminoid state (Turner 1967). She rejects what the medical marketplace offers her - but does not yet have another source of answers.

Van Gennep's (1960) deconstruction of life passages sees *separation* from a former state, role or status followed by a *liminal phase* in which a person passes from one role or state into another. In the case of a complex and little-understood disease like multiple myeloma, the simple physical realities of the illness itself are imbued with the sort of ambiguities and uncertainties that foster liminality. It is characteristic of multiple myeloma that periods of illness can alternate with periods of good health –

active disease and remission. Diagnosed with the disease but feeling well, Daniel recounts how he retains his active lifestyle:

> **Daniel:** You know, I do all the physical things I used to do. I'm an avid gardener, and I'm back to road biking. I was out last night, you know I didn't go real far, it was about 25 miles roughly… And that's the thing that's hard, I've gotta remember that I've got a disease and I've got to take care of myself and it can come back at any time.

This ambiguity, nonstatus and unfixed identity (Turner, 1969) conforms to Pavia and Mason's (2004) account of consumers diagnosed with serious illness in a kind of 'limbo' where they are neither dying nor cured. In the terms of Sontag's illness metaphor, Daniel is a (regretfully) conscious embodiment of dual citizenship.

> "Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place." (Sontag 2002: 3)

The myeloma sufferer's ambivalent identity does not stem simply from their unstable physical condition, or even from the myriad uncertainties delivered by the medico-adminstrative role. Social pressures motivate many newly-diagnosed patients to attempt to retain at least the appearance of their old selves in a culture of stigmatisation (Goffman 1963). Frank (2000) believes things have changed for the so-called stigmatised since the writing of Goffman's work. He asserts that 'separate systems of honour' (Goffman 1963: 17) are resurging:

"After Black Power, several waves of feminism, Gay Liberation, and the assertion of many other local "pride" and "liberation" organizations and public rituals, a case can be made that separate systems of honor do exist and many individuals whose identity was once "spoiled" (in the words of Goffman's subtitle) now openly claim that identity and even claim it as a privileged state of being. Far from "passing" the non-visibly stigmatized proclaim their disease or diseased-related sympathy by wearing variously colored-coded ribbons (with distinct colors for AIDS, breast cancer, and lost children), or wearing tee-shirts that express pride in identities, or displaying bumper stickers including those that make affiliation with Alcoholics Anonymous less than anonymous." (ibid: 137)

While we can view the myeloma community as a 'separate system of honour', where the 'spoiled' (Goffman 1963) identity can be repaired, Frank's notion of claiming an identity is not necessarily open to all, nor even desirable. Unlike Kozinets' (2001) Star Trek fans who embrace the social stigma of the fan community in order to belong, this study's informants speak of wishing to be 'normal' again – by which they express the twin aspiration to feel normal in themselves, and to be *seen* as normal. In this regard, patients who attend support groups are often keenly aware of negative preconceptions about these gatherings - preconceptions they may hold themselves, as well as those held by others in the wider world. Such prejudices can act as a barrier:

Kate: [The idea of a support group] was totally new [to me], totally new. I'm not even sure that the term is good, you know, support group. I mean you think, I don't need a support group. It's almost like a negative term. I said [to friends] I go to support group, and they said "Oh you go to support

group", you know it's sort of like: "Oh, support group – gee, here we thought you were all put together - and you need all that support?!" (laughs).

Julie recounts her efforts to preserve her professional persona while confining immense emotional pressures within:

> **Julie:** I went through the entire time from [diagnosis in] September to May - I went through all that, I [even] went through the [stem cell] transplant, without ever talking to another person who had myeloma. I was (emotion in voice) on top of everything. Everybody said, you're going to slide through this just fine, you're on top of it. Yeah. It was only after I got through it that I needed just one person to say: "Julie, you sound like you're really scared." I still cry now when I think about it. And of course, it was my role to keep my spirits up. I always dressed professionally; I had shingles, and I bought my own clothes, because I couldn't wear anything with a waistband. I lost my hair of course, so I went out and bought a ton of cheap hats, and had a hat to go with every outfit. And you've got to think of yourself positively and professionally: "I'm going to make it, this is just a temporary [thing]…

Viewing her illness as a series of problems to be solved, Julie explains that her way of coping was to be 'on top of everything' – even to dress 'professionally' (her multitude of hats a visible solution to hair loss, and emblematic of her need to put on a "brave face"). Julie stresses the importance of professionalism; to think of oneself 'professionally' is linked in her narrative to positivity and indeed to survival – 'I'm going to make it'. Julie alludes to her "other", the scared and isolated individual who the healthy Julie, a partner in a large law practice and accomplished businesswoman, was unfamiliar with. However it was not just Julie who was unused to this; those *around* her could not think of her as a vulnerable person. It was Julie's role 'to keep her spirits up' and confine this vulnerable, fearful "other" out of sight.

We might conjecture that a culture that stigmatises illness conditions its citizens to disdain their own ill selves.

> **Jill:** You always feel like you're marginalised because you got this. "I got this disease. I'm sick".

As we have observed, the role of 'cancer patient'[1] is often seen by informants as a poor fit with their pre-existing sense of self. Some negotiate this by maintaining the concealment of their private diagnosis, resisting the disclosure of the new identity to the outside world - what Goffman would call 'passing' (1963: 64). With some, there is a sense of ongoing negotiation of identities. Central to Schouten's (1991) conceptualisation of identities in transition is the notion of identity play and 'possible selves', and perhaps we can observe this study's informants engaged in the task of formulating and evaluating their possible roles (Schouten 1991: 421).

> **Daniel:** I like to try to be as normal as I can, you know, do the things that normal people do, this type of thing. You know, I'm not gonna walk around with a T-shirt – you've probably seen 'em – that says 'Cancer Sucks' on it. I mean I'm not that type of person.

It should be said that while Schouten characterises the process of reformulating the self as "identity play", we might better term it, in the current context, as "identity work". The conscious changing of who one *is*, is a difficult, elusive process, under considerable pressure from grave social, physical and medical issues. We have noted how Lupton (1994) has alluded to Van Gennep's (1960) conceptualisation of

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[1] Even the vocabulary has long been problematic. In 1986 the National Coalition for Cancer Survivorship (NCCS) set out to change the parlance from cancer "victim" to cancer "survivor", and now claims the latter term is the norm "in the cancer community and beyond" (NCCS website 10/08/09).

liminality to assert that the period of ambiguity that signals transitional identity does not have a fixed term; patients, indeed, may never achieve the stability of reincorporation and move beyond a liminoid state. This limbo can be cruelly disempowering and vulnerable; a support group leader recounts his unsuccessful attempts to help a patient progress beyond it:

> **Colin:** [patient's name] came to half of one meeting. Went out crying, in tears. We talked about all of his symptoms, I went to visit with him, talked to him on the phone for hours, talked to the people at the clinic he's at, that worked with him… He seems to think, that "I'm okay today, but tomorrow, it's gonna be bad. It's gonna be bad tomorrow." It's not going to be that way, you know – and he can't quite get that through his head. So – I've even had a call the day before a meeting, saying: "Colin, when is the meeting again? I'll be there!" But I know I won't see him. He's not there.

Colin presents the story of a fellow member who finds it difficult to be a member of the group. As Colin sees it, (despite hours of one-to-one contact) this person cannot take on Colin's viewpoint that there are things to be hopeful about. The group and its 'ethos, rituals and consciousness of kind' (Muniz & O'Guinn, 2001) are not accessible to everyone. In this sense the community self-selects members who *want* to view their illness positively.

4.3 Enabling identity work

We have seen how, dislocated from their previous, "healthy" selves and uncomfortable with the role ascribed to them by the medico-adminstrative identity, the newly-diagnosed myeloma patient experiences an unfixed, liminal state. This

section observes how, acknowledging their condition as a person with myeloma, the informant takes the step of joining the support group and begins to negotiate a new identity. The community provides many resources for this identity work, accommodating a wide range of narrative models and possible roles, delivering information, explanation and interpretation, and above all transmitting the core values of the group ethos: positivity, personal responsibility and helping others. We see how both the community and the work of individual identity development are sustained by a range of group practices, from the use of ritual, myths and exclusive language to a hierarchy which is ascended through long service.

4.3.1 Joining the group

How does one reconstruct identity? For the informants of this study it has required the active taking of several difficult steps - not the least of which is an *acceptance* that one is a person who has an illness, whatever cultural prejudices this may engender.

> **Jill:** The first time [I had chemo and lost my hair] I was a little upset and embarrassed, but the second time I said I'll wear a wig when I go out. But this [ie, bald] is who I *am*, even if you don't like it. Wigs are itchy and a pain.

It's certainly not possible to access a multiple myeloma support group without conceding one's relationship to multiple myeloma. Daniel describes crossing a threshold, one that is 'scary' to confront, since it involves acknowledging that he has cancer.

Researcher: What was that experience like when you went to your first support group meeting, can you remember it?

Daniel: Yeah, it was like walking into the cancer centre the first time. I was just real uneasy the first time - you know it was a whole new thing, new people, dealing with the issue yourself, that you've got this disease… It was, um (pause), it was scary. ; it was also kind of settling to know these people had what I had and um, you were part of it and it was kind of like: I shouldn't be here, why am I here? And that's… you know, like telling myself, yeah, I've got this and I'm not any different from these people, and you know, I need to be here. But after I went, I got in the room and sat down; it was fine, and you know [the support group leader] is so open with everybody, and he introduces people when they're there, and then brings them in, and makes them part of the group. So you become integrated quickly.

Here we see Daniel is incorporated into a new community, a step we could view as the beginning of the end of his liminoid state (Turner 1974). If the moment of diagnosis is a prescription of differentiation, the approach to the support group could be seen as the re-commencement of affiliation. Walking into the group, Daniel is walking away from his former self; he has acknowledged and confronted the reality that he has cancer and that he needs the group. As Frank puts it; 'almost every narrative contains some reference to the "new" person that illness has produced out of the old self' (Frank 1993:40). The group performs a normalizing function in Daniel's illness experience since it provides him with a space to emotionally come to terms with his estrangement from his 'healthy' state and moves him to a new 'integrated' state. Such comments draw our attention to the powerful

role of the group in coming to terms with illness and offering participants a 'passport' from the 'night-side' (Sontag 2002).

This willingness to overtly negotiate with one's new identity could be seen as the crucial condition for the conscious *becoming* of something new. The consumption literature is sparse on the subject of the literal disempowerment of the medical patient – the removal of avenues of action; disorientation, denial of knowledge, isolation and cumulatively the rendering inert. But mindful of Frank's description of passivity as the 'dominant cultural conception of illness' (1995: xi) it might be possible to suggest a theory of agency that aligns with identity; in other words: *identity is necessarily an active process*.

If diagnosis can be seen as the crucial moment of the "passive" patient experience, then joining the support group might in some cases be interpreted as the defining moment of "active" agentic patient behaviour. The enacting of one's intention to change: the taking of control.

> **Kate:** I'm just not the kind of person that [gets a terminal diagnosis and] goes, "Oh gee that's too bad I'll go home and get my affairs in order". I *want* to make things happen, and I want to make them happen right now, and I want a lot of help, and the best help. And I don't remember how I got [the support group contact's] name, somebody knew that somebody else had it – this is before the support group got started. And I called this wonderful woman on the phone and she invited me for lunch and of course we just became fast friends. And she's the one that gave me all the information and told me they were about to start a support group meeting, so I was at the first meeting. It was *very* badly needed.

In informants' illness narratives this enormous step – the crucial crossing of a threshold – embodies substantial symbolic and ritual aspects.

> **Kate:** I had chemotherapy for whatever, almost two years maybe, um… and I went into remission. They don't call it remission; it was successful, and my counts got normal, and within a year [the disease] was back. And I had been to the support group – I'm going to tie the support group into this if I may, because I had been to the support group all during that period - and after I so suddenly came out of remission… And my doctor, whom I love dearly, has no, um, right way of dealing… They did not have a good way of dealing with people, or with this thing [myeloma]! (anger in voice)… And I can remember I was *so devastated*, the second time. My husband and my daughter and I – God bless that support group – went to the support group meeting, and I just stood at the door and I just said *HELP!, I don't know what was going on, I don't now know what is going on, I'm just devastated - I just really need help* (speaking quickly with much emotion in her voice). My daughter was there, my husband was there, *these people just came up and hugged me!* One at a time. And then we just took it from there, and went back and took more treatment.

Kate's dramatic narrative tells of a period of crisis where her disease has come out of remission and is active: a crisis that has instigated a loss of control. Kate, literally and symbolically standing at the threshold, surrounded by her family, neither in the group nor out, asks for help. In the perceived absence of direction from her doctor, she takes the crucial step (re-enacting a journey she made once before, when she was first diagnosed) and reaches out to the group for a signpost: where has she been, and where is she going? In this situation, it appears that the group responds physically, moving to her, in her threshold position, and embracing her. This strong statement describes a new beginning for Kate – beginning to combat the disease

again with a fresh round of treatments - but also a physical reintegration into the group where she can begin the process of remaking herself for these new circumstances.

4.3.2 The group journey

Thompson (2004) has unpacked the way in which the Eden myth (modified by Romantic and Gnostic traditions) has shaped the Natural Health movement's view of the world as a corrupted place that needs to return to natural wellness. Indeed to Thompson, the natural health marketplace's mythic appeal is one of the factors that ideally positions it to take advantage of the disempowerment and dehumanisation engendered by modern medicine's bureaucratic and technocratic structures. The myeloma community, too, provides refuge from the objectification and attenuation of uniqueness fostered by becoming a medical 'case' Frank (1995).

Afflicted by a complex degenerative disease, though, the members of the myeloma community have little access to stories about returning to paradise, whether it is the Eden of natural health or of Western medicine's restitution narrative (Wong and King 2008):

> **Jean**: They say that cure is not a word yet in this affliction, so I don't know; I can just hope for remission.

Lack of a cure, however, does not mean the myeloma patient can not undertake passage to a better place. As illustrated in 4.2, diagnosis with a serious illness can cause a break from 'known' identity and occasion a search for new understanding.

Illness brings in another "I", and in this context the support group can be seen as a pathway to discovery of new identity. The community offers a positive new place to move to, and motivation to move, providing information and emotional support that over time will help the patient to normalise and adjust to their new self. It provides the signposts for the patient's progress, and a safe vehicle for the journey.

It is characteristic of the informants of this study that they report feeling surprise on crossing the significant threshold to become part of the myeloma community:

> **Colin:** [after diagnosis] April was hard, May was hard, then in June, life started looking up. By October of that year I went to my first IMF [International Myeloma Foundation] seminar. I figured that I was going to be tripping over all these people's canes and wheelchairs, crutches and everything else. And still to this day, I can almost picture the room, and picture the people; I can picture some of the people that are gone, where they were standing, you know, by the doorway. Because it was one of the most upbeat meetings I've participated in. These people weren't sitting moaning about problems; they were celebrating what *could* happen, on the good side.

This surprise could be described as a symptom of new (and improved) circumstances. It is a pleasant surprise, and it is twofold. Unexpectedly, the newcomer finds him/herself looking at a relatively healthy gathering (quite unlike what their imagination, dominated by the grim discourses of the chaos story, had prefigured [Frank 1995]). They are also struck by the tone of the meeting - its positivity, its sense of hope. This prevailing ethos could be described as the myeloma community culture, and as will be seen, it encompasses a guiding model for identity work: an idea of "the right person to be". The medium in which this work is enacted is narrative.

4.3.3 A flexible narrative

Effective group discourses appear to require some degree of flexibility. Thompson (2003) describes how, in the diversified marketplace of the natural health movement, 'the consumption of holistic healing alternatives easily takes on a mix and match quality that avoids dependence upon (and therefore confinement within) any one approach or single authoritative definition of their bodies and identities.' (ibid: 103)

Indeed Thompson's (2005) research findings seem to demonstrate ways in which an alternative or oppositional identity (or to use the phrase he borrows from Raymond Williams (1977, 1979) 'structure of feeling') can itself become as confining and even oppressive as the orthodoxy. Forced to compromise their adherence to the path of natural childbirth by urgent medical crises, several of his informants reported regret, guilt and self-doubt at their capitulation to medical procedures.

The variety of the individual stories that circulate within the myeloma community demonstrate a subtler and more pliant strength operating within its practices.

> **Martha:** The first time I went, I was kind of nervous, but I didn't feel like an outcast at all. [the members] just went round the room and talked about themselves – you know, my name, how long I've had this, and the things I've been through. And it was really helpful, because there was a lot of people there that night, and going around the room hearing the different stories, it was like: there was no two alike, and that helped me to understand,

there's no one "you've got this, and this is it." There's always different things that can happen.

Within the consistent values of the group narrative experience, there are many different circumstances and outcomes available as models, flexibly accommodating the wide range of patients who join the group. In this context, individual uniqueness becomes an agent of inclusion rather than division. Diagnosis with a serious illness can remove a patient's sense of individuality, and stories allow a patient to regain that individuality, each narrative reflecting a unique experience of illness.

Frank (1993) and Sontag ([1991] 2002: 31) both talk eloquently of illness being an 'individual' experience. Illness, they say, is no longer a story of mass experience, as it may have been during, for example, the era of the plague. Rather Frank (1993) maintains that even diseases which affect large numbers of people, such as AIDS, tend towards 'distinct' and 'remarkable' individual stories (ibid: 40). Such 'remarkable stories', are a strengthening factor in the myeloma community: the individuality of each sufferer's experience acts as a resource to another. The production and consumption of 'lay expertise' (Allsop et al 2004), occurs through the telling of 'illness narratives', as Frank (1993) calls them. Stories shared at support group meetings provide history, context and continuity, and allow new community members to become embedded through participating in such rituals, and the gathering of specialist knowledge (Goulding et al, 2004).

The group accrues a rich collection of experiences, of various symptoms, divergent treatment regimens and contrasting lifestyles. It provides not one template but a shifting mass of stories which forms a frequently renewed and replenished reserve

of information, advice, hope, and encouragement to others. Describing the responsive operation of this exchange mechanism, Jill vividly conveys the strong emotional component of the process:

> **Jill:** After a couple of meetings you could say "I have this problem, does anyone else have this?" And they'd come back with "no" you know, if it's something that isn't multiple myeloma. Or they'll say - I have this problem, and the doctor prescribed this for me, and this is how I cope with it. And that just is an awesome, secure feeling.

As Frank, (1993) states: 'the commercial availability of illness narratives qualifies them as technologies of the self, but they remain open-ended resources of "see what happened to me" not closed prescriptive forms of "this will happen to you".' (ibid: 49).

4.3.4 Flexibility: accommodating complex identity

One of the coping mechanisms the group supports is the patient's ability to compartmentalise their lives. We have seen how patients can oscillate between ill selves and healthy selves, and how there can be powerful social reasons for wanting to hide away one's "ill self". Some myeloma patients, like Tom, choose to maintain their healthy selves publicly, in denial of their disease – and continue to keep up this dual identity after becoming members of the support group.

> **Tom:** Even today, I won't admit that I've got anything wrong with me. I can't live like that. I've been healthy all my life. I don't tell anybody outside

the immediate family, and I don't want people feeling sorry for me or saying "There he goes," or that kind of thing. It's none of their business, anyway.

