



CREATE

Canterbury Research and Theses Environment

Canterbury Christ Church University's repository of research outputs

<http://create.canterbury.ac.uk>

Copyright © and Moral Rights for this thesis are retained by the author and/or other copyright owners. A copy can be downloaded for personal non-commercial research or study, without prior permission or charge. This thesis cannot be reproduced or quoted extensively from without first obtaining permission in writing from the copyright holder/s. The content must not be changed in any way or sold commercially in any format or medium without the formal permission of the copyright holders.

When referring to this work, full bibliographic details including the author, title, awarding institution and date of the thesis must be given e.g. Fihosy, Sonia M. (2015) Exploring culture and illness. D.Clin.Psych. thesis, Canterbury Christ Church University.

Contact: create.library@canterbury.ac.uk



MAJOR RESEARCH PROJECT
EXPLORING CULTURE AND ILLNESS

Sonia M. Fihosy BSc (Hons) MSc

Section A: Cultural influences on the perceptions and experiences of chronic illness: A review of UK studies

Word Count: 8000 (8091)

Section B: A qualitative exploration of the impact of culture and faith on illness adjustment in adolescents with liver disease

Word Count: 8000 (8092)

Overall Word Count: 16000 (16183)

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

JUNE 2015
SALOMONS CENTRE FOR APPLIED PSYCHOLOGY

Acknowledgements

First of all, I wish to thank the inspirational young people who agreed to take part in this project and who so willingly spoke from their hearts. Thank you to my research supervisors, Dr. Helen Ellis-Caird and Dr. Anna Hames for all their input because without them this research would not have happened.

My lovely friends have been so encouraging in seeing me through this work, but I must give a special thank you to Sophie, who has been a rock throughout this journey. Thank you to all my family for all their support, but especially Jacob for his cups of tea and Joseph, for his sympathy. Finally, I wish to thank my Heavenly Father for everything that has led to this project and for all that is to come.

MRP: EXPLORING CULTURE AND ILLNESS

Summary

Culture is an inherited and shared collection of guidelines for how to perceive and relate to the world and others. Illness is amongst the many aspects of life which are viewed through a cultural lens. Therefore, perceptions and experiences of illness are shaped by culture. This research portfolio consists of:

Section A: Cultural influences on the perceptions and experiences of chronic illness: A review of UK studies. The findings from 18 studies were applied to Leventhal's framework of illness representations. Whilst perceptions and experiences of chronic illness are shaped by culture, these influences appear to be mediated through a range of factors, including family and gender dynamics, coping strategies, age and class. This indicates that culturally-sensitive healthcare provision needs to be truly person-centred care.

Section B: A qualitative exploration of the cultural and spiritual influences on the illness perception and adjustment to chronic liver disease in a sample of adolescents. A model of adjustment to illness was developed which took account of socio-cultural and spiritual influences. Illness-related spiritual or socio-cultural crises reported appeared to be entangled with adolescent development. However, most participants reported an eventual turning point, leading to acceptance, personal development and sometimes, spiritual growth.

Section C: Appendices and supporting documentation

MRP: EXPLORING CULTURE AND ILLNESS

MRP: EXPLORING CULTURE AND ILLNESS

Contents

1	Section A: Abstract.....	9
2	Introduction	11
2.1	Multi-cultural Britain	11
2.2	Defining Ethnicity and Culture.....	11
2.3	Cultural Influences on Illness Perceptions and Behaviours	13
2.4	The UK context	15
2.5	Rationale for this Study.....	17
3	Method.....	17
4	Results	20
4.1	Beliefs about Causes of Illness.....	29
4.1.1	Beliefs Linking Illness Lifestyle/Life Stressors	29
4.1.2	Supernatural beliefs about Illness.....	30
4.2	Timeline	31
4.3	Consequences	32
4.3.1	Cultural Expressions Shaping the Experience of Illness.....	32
4.3.2	The Stigma of Illness.....	33
4.3.3	Childhood/Adolescent Perspectives on Impact of Illness.....	34
4.4	Beliefs about Cure/Control.....	36
4.4.1	Beliefs about Control of Illness.....	36
4.4.2	Exercise.....	37
4.4.3	Dietary Beliefs and Experiences.....	38

MRP: EXPLORING CULTURE AND ILLNESS

4.4.4	Managing illness with Social Support?	40
4.4.5	Other Coping Strategies and Solutions	41
4.4.6	Alternative Healing.....	42
4.4.7	Class Influences on Control Perceptions and Health Service Expectations	43
4.4.8	Cross-Cultural Challenges Difficulties Accessing Health Services	44
5	Discussion	46
5.1	Discussion of Findings.....	46
5.2	Critique.....	47
5.3	Limitations of This Review	50
5.4	Implications for Research and Practice