Goulding et al (2002) describe this type of compartmentalisation in the lives of 'weekend ravers'. The escapism of the rave culture allows the enactment of multiple identities – ravers have a weekday "work" persona and weekend raver persona, and can be seen to hold fragmented identities. Similarly, the myeloma community acts as a site for expression of the alternative self (Goulding et al, 2002, Kozinets 2001, Schouten and McAlexander 1995). The support group enables Tom to feel that he sustains his healthy self in public, and contain the burdens of his ill self in a private 'safe' place. The group provides a protected space to interact with illness – to make sense of experiences through forming them into narratives and sharing them with others. Tom identifies himself as a healthy individual, despite his disease, and feels that to be known as an ill person is to stand out, to be noticed as different and to be pitied. He feels it is a private, family matter, and denies his ill self to the outside world. But at group meetings, ownership of multiple myeloma is the norm; Tom discusses his disease here and interacts with his ill self.

As we have learned from the consumption communities literature, such sites can be seen to offer safe space for identity construction (Belk and Costa 1998; Goulding et al 2002; Kozinets 2001, 2002; Schouten and McAlexander 1995). A key link in this process is the negotiation of one's "ill self". The support group is a site of cultural production, where members take an abstract diagnosis and make it explicit. In this way, the myeloma community, like Cova's tribes (1997) or Muniz and O'Guinn's (2001) brand communities, acts as the medium for the co-creation and movement of

consumption meanings. It offers members a site beyond their interactions with medical professionals in which to negotiate their new, "other" selves.

4.3.5 Currencies of the group: knowledge

The currency of discourses within the myeloma community is manifest in forms as pragmatic as the practical mediation of information. The myeloma support groups have access to printed and web-based medical information - through national charities such as the International Myeloma Foundation - that can help to fill the knowledge-gap suffered by most patients. As well as this (and locally-sourced written information), the group acts as an advice forum on areas relating not only to the illness itself but to all the areas of life it affects. Patients and carers have strong motivation to process this information, as knowledge in itself can feel like power, and can help one cope with the unknown future:

> **Claire:** Just one of my ways of coping is to get lots of information and keep track of the data, and so I at least have some semblance of control over the disease - which I don't, obviously, but it makes me think that I do.

Claire, who is carer to Duncan, uses the act of research and the knowledge she amasses as a source of comfort. She finds reassurance in identifying and listing (in highly organised spreadsheet form) the clinical trails and drug combinations that Duncan may use at some point in the future. Claire acknowledges that she cannot control his disease, but the act of gathering information about treatment options helps her cope through developing a *sense* of control over it. If one treatment fails, she is ready to ask Duncan's doctor if they should try another combination of drugs from her spreadsheet. While there are treatment options, there is hope. Pavia and

Mason (2004), in their study of breast cancer patients, find that consumption of everyday items or larger purchases such as holidays allows a patient to exercise control over their well-being and thus cope with a destabilising diagnosis. The authors point out that this is particularly true of the early stages of illness, where treatment decisions are made. This may be the reality for most breast cancer patients, but myeloma patients will have several periods throughout their illness where treatment will have to be considered (or they may receive a variety of treatments throughout the course of the disease). Thus we can view the decoding and consumption of medical information as an ongoing project for the myeloma patient.

Jean demonstrates how medical information has restored some sense of understanding of her body. The knowledge she gets from the publications the group provides, and from its stories, enables her to reinterpret physical sensations as medical symptoms.

> **Researcher:** I was going to ask you about information about myeloma: do you get booklets?
>
> **Jean:** Oh yeah, all kinds of pamphlets [goes to get booklets to show], some of them I have to keep reading over and over. [Shows a booklet] But many, many other kinds, this one has enough information in it that I have to go back over it once in a while. And so, there's just tons of information out there. See there's just tons of things like this. [Shows another booklet]. This was the first one I read because I thought I had lymphoma. And here's one, have you seen that one? [gives the researcher a spare copy]. There's something in each one that I felt I might want to reread. It's hard to, it's just hard to digest all the information all the time, so like I said I keep a copy of

that [shows booklet] where I keep my daily reading, and many times I have to go back over it because I misinterpret something I read, or I can't remember what I read (laughs).

Researcher: And do you like reading these, do you find them useful?

Jean: At first when you find out all the symptoms, all the things that can happen, the deterioration that can happen to your body because of this - it's pretty scary. And then I thought, I'm not gonna read any more, this is making me sick. But then I thought about it, and I thought: "*No!* If something happens, then you'll know if it's part of the myeloma, or something else," you know. So at first when you're diagnosed I think everything is a little scary, because it's weird. But I just made up my mind that - hey, everybody has an affliction of some kind probably, so I'll just keep reading, and hoping I won't have any of these things that happen to you. You know like the people [in the support group] that say, like the numbness - some people's feet are entirely numb sometimes, or their hands or their arms, and people have different symptoms, you know. At first it's a little scary. But then you think, well, at least I'll know where it's coming from if I have any of those same symptoms, you know. And if I have anything that I think is a symptom I report it to my doctor.

Foucault (1975), who worked for three years in a psychiatric hospital, has described the disciplinary power of the 'technology of the body', which he locates in prisons, hospitals, schools, factories and other confining institutions:

"There may be a "knowledge" of the body that is not exactly the science of its functioning, and a mastery of its forces that is more than the ability to conquer them; this knowledge and this mastery constitute what might be called the political technology of the body." (ibid: 25-26)

The support group's delivery and mediation of knowledge about multiple myeloma arguably represents a reclaiming of this technology for the patient. Jean's account exemplifies the way in which the material resources of the medical marketplace do not just offer understanding of a disease, but can be applied in such a way that they demystify one's own body. Reading and rereading such materials takes the unfamiliar ('weird') and makes it familiar. Again, we can see that such educational materials help allay fear. Jean, like Claire, follows the maxim "to be forewarned is to be forearmed". Such resources play an important role in the identity work carried out by the ill; as Barker (2002) asserts, the consumption of self-help literature can alter self-identity.

In Jean's case the interpretation of informational materials was largely an individual pursuit. But the group also engages in this collectively. Colin, an unusually well-informed patient, uses the knowledge he builds up about myeloma and its treatment not only to guide his own medical care but also to educate (and to use his word, '*direct*') other patients:

> **Colin:** If you're somewhat of a teacher, a teacher learns more than a student. It forces you to try to be clear, and investigate what you're talking about, because you don't want to go out there and just be air-headed about things. And also to try to give direction; if you know a little bit more about the science than most of the people in the group do, you can kind of keep them on the narrow when they get too far off… Some people read well, and some don't, for whatever reasons. When [the International Myeloma Foundation] came out with the guidelines, the red book about three years ago, I actually took one hour and went through it with [the members of the group] page by page and underlined the things I thought they really ought to consider.

In this way we can understand the support group as an interpretive community (Fish 1980), working together with given marketplace materials, making mutual sense of a diagnosis and its consequences for treatment and quality of life. The group provides members with *an* interpretation of the materials to hand, and indeed of the disease itself, and what it is to be a patient.

In the example above, the group's consumption of a particular sample of self-help literature is guided by one member of the group. Colin states that he 'underlined the things I thought they really ought to consider.' We can conclude from this extract that Colin considers there is a right way and a wrong way ('when they get too far off') to approach the treatment of myeloma, and that he is confident in communicating this message to his fellow group members. His personal interpretation of the information at hand is disseminated throughout the community, with the consequence that his beliefs form a core set of values in the group. Kates (2002a) observes that people living with AIDS become part of an interpretive community through a process of self-disclosure with a support organisation. Within this AIDS community 'broadly similar' views are held about death, dying and grieving. It can be said that the informants in the study at hand held broadly similar views about and understandings of the disease, its treatments and, importantly, about the best way of *being* a myeloma patient.

Barker (2002) found that a geographically disparate self-help community acquired a shared illness identity. She describes how the consumption of a shared 'bank' of self-help literature can lead to a change in self-identity. And beyond individual empowerment, the transaction the myeloma support group's mediation of

information embodies is a basic building block of the group's collective values. The group is built on the passing on of knowledge. To patients who have been left feeling frustrated and helpless in the face of complex science, this guidance can take effect as empowerment.

4.3.6 Staying positive: group (and narrative) boundaries

A way to define what the guiding support group narrative is and how it works is by looking at its limitations. The members are quite clear about the way to behave in the group, and to contribute to its prevailing ethos. They can say with some precision what the group isn't, in these terms, as well as what it is.

> **Martha:** My husband's initial reaction – he's never been to a meeting – his initial reaction was, it was a bunch of people who had been in the same experience, cancer or whatever it was, and they'd all sit and cry and whine about their disease. And I guess I kind of had a little bit of that, too.

The tone of group meetings is not the way Martha expected it to be.

> **Jean:** It's not a *sympathy* group, which I like. Nobody feels sad - well they feel sad if somebody that they know has passed away, but they don't feel… they don't seem like they say "poor me, my condition is worse than yours" even if it is. And that's what I like, you know. Nobody just sits there and says 'I think I'm gonna die'. You know, they just have a very positive, for the most-part, outlook.

In accordance with the pliant and responsive ethos of the collective, these boundaries of group culture are maintained without any explicit rules or guidelines.

Mortality is a more vivid certainty for people who have been diagnosed with myeloma than for most of us, for example - but it is one of the distinctive features of the support group that death is not allowed to dominate the members' interaction. Such is the strength of belief that death infringes on the ethos of support groups, that in 2006 a group based in a large city on the West coast of the USA chose to discontinue conducting a remembrance ritual (lighting a candle and sharing memories of the individual, or sharing thoughtful silence together). It was thought by one of the group leaders – herself a myeloma patient – that this type of ritual acknowledgement of death, coupled with the frequency with which members passed away, frightened new members and deterred them from returning [re-told from fieldnotes recorded at IMF Support Group Leader's Retreat 2006, Arizona]. The myeloma community positions itself strongly in resistance to the ultimate outcome of the disease, and focuses rather on "living well with it".

Jill gives an individual perspective on how the group offers an alternative to a story often told on the internet; a story she did *not* want to hear:

> **Researcher**: So you feel you learn at the group?
>
> **Jill**: I do. As I said, I tried going online and it was "so-and-so died of multiple myeloma". …I don't need to know that.

4.3.7 Ritual, language and myths

Rook (1985) describes ritual as 'a type of expressive, symbolic activity constructed of multiple behaviours that occur in a fixed, episodic sequence, and that tend to be

repeated over time. Ritual behaviour is dramatically scripted and acted out and performed with formality, seriousness and inner intensity.' (ibid 252).

A regularly recurring meeting is itself a ritual. The support groups meet monthly in the same venue (generally a hospital or healthcare setting). Seating is arranged in a circle, and members take their seats and begin catching up with one another. The meeting will be called to order by a group leader. New members are then introduced to the rest of the group by the leader. Anthropologists have identified as *rites of passage* (van Gennep 1960) the social observance of events that symbolically mark individuals' changes in social status, and Mol's (1976) definition of such rites as 'symbolic devices that accentuate the permanent quality of a status change' (ibid: 239) is evocative of the formal qualities of support group meetings, where individual status is re-established.

The most common form of ritual performed at group meetings involves each attendee in turn round the circle telling the rest of the group how they are doing. This takes the form of a short narrative describing what treatments they are on, tests they have had, and any symptoms or side-effects they are experiencing. This superficially technical ritual reaffirms the individual's membership of the group, and is a verbal rehearsing of "where they are" as an ill person.

Members make an investment of self in the group; they are bound by a mutual recognition that each of them is suffering from the same terminal disease.

> **Kate:** The thing that's been even more helpful is when [the group members] share their reactions to [the disease]. There are just symptoms of multiple

myeloma, like one time somebody said you're clumsier, you're not as…[well-co-ordinated] And I'd actually like to pursue that more, I did not know that. I came home and stubbed my toes and I said well this is part of my illness because I'd just found that out! But it is very nice to know that somebody else understands that and explains it, and sometimes explains it before *you* get it, so that you're ready.

Like stories of war wounds, the enumeration of symptoms is evocative of rites which each member of the group has undergone, or may face in the future. Sense of community is an outcome of shared ritual; 'both objects and actions form bases for generating feelings of community' (Belk and Costa 1998:230).

There are other aspects of group culture where formal mechanisms emphasise commonality. As discussed in 4.2, myeloma patients can feel a sense of disconnection from their previous lives after diagnosis, and they may also feel a disconnection from those around them. Belk and Costa (1998) highlight that this sense of contrast with the cultural background or 'outside world' creates meaning and fosters communitas within consumption communities.

Having been jolted from their previous lives into the medical marketplace, new patients can find themselves struggling to decipher a world of complex science and specialist vocabulary. Informants describe how the community helps them to learn the 'new language' of medical terminology and pharmaceuticals that are common parlance within the medical profession - and at support group meetings.

> **Jill**: When [the doctors] start in with the kind of treatments, well now I kinda at least know the language.

> **Researcher**: And you learned the language at the group?

> **Jill**: Yeah.

The process of assimilating the language also encompasses accepting the group ethos of understanding, taking responsibility for managing, and making choices about one's disease. As such it is an important stage in a new member's transition into the collective, as well as an important step in their identity work.

The language itself, like ritual, also functions as a formal enactment of commonality. Because of its very specialised nature, in reference to a relatively rare disease, the vocabulary (like the illness it negotiates) is largely exclusive. As Julie points out, the experiences of myeloma patients are quite particular, and far beyond the familiarity of the great majority of people. But not in the group:

> **Julie:** There's a woman who came to the last meeting, and she's just started on all of this. And there isn't anybody else you can talk to. You know, none of your friends have any idea; they're concerned, but they don't have any idea about the research on thalidomide, or second-generation thalidomide with revlamid plus dex [dexamethasone] or, you know, harvesting stem cells. [We'll talk a lot about] side-effects, too, particularly of people in the group. Any of us that's been on dex, we all have our "dex stories"!

It seems that the *depth* of knowledge made available to, and sought out by, myeloma community members sets them apart from those around them. Through

learning the language and frames of reference, members move away from their previous selves and become embedded in the group.

Circulating in the myeloma community are the sort of archetypal, broadly similar stories that could aptly be defined in Goulding et al's (2004) terms as myths. Little deconstruction is required to decode the group values embodied in the "patient-who-outlives-the-prognosis" story, which is probably the most commonplace support group anecdote, and an illustration of the way in which group members come to resist definitions handed to them by the medical establishment. Many group members are overtly recognised as having lived beyond the 3-5 years average life-expectancy communicated to them by doctors upon diagnosis.

However vying for equal popularity among support group members, and expressing a similar position (backgrounded by what we will come to term the "patient expert") is the "patient-who-knows-more-than-the-doctor" story:

> **Colin:** We did an MRI, and the doctor said, [Colin], that looks like a little arthritis in your neck. Well I always like to see copies of everything, and I said, that doesn't look like arthritis to me. He said my God, it's not…

4.3.8 The "bad doctor" and a critique of institutional health care

Stories of unsatisfactory encounters with medical professionals and conventional medical settings are common at support group meetings, and serve an important function in terms of discursively positioning the myeloma community outside the

medical establishment (Kozinets, 2002). Such stories of a "shared adversary"

enhance the group's sense of community (Crowther and Cooper 2002).

> **Kate:** [the support group contact] gave me all the information and told me they were about to start a support group meeting, so I was at the first meeting. It was *very* badly needed. And you know – and of course I know I've been very fortunate – my feeling now is that if people *think* they are going to die, it's a lot easier to just die. You don't know anything, [so you're vulnerable to a doctor saying] "oh we'll give you some chemotherapy, you're going to die".

Typically among members, Kate discursively links the support group with knowledge, and knowledge to survival. The informants' illness narratives frequently characterise acquisition of information in response to the *deficiencies* of the medical establishment. Kate dramatizes her story by parodying the pessimistic medical professional - "oh we'll give you some chemotherapy, you're going to die" (a caricature which often features in cautionary tales told at support group meetings). Significantly, the doctor in Kate's story prescribes chemotherapy, a standard general treatment for cancer, rather than one of the new and novel therapies for multiple myeloma currently reaching the US market. The doctor's 'pessimism' (and lack of perceived ingenuity) contrasts with the hopeful industry involved in setting up of the support group, just as the doctor's limited knowledge is contrasted with the expertise of the support group member.

Lupton (1997) draws attention to the importance of the physical encounter with one's doctor (or what is known in lay terms as the "bedside manner"):

"The touch of the doctor and the way she or he interacts with the patient, the doctor's tone of voice, the manner, the words chosen, are all central to the "consumption" experience, as is how the patient "feels" during and after the encounter." (Lupton 1997: 379)

The themes of "bad doctor" stories tend to be unnecessarily delayed diagnosis, inadequate expert knowledge, and ineffective or tactless bedside manner.

Tom: The week before I was diagnosed with myeloma, because of back pain, I had a complete physical [check-up] – which I did every year – and had a clean bill of health. You know, there was nothing wrong with me. And that tells me there's something lacking in the medical profession, you know. It should have been caught years before.

In such narratives the doctor is in the position of power. The patient at diagnosis is passively reliant on the doctor for information, and at this juncture the doctor knows something about the patient that they do not. There is a dramatic imbalance of knowledge and power. As Laing et al (2005) point out, the availability of knowledge is key to consumers challenging traditional power structures, and we have seen how the delivery of information, explanation and interpretation is a fundamental support group practice. The rehearsing of the "bad doctor" story stands in opposition to the control of the medical establishment, enacting the communitas and power of the support group.

4.3.9 The transformative power of personal stories

> **Bill:** Last meeting I had two or three people talking about what I went through, and that made me feel great. I feel like I'm giving them something they can use one way or another.

From his words we can infer that the notion of utility is important to Bill. The fact that his experiences might be useful to his fellow support group members makes him 'feel great'. Helping others is commonly given as the motivation for sharing illness narratives (Frank 1995). The support group provides the opportunity to turn experience into capital and to help others with myeloma. Storytelling, in fact, is itself a means of creating and maintaining community, and importantly, is a *transformative* experience that links patients to one another:

> "As wounded, people may be cared for, but as storytellers, they care for others. The ill, and those who suffer, can also be healers. Their injuries become the source of the potency of their stories. Through their stories, the ill create empathetic bonds between themselves and their listeners." (Frank, 1995: xii)

As a storytelling forum, the group fosters this transformative power. Group members can make something to encourage others from their own history, and by proxy take on an important role in the group:

> **Jill:** When somebody new walks in, is when you can say: "Look, I've had that, I've been there, and look I'm healthy - and you could be, too".

Here we see that the 'wounded' journey from a position of reliance to one of self-reliance, to one of resource to others (particularly those new to the group and/or myeloma). The movement here is from passive (patient) to active (agent of change). The support group harnesses the industry of the individual's identity work, passing on their self-defining narrative in encouragement of the new patient's identity transition.

4.3.10 Belonging: a sense of caring community

> **Kate:** You see [the support group members] and you know, that's emotional. It's nice to see them, I'm happy to see them, I feel welcome, I feel loved.

The relationships between support group members are consciously circumscribed – they generally know each other only by their first names, and few will meet outside of the group – but they can be both intimate and profound. The group addresses emotional needs, and combats isolation through providing a place to 'belong'. The group ethos is one of caring.

> **Jill:** The best part about [the group] is the fact that you know you are not alone doing something. And if you've got a problem, there's somebody that's at least *had* the same problem, and you can talk to them.

The group acts as a source of friendship to members, and these friends engage in 'working together' in order to realise progress with the treatment of their disease and to share some of its emotional burdens. Through these processes, too, they are

reshaping themselves. Kate, noting that she could not 'do it' on her own, acknowledges that she relies on the group to help her live with multiple myeloma:

> **Kate:** The group is made up of people that change from meeting to meeting, open up and become friends. I don't know a lot of group psychology - it's very interesting - I like the people, and the working together! I don't know how I thought I could do it on my own. Well, I didn't…

Several informants stated that they did not seek out the group explicitly looking for emotional support (rather they were motivated to understand the disease). Yet this communitas is a welcome aspect of membership.

> **Claire:** I'm not as touchy-feely as some people are, but I do need some of that, too - just knowing that other people are there, and knowing that they're going through some of the things that we are. And knowing that if something happens, they'll be there for me, too. All of that's important.

Fellow-feeling - the empathetic sense that other people experience the same things as oneself - is a source of emotional support:

> **Martha:** It's like we're a big family, you know.

These 'family' bonds can become so substantial that some carers (generally spouses and family members) will keep coming to the group meetings after the death of the patient they were previously accompanying. They are bonds that have taken commitment and work to develop. Jill describes how the building-up of trust over several meetings has allowed her to 'share' her story and become embedded in the community:

Jill: I don't make close connections real quick. So it took about three or four meetings before I was able to actually share anything. It just gives you a funny place to belong. That's what it is: it's belonging.

Unlike many of the consumer communities depicted in the literature (Schouten and McAlexander, 1995; Belk and Costa 1998; Kozinets 2002), there is no call on myeloma community members to be 'authentic' or to 'participate' at support group meetings. Maffesoli (1996) in his discussion of neo-tribalism describes how collective identifications can be fluid, shifting and temporary. Tribes in this view are communities of shared beliefs and feelings, but not of shared obligation or moral responsibility; they are friendship groups built on sociality rather than a common purpose or aim.

While it is true that the flexible, responsive culture of the myeloma community enables members to come and go as they please and take what they need from the group without ever 'giving back', it is also true that most members report wanting to help their fellow citizens when they can.

4.3.11 Citizenship

"Journey stories provide signposts, a way forward - and can be seen as a gift."

> (Greg Pacini, Group Therapist, extract from fieldnotes from Support Group Leaders' Retreat., group therapy session, 20/5/06)

The consciousness of kind created through shared myths and traditions (Muniz and O'Guinn 2001) provides a platform for civic engagement (Kozinets' 2002), and

social support (Schouten and McAlexander 1995). The caring ethos of the myeloma community leads informants to express a need to "reach out to" and provide emotional support to other patients and carers. They articulate empathy, solidarity and an "I've been there" spirit in their narratives.

> **Bill:** I like the camaraderie you feel with everybody there. I feel a little down for people that are having a hard time - and can't help it – I admire them for being there when they are not doing well. And I would do anything to help them get feeling better. You know if I could talk to them or make them smile or do something, I would do anything to do that, you know. Sometimes it's very difficult when you are suffering, some people live alone – well I've been living alone for a few years too – some people have a hard time dealing with it, loneliness and stuff and some people might have somebody and still be lonely. That's the sad part. I enjoy when I see people coming with caregivers – somebody that wants to help them a little bit, somebody that's trying to pull them out of the doldrums. You know, I just love it.

Bill empathises with those who are lonely and feeling depressed. His own experiences – "I was there" – allow him to recognise when others are 'having a hard time'. He is particularly concerned about others' mental state – depression, loneliness and lack of hope. It can be suggested that members feel a sense of *responsibility* towards fellow group members; a duty to help and care, particularly for those who do not have a care-giver, those who are lonely, or those who appear to have difficulty coping with the emotional ramifications of having multiple myeloma:

> **Jill:** I've got [another patient's] email address, and I'm not real good at it but I try to email her once in a while. She lives alone and she gets scared, so I send her jokes (laughs).

In Bill and Jill's narratives we can see that humour is important – they both take on the role of comic in a bid to bring levity to the lives of the lonely. Bill also shares jokes at support group meetings and conveys this comic role and sense of fun visually by the wearing of brightly coloured "Hawaiian" shirts.

A desire is expressed in these personal accounts that the fellow-feeling and support experienced in the community be offered to those who need it outside of the prescribed meeting hours. Reaching out through emails acts as an extension to the support offered and experienced at group meetings. This form of citizenship is common among community members, who frequently described taking the newly-diagnosed 'under their wing'.

Caring acts shared among group members - the knowledge passed on through illness narratives, the emotional support offered, the jokes shared - form a gift economy within the myeloma community. For Belk and Coon (1993) a gift can be defined as 'a good or service (including givers' time, activities and ideas) voluntarily provided to another person or group (Belk 1979) through some sort of ritual presentation' (ibid: 394). This economy, based on *sharing* within a group, is not dissimilar from Geisler's (2006) consumer gift system. Critiquing the dyadic model of consumer gift-giving, Giesler (2006) conceptualises the 'consumer gift system [as] a system of social solidarity based on a structured set of gift exchange and social relationships among consumers.' (ibid: 283).

Reciprocity and gift-giving, in fact, can be seen as the fundamental mechanism sustaining the myeloma community (Kompter 2005; Mauss 1966). Cheal (1988) asserts that gifts 'are, for the most part, redundant transactions that are used in the ritual construction of small social worlds' (Cheal 1988: 16 in Belk and Coon 1993: 402). However gifts of narratives and knowledge, while instrumental in creating the 'social world' of the myeloma community, are far from inherently redundant. Such gifts are part of the service one myeloma patient can provide to one another, and have more in common with Belk and Coon's (1993) conceptualisation of the romantic mode of gift-giving where 'agapic love valorises expressive altruistic gifts that reveal and celebrate powerful emotions' (ibid: 393). In as much, the groups have step-wise economies, where A gives to B and B gives to C (Williams 1995):

> **Jean:** The calls that I got originally were very uplifting to me, [and] I just feel like it's time for me to get back again and see if I can't do the same thing for somebody else.

It has been observed by Williams (1995) that 'receipt of support creates an emotional cost for the recipient' (ibid: 401). Recognising the value of the assistance she received when first diagnosed, Jean would like to pass on that benefit to another patient in need. From her acknowledgement of her ability to help others we can infer that Jean has moved from a position of need to one where she feels she has the capacity to give back.

New (or newly-diagnosed) members become a focus at group meetings. They provide longer-term members with someone to help, someone to benefit from their experience – *someone to give back to*. The process of 'helping' those new to the

myeloma community - through the passing on of knowledge encoded in illness narratives - acculturates new members to the ethos of the group. This passing on of cultural values reproduces community. Those who give, receive benefit as well, either through the information and support passed on to them or from the positive feelings they experience when helping others:

> **Researcher:** You said that you are going along to the group now more for other people rather than for yourself, is that a correct interpretation of it?

> **Kate:** That's what I said, but that's probably not true. I thought that. But I get a lot out of it, I get a lot out of it. You give and get; it's just both.

In brief, the guiding narrative of the myeloma community could be described as "I have an illness, but I'm coping well, I'm taking responsibility, my outlook is positive, and I'm helping others." In their specifics, many personal narratives from long-term support group members are remarkably consonant with Frank's "quest story": the negotiation of a new self being borne out of the hardship of illness and the framing of illness as an *opportunity*, with an emphasis on positive life changes and personal enrichment through helping others.

> **Colin:** I think if I was to pour it all out on the scale, I think [having had myeloma] would tip to the balance [towards] good. I think it opened up insights into what's more important and what's less important, at lots of levels. I think it's brought me to people that I would never have been able to have a chance to meet, that just have wonderful gifts. I think it has opened up areas in terms of the benefits of something that I knew inherently, but I could demonstrate now more vividly – the value to one's person when you can provide help to others that need help.

It could be deduced from the above narratives that helping fellow myeloma patients is employed as a *coping mechanism*, one that allows the diagnosed to understand their experience as something from which positive benefit can be derived – both for the self and others. Frank describes this sense of duty to others when he states:

> "People who tell stories of illness are witnesses, turning illness into moral responsibility." (Frank, 1995: 137).

It is this sense of moral responsibility that enables the group to negotiate the darkest aspects of the illness it works to mediate. In the cycle of the community from a member joining to their dying or becoming too ill to continue, experience - long service - confers status and responsibility. Kate describes how the cumulative deaths of fellow members became a near-intolerable pressure for her. The thought of new members being discouraged by the demise of those nearer the end of the cycle (like herself) makes her reluctant to attend. Her resumption of the group, though, is a realisation not just of her own resistance to the fact of death, but of her own sense of her value in the community:

> **Kate:** To see those people that you start with and you meet with and then they die - and you know for a while I couldn't bear it, and I couldn't go, and I thought it's too depressing, I can't, I can't go… (pauses) And then I thought, well it isn't always about *me* - and then you know another person died – and I'm like well, it's about the new people coming in that don't want to feel, you know…[that death is looming] And it's just changed so incredibly much, I just can't tell you. The three people, Colin was the one that started the support group and he's still there and he was with two other people and they're gone, they died. People die of this! … For a while there when it was depressing and

people were dying, I didn't go - and then I started to go again because I thought well it's not just what I get because maybe I can *give.*

It is not only the collective that is strengthened by moral responsibility. Mindful of Badje's (2006) exhortation to the researcher to cast an acute eye over consumers' negotiation of "self" and "other" via other-centred behaviour, this study observes that at least, the giving behaviour by support group members fosters a context of support and trust. Within this context, led by encouragement and example, the consumer reconfigures themselves into the other, "the right person to be". Acting for others, in fact, engenders reward and individual empowerment.

> **Colin:** More than once we've been driving back from [a city to the far North] at night, we're getting home after a program that finishes at nine o'clock at night, and we're exhausted, or we've been somewhere else across the state, or we've been on the road for three days, working with different groups, and saying, "We've really put ourselves on the line." But we're all over the state, when somebody says "Thank you – that was helpful." And there's truth in that. Why do we travel to [another town], on a Sunday [when the State football team is playing], to talk to [patients] in the area? There wasn't a real need to do it. But these people wanted help, and they asked us for help. And that's the reward, the satisfaction that you're making a contribution to them.

Colin describes the ways in which he and his wife make considerable efforts to visit and talk face-to-face with other myeloma patients throughout their State. Recognising that there is no 'need' to do it and that it has often been inconvenient – like travelling when the roads will be busy with football fans – Colin nevertheless believes that this service provides its own reward. From his narrative we learn that

he feels a powerful draw to answer calls for help from other myeloma patients. In earlier passages he describes himself as a 'teacher' and recognises that his own abilities and superior knowledge of the science of the disease and its treatments can be useful to others. Sharing these gifts with the myeloma community serves to bring new members into the fold, while strengthening Colin's role as a leader.

4.3.12 Hierarchy, leadership and example

The support groups confer status on their members through empowering roles. A number will be involved in running particular aspects of the group, or participating creatively (from baking cakes to designing flyers), or contributing in other areas of expertise. Some patients and carers also act as group leaders, taking on the duties of organising and facilitating meetings, scheduling guest speakers, compiling and mailing out newsletters and welcoming new members. Julie describes how she took on the running of her support group:

> **Julie:** Nobody asked me to do it, really; the group had never had a co-ordinator or chairman, but I had a full-time secretary, and it just felt natural to move in to it. And it felt so good; it really gave me a feeling of fighting back.

For Julie, being involved in the group in this way is an act of resistance to the disease. She uses a familiar metaphor – that of 'fighting back' to describe her active role (Sontag 2002). Combative metaphors ("battle with cancer", "brave fight", "going to beat it") are associated with the restitution narrative, which tells that cancer can – through the use of medical treatments – be beaten, and one's previous

life restored (Frank 1995; Wong and King 2008). Yet for Julie, to whom this narrative is unavailable in its usual form, it is the act of taking on a role of responsibility in the *group* that enables an identity that is active, rather than passive.

It is characteristic of support group practices that they serve a dual function, enriching the collective by individual input as well as enriching the individual by their interaction with the collective. Another group leader, Colin, talks about the way he fosters the group discourse:

> **Colin:** I try to get people to understand that there is a bright side on almost everything that's out there - and you can *choose* which side of the ledger you want to focus.

What Colin is describing is to do with the individual's most basic, personal relationship to the world. However it is something he is intent on modifying: "trying to get people to understand". As support group leader, Colin is in a sense both the *editor* of the group's stories and the chief purveyor of its discourse, and his words help to illuminate the crucial way in which the group narrative is cultivated through leadership.

The archetypal metaphor for a leader-figure who sees his role as centring on care and illumination of others is the "missionary". Support group members view Colin in this way:

> **Kate**: I have been to meetings that have been chaired by other people, but really [the group leader] *is* the meeting. A very powerful man. But you know, he is not only a good leader and educator; in addition to that, he's a

real missionary. Him and [another senior member of the group], they're real missionaries. If somebody new is coming to the meetings, they pick them up, they bring them to the meetings, they take them home. They do good work. I see it as caring; looking after [people].

The analogy echoes down through a hierarchy that is largely informal, its positions of authority predicated on factors like logistical or social responsibilities and length of time in the group. There is little perceptible resentment of this ranking; the most commonly-used metaphor for the collective by its members is "family", and one might observe that families are collectives where seniority is broadly accepted as a given.

As a general rule it is patients and carers who have attended the group for some time, and who have become knowledgeable through both experience and education, who will adopt the role of mentor. Schouten and McAlexander (1995) note that status changes in the Harley Davidson subculture of consumption are effected through information gathering and processing and community participation, and that the most "committed" members serve as opinion leaders. Such actions allow myeloma community members to move through the group hierarchy to a position where they are considered arbiters of knowledge – opinion leaders - by other members.

Another commonly-observed aspect of families is the way in which senior members act as role models for the juniors, and a feature of the support group is that leadership involves setting an example that acts as a positive model for those engaged in identity work. The idea of example – an inspiring model – is one of the

core mechanisms of the group, and functions at many levels. As a young myeloma patient who continues to pursue his career, Morris is aware that he may provide inspiration to others:

> **Morris:** I had a couple of reasons for attending [the group]: one just to see what other people were experiencing - then there was probably a little bit of an ego thing. I knew myeloma was typically among older people and I was on the younger side of that, so I thought let's just go and I can show them what the range is of age and how I'm still able to work, so you can too; without having to *say* that - just to be there.
>
> **Researcher:** So, for you to be a kind of example of positive things?
>
> **Morris:** Oh yeah.

One of the ways the group will combat losing its members to the disease is through new life – introducing new, and often younger members.

> **Duncan:** [The group] almost seems like a family after a certain period of time. Unfortunately we've lost some dear friends that were in our family, but we're meeting new people, and they become part of the family also.

The authority of leadership extends outwards from the group leader in a hierarchy of passing-the-message, and the long-term members of the group have a particularly significant relationship with the newcomers in this respect.

> ***Extract from fieldnotes, visit to Duncan and Claire's home, 3/5/06:***
>
> …Both Claire and Duncan are involved in speaking to new members and those newly diagnosed. They talk rather animatedly about this. It seems

important to them. Claire uses the expression "take them under our wing". They say they have seen their influence have a positive outcome and clearly feel good about this.

This, of course, is how Duncan and Claire themselves were looked after, years before, when they were newcomers to the group.

4.3.13 Personal responsibility

*"The most important thing is to be active in your own care decisions, captain of your ship. Even on the worst chemo day, when the best you can do is go below and try to keep from losing your lunch, you're still the captain. While it is sometimes best to have someone else on the tiller, you're **always** the captain."*

(Meg Gaines, Director, Centre for Patient Partnerships, *Talking With Your Doctor About Treatment Options*, Leukaemia and Lymphoma Society guest speaker, February 2009, quoted in myeloma support group newsletter March 2009)

In keeping with the flexibility of the group culture, the "mentoring" of new members is not a simple process of new recruits replacing the authority of a healthcare professional with capitulation to an alternative authority figure. The group may be hierarchical and founded on other-centred exchange, but its discourse is firmly focused on personal responsibility. The journey to the point of "taking control" is a subtle, incremental one, but perhaps we could see its beginning as a feeling of resistance – defiance, even, of the limitations imposed by the illness.

Jean: Some [members of the group] are having a rougher time [than others] because of the degree to which they are afflicted, you know, but they all seem to be coping. Which is marvellous.

The group culture encourages members to challenge, rather than accept, negative experience – and indeed a group meeting is a context that is accepting of many different expressions of life-affirming defiance:

Tom: I've got one gal, when I tell her what I went through, when I got this treatment, I watch her in the support group – she's got some terrible problems, she's got re-occurring different cancers and what-not, [it's been] so much more difficult for her than it was for me – but anyhow, she'll stick her tongue out at me, when I'm talking.

Ultimately the positivity of the group culture is directed to active purpose in helping others and above all oneself, whatever external discouragements may be offered. Myeloma community members co-create a particular culture of illness (Kates 2002a), one where a positive outlook, personal responsibility, knowledge and empowerment are privileged.

Kate: Sometimes you feel like you're not doing enough… there's this one person… but he was only there once. Actually what I should have done was got his name and called him at home to see how he was doing, because he never came back! He was in his seventies, he was the kind of person who was clearly not decisive at all – oh I'm going to have to start keeping track of names! – he had my same doctor, my same treatment and I asked him if he'd looked into this and that and the other thing [treatments] and he said no, whatever they decided was okay, and he just never came back to another meeting.

Researcher: I got a little bit from that that you think it's important that patients don't just go along with what they are offered, that they think about it a bit more. Would that be right?

Kate: *Oh yes.* And you have to be in charge. And going back to this man, I said, you know, this is very difficult stuff. I said do you have any children who are smart – and he is about seventy-five-ish, and, you know, just didn't have a really big involvement in life – but you know, oftentimes you have children who are educated, and can help you. I asked him, how many children - and he had six children and said "Oh nothing like that" (laughs). I think I did tell him that he needed to talk to [the support group leader] more, I mean I just didn't want him to just go. But I'll bet that's what he did, I'll bet he just went and… but maybe that's okay for him. But I don't think it's okay, I don't think it's okay for anybody. I think we have to take charge of our own life, and if you're just a too easy-going person someone has to help you a little bit; not that they should take charge of you life, but that they can help you. And there's always something more, there's just always something more and always something better. I just believe that.

Researcher: In terms of treatment?

Kate: Treatment, reaching out. Yeah, because how do they know all about the treatment? The doctor doesn't know everything either! Yeah, going to a support group and keeping up with everything that's going on. You know [researcher's name], you're surrounded by really educated people, but some people just don't have the wherewithal to reach and search and understand. And they're scared! I got angry - but the other side of anger is fear. And if you're really scared you can't do stuff.

Kate expresses the crucial positivity of the group ethos ("there's just always something more, and always something better") as well as the sense of personal responsibility ("we have to take charge of our own life") and the urgent obligation

to encourage and help others. Her advocacy for "this one person" is a vivid illustration of the paradoxical implications when personal responsibility becomes a communal cause, as well as of the motivating power of the ethos.

The culture of personal responsibility, backed up with information, guidance and support, means that it is not unusual for myeloma patients to be acutely involved in monitoring their disease and making treatment decisions. Patients routinely have access to and can analyse their blood test results. The support group often acts as a site for interpretation of these readings, but it is the individual who is responsible.

Martha has been in remission since 2002, and describes how she assesses and evaluates her condition and possible treatment:

> **Martha:** I see my doctor four times a year, and he has the full lab work done to check my blood counts and everything.
>
> **Researcher:** And do you keep up with your counts? Do you record them yourself?
>
> **Martha:** Yes I do. I take a print-out home, and I have an Excel spreadsheet that I log them on, so I can see… Because even if they're within the [hoped-for] range, I want to know, you know – I trend them, to see if they're going up or down.
>
> **Researcher:** So you do your own kind of data analysis on them, and create graphs?
>
> **Martha:** Yup. Especially the IGG, IGA, IGM – those three. I don't know why, but those really interest me. I was getting sick with bronchitis, I had it three times the first year, so I was doing the IGIV treatments, and my insurance changed and that was going to cost quite a bit for me. And so I

stopped doing them, because that's really an optional treatment, to help your immune system. And so I decided, well I'm a couple of years out now, I should be fine. And I did get a real bad cold a few months after I stopped, but really since then I've been okay. But I like to watch those numbers especially - because if I need to go back on [IGIV], if I see them dropping back off, then I would start paying the money. And I did see a drop about six months ago, but then three months ago it was okay. Even though [my doctor] says it's fine, I can see that it dropped quite a bit, and that's kind of a signal for me, too, to start taking better care of myself, and the vitamins that I forget to take a lot of times, (laughs) – start taking them again!

Martha's mastery of the "technology of the body" (Foucault, 1975) is methodical, detailed and sophisticated. Her monitoring of the various readings from her blood counts, while consciously lacking in comprehensive scientific rigour ("*I don't know why*, but those really interest me,") forms part of a complex pattern of judgements that connect her health, her bank balance and her medical care. The patient takes readings, studies trends, interprets the results and accordingly adjusts the way she behaves towards her body, her finances and her doctor.

4.3.14 A new identity

Through exchange and mediation of information, rituals, language and myth, empathetic connections and community identity, and circulation of advice and personal stories, the group practices enable the personal work of identity transformation.

> **Researcher:** So would you say the group has changed the way you approach the disease?
>
> **Jill:** Yes, because I'm not as upset about having it. You know, I just look at it and say, I've got a disease but it's managed, I'm not sick. It's OK. I'm not sick anymore, now I'm healthy and everything is going fine. I'm happier now.

Jill states that her disease is 'managed' and this sense of control allows her to feel that she is 'not sick anymore'. We can also understand from her narrative that she is less 'upset' about having multiple myeloma because she perceives it to be under control. This feeling of control has been, in Jill's case, fostered through a change of doctor, increased understanding of the disease derived from information gathered at support group meetings, and perceived increased 'involvement' in disease treatment and management decisions.

> **Claire:** I've seen some interesting changes in some people, after coming [to the group] for a long time, too. [There was] One particular member that was very very negative for a long time, and then took some advice from the group. And now, [she's] much more positive and coming all the time, and seems to share a lot more. [I've seen] Some changes like that, being in the group, and coming all the time.

From the minute a new member crosses the threshold, this positive way of looking at one's situation is not only discernible to them in what they see among the other group members, but is available to them as the cornerstone of a new, empowered identity.

181

Jean: [A fellow member's] getting married – I thought, that's kind of positive isn't it? And so he said he was diagnosed when he was 65, and he must be well past that now. But you know, that's still making the most of every day in your life, which is the kind of attitude you pick up just from being with all these people.

Building on this, the support group member is provided with the resources to actively manage their new identity, including the learnt skills to negotiate the marketplace, and the confidence to assert their new selves.

4.4 The skilled consumer

The practices of the support group, as we have seen, constitute the vehicle that enables the newly-diagnosed myeloma patient to move on from their unfixed, liminal state and negotiate a new identity. The processes of identity work culminates in something quite particular and beyond the theorisation contained in this thesis thus far, we term this phenomenon the 'skilled consumer'. In this section we will detail our observations of the ways in which, having progressed from patient to agent, the transformed consumer returns to the marketplace. Here, empowered with the skills to manage their consumption effectively, their identity work will continue.

4.4.1 The support group as training-ground

"You may find yourself in unfamiliar territory as you begin your journey as a cancer survivor. Part of the challenge is a new vocabulary and a technical environment that a patient can not avoid. To the extent that you can familiarize yourself with this foreign environment, you will be empowered with great control over your condition and over your needs for health care."

(National Coalition for Cancer Survivorship, (1996), *A Cancer Survivor's Almanac: Charting Your Journey*, edited by Barbara Hoffman, p5).

The National Coalition for Cancer Survivorship (the oldest survivor-led cancer advocacy group in the USA) cautions patients that they can control their cancer experience by becoming more adept consumers; through learning the parlance of medicine and technology, it advises, they will become 'empowered'. This study's informants concur:

> **Rosalind:** I have a better understanding of the medical side of life, not because I've been all that interested, but because I've been forced into learning more about it so that you can navigate the system to get what you need.

The support group can be seen as a kind of training-ground for the skilled consumer, enabling them to become equipped for navigating of the "system". The disease and its various treatments, their future lives and the degree to which they might be incapacitated, suffering or soon to die – all of these are uncertain for the multiple myeloma patient. The group enables them to become people who feel that they have a measure of control over themselves and their place in the world,

actively negotiating the available choices to "get what they need." The marketplace is where this control is enacted.

The treatment of multiple myeloma can involve complex choices about different therapies, and typically a support group member like Kate will become equipped not only with the good working knowledge required to understand (and often influence) those choices; she will also acquire the wherewithal to best navigate the multi-layered *structures* of institutional medicine:

> **Researcher:** Did you make treatment decisions, do you feel, in those early days?
>
> **Kate:** It was very, very, very difficult to make a decision. We did choose not to have a stem cell transplant, and I did spend a day at the University of Wisconsin talking to those people and decided to um, opt for the other [treatment]. So we made that decision. The actual drug or chemical, that was not my decision. And it worked. And at some point along the ways – eight years now – [the support group leader] was urging me, not personally but everyone - he treats *everyone* the same – to get another opinion. So I did, I went to [The] Mayo [Clinic].

Kate recognises the *difficulty* in making a treatment decision. It is generally acknowledged in the myeloma community that making one's own treatment decisions (rather than having a doctor make them for you) is desirable. Yet patients must be informed and understand the parameters of what they are being asked to do. Kate's control over her treatment is not boundless. She records how, once she had decided to choose a drug regimen rather than a stem cell transplant, the choice of which drug she would be taking was out of her hands (it is unclear whether she

would actually have wished to participate in this choice, or even if there was a choice at this time). Yet her story of the support group leader's instrumentality in her seeking a second opinion from a myeloma expert is recounted with approval. The canvassing of alternative expertise – a consumerist fundamental – can be a difficult step for patients, but it is a step in Kate's narrative that illustrates her progress as a skilled consumer.

4.4.2 Consuming hope

The conviction that membership of the support group can help a patient live longer and "better" with multiple myeloma (i.e. with fewer symptoms and a good quality of life) through greater understanding of the disease and its treatments, is common in informants' narratives (and frequently observed in the discussion at group meetings). This belief could be described as a core value of the myeloma community, and it is a key facet of the positive ethos of the group.

> **Claire:** When the diagnosis [of myeloma] came back, the doctor that we were at – he was just an oncologist and so he didn't really know that much about it. So there wasn't a whole lot of hope there. And it was pretty backward: you could do melphalan and prednisilone or you could go for a transplant - but [he said] the transplant's really risky. [Whereas in actuality] it wasn't that risky.

Claire's narrative highlights that what patients need from the information doctors provide at diagnosis is *hope* – hope in the form of available treatments. When a myeloma community member approaches the medical marketplace hope is one of the things they are most keenly looking for: the faith that something good will

happen. They are seeking, in medical goods and services, a confirmation of the possibility of better health.

Claire suggests that the information she and her partner Duncan – the patient – received at diagnosis was substandard, as the doctor in question was "just an oncologist" rather than a myeloma specialist. Looking back on the experience, Claire describes the doctor's advice as "backward" because he provides only "basic" treatment options – chemotherapy or stem cell transplant (as opposed to newer combination therapies).

Within the support group, the prevailing positivity and the need for hope find expression in a strong belief in medical technology. We have seen (4.3) how Martha, like many other support group members, tracks and analyses (and develops treatment responses to) the data from the blood counts recorded by her doctor. Whatever stories may be circulating about unsatisfactory encounters with medical professionals, members are simultaneously keeping keenly abreast of new developments in medical research and clinical trials, too. These advances – such as a new drug regimen or novel combination of therapies – provide wider options, and therefore greater hope, to patients and their loved ones.

> **Julie:** I've been in remission since 2002, and the longer this time period goes… I will relapse; but when I do, I feel real confident that [because of the ongoing advances in treatment] I will see my grandchildren grow up.

Here we can see the impact of such hope in Julie's life – the real possibility that she may see here grandchildren grow up. In this optimistic context of perceived

186

progress in treatments, certain new therapies seem to acquire near-mythological properties among group members. During the research period the buzzword was 'Revlamid', an oral medication that can stop or slow the growth of cancerous myeloma cells in the bone marrow. It might be conjectured that Revlamid was particularly sought-after and mythologised (Thompson 2004) in the myeloma community because at the time it had yet to be passed for widespread use by the regulatory authority.

> **Martha:** I like to keep up on the latest news releases – what's happening, what's being tested, what's been approved. The Revlamid was huge, because we've seen first-hand how well that worked. [Another group member] was about a year ahead of me in her diagnosis, and she went through the same treatment I did, went into remission – and just months later, relapsed. And they put her into this [Revlamid] trial. And she was back in remission, and she's been back in remission ever since then. And she's feeling great, she's out doing everything, she's a gym teacher, she does this charity work in Romania every year, she's really great. And it was good to see that at first hand, and, you know, have that information.

Martha refers to keeping up with the latest advances in the treatment of myeloma. Community members have access to the latest news on clinical trials and treatment advances from organisations such as the International Myeloma Foundation (IMF). At support group meetings "learning from each other" as informants put it, often takes the form of sharing detailed and specific information regarding this sort of treatment option, with particular emphasis on the side effects and efficacy of new and experimental drug regimens. The experiences of other patients provides hope – if a treatment has worked for a fellow member, it may work for them.

Such is the authority of this pool of collective learning that informants often judge the resource to be more useful than meetings with doctors:

> **Tom:** People sharing their experiences with one another - I think I gain more from that, than I do even meeting with my physician. I would say a support group is going to help heal you as much as the medical profession: a major factor in determining the outcome of your disease.

Informants will typically take information out of the group and bring it to their medical team when reviewing treatment options, actively participating in the instrumental decisions about their medical care. The skilled consumer will not only be evaluating the quality of the treatment; they are also equally likely to be making judgements on the people *delivering* the service.

4.4.3 The patient expert

The sharing of doctor stories equips members of the community to critically review and compare their medical care (cf Thompson, 2005). This 'critical reflection', in some cases, serves to highlight differences in service provision and can destabilize - and re-stabilize – confidence (Thompson, 2005: 235), as Jill expresses:

> **Jill:** The rub with [doctor's name] just kept coming, because at the [support group] meetings they would start talking about different blood levels, and I never heard any of those. So onetime I kind of found a prescription, and I was looking at it, and I asked - well what about this kidney level, it's all screwed up? And he gives me this real flippant answer, that: "Oh, don't worry, when it gets bad enough we'll put you on dialysis." And I told him

that that wasn't a very good quality of life - and I told the nurse I wasn't gonna come back! (laughs). "I won't come back unless I have a new doctor."

Jill hears other patients at the support group recounting their various blood test results and realizes that she has not been given her own (many patients in the group are routinely given copies of their test results by their doctors or health insurance providers). Her newly-found awareness of the types of knowledge held and exercised by fellow group members creates doubt in her mind regarding her own medical care, and ultimately empowers her to find the "courage", as she later terms it, to confront her doctor.

The informed patient will be regularly assessing (and possibly changing) the medical professionals who are treating him or her. The "good doctor" turns up frequently in their stories - a counterpoint to the mythology of the "bad doctor".

> **Researcher:** Do you hope to be involved in treatment decisions, when they come up?
>
> **Martha:** Yeah. Yeah. I do rely on my doctor, though, to know his stuff, so… That's why I really liked [doctor's name], he was very knowledgeable, and if [a new drug had just been released], he knew about it. You know, I wasn't the first one to tell him. And I like that.

The myeloma community ethos of positivity and pro-active "taking control" fosters a culture of learning that is close to overtly *competitive* with the "expert" authority of the medical establishment. Diagnosed in 1993, Bonny started a myeloma support group in 1997, where she is known jokingly for her expertise as "Dr Bonny". She believes her own pursuit of education about the disease affected her treatment

"absolutely", and a cornerstone of her philosophy is "to educate patients in order to educate doctors."

We have seen how the collective can mediate medical information, but the self-assertion Bonny is describing constitutes a direct challenge to what Thompson (2003) calls 'the more intractable modernist features of the medico-administrative system' (ibid: 103). Indeed, understanding the importance of information as the key resource for individual agency in negotiating the conditions of their illness, some group members have educated themselves to the extent that they could appropriately be called "*patient experts*" (Department of Health 2001).

> **Rosie:** I've heard [another member of the group] suggest different treatment options with patients, and I suppose that's helpful - although at the time, I thought "This almost borders on practicing medicine!" (laughs)

The empowerment conditioned by the support group creates a reversal of traditional doctor/patient roles that sharply evokes Thompson's (2003) observation of the attenuation of professional medical authority. The group-empowered identity does not blindly accept the traditional (and increasingly eroded, [Laing et al, 2005]) power balance.

> **Bonny:** As a support group leader there are things I can *not* do, so as not to offend the medical community. I can not recommend doctors. But educating patients - that changes the way they are treated.

This study's informants give emphatic support to the contention that expert knowledge, such as medicine or science, is no longer accepted at face value (Lupton 1997).

> **Marie:** Our cancer [myeloma] is a one percent of the cancers out there. So how knowledgeable do you think those doctors are, that are treating a cancer with one percent versus cancers that are a lot more prevalent, as far as them studying them?

Lupton (1997) suggests that lay people may be both "passive patient" and "consumerist" in their interactions with healthcare workers, and certainly informants tell of asserting their requirements in the marketplace. Having educated herself about the neuropathy that is a common side-effect of using thalidomide (many patients suffer nerve damage in their extremities), Marie will take a treatment she is afraid of on her doctor's advice. She is not prepared, though, to accept the doctor's recommended dosage:

> **Marie:** So I met my oncologist, and he's trying to give me this drug, and I says, well how many milligrams you gonna give me? He says, two hundred. I says well that's too high. I said, I'm no way gonna take two hundred milligrams. So he dropped it down to a hundred.

We can see that information gleaned at the support group has created doubt in Marie's mind regarding thalidomide therapy; wishing to avoid painful neuropathy she opts for a lower dose of the drug. In contrast to the majority of consumers in the marketplace, those with serious illnesses are faced with particularly complicated and difficult decisions that may carry the burden of life-or-death consequences. Patients' lives are caught between the uncertainties of an unpredictable illness, and

of a range of treatments which are equally unpredictable in their efficacy and (often gruelling) side-effects. Yet support group members like Jill, Marie and Martha show few signs of behaving like 'passive patients' (Lupton 1997). Their participation in the marketplace is more reminiscent of Toffler's (1980) "prosumer," the consumer who takes part in the production process to the extent even of specifying his/her requirements at the design stage.

Support group members' consumption is both empowered and shaped by discourses beyond that of the healthcare establishment. Indeed they show a marked willingness to trust their own instincts and the experiences of other group members more than the statistics, scientific expertise or medical advice received from healthcare providers.

> **Martha:** I've seen patients on Velcade and I've seen patients on Revlamid; seems like Revlamid is just – just works better, for some reason. And I'm only looking at a handful of patients, but, so, you know… [The healthcare professionals'] figures are saying Velcade works great too. But in my little group, I haven't seen that.

4.4.4 Manipulating the marketplace

Investigating another community built around healthcare issues, Thompson has observed (2005: 246): '[t]he natural birth model serves [an] antiestablishment identity project by functioning as an ideological antithesis to the technocratic and often impersonal nature of medical care and by symbolising a domain of self-directed choice, self-discovery, and spiritual epiphany.' As with the myeloma

community, self-definition is actually enabled by stepping outside, and seeing oneself in contrast to, the prevailing medical model.

Daniel's account exemplifies the way in which patients use the support group as a tool to stand apart from, critically reflect on, and ultimately modify their consumption of medical care:

> **Daniel**: You just don't get the pros and cons and things with your doctor, you don't understand treatment options, what's coming down the pipe… I was at one of the support group meetings and we were just going around the room talking about things and [the group leader] mentions "Daniel is thinking about [getting] a transplant". So they kinda went around the room, and as you know in these groups um, it's just a great big pot of everything you can think of, every combination of something that people have gone through. And then [you've got the support group leader] up there: "Well I was at this meeting, I know about this drug going to the FDA, and should be on the market". He knows about the cost of it, you name it he's got the information. So that group is real important. I come back with stuff from the group that I bring to my doctor: "Why aren't we looking at this or that? When are we going to be testing for this? You know, what's the future treatment plan?"

As we have seen, patient-leaders of the group also exert an influence on the way members interact with their medical professionals, even to the point of *changing their medical care*. The group culture can be understood as fostering grassroots activism (Kozinets and Handelman 2004). As Cova and Cova (2002) put it: 'a tribe is capable of collective action, its members are not simple consumers they are also advocates.' (ibid: 602).

Just as brand communities and subcultures of consumption negotiate brand meaning (Muniz and O'Guinn, 2001, Schouten and McAlexander, 1995), the myeloma community collectively mediates the discourses around the disease and its treatments independently of the orthodoxy transmitted by the medical establishment. Indeed, it is the aim of group leaders like Bonny to carry this mediation into the way myeloma is perceived by the medical profession - as a disease that is difficult to treat and without much hope of lengthy survival - by educating patients to take on the role of advocates. If multiple myeloma is a brand around which the community coheres (Muniz and O'Guinn 2001), then the intention is to modify the brand in the perception of those who supply its (medical) support.

However it the researcher's opinion that these group practices, while independently generated and certainly a challenge to the status quo, are not fostering what Thomson (2005) calls 'an anti-institutional construction of self' (ibid: 246). It has been shown that it is intrinsic to the support group discourses that they remain flexible; rather than defining themselves by opposition to the healthcare establishment, informants typically describe the process of acquiring an enhanced ability to make effective *use* of the establishment. The group culture does not cultivate a rigid oppositional posture (which might in itself alienate some members, and would certainly constitute a confinement of treatment possibilities) but remains responsive to individual needs.

> **Susan:** We've learned a lot about hospitals, and paperwork, and doctors, and [laughs] being extremely upset when we needed to be, and the emergency room. My mother has been in and out of the emergency room I don't know

how many times. And, you know, we've learned that if you go there, you better plan on being there for half a day at least before you get into a room, and all that stuff. And having somebody there to really advocate for you, and even get you water, and things like that!

This is not to say that the support group ethos does not constitute a centre of consumer power which can resist, inflect and even to an extent manipulate the marketplace. We have seen how group members can reject or modify any of the goods or services provided by the healthcare establishment, from treatment regimens to doctors. The power of the group discourse extends further, though, penetrating even into the field of medical research. The key group value of insisting on the very best medical option has had serious consequences for multiple myeloma researchers.

Extract from fieldnotes from Support Group Leaders' Retreat, clinical trials teleconference, 21/5/06

"Support group leaders and patients are in a teleconference with doctors from the Mayo Clinic in Rochester, New York, and others who are at the cutting edge of myeloma research. Six planned or proposed clinical trials are outlined. It's clearly in the interests of the medical researchers to listen to feedback from patients, and to do their best to encourage patients to participate in the trials.

But it is remarkable the extent to which the patients control the meeting with their own interpretation of, and judgement on the research. The typical trial would divide participants into two groups with slightly differing treatment, and compare the results. A typical *patient* response was to assess the more desirable of the compared treatments (displaying a ready and detailed

knowledge of the drugs, drug-combinations, side-effects and other aspects of the trial) and express dissatisfaction at the possibility of being a participant who might wind up in the group with the less favourable treatment.

The doctors were at pains to point out that the trials were comparing alternatives where there was no certain knowledge about which therapy was better (as one doctor pointed out, to do anything else would be unethical). But whatever the reassurances, the patients remained sceptical, and certain in their own judgement. As one doctor said despairingly down the telephone line: 'We struggle to do one tenth the amount of clinical trials they do in France. This reluctance here is really slowing up the process of finding better treatments."

There is an irony in the idea that the empowered consumers' expertise – their confidence in their own knowledge and their own right to choose what is best for them – is actually impeding the development of therapies. In a sense, it appears as if the solidarity of the myeloma community obviates the possibility of its members turning their ethos of citizenship, other-centred behaviour and helping to a wider healthcare community. The possibility arises that the ethos of the support group is actually more important to its members than real (if unquantifiable and possibly indirect) advances in treatment.

4.4.5 The transforming consumer

It is characteristic of identity work viewed in a consumption context that all transactions are multi-faceted, serving purposes that are at once personal/ontological, collective, and commercial/industrial. In this light it is natural to conceptualise the support group member's critical reflection and consumerist tailoring of their treatment itself as identity work. Lupton (1997) argues that there is

congruence between the notions of the "consumerist" patient and the "reflexive actor" engaged in the project of the self (Giddens 1991):

> "Both are understood as actively calculating, assessing and, if necessary, countering expert knowledge and autonomy with the objective of maximising the value of services such as health care." (ibid: 374).

Identity work is not a journey with a fixed destination. The transformed consumer, his/her self reshaped through the group practices of the myeloma community, is still transforming. Beyond the support group, the marketplace is the key site for that ongoing negotiation.

4.5 Conclusion

A three-stage process is observed through the study's informants. The way in which the experience of diagnosis precipitates a transitional identity is explored as an entry point to the emotional context of the research. Tracking the self in motion, the study observes how the destabilisation of identity is exacerbated by both society (which stigmatises the sick) and the marketplace (where institutional medicine enacts a crude and inflexible model of what a patient should be.) Disempowered and fearful - "I'm hanging here on a far limb on a cliff" - the dislocated self is caught in limbo.

Investigation then turns to the support group as the site where remedy is sought for this dislocation and disempowerment. The research records a range of collective practices within the community – among them the sharing and mediating of information, helping, storytelling and the fostering of personal responsibility -

which both sustain and energise the collective and enable the individual identity work of the group member. The study concludes that the robust and flexible culture of the support group is instrumental in the hard-won personal transformation of the patient.

Finally the research turns to the effects of this transformation on the consumer's relationship with the marketplace. The acculturated support group member, it finds, is strongly motivated to seek hope in their consumption, and both knowledgeable and assertive in negotiating the best products and services to satisfy. The marketplace is where their new empowerment is enacted, and where they continue their identity work. The patient-consumer is transforming – and in so doing, is transforming the market.

The following section will further develop conclusions from the findings presented above, with attention to this study's contribution to consumer research and marketing management practice.

Chapter Five

Conclusions, Contributions and Reflections

Summary

This chapter draws the thesis to a close and in doing so offers reflections on the value of the empirical study. Section 5.2 presents conclusions regarding the notion of 'identity work', juxtaposing this with the 'identity play' depicted in the consumer research literature; 5.3 catalogues the collective practices undertaken in the myeloma community and highlights the emotional quality of these; 5.4 expands the discussion of emotional practices in consumption communities. Section 5.5 presents the implications of this study in the arena of marketing management, while 5.6 offers the researcher's reflections on the limitations of the study at hand. Lastly, 5.7 describes pathways for future research leading from this study.

5.1 Introduction

> *"[T]he field of consumer research has generally under-prioritised scholarship for alleviating problems and advancing opportunities for well-being."*

(Mick 2008: 377)

This study set out to contribute to the field of consumer research by exploring the collective practices that enable the transformation of consumer self-identity. Its research analyses the ways in which *a particular manifestation* of consumer culture – the myeloma community - is constituted, sustained and shaped by broader cultural

forces. The overall aim was ***to penetrate the complexity of the simply-stated idea that consumers turn to consumption as a means of self-determination***. Following this aim, the objectives of the study were:

- to contextualise the phenomenon of consumer identity transition;

- to explore the experiences, processes and structures underlying the production of collective culture;

- to investigate the co-creation of social resources within this context;

- to identify and illuminate the collective and co-productive practices through which consumers negotiate a sense of self;

- to identify the social situations, roles and relationships that foster the construction of these practices.

Chapter Four presented the findings of the study. These findings depict the journey of ontological reconstruction patients undertake following a diagnosis of serious illness, identifying and illuminating the practices through which they achieve transformation. Attention is drawn to an under-explored phenomenon, the collective enablement of self-identity. The personal movement revealed is from a position of passivity, fear and objectification to one of perceived control, understanding and skilled navigation of the marketplace. An emotional community offers the informants of this study *access* to a new self, we see - and in transforming into a skilled consumer, they are transforming the market itself. This chapter will summarise and discuss such findings and draw conclusions from them, presenting the ways in which the study contributes to the arena of consumer research. In so

doing, it aspires to scholarship that 'alleviates problems and advances opportunities for well-being' (Mick 2008).

5.2 Identity work and identity play

Consumer self-identity remains a central focus of the consumption communities literature (Arnould and Thompson 2005). Much of the extant research has focused approvingly on the market's creative ability to provide, depicting a material world where consumers seek to forge their own identities and meanings, whether collectively or individually (Holt 2002; Kozinets 2002; Thompson 2003). Here, '[c]onsumption…becomes a means through which individuals can creatively construct and express the multitude of identities that are open to them.' (Goulding et al, 2002: 265). Indeed for Holt (2002), the consumer is self-consciously complicit in the process; brands have become more commercially successful than ever by matching the postmodern consumer's sophistication, he asserts, presenting themselves to the brand-aware consumer 'not as cultural blueprints but as cultural resources, as useful ingredients to produce the self as one chooses.' (ibid: 83)

This view of the consumer suggests someone who has control over their own identity, experimenting and playing with it through the resources made available to them in the marketplace. The findings of the study at hand, though, indicate that where there are serious and substantial issues of self-hood at stake; 'identity play' (Arnould and Thompson, 2005; Schouten, 1991) is an inadequate description of the difficult and laborious remedy required. For those who suffer something as ontologically damaging as a diagnosis of terminal illness, challenging, incremental

identity *work* lies ahead. Identity, in its fundamentals, is hard won, as we see from informant Daniel's words:

> **Daniel:** [Joining a support group] was like walking into the cancer centre the first time. I was just real uneasy the first time - you know it was a whole new thing, new people, dealing with the issue yourself, that you've got this disease… It was, um (pause), it was scary. ; it was also kind of settling to know these people had what I had and um, you were part of it and it was kind of like: I shouldn't be here, why am I here? And that's… you know, like telling myself, yeah, I've got this and I'm not any different from these people, and you know, I need to be here.

Lupton has noted (1997) that where the patient as consumer is examined, the privileged representation is that of 'dispassionate, thinking, calculating subject'. She argues that this depiction draws heavily on models of consumer behaviour where consumers are seen as rational economic decision-makers who benefit from sovereignty of choice. The archetypal *counterpart* to the consumerist patient is the passive or dependant patient, a model of unquestioning compliance (ibid: 374). The study at hand would suggest that beyond both of these simple conceptualisations, substantial emotional and social turmoil conditions a complex disempowerment in the diagnosed.

Where the fundamentals of identity are challenged, then, the individual dislocation is both more emotionally difficult and more problematic to remedy than the bulk of

the consumer research literature would suggest. This is not to allow, though, that this study's informants are somehow less consumers, or less connected to the discourses of the marketplace and the wider culture than the informants in the extant consumption/identity studies. The literature observes that individual identity is challenged during transitions (Schouten 1991) and that transitions can lead to disruptions in consumption (Mason and Pavia 2004). The identity work of the informants in the study at hand may take place in sharper relief than Goulding et al's Goths (2004) or Kozinets' Star Trek fans (2001), but the processes are the same: identity is enabled through community, and enacted in the marketplace.

The scale of the research subject is helpful in this respect. If the urgency of the informants' circumstances is revealing of the extent to which identity work is underestimated in the extant consumption literature, the myeloma community allows us to observe in detail, through a very specifically focused lens, the operations of a relatively small collective. It is a perspective that illuminates the ways in which individual self-management is intertwined with both the practices of the collective and the contingencies of the marketplace.

Research into the healthcare consumer has not been bountiful, and Craig Thompson's subtle and acute studies have stood out in the field in recent years. However, characteristically Thompson's informants who construct their own microculture (Thompson and Troester 2002) and discourses (Thompson 2004) to challenge medical authority and resist the dominant ideology are adherents of a "broad church" such as the natural health marketplace, which encompasses millions of sufferers from many different types of illnesses (and no illness at all), producers

and marketers of goods and services, all linked through a cultural meeting-place of shared lifestyle choices, value and attitudes. The myeloma community is by comparison a small and much more clearly-defined grouping, where the effects and characteristics of its sustaining narratives and practices are also more clearly-defined and discernible. Perhaps, presenting as it does the processes at issue within a proportionate and approachable structure, it could be seen as a self-contained and fruitful *model* of collective enablement.

5.3 Mediation of the marketplace: collective practices

We understand that identity is fluid; something that can be revoked (Bauman 2004), or consciously altered (Goulding et al 2004) and worked on in the form of 'identity projects' (Thompson and Tambyah 1999). Giddens' (1991) influential work speaks of such 'projects of the self' and the wider social influence they can have:

> "The self is not a passive entity, determined by external influences in forging their self-identities, no matter how local their specific contexts of action, individuals contribute to and directly promote social influences that are global in their consequences and implications." (ibid: 2).

Yet the actual *practices* of identity work are often overlooked (Epp and Price 2008). Such omissions lead Warde (2005) to call for a revival of interest in theories of practice. This study seeks to redress the oversight, offering here a catalogue of the collective practices which enable the empowerment of the 'skilled consumer'. Such practices are central to our understanding of collective consumption and identity formation, as Warde asserts:

"An individual's pattern of consumption is the sum of the moments of consumption which occur in the totality of his or her practices. If the individual is merely the intersection point of many practices, and practices are the bedrock of consumption, then a new perspective on consumer behaviour emerges. New explanations of contemporary identities and the role of consumption in identity formation suggest themselves." (Warde 2005: 144)

The concept of 'skilled consumer' draws attention to the fact that the marketplace requires mediation. As we have seen, the consumption of goods and services is a transaction that offers substantial opportunities for creative self-realisation. However, to make the most effective use of the marketplace - as this study shows - requires much of the consumer: initiative, knowledge-gathering, energy and stamina, entrepreneurship and wise judgement are among the qualities that enable exploitation of its opportunities, as informant Marie's narrative highlights:

> **Marie:** So I met my oncologist, and he's trying to give me this drug, and I says, well how many milligrams you gonna give me? He says, two hundred. I says well that's too high. I said, I'm no way gonna take two hundred milligrams. So he dropped it down to a hundred.

Access to the development of personal resources, though, can be a controversial matter as depicted in the literature. Holt (2002) maintains that consumers who 'locate their identity work within the marketplace rather than other organizing spheres such as family, religion, community, and work' (ibid: 79), simply reproduce dominant capitalist ideology. Others (Firat and Venkatesh 1995; Hetrick and

Lozada 1994; Kozinets 2002) have argued that the consumer's best hope of emancipation lies *outside* the marketplace. The study at hand has proceeded rather from a perspective akin to Thompson (2004):

> "[P]oints of conflict are where localized forms of resistance arise, and they constitute pressure points where social and institutional shifts occur. Rather than assessing whether the resulting transformation is genuinely emancipatory or paradoxically reproduces a dominant ideology, the critical objective is to understand the new configuration of power relationships that have emerged, the identity positions and identity practices they engender, the new array of ideological agendas that are formed, and the new opportunities for localized resistance that are produced in this matrix of overlapping discourses of power." (ibid: 173)

To further the understanding of the subtle particulars at work in the three-way dynamic between individual identity, collective mediation and the marketplace, this study has codified the group practices that constitute the structural framework of the processes observed. In so doing it is influenced by the study by Schau, Muniz and Arnould (2009) entitled *'How Brand Community Practices Create Value'*. Arguing that 'a revolution in both marketing thought and practice is at hand', their study employs social practice theory to reveal the collective processes through which consumers realise values in a brand *beyond that which the producer creates* (ibid: 3). Consumption follows from collective practices, they assert, rather than the other way round. Those practices they identify institutionalise and intensify consumption, and enhance the value of the brand in focus. Citing the work of Vargo and Lusch

(2004) they affirm the importance of co-creation: 'co-creation will ultimately move firms to collaborate with customers to co-create the entire marketing program' (ibid: 4). The focal point of their much-anticipated paper is a table codifying twelve common practices of brand communities which they believe represents 'a consumer-centric delineation of the mechanism whereby value is collectively created' (ibid: 3). Lamenting the historical paucity of studies focusing on collective co-creation of value, they suggest that those studies there *have* been, have tended to focus on the idiosyncratic at the expense of uniformity and generalizability. By contrast a greater understanding of general practices, they assert, should enable corporations to participate collaboratively in the process of collective value creation to effect the enhancement of their own brands.

As Appendix Eight shows, the practices codified to this end by Schau et al (2009) bear a close correspondence with the processes observed in the myeloma community. In the study at hand they are characterised as 'identity practices' – ways of being in the world that enable community members to reconstruct their sense of self after a period of transition. Yet it is evident that they could equally be viewed as the value-creating practices of *collective consumption.* The distinction is cosmetic; the creation, shaping and sustaining of value, we would argue, is a fundamental facet of identity (Cova et al 2007).

The study at hand is concerned with contextualising this process in the community where individual identity work is enabled, unpacking the group practices that structure individual self-realisation. For this reason the research focus is different to that of Schau et al. (2009) – more limited in site, more concerned with individual

development, deeper in exploration and more detailed in analysis. However the ambition - to extrapolate from findings in the field and generate an enumeration of the collective practices that condition consumption - is shared.

The study expands the analytical palette presented by Schau et al to include a further eight practices emergent from its particular data: the 'doings and sayings' of the myeloma community, as Warde (2005: 134) would have it. As illustrated in the table below, these supplementary (but, we would assert, equally significant) practices are: Joining, Leading, Ascending the hierarchy, Mythologising, Assimilating, Serving, Teaching/Learning and Acquiring Specialist Language.

Table 3: Myeloma Community Identity Practices

PRACTICE	DESCRIPTION	DATA EXAMPLE
Joining	Crossing the community's threshold in acceptance of one's membership eligibility.	"It was a whole new thing, new people, dealing with the issue yourself, that you've got this disease…" (Daniel)
Leading	Directing community culture and activities through initiative, authority and example.	"I try to get people to understand that there's a bright side to almost everything that's out there." (Colin)
Ascending a hierarchy	Gaining in status and authority through long service and commitment.	"When somebody new walks in, is when you can say: 'Look, I've had that…'" (Jill)
Mythologising	Using language, ritual and stories to give symbolic weight to group activities and common experiences.	"Any of us that's been on dex, we all have our 'dex stories'!" (Julie)
Assimilating	Acculturing to group values to become "the right person to be".	"I've seen some interesting changes in some people, after coming for a long time." (Claire)
Serving	Acting on the responsibility to "Give back" through other-centred behaviour.	"I feel like I'm giving them something they can use one way or another." (Bill)
Teaching/ Learning	Sharing, explaining and interpreting information about the brand.	"They'll say – I have this problem, and the doctor prescribed this for me, and this is how I cope with it." (Jill)

Acquiring specialist language	Building up and using a vocabulary of brand specific terminology, such as drug names.	"[Your friends] don't have any idea about… second-generation thalidomide with revlamid plus dex or, you know, harvesting stem cells." (Julie)

Of the additional practices catalogued above, several (specialist language, mythologising and ascending a hierarchy) are analogous to (but significantly distinct from) 'social networking' and 'community engagement' behaviours such as 'milestoning' and 'welcoming' already identified by Schau et al (See Appendix Eight for further discussion). By drawing on nine instances of variously-intentioned prior research relating to distinct brand communities, Schau et al. are explicit about their 'hope that we might inspire researchers to return to the data sets we assessed, or collect new data to unpack the operation of a broader set of practices' (ibid: 35), and this study would aspire to have answered this invitation, at least in part.

The further additional practices identified in the study at hand – Joining, Leading, Assimilating, Ascending a hierarchy, Mythologising, Serving, Teaching/Learning and Acquiring specialist language – represent, we would argue, an area of consumption behaviour that is consistently under-explored in research: the centre of power where emotions and ethics are dominant.

5.4 Emotional community and consumer research

Consumer research has largely neglected the emotional quality of exchange in consumption communities (Kozinets 2002). Authors such as Kates (2002a) and Moisio and Beruchashvili (*forthcoming*) point to the importance of the social

cultivation of emotions and the crucial role they play in facilitating consumer well-being. This study adds to their work by unearthing the emotional texture of collective practices, and asserting its importance.

Beck and Beck-Gernsheim (2002) have described how the social trend towards individualisation has altered communities – they use the family as an example - from 'communities of need' into 'elective relationships' (ibid: 85). They maintain that we do not need each other in the same way that we may have when communities produced their own resources together. The study at hand is a demonstration not only of the ways in which community is (to use Foucault's term, 1988) a *technology* employed to develop the self and navigate the market, but how a consumption collective – in its mutual disclosures and trust, shared hope, sense of belonging and other-centred ethos – can produce valuable social resources and construct the emotional bonds of traditional community.

Consumption communities can be considered a consumer-led solution to the dark side of empowerment – the burden of personal responsibility (Davies and Elliott 2006; Lupton 1997; Shankar et al 2006). In this respect we can view support groups as consumer communities and consumer communities as support groups, answering Kozinets' (2002) call that consumption communities should be characterised as an ameliorative to the effects of the marketplace. The extant literature has been slow to identify and explore helping behaviour in consumption communities where the exchange of social and emotional support is manifest. The study at hand, though, affirms the extent to which the other-centred ethos of the collective is not just founded on emotional bonds, but underpinned by an ethical framework. This moral

code is fundamental to the identities and relationships at issue, and makes an urgent claim for greater consideration in the consumption literature.

5.5 Implications for marketing management

The market's ability to provide, this study observes, is shifting, inconsistent and unpredictable. The extent to which it requires mediation to be of best service to the consumer will naturally vary from one provider of goods and services to another. In the case of the medical marketplace where, as has been shown, consumers are often struggling in a limbo of dislocated identity, the provision evidently falls short. As we have seen, the ill do not just have to reconstruct their identity - they must *reclaim* it from the grip of a medico-administrative system that broadly fails to conceive of its consumers beyond a confining model of passivity, "the patient", who is destined either to be cured or to suffer.

It seems credible to suppose that the particular inadequacy of the market's provision for consumers of medical care is related to the broader social stigmatisation of the ill (Goffman 1963). Perhaps, too, we may draw on Price & Arnould's assertion (1999: 40) that 'buyer-seller or service provider-client relationships often pit the goals of one against those of the other' to conclude that the structural imperative of institutional medicine to make a profit (in the U.S.A. at least) inherently limits its ability to deliver the type of care desired by consumers. Nevertheless, this is still a market where the well-being of the consumer is the proclaimed mission of the service provider. "Make the care of your patient your first concern" is the opening

precept of *The duties of a doctor registered with the General Medical Council* ('Good Medical Practice' UK, 2006).

The consumerist approach to health care has received support from patient advocacy groups, public policy makers and from proponents of a market economy model (Lupton 1997). Yet the question still looms large: how are consumers supposed to negotiate such a responsibility when the marketplace equips them so poorly? Thompson (2005) suggests that ill people cope by moving away from scientific and medical authorities - which are no longer regarded as sacrosanct - towards communities of fellow patients (such as self-help groups) where they can find the narratives that provide the best "fit" with their sense of self and desired outcome. This, certainly, is the movement observed in the study at hand.

The evidence would seem to point to two possible areas for improvement when the consumer/market relationship is problematic. The first is empowerment of the consumer – and this study has shown how effectively community can act as an agency for enabling the consumer to carry out adaptive identity work and acquire the skills to make effective use of the marketplace. Indeed the support group is a persuasive demonstration that discourses to effectively challenge the inadequacies of the prevailing identities ascribed by the marketplace can be generated and sustained on a microcultural level.

The second potential point of improvement is the development of the market's goods and services to fit better with the *needs* of the consumer. On this latter note, the study's findings have implications for patient information services,

doctor/patient relations and the wider culture of institutional medicine. The planning of effective healthcare services would take account of the current deficit in acknowledgement of the consumer's involuntary renegotiation of self. As put by Frank (1995): 'The scope of modernist medicine – defined in practices ranging from medical school curricula to billing categories – does not include helping patients learn to think differently about their post-illness worlds and construct new relationships to those worlds.' (ibid: 6) In practical terms, a deeper understanding of the processes of patienthood would seem to involve an acceptance that self-empowerment through narrative is key to the journey from passive suffering to agency.

The study at hand discovers community to be the crucial context for the process – and, it might be suggested, provides in the support group a model of how the collective practices that enable adaptive identity work can be enacted. If the culture for healthcare is becoming ever more "consumerist" (Lupton 1997), the need to address the shortcomings in market provision – both for business and for humanitarian reasons – grows more pressing. A recognition of the extent to which outside support groups can facilitate the consumption process is needed.

Further, the processes revealed in this study's investigation of the myeloma community suggest ways in which *all* agents of influence in the marketplace can better facilitate their relationship with consumers. It seems self-evident that a better understanding of the practices through which community enables and shapes consumption – and vice-versa – will provide producers of goods and services with an improved technology to generate more fruitful transactions. Shi and Handelman

(2006), exploring the 'You-Can-Do-It-We-Can-Help' practices of the company Home Depot, conclude that 'a perceived journey toward emancipation within the market-place is possible and that corporations can play an active role in this process.' (ibid: 374) For Shi and Handelman (ibid), Home Depot provides both enabling opportunities for consumers (fostering a community culture that is, as they would have it, free from social/gender barriers and overt commercial manipulation) and the transfer of emancipatory knowledge to enhance consumers' abilities. The company can even be seen to enable identity work, exemplified in the case of the particular informant, a physician, who enjoys "dressing down" for his visits to the store: 'This is something completely different from my career. I enjoy doing that.' (ibid: 372)

Home Depot in Shi and Handelman's research stands as an encouraging model of the way in which the practices explored in the study at hand can be enacted to the mutual benefit of the consumer and the market. The importance of emotional community as emphasised in the findings demonstrates that if emancipation is to be achieved in the marketplace, it is through listening to, empathising with and giving to the consumer. These are human qualities, of course; but they are good business practice (Shi and Handelman 2006). Murray and Ozanne (1991) conceive a marketplace where corporations could use the 'critical imagination' to examine and improve their practices' suitability for consumers, and this study indicates that a good entry point would be to prioritise an environment that fosters emotional and social support - including a sense of belonging, sharing, helping, and other core practices as identified.

There are already successful precedents. Schouten and McAlexander's (1995) analysis of the way in which Harley-Davidson – which manufactures motorcycles but cannot produce the "biker" identity on the assembly line – facilitates the communities where that commercially vital consumer identity is fostered:

'In addition to providing the necessary objects for the functioning of the subculture, marketers may also assist in the socialisation of new members, facilitate communications within the subculture, and sponsor events that provide havens for the activities of the subculture.' (ibid: 59)

In return, Schouten and McAlexander (1995) report, Harley-Davidson has profited by making biker communities accessible to new consumers, enlarging their market, fostering customer loyalty and generating invaluable consumer feedback, increasing sales opportunities at organised events, and boosting general publicity in the wider world. Another substantial benefit to the motorcycle company of their relationship with consumption communities - 'the phenomenon of "grassroots R and D" that occurs as highly involved consumers generate stylistic and technological advances for existing consumer goods' (ibid: 57) - evokes a slightly different collective setting that is beginning to be understood as valuable to businesses: the community of practice.

Many of the characteristics of consumption communities as the study at hand has framed them are the same traits observed by Wenger and Snyder (2000) in 'communities of practice' – that is, informal collectives of self-selecting members who establish their own leadership and cohere around a common interest to 'share

their experiences and knowledge in free-flowing, creative ways that foster new approaches to problems.' (ibid: 140) Wenger and Snyder's collectives typically comprise individuals from within a firm or profession, and the authors illustrate their influence in the marketplace by describing how the World Bank funds the informal communities within its own organisation, benefiting reciprocally from a drive in strategic direction. The participants in the communities of practice observed by Wenger and Snyder (2000) learn together by focusing on problems related to their work:

> 'In the short term, this made their work easier or more effective; in the long term, it helped build both their communities and their shared practices – thus developing capabilities critical to the continuing success of the organisations.' (ibid: 143)

The study at hand would argue for its demonstration of an analogical value in the practices of the consumer community, where its members' negotiation of the marketplace is equivalent to the work duties of the professionals in communities of practice. Wenger and Snyder (2000) supply a further fruitful suggestion in the idea that the usefulness of such communities in managerial and commercial terms is best assessed via non-traditional methods of measuring value, because the benefits are often manifested indirectly. Interestingly, they suggest that the best way of appreciating these benefits is through the medium the study at hand understands as the bedrock of the support group: members' stories. If American Management Systems found from such stories among its employees that communities of practice had saved the company $2-$5 million and increased revenue by more than $13

million in a year, as Wenger and Snyder (2000) report, what might be the measurable influence of consumer communities of practice in the marketplace, should we try to assess it?

5.6 Limitations and critical reflection

Any study that is thoroughly contextualised within a particular area or phenomenon can encounter a questioning of validity. It is hoped that the methodology chosen for the study at hand will be approved in its fit for the purpose - but there should be a recognition that research strengths can also be weaknesses.

On this note, the recruitment of participants is worth revisiting (see sections 3.4.1 and 3.8.1). The sensitive nature of the research topic required the researcher to work with a gatekeeper to access participants (through purposive and snowball sampling). Whatever assurances of objectivity and open-ness were undertaken on both sides, it is apparent that this method of recruitment conceded an element of controlled access from the outset, at the discretion of the gatekeeper (who was the leader of one of the groups). Indeed, the formal point of entry to the group may arguably *in itself* have been a factor which influenced the informants' position towards a researcher introduced by the gatekeeper.

Beyond this it seems reasonable to speculate that the community ethos of fellowship and positivity, allied to members' very considerable loyalty to the group (and to group leaders such as the gatekeeper) resulted in a reluctance among informers to tell tales about negative aspects of the support group experience. Before critiquing

the implausible lack of conflict within the group culture, though, it should be remembered that this is a community engaged in constant negotiation with points of conflict, variously within individual members' identity work, in relation to the challenges of the medical marketplace, and through the vicissitudes of the illness itself. Conflict resolution could be characterised as a core function of the group - and perhaps it is not surprising that the collective ethos should seek to minimise conflict *within* what is, after all, a highly effective community.

On the other hand patients who do not attend, or who had attended and left, as well as patients who do not have access to support groups, were not part of this study. This is offered as a limitation to the stated aim of approaching an understanding of the lived experience of myeloma. The voice of these patients has not been heard. Yet, this was a study of community processes and practices - and the focusing of attention on those who were members of the community under examination is defended as appropriate.

5.7 Future research

This study's findings affirm the extent to which group culture and the collective social resources made available in the myeloma community inform and affect members' treatment decisions. The understanding of the disease and its treatments garnered at support group meetings alters informants' interactions with their healthcare providers, penetrating even to the point where it can exercise a decisive influence on medical research (see section 4.4.4). In a wider context, consumers of healthcare products and services can often find themselves making significant

decisions (with important outcomes for their well-being) without ever feeling truly 'informed'. The conclusions drawn herein highlight the challenging reality of consumer decision-making, and the power of lay expertise. Further research is needed to more fully assess the importance of consumption communities in the enabling of the relationship between consumer and marketplace.

In assessing such complex matters, though, issues of method loom large. The application of analytical rigour is elusive, and perhaps direction can be drawn in this regard from the companies enjoying the benefits of Wenger and Snyder's (2000) 'communities of practice', which have measured the – indirectly manifested- benefits of the collectives in question by interpreting the stories community members tell. The argument for non-traditional methods of assessing the value of such communities seems persuasive.

Measurement, too, must attempt to encompass the subtlest personal responses of the individual consumer. Lupton (1997) has shown how within a healthcare context patient responsibility for treatment decisions is sometimes unwelcome. Shankar et al. (2006), further, argue that the prevailing idea of consumer choice equating to consumer empowerment is *in itself* questionable, citing studies that suggest a wealth of choice can present a confusing and unhappy experience (Bush 2004, Schwartz 2004, Wathieu et al 2002). The question arises: is consumer choice always desirable? Only the individual consumer can tell. Greater investigation is clearly warranted, though the study at hand would argue emphatically for its findings' demonstration of the value of empowerment with regard to one's own consumption.

The limitations highlighted above (5.6) open up further space for future research. Questions regarding intra-group conflict and its role in the community dynamic could be usefully addressed. There are issues, too, about the possible *negative* implications of the power of consumption communities and lay expertise. For example, the circulation of "misinformation" between healthcare consumers is identified by Wong and King (2008) as something which affects market choices. In their study women chose to have more radical surgery than was medically necessary to treat their breast cancer. Wong and King (2008) attribute this, in part, to misleading lay expertise. Ignoring for now the objectionable notion that these women are seen to be "wrong" in their very personal and challenging decision-making, the findings do illuminate the possible negative effects of consumer collectives - particularly in the context of healthcare. Better understanding is called for.

On a broader scale, the notion proposed in this study of 'Consumer Communities of Practice' invites investigation in wider contexts. Comparison with other sorts of communities – such as Muniz and O'Guinn's (2001) brand communities - should facilitate further understanding of the extent to which the processes and practices identified herein are generally applicable; and of the importance of such processes and practices in the marketplace.

Finally: this study has observed the emotional bonds that cohere the process of transformation, shaped and underpinned by a code of social values which might be termed the community ethos. It has been noted that this ethical dimension to the nature of interaction within consumption communities has been little investigated in

the extant research, and the evidence of this study argues that this is a culpable omission. If we are to begin to penetrate the complexities of these processes, a deeper understanding of the consumer must encompass not only the central issues of identity and collective mediation, but dig into the little-mined depths of their emotional foundations and ethical underpinning.

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Appendices

Appendix One: Background Notes on Context

Multiple Myeloma

Multiple myeloma (also known as simply 'myeloma') is a form of bone marrow cancer for which there is presently no cure. Symptoms of the disease include bone pain, kidney failure, bone loss, anaemia and immune system suppression. It is estimated that there are 75,000 – 100,000 myeloma patients at any one time in the USA, and upwards of 15,000 in the UK. Myeloma is more prevalent among men than women (3:2) and incidence of the disease increases with age. It has an average life expectancy of three to five years from diagnosis.

The most common treatments used for this disease are chemotherapy, radiotherapy, steroids, and stem-cell transplantation using the patient's own cells. All of these carry a risk of side-effects which will necessitate further therapeutic remedies. Among common pharmaceuticals employed in treating myeloma are chemotherapy drug combinations like melphalan and prednisolone or dexamethosone and thalidomide. More recent treatments approved by the U.S. Food and Drug Administration include bortezomib (known as Velcade, and FDA-approved in 2003) and lenalidomide (known as Revlamid, and FDA-approved in 2006).

Myeloma has been described as a chronic condition which is characterised by periods of active disease and symptoms, and periods of stability or remission where symptoms may not be experienced. Some patients will have to consume maintenance treatments throughout their illness, but more typically a patient will undergo several rounds of chemotherapy and radiotherapy and/or stem cell

transplantation after diagnosis, and may then enjoy a period of months or years where symptoms are lessened or absent and little or no treatment is consumed. In most cases symptoms will eventually return, and treatment options which have been successful in the past may then prove to be ineffective. In such instances the patient may choose to adopt a palliative strategy to lessen symptoms. (Source: Durie, 2003).

Myeloma Support Groups in the Midwest

In 1999, when the principal support group observed in this study was founded by three recently-diagnosed myeloma patients, there had previously been no myeloma support group either in this state, or the surrounding states. Two further groups were set up in other cities in the state in 2002. The groups try to recruit by encouraging medical professionals (for example at cancer centres where patients will be receiving chemotherapy) to inform new myeloma patients about their presence.

The longest-running group is highly active, hosting experts on topics as varied as mindfulness meditation, healing touch, nutrition, acupuncture and Tai chi, as well as sessions featuring experts explaining the latest myeloma research and treatments. It publishes a monthly newsletter that serves a mailing list of people from Alaska to Florida. Some groups provide food and drink, but not this one ("Unless I bake something or someone else bakes something we don't have anything! And I didn't want to get in to being a food delivery service, kind of a thing…" Colin), and there are few financial outgoings. The group gathers in a meeting room at a local hospital, and what money is required for stationery, printing etc comes from donations, fundraisers, sponsorship from pharmaceutical companies and bequests.

All the support groups under study herein are themselves supported to a greater or lesser extent by the International Myeloma Foundation (IMF). This umbrella charity was founded in 1990 by a myeloma patient, his wife and doctor. It is based in Los Angeles, California and provides information and support services to those affected by myeloma throughout the USA and beyond. The charity is also active in the medical community, organising educational seminars for doctors and nurses and awarding research grants annually. The IMF holds an annual Support Group Leaders' Retreat – on three occasions attended by the researcher - where leaders of myeloma support groups from all over North America come together to share ideas about best practice.

Appendix Two: Informant Biographies

'Anne and Susan'

Anne is in her eighties, laughs easily, and has a bright, switched-on, interested personality. She suffered a sarcoma on her leg ten years ago, then breast cancer five years ago. She was diagnosed with multiple myeloma in January, 2006, not long after the death of her husband. She has recently moved to live full-time with Susan, one of her three children, and is enjoying her new surroundings. (Susan: "She looked after me when I was little, and now I'm gonna look after *her*.")

'Bill'

An early retiree and former National Guardsman, Bill is a father of three grown-up children. He lives in a small Midwestern town and was diagnosed with multiple myeloma in 1999. Now in his sixties, he has recently remarried after meeting his wife online. He shared his wedding photographs with the researcher.

'Claire and Duncan'

Claire and Duncan met in 1998, after Claire answered an ad in the local free newspaper: "Hiking, biking, kayaking, cross-country skiing and dinner." They live in the countryside, with panoramic views over farmland to distant bluffs, and share a love of travel and the outdoor life. They have visited many far-flung destinations, like the Ukraine and the Galapagos Islands, and have a mutual habit of gauging Duncan's health by his fitness to go kayaking. Duncan was a pharmacist in a hospital, and misses the working life that illness forced him out of (he was diagnosed with multiple myeloma in 2001). He likes to keep busy with projects in the house; he has recently remodelled the bathroom. His wife Claire holds a PhD, and as well as teaching science in the local high school, conducts classes for teachers at the state university in the summer. The couple married six weeks after Duncan's diagnosis, and for some months after this Claire attended the support group on her own. Then Duncan came with her. He is now regarded as an "elder statesman" of the group. The couple are in their late forties.

'Colin'

A retired university professor, Colin is a support group founder and leader. Aged 70, he is active in his local community and church, and a keen gardener. He writes the monthly support group newsletter, which features extensive information on the

latest scientific advances in the treatment and management of myeloma, and has contributed to clinical trial design as a patient advocate. He and his wife Paula have a large family with many grandchildren; they are planning to move from the family home to an easier-to-manage condominium.

'Daniel'

A fit and healthy-looking man in his early fifties, Daniel is a working senior academic in the field of botany. Being active and outdoors has always been very important to him; he is an avid gardener and road-biker. His wife comes with him to all the meetings of his local support group. He has had two stem cell transplants, and is in full remission at the time of interview.

'Jean'

Jean (80) and her retired-teacher husband are both from the Midwest. An office worker before she married, she went back to this for ten years after her children had grown up. Both she and her husband have been busily involved in voluntary and church work; Jean has served on the church board of trustees and directed the choir, and collected money door-to-door for various charities for many years. The couple have grandchildren aged 6 and 9, both of whom suffer from Asperger's syndrome, and their daughter-in-law has set up a support group "sharing all her resources with other people". Jean was diagnosed with multiple myeloma in early 2006. She follows a keen exercise regime, walking in the morning, and using a treadmill in her basement when the weather is cold.

'Jill'

One of six sisters, Jill is married and in her late fifties. She worked as a microbiologist for 20 years, first in a laboratory, and then in middle management; then for 15 years she had a business stripping and finishing furniture. In 1999 she was diagnosed with ovarian cancer, and treated with surgery and chemotherapy. Shortly after this, she was diagnosed with multiple myeloma, undergoing a stem cell transplant in 2000. In 2001 she went to her first meeting of the local support group.

'Julie'

Aged 68, Julie is married for the second time. She was a partner in a Midwest law firm when she was diagnosed with multiple myeloma in 2001. She now runs her local myeloma support group, as well as other cancer-related event organising.

'Kate'

Aged 70, Kate lives with her second husband and describes herself as "a home-maker," spending her time looking after her house, her garden and her grandchildren. Between them the couple have five children and eight grandchildren. She was diagnosed with multiple myeloma in 1998, and was one of the first members of her newly-founded local support group.

'Marie'

Aged 62 and with grown-up children, Marie lives in a small town. Her ex-serviceman husband Bill is a Harley Davidson enthusiast, and the couple have travelled all over the United States with Marie riding pillion. A former hairdresser, a home-maker and country music enthusiast, Marie was diagnosed with multiple myeloma in 2005. Her faith is very important to her; she reads particular passages of the Bible ("healing scriptures") before taking her medication each day.

'Martha'

Martha works in a managerial position for a telephone company. She compiles and designs the newsletter for her local support group – which she developed from what used to be simply a monthly email. She is also active in organising guest speakers and funding/sponsorship projects for the group. Now 47, she was diagnosed with multiple myeloma in 2001. She is married with a young family, and a regular churchgoer.

'Morris'

Morris was diagnosed with multiple myeloma in 2002, when he was 46. One of four siblings, he underwent a stem cell transplant using cells donated by his sister, and has since returned to work part-time in IT for a financial institution. He is married to Barbara, a classical musician; they are both churchgoers.

'Rosalind'

Roaslind was born on a farm in Iowa. She worked as a music teacher before taking holy orders and becoming a nun. She was working as a pastor in a priestless parish when she was diagnosed with multiple myeloma in 1996. Aged 65, she lives in church accommodation. She lives on disability benefit, and organises community events and gives music lessons.

'Rosie'

Rosie works at a bank, and runs a cake-making business at the weekend. When she was diagnosed with multiple myeloma in 1996 she was a year into a Masters course in San Diego, California, and she abandoned the course to return to the Midwest. She lives alone.

'Tom'

Aged 69, Tom was a director of public works until multiple myeloma forced his retirement in 2003. He now lives with his wife and their dog in a comfortable suburban street. Their children have left home. The couple enjoy travel throughout the United States, picking up mementos as they go. Tall and well-built, Tom is quite a physical man; he likes working with wood and reconditioning furniture, and his large extended family are very important to him.

Appendix Three: Craig Thompson Methodologies Table

Paper and Context	Method	Access	Participants	Interview	Analysis
Thompson, Locander, Pollio (1989) Theoretical	Existential-phenomenolo-gical study. "The research focus is on *experience* as described from a *first-person* view."	n/a	n/a	The course of the conversation is largely set by the respondent. Interviewer uses lead question but does not have a list of a priori questions.	Hermeneutical circle: Part-to-whole process in two phases. First seek understanding of individual interview,second level takes all interviews and relates them to each other through common patterns. Use of interpretive group.
Thompson, Locander, Pollio (1990) 'experiential world' of contemporary married women, Southeastern USA	Existential-phenomenolo-gical study.	Not specified	10 married women	Phenomenolog ical interviews. Use of lead question then questions arose from dialogue. Interviews Audio taped, 1-2hrs	As above
Thompson, Pollio, Locander (1994) Contemporary married women, Southeastern USA	Hermeneutic Approach	Respondents recruited through local church group	3 married women with children	As above	As above. Use of symbolic metaphor 'highlights and summarizes patterns of meaning that have been derived from the interview texts.'
Thompson and Haytko (1997) College students, Midwestern USA, Fashion	Phenomenolo-gical study	Not specified	20 volunteer participants	Phenomenolo-gical interview. Conversational quality, course of the interview largely set by participants. 45 mins to 2hrs	Hermeneutical circle. "In this process, earlier readings of a text inform later readings, and, reciprocally, later readings allow the researcher to recognize and explore patterns not noted in the initial analysis." Use of "dialectical tacking" (see below)

Appendix Three: Craig Thompson Methodologies Table Continued

Paper and Context	Method	Access	Participants	Interview	Analysis
Thompson and Tambyah (1999) Expatriate professional workers, Singapore, Cosmopolitanism	Phenomenolo-gical study	Personal referrals	14 participants (2 couples), 2-3 year period	'phenomenologi-cally oriented' depth interview. Used "grand tour" question to begin interviews (McCracken 1988). Interviews took place in participants' homes or place of work, 1 – 3 hours. Multiple interviews with 4 participants over 2-3 year period	Textual analysis post-structuralist interpretation Both researchers read transcripts – 'noting salient thematic categories' p222 'Tacking between' 'emic constructs' and 'etic constructs' used to develop theoretical understandings
Thompson and Troester (2002) Natural health microculture, Midwestern, USA	Phenomenolo-gical study	Adverts in natural health shops, referrals and personal acquain-tances	32 natural health consumers, 4 year period	Phenomenolo-gical interview	Hermeneutical process – 'continuous movement' between individual texts and full set of texts

Appendix Four: Excerpt from Interview

Date: 08/06/06
Interviewee: 'Jill'
Location: Coffee shop

S: Well I suppose I'm just interested in your story, when myeloma came into your life really to begin with.

J: Um, myeloma came in kind of sneaky, I think I mentioned it at the meetings, 1999 I just didn't feel right and they found ovarian cancer and that was at stage one and so they did the surgery over labor day and chemo everything and then I said ah, I've gotta get back to doing something. So I got a hold of the athletic club and I said that I wanted to do stuff they said well you need a doctors' permission – you know with the health background – so I went to a doctor and told him, "oh sure" and he did a blood test and I was anaemic so this went on from probably February until May, every month, and so finally he said, "I think we better do some more tests". And then the next time I saw Dr Y, the ovarian cancer guy, he took me over to see the haematology people and then my husband had to come in and all that and that's when we found out about the myeloma. 1.58

S: And had you been feeling OK at that point or did you know that something wasn't right?

J: No I was feeling OK, I didn't notice anything but its hard to know if you don't have any energy or ambition if you've just gotten done with three rounds of chemo.

So then they did the VAD all summer and then I had – I had no hair, I hadn't had hair for 2 years – it was almost back after the ovarian chemo

S: That's hard. And how did you feel about that side of things?

J: The first time I was a little upset and embarrassed but the second time I said I'll wear a wig when I go out but this is who I am even if you don't like it, wigs are itchy and a pain.

3.30
J: So we had the stem cell transplant and I was home for Christmas Eve, it was in 2000. I still have no clue where some of these presents had come from because they just got put away, I don't know where they came from, none.

S: So you had lots of people sending you presents, thinking of you?

J: Yeh I've got five sisters.

And so then in March then we went on Thalidomide, March 2001. And it really didn't give me any side-effects. I'd been on it almost a year when my feet started to get numb and my finger numb but otherwise no problems.

S: And so when you were diagnosed with myeloma, how did they tell you, what happened at the consultation?

J: What happened? (pauses). Well I had never heard of it. You know, it's not one of your common diseases. My husband came in and Dr X stayed late to talk to us and basically he said you know if we don't do anything, we don't have to do anything or we can treat it and if you don't do anything you've got six months. So that was kinda scary. And I don't know if you've met Dr X, or heard much about him?

S: I don't think so, no. I think I recognise the name.

J: He's an [nationality] fella. Nice looking guy. But I got so frustrated because he would never tell me what was coming next. I found out I was having a stem cell transplant from one of the nurses.

S: How did that feel?

J: It was just kinda like, oh that's what's happening. And then I tried to find out when this was happening and [puts on Drs voice] "I haven't talked to the insurance people yet". Wait a minute we've been doing this all summer, why haven't you talked to them? (laughs). There were just stupid things like this that really *really* upset me. And he never did say anything at all about the support group. I was listening to public radio one day and Meg Gaines was on and she was talking about being a liaison for um cancer patients and insurance brokers. And she had ovarian cancer and so I thought, I'm gonna call her. A couple of weeks later she finally called me back and I told her that I had myeloma and she said "Oh there's a wonderful support group, I'll give your name to Chuck Koval." And that was the first I'd ever heard of it. So I really did not get to go to a group meeting for probably a year and a half.

S: And so did you eventually go to a meeting before your stem cell transplant or was it after?

J: It was almost um six months after. So the stem cell transplant was a complete unknown. But see I didn't go through the normal channels, I was referred from an oncologist to an oncologist and so I just never got all the stuff, if there would have been a nurse in the room she would have gotten me the information. So it was kind of hard, it was hard for [her husband]. You know, we both had been healthy for so long and all of a sudden there's an elephant in the living room. (pauses)

But the rub with Dr X just kept coming because at the meetings they would start talking about different blood levels and I never heard any of those.
So onetime I kind of found a prescription and I was looking at it and I asked, well what about this kidney level, it's all screwed up. And he gives me this real flippant answer that, Oh, don't worry, when it gets bad enough we'll put you on dialysis. And told him that that wasn't a very good quality of life and I told the nurse I wasn't gonna come back! (laughs). I won't come back unless I have a new doctor.
Begins: 7.24 Ends: 9.36.

I just think that he and I just don't get along.

S: So you wouldn't say that you made a treatment decision, you were prescribed a treatment?

J: No, I was an object that was being treated. I had no clue if I was getting better. You know, what should I be doing? If I complained, then I'd have another whole set of pills to take. I don't need to take pills.

S: So what happened then, you saw [which doctor]?

J: [answers] Dr Z.

S: And what made you switch to her particularly?

J: She had just started, so it was logical for me to go from one doctor to a lady doctor. And em, she's a multiple myeloma specialist, and she says you've had the bisphosphonates for so long, she says, you're not gonna get any more of those. Oh, OK!

S: And what did you think about that?

J: I didn't know what to think but I'd been hearing so much about all of the different side effects that I thought, good.

S: Had you heard about the side-effects at the support group?
10.41
J: Yeh, at the support group. I looked up multiple myeloma on the internet, and every time I'd look up something it would be eh, "so-and-so died from his valiant struggle with multiple myeloma" (laughs) Wait a minute, I don't need to know that, I just don't need to know that. So I just quite looking because what I was being given as information isn't anything I cared about.

S: So you found the group through Meg Gaines, and then what did you do, did you go along to a meeting?

J: I went all by myself. I just walked in – this was when Chuck was eh, right after his surgery and he had his neck in a brace and he wasn't there. So um, I just said OK, I'm gonna go to this. I'm usually too shy to just walk in most situations, but I did and I met a gal that I knew from [where she lives], she had since died.

S: I'm sorry

J: I didn't know her well, I knew the family more than her. Anyway, so it was interesting after a couple of meetings you could say "I have this problem, does anyone else have this?" And they'd come back with "no" you know, if it's something that isn't multiple myeloma or they'll say I have this problem and the doctor prescribed this for me and this is how I cope with it. And that just is an awesome, secure feeling and if it's something else that nobody's had, you can look

at it and say this is something that doesn't go with multiple myeloma and I probably don't have to worry about it. 13.13

S: At your first meeting, was there a speaker?

J: There wasn't a speaker and it was over in [town] in the library basement on Saturday mornings. Which was a pain to get to but. It was interesting and then when somebody would come and there'd be a speaker it would be very interesting, a learning experience.

S: So you feel you learn at the group?

J: I do. As I said I tried going online and it was "so-and-so died of multiple myeloma".

S: Is this in a chat room scenario?

J: It would just be in different sites that you could look up. I don't need to know that. And when they start in with the kind of treatments well now I kinda at least know the language.

S: And you learned the language at the group?

J: Yeh

S: I think that's an interesting point, it is a new language.

J: Oh it is.

S: So the group helped you learn the language and has taught you about myeloma, do you take emotional support from the group as well do you feel?

J: Sometimes yeh, but the best part about it is the fact that you know you are not alone doing something. And if you've got a problem there's somebody that's at least had the same problem and you can talk to them. And of course in the group we have got people who are real educated, we can really learn from each other.

J: [Husband] has come to one meeting, he's normally working when the meeting's on and um he hasn't been there often enough to learn the language and the people, so I'm there alone but he encourages me to go.

S: And is he involved in any other aspect of your treatment and management?

J: Not really. He got to cope with um, colon cancer about three years ago. Oh yeh we've had the gamut recently.

S: And is he OK now, how's he doing?

J: Mhum, he's fine.

S: Did you notice differences in the way he approached his disease and you approach yours?

J: They offered him chemo and his thing was, "I saw what Dori went through, is it gonna help? Can I take it anytime? I don't wanna go through that if it, if you got it all." And then he decided if it shows up later I [husband] can still take the chemo. And he says I saw what chemo does, he says "I don't want anything to do with it".

S: And did he seek information and support services about his cancer?

J: No, no. But he was pretty scared. Normally women go to support groups more than men but multiple myeloma's got a lot of guys, I'm surprised.

S: So when you started see Dr Z, had you at this point learned a bit more about the disease do you feel?
18
J: Boy, oh boy… I guess I had learned what I didn't want, and I had learned some of the words. I'm still pretty ignorant when it comes to some things but next week I get to go and give them some blood and then all the test results. And I can get them on the internet so I can look and see which ones are normal and I knew what questions to ask.

S: That's really interesting. So is it you HMO provider that deels with that?

J: Mhum

S: So your HMO has a website which has you page, if you like?
19.30
J: Mhum. And I print them out and compare them to last month, so if I notice something I tend to bring it up. But until I switched to Dr Z, they were taking blood at [the hospital] and I would never get results.

S: Did you look for support and information for the ovarian cancer?
20.35
J: No. But I was real upset because I had… there was one thing that really bothered me because I know that there was support groups for breast cancer and I knew that there was other support groups but there wasn't any for ovarian cancer.

S: So you looked out for one?

J: I looked for one but there wasn't anything and then I thought, I got so frustrated because here there was this – I think it's this weekend where they do the walk for cancer – and ah here we've got these people who've had cancer, who've had chemo and all that, they can run and I can't even walk around. Why not? And that's what upset me as far as ovarian cancer goes, because it just seemed like they took something from me, and my ambition, my energy, everything was gone. And I wanted to be in life again, and then they found the multiple myeloma. And so that was kind of a problem and I could remember sitting in [the doctor's office] at one time and I was just basically so upset, I was just in tears and I said, I've had this

disease and I said people die, it was almost a guilt thing that I wasn't gonna die. 22.14

J: So that's what really upset me, and he says "no people live, there's a gal upstairs that was one of my patients" and he says "I can get her down to talk to you", No it's fine (laughs). But when all at once you really confront it and actually realise they've had something I've survived, somebody else isn't going to.

S: And how does it make you feel?

J: Scared.

S: And do you feel the same way about the myeloma?

J: No. Because I didn't really ever - except for fatigue – I didn't really have [symptoms]. To me myeloma is just a chronic thing that I have. 23.56

S: So it's less immediately scary?

J: Yes, And of course I've already been told that I have cancer. The second time isn't as frightening.

S: So what made you seek out the group for myeloma?
24.08

J: I guess it's just the fact that here I have something I know nothing about, it was just kind of a lonesome, alone feeling. (Pauses) That's the thing that bothered me more than anything, I'm by myself and I don't know anything about this disease.

S: So it was looking for more knowledge of the disease and I suppose wanting to meet other people who have it?

J: Yeh.

S: And when you finally met the people who had it, what did you think?

J: It took a while, I don't make close connections real quick. So it took about 3 or 4 meeting before I was able to actually share anything. It just gives you a funny place to belong. That's what it is, it's belonging.

S: And you feel a sense of belonging to the group or to the wider population of people with myeloma?

J: Probably both, because my husband's cousin, he's older, he had myeloma and he was older, he was up North, he was too old for a stem cell transplant, and so he would call. And I'd say, have you heard of this, have you tried that? you know, all that stuff. And so we would rap about it and he had a place to mend. And Dick's sister-in-law has MGUS, she has not gone to the myeloma phase yet but I've a hunch that when she does she'll be on the phone and you can give some reassurance that you might have this elephant in the living room but you're not gonna die.

S: And id that something you enjoy doing, speaking to people who have the disease or may be affected by it?

J: I don't mind. But it's hard for me to…um… I don't know all the big words, I don't go to the meetings you know the big meetings that they have here in Milwaukee or wherever. I've got a life! (laughs) and it isn't revolving around myeloma. In fact I don't even think about it until the week before an appointment because I have to always call them so I can get the bloodcount. 27.32

S: So it's out of your mind until you have to go and get those blood test results?

J: Yeh, and I pay attention if anything starts to go up.

S: So by look at your results on your webpage you can more or less gauge how you're doing?

J: Well, you can say "Oh this is out to lunch", but at the same time it's exactly what it was last month, and if something is really weird then you can ask about it. But the kidney functions are the ones that are almost always out to lunch, last time I actually had a low normal haemoglobin, that's as good as it's ever been.

S: Would you say that you're more involved in your treatment since you joined the group or since you switched to Dr Z?

J: Yeh, the two came kinda together. I just kept getting more and more frustrated. Somehow after you've been to a doctor for three years and seen him every other month, I just really felt peeved because I thought he should know what my name was. And not Ms [surname], oh I hate that! So, and to never know what the test results were bothered me so I just told them, unless I get a different doctor I'm not coming back. I don't think he realised the effect that he was having. And I wanted to be treated as a person not as something that he had to work with, you know, "my job is to take care of this object and this one and this one" and never let me know what comes next, that that was so frustrating. When I worked in the lab, a gal say, she always called it one-stepping.

S: What did she mean by that?

J: Well, she'd start a step and they'd say, stir this for 15 minutes, and they'd give her another step, and they do that then another step.

S: So she never knew when the task was going to end, just the next step and the next step?

S: So you worked in a lab, what was you profession?

J: Microbiology. I tested vitamins. So when they start talking about drugs and vitamins [at the support group meeting] I know about that stuff.

J: I don't believe in taking these mega doses of vitamins because I know that some can be very toxic. And the vitamins are all water soluble, so you take this megadose of vitamin B1 or vitamin B2, you know what you do? You pee yellow because that's the colour of [colourant]. So that sort of thing, I don't go with that.

S: So you don't go in for the alternative side of things too much?

J: Some yeh. But don't start with natural vitamins on me…what is the point of spending 3 or 4 times as much for vitamins when you really don't have to.

S: So how long were you involved in the lab work?

J: About 20 years.

S: Did you retire or did you have to leave because of illness?

J: I got too old. I got too old. I was in middle management and for three years "You're salaried, you can come in Saturday", finally after 3 years I said no, I was getting sick. As soon as somebody who was a little ways up in the company would get into their late 40s they'd start pushing them out the door. And it happened to more than one. Then when they did push them out the door, people would disappear, you wouldn't even run into them on the street. This was all before the age of age discrimination.

S: And it was before you became ill?

J: So for 15 years I had a business stripping and finishing furniture... 35.13

Appendix Five: Sample Coding Table from Interview

Jill	
8/6/06	
Coffee shop	
Begins: 7.24 (time code for interview recording)	
Ends: 9.36	
J: But see I didn't go through the normal channels, I was referred from an oncologist to an oncologist and so I just never got all the stuff, if there would have been a nurse in the room she would have gotten me the information. So it was kind of hard, it was hard for Don [husband]. **You know, we both had been healthy for so long and all of a sudden there's an elephant in the living room.** (pauses) But the rub with Dr X just kept coming because at the meetings they would start talking about different blood levels and I never heard any of those. So onetime I kind of found a prescription and I was looking at it and I asked, well what about this kidney level, it's all screwed up. And he gives me this real flippant answer that, Oh, don't worry, when it gets bad enough we'll put you on dialysis. And told him that that wasn't a very good quality of life and I told the nurse I wasn't gonna come back! (laughs). I won't come back unless I have a new doctor.	How you come to the disease – setting the scene emotionally. Is there a normal way to come to it? Nurse Vs Dr - Jill wasn't told there was a group available to her. Info about disease and support group. Change, unspoken, uncomfortable Doubt – see Thompson Community of Reflexive Doubt Information, control, empowerment Character and quality of relationship with medic – quality of life and issue for her, is it for Dr? She feels he does not.
S: So you wouldn't say that you made a treatment decision, you were prescribed a treatment?	
J: No, I was an object that was being treated. I had no clue if I was getting better. You know, what should I be doing? If I complained, then I had a new set of pills to take. I don't need to take pills.	Jill feels she was no longer seen or treated as a person. No role, employment in the process of getting better.
Begins: 15.00	
Ends: 15.28	
J: The best part about it is the fact that you know you are not alone doing something.	Illness is a lonely experience

And if you've got a problem there's somebody that's at least had the same problem and you can talk to them. And of course in the group we have got people who are really well educated, we can really learn from each other.	Learning makes you less lonely
Begins: 24.01	
Ends: 27.32	
S: So what made you seek out the group for myeloma?	
J: I guess it's just the fact that here I have something I know nothing about, it was just kind of a lonesome, alone feeling. (Pauses) That's the thing that bothered me more than anything, I'm by myself and I don't know anything about this disease.	Alone, liminal? Altered state? Isolation Lack of knowledge/control
S: So it was a looking for more knowledge about the disease and I suppose wanting to meet other people who had it?	
J: Yeah.	
S: And when you finally met the people that had it what did you think?	
J: It took a while; I don't make close connections real quick. So it took about 3 or 4 meetings before I was able to actually share anything. **It just gives you a funny place to belong, I think that's what it is it's belonging.**	TRUST required to "share" Sense of BELONGING
S: And you feel a sense of belonging to the group or to the wider population of people with myeloma?	
J: Probably both, because my husband's cousin, he's older, he had myeloma and he was older, he was up North, he was too old for a stem cell transplant, and so he would call. And I'd say, have you heard of this, have you tried that? you know, all that stuff. And so we would rap about it and he had a	Step-wise support

place to mend. And Don's sister-in-law has MGUS, she has not gone to the myeloma phase yet but I've a hunch that when she does she'll be on the phone and you can give some reassurance that you might have this elephant in the living room but you're not gonna die.	Mending. Broken by diagnosis.
S: And is that something you enjoy doing, speaking to people who have the disease or might be affected by it?	
J: I don't mind. But it's hard for me to… **I don't know all the big words, I don't go to the meetings you know the big meetings that they have here in [the city]** or wherever**. I've got a life! (laughs) and it isn't revolving around myeloma.** In fact I don't even think about it until the week before an appointment because I have to always call them so I can get the bloodcount. 27.32	"Big words" – complex scientific language used at group meetings by some members Level of knowledge desired by group members varies. Important to differentiate myeloma from rest of "life" Altered state
Begins 37.50	
Ends 38.44	
S: Do you feel like at the group you get the opportunity to help people?	
J: I hope so, I hope so. I don't know if I do or not.	
S: Yeah, well I think speaking about your own experiences…	
J: I guess **when somebody new walks in is when you can say, look I've had that, I've been there and look I'm healthy and you could be too.** Now I've got [another patient]'s email address, and I'm not real good at it but I try to email her once in a while. She lives alone and she gets scared, so I send her jokes (laughs). I don't know if that makes a difference to her or not.	I've been there. Viewing oneself as a positive example for other patients. She regards herself to be healthy Reciprocity – stepwise or otherwise
39.24	

S: So if I asked you what you feel you get from the group what do you think your answer would be?	
J: (pauses) **You get pumped up and you get a feeling of belonging.**	Belonging
Begins: 40.47	
Ends: 41.27	
S: So would you say the group has changed the way you approach the disease?	
J: Yes because I'm not as upset about having it. You know, I just look at it and say, I've got a disease but it's managed, I'm not *sick*. It's OK. Before you know, you always feel like you're marginalised because you got this, "I got this disease, I'm sick". I'm not sick anymore, now I'm healthy and everything is going fine. I'm happier now. **A mantra? A state of mind?** **Sense of renewal** **Control/loss of control = healthy/sick**	It seems that Jill wanted to get to a place where she would not consider herself to be sick. She does not bring in the symptoms here i.e. pain 'I'm not in pain' but instead talks of the disease as MARGINALISING her. It's about the idea of who she is. See Sontag. Sick me Vs healthy me The group has helped her come to terms with it and feel less alone. She is happier. Does lack of control/knowledge create this feeling of being marginalised? Transition/transformation/renewal Identity is fluctuating Normative pressure in group Is she healthy or has she adjusted? Has she repaired herself? Denial?

Notes:

Does community have a discursive function? Providing vocabulary and concepts that enable them to think of themselves as healthy not sick. Function of community/subculture has expert arcane vocabulary, establishes distance between community and some other.

Position – marginalised, position of liminality, moving between one place and another. She uses it to suggest being isolated. Movement. Margins – when you are sick, loose sense of community and belonging, healthy you are in the core.

We identify ourselves as citizens of one kingdom or other – but MM patients oscillate.

Appendix Six: Themed Coding Table

Giving to the group and helping others

Extract	Memo
Extract from fieldnotes from SGLR, Greg Pacini, Group Therapist session, 20/5/06: **"Journey stories provide signposts, a way forward, and can be seen as a gift."** **Morris and Barbara** Begins: 12. 37 Ends: 13.49 S: So when did you become aware of the various outside support systems that are available to you? M: I'd actually heard of [the support group leader] from some people at Church and family friends, neighbourhood friends had mentioned his name to me and I guess they mentioned my name to him. B: Because he actually called the house. M: That's right. At the time they were actually holding the monthly meetings on the weekends and so I would attend. I had a couple of reasons for attending, one just to see what other people were experiencing, then there was probably a little bit of an ego thing, I knew myeloma was typically among older people and I was on the younger side of that, so I thought let's just go and I can show them what the range is of age and how I'm still able to work, so you can too, without having to say that, just to be there. S: So, for you to be a kind of example of positive things? M: Oh yeah. **Bill** Begins 25.57 Ends 27.44 S: So what would be a good support group meeting, what do you like about it, what would be good aspects if you were to describe a particular meeting that you would enjoy?	*(note: this quote served as symbolic metaphor for the following analysis).* Sharing personal experiences and illness narratives can be seen as a gift. Morris's reasons for attending are interesting – to offer himself up as an unusual and positive example of a MM patient. Uses the word ego – he was aware he was "special". Inspiring others through giving a positive example. He seems aware that his experiences and the way he lives with his disease could be helpful to others.

B: I like the information that comes out of it. The camaraderie you feel with everybody there. Trying to motivate people or help them, inject humour if they're feeling down, some people are really down almost every meeting. They're just totally.. "I can't do this I can't.." you know. I've a hard time dealing with that, not I'm worried about it, it doesn't bother me, but to get them to see another side of it, you know. And it's easy for me because I'm not in trouble right now but when I was going through that depression and I lost all my weight I was there. So I've been down to the bottom of the barrel and I've been back up again, but you never really get back up unless you help yourself and at the meeting *always,* no matter when I go or how often I go I always get something out of it. I may walk away feeling better for myself, I may walk away praying for somebody, I may walk away for whatever reason just feeling good about being there, helping somebody. Maybe somebody said "you did what?" you know or people speak… last meeting I had two or three people talking about what I went through, and that made me feel great. Feel like I'm giving them something they can use one way or another, it doesn't make any difference. (how they use it) That's the part I like about the meetings it's the camaraderie, it's the information, it's just everything that's there if you want it.	Bill appears to have a philosophy, a way of dealing with the disease emotionally that he wants to share with others. His own experiences – "I was there" – allow him to recognise when others are "in trouble". He is particularly concerned about others' mental state – depression, loneliness and lack of hope. He sees himself as a joker who can add levity to a situation and seems to derive some satisfaction from being able to make people smile/laugh. Helping others makes Bill feel good. ROLES in the group – Bill as a JOKER brings humour.
S: And if there was anything you could say about the meeting that you didn't like, would there be anything in particular? Or particular meetings that you have not enjoyed?	
B: I don't think so, again I think I feel a little down for people that are having a hard time - and can't help it – I admire them for being there when they are not doing well. And I would do anything to help them get feeling better. You know if I could talk to them or make them smile or do something, I would do anything to do that, you know. Like I say with [the support group leader] and that and everything else that's happened all this time it's just wonderful, I just don't know, I feel sad for people that can't find a way to get out of it. Sometimes it's very difficult when you are suffering, some people live alone – well I've been living alone for a few years too – some people have a hard time dealing with it, loneliness and stuff and some people might have somebody and still be	Bill seems to take RESPONSIBILITY for others in the group.

lonely. That's the sad part. I enjoy when I see people coming with caregivers – somebody that wants to help them a little bit, somebody that's trying to pull them out of the doldrums. You know, I just love it.	
Kate	
K: And that support group was really (pause) *unbelievable*. And to see those people that you start with and you meet with and then they die, and you know for a while I couldn't bear it and I couldn't go, and I thought it's too depressing, I can't, I can't go (pauses) and then I thought well it isn't always about *me* - and then you know another person died – and I'm like well, it's about the new people coming in that don't want to feel you know…	Who was dying? Founder member, [name]? Scale of importance in group – certain members more INVOLVED IN COMMUNITY.
Later in interview:	Suggests a HIERARCHY. Levels of membership.
S: And you said that you are going along to the group now more for other people rather than for yourself, is that a correct interpretation of it?	What are new members NEW to? New to disease, group, new to a way of dealing with the disease, new philosophy?
K: That's what I said but that's probably not true. I thought that. But I get a lot out of it, I get a lot out of it. But I started for a while there when it was depressing and people were dying and I didn't go and then I started to go again because I thought well it's not just what I get because maybe I can *give*.	Members have a ROLE and make contributions to the community.
Extract from fieldnotes, visit to Duncan and Claire's home, 3/5/06:	BOUNDARIES of community – those who leave. Attendance is affected by the death of other members.
"Both Claire and Duncan are involved in speaking to new members and those newly diagnosed. They talk rather animatedly about this. It seems important to them. C uses the expression "take them under our wing". They say they have seen their influence have a positive outcome and clearly feel good about this. (They recommended D's Dr to another group member, this person took their advice and is pleased with the result. D and C describe her as being "totally changed in her attitude to the disease since changing Dr.")	Kate, like Bill, feels a sense of OBLIGATION. Who is it to? The group?
Extract from fieldnotes, interview with Amy and Terence, 6/5/06:	

Amy tells me that another group member sent information to them about having teeth out and the possible side-effects of this (caused by one of the drugs taken by MM patients). They have passed this information on to their dentist. "Now they are aware and know to look for it." They also passed on the information to another patient. Amy tells me about a time when Terence "was helpful to the group". Terence got a second opinion and found that his calcium levels had increased due to a perithyroid (?) condition (rather than the disease, which would normally be considered the obvious cause). He passed this on to the group and A and T believe this would be helpful to others. They both seem happy to have been able to contribute to the group.	This gives an idea of the currency of the group – information is passed from group member to group member. In this case the information was passed on outside of the group as well to a health professional with the aim of informing and educating them. The group has a gift-economy. New people coming to the group or newly diagnosed act as a focus for the group – as seen at the [other city] meeting (which seemed like a practiced and unspoken ritual) – they provide members with someone to help, someone to benefit from their experience – something good, something beneficial, even therapeutic can come from bad experiences. Someone to give back to. Stepwise. REPRODUCTION – of community, of gift.

Notes:

The group has a gift-economy.

New people coming to the group or newly diagnosed act as a focus for the group – as seen at the Milwaukee meeting – they provide members with someone to help, someone to benefit from their experience – something good, something beneficial, even therapeutic can come from bad experiences. Someone to give back to. Stepwise.

Appendix Seven: Extract from Fieldnotes May 3

Date: 3/5/06

Interviewees: Claire and Duncan

Location: their home

No recording device used as I thought asking to use it might intrude on informal atmosphere. The roles seem to be that they were hosts and I was a guest – not a formal researcher/subject situation.

Informal meeting over dinner at their house. (Duncan cooked which he often does as Claire goes out to work. Claire is very complimentary about Duncan's cooking skills).

Claire and Duncan welcome me into their large, comfortable home and we sit in their "den" looking through large windows at a panoramic view of the surrounding countryside and the bluffs in the distance. We drink a glass of wine each and Duncan asks me questions about Scotland, Edinburgh, myself and my family. (Duncan seems to want to talk about anything but myeloma!) We discover that we have a love of travel in common and so the conversation moves to places we have been. They have been to many far-flung destinations (e.g. the Ukraine and Galapogos Islands) and enjoy talking about these trips.

Kayaking is also an important part of their life and they seem to gauge Duncan's health, to a degree, on whether he is fit enough to go kayaking. Things are good when they can manage to go kayaking or hiking. The outdoor life seems central to their well-being. Duncan expresses frustration at his lack of energy and physical fitness, contrasting his old "super-fit" self with his new ill self. He laments this loss.

Duncan is a retired Pharmacist and misses his working life, which he enjoyed. He retired due to ill health caused by MM. He talks about projects he has in the house to keep him busy – he has recently remodelled their bathroom.

Claire is a science teacher in a local high school, she also holds a PhD. which she took on as a side activity. She works with UW in the summer conducting classes for teachers. She seems to be a highly motivated and involved educator.

Duncan was diagnosed in 2001 "it's been a long haul" he says . Claire found the support group almost right away. She describes herself as being "a researcher" and a talker/sharer. She belongs to other groups and enjoys talking things over.

Duncan was reluctant to go to the support group at first because he was "in denial" and he "didn't think he had long to live" (Claire's words). "What's the point in talking about it?" (Duncan's words). After 6 months Duncan went to the group. It took him a while to settle in to it and feel at home with it. Now he is kind of the elder statesman of the group and knows everybody.

Both Claire and Duncan are involved in speaking to new members and those newly diagnosed. They talk rather animatedly about this. It seems important to them. Claire uses the expression "take them under our wing". They say they have seen their influence have a positive outcome and clearly feel good about this. (They recommended Duncan's Dr to another group member, this person took their advice and is pleased with the result. Duncan and Claire describe her as being totally changed in her attitude to the disease since changing Dr.)

Appendix Eight: Community Practices

The table below provides a summary of the community practices identified in Chapter Four. It represents the reframing of a table contained in the forthcoming study by Schau, Muniz and Arnould (2009) entitled *'How Brand Community Practices Create Value'*. Their study employs social practice theory to reveal the collective processes through which consumers realise values in a brand *beyond that which the producer creates*. The authors draw on prior fieldwork to codify twelve value-creating practices at work in consumer communities. Each practice is a set within a larger category, these are: Social Networking (practices that create, enhance and sustain ties among community members); Community Engagement (practices that reinforce members' escalating engagement with the community); Impression Management (practices that create a favourable impression of the brand and community to the outside world); and Brand Use (practices to improve or enhance use of the brand). These categories are employed in the table below. The study at hand expands the analytical palette to include a further eight practices (Joining, Leading, Assimilating, Ascending a hierarchy, Mythologising, Serving, Teaching/Learning and Acquiring specialist language) emergent from its data. These practices appear in bold in the table to ease identification. Schau et al's (ibid) descriptions of each practice have been drawn on and in some cases modified, while the 'data example' column of the table presents data from the study at hand. Please note that for the purposes of this study multiple myeloma acts as the brand that is the common factor around which community is fostered.

Table 7 Community Practices

CATEGORY	PRACTICE	DESCRIPTION	DATA EXAMPLE
Social Networking	**Joining**	Crossing the community's threshold in acceptance of one's membership eligibility.	"It was a whole new thing, new people, dealing with the issue yourself, that you've got this disease…" (Daniel)
Social Networking	Welcoming	Greeting new members, ushering them into the fold and assisting in their community acculturation.	"[The support group leader] is so open with everybody, and he introduces people when they're there, and then brings them in, and makes them part of the group. So you become integrated quickly." (Daniel)
Social Networking	Empathising	Giving emotional support to other members.	"These people just came up and hugged me! One at a time." (Kate)
Social Networking	Governing	'Articulating the behavioural expectations' within the community and defining community boundaries.	"Nobody just sits there and says 'I think I'm gonna die.'" (Jean)
Social Networking	**Leading**	Directing community culture and activities through initiative, authority and example.	"I try to get people to understand that there's a bright side to almost everything that's out there." (Colin)
Community Engagement	Staking	Recognising variance and similarity within community membership.	"Some [members] are having a rougher time because of the degree to which they are afflicted, you know, but they all seem to be coping. Which is marvellous." (Jean)
Community Engagement	Documenting	Storytelling of the 'brand relationship journey'.	"[The members] just went round the room and talked about themselves – you know, my name, how long I've had this, and the things I've been through." (Martha)
Community Engagement	**Ascending a hierarchy**	Gaining in status and authority through long service and commitment.	"When somebody new walks in, is when you can say: 'Look, I've had that…'" (Jill)

CATEGORY	PRACTICE	DESCRIPTION	DATA EXAMPLE
Community Engagement	Milestoning	Recognising 'seminal events' in brand consumption and community membership.	"I had 13 radiation treatments on my back… And then I got to go to [another hospital] for chemo, and I had about four months of that, and then I had my stem cell transplant." (Marie)
Community Engagement	Badging	'Translating milestones into symbols.'	Wearing of IMF badges, caps, t-shirts etc.
Community Engagement	**Mythologising**	Using language, ritual and stories to give symbolic weight to group activities and common experiences.	"Any of us that's been on dex, we all have our 'dex stories'!" (Julie)
Community Engagement	**Assimilating**	Acculturing to group values to become "the right person to be".	"I've seen some interesting changes in some people, after coming for a long time." (Claire)
Community Engagement	**Serving**	Acting on the responsibility to "Give back" through other-centred behaviour.	"I feel like I'm giving them something they can use one way or another." (Bill)
Impression management	Evangelising	Sharing the brand community 'good news'.	"We've finally had the spin-off [groups getting going]. And I would like to see one in [the North of the State], I would like to see one in [the East]." (Colin)
Impression management	Justifying	Deploying rationales for devoting time and effort to the brand and collective to outsiders and marginal members.	"I would say a support group is going to help heal you as much as the medical profession: a major factor in determining the outcome of your disease." (Tom)
Brand Use	**Teaching/ Learning[2]**	Sharing, explaining and interpreting information about the brand.	"They'll say – I have this problem, and the doctor prescribed this for me, and this is how I cope with it." (Jill)
Brand Use	**Acquiring Specialist Language**	Building up and using a vocabulary of brand specific terminology, such as drug names.	"[Your friends] don't have any idea about… second-generation thalidomide with revlamid plus dex or, you know, harvesting stem cells." (Julie)

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[2] Teaching and Learning can be viewed as an ongoing, deeper progression of what Schau et al (2009) call 'Welcoming'.

CATEGORY	PRACTICE	DESCRIPTION	DATA EXAMPLE
Brand Use	Monitoring/ adjusting[3]	Tracking developments and trends in the brand and amending treatments/ health regime.	"Even though [my doctor] says it's fine, I can see that it dropped quite a bit [a particular blood count], and that's kind of a signal for me, too, to start taking better care of myself, and the vitamins that I forget to take a lot of times, (laughs) – start taking them again!" (Martha)
Brand Use	Re-imagining[4]	Modifying the concept of brand to suit group level or individual needs.	A lot of the statistics and stuff are way outdated, so consequently it's useless information, you know. If you want to make yourself feel real bad, you start reading some of the statistics and what-not on there [like life expectancy figures], that are not relevant to the way things are today. (Tom)
Brand Use	Commoditising	'Distancing/ approaching the marketplace'; includes resistance to inadequate products/services.	"They said, we've got this clinical trial all set up for you… we're all set, we're ready to go. I said, well I don't want this clinical trial, it's out-dated." (Colin)

(Adapted from Schau et al 2009: 47)

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[3] Schau et al (2009) use the term 'Grooming' to depict '[c]aring for the brand (washing you MINI) or sytematizing optimal use patterns(clean skin before applying Stri Vectin).' (ibid: 41). This term sits uneasily in the context at hand and has been replaced by monitoring and or adjusting to indicate the practices undertaken by myeloma patients to tend to their own health.

[4] Here the term 'Re-imagining has been used in favour of Schau et al's (2009) use of 'Customising'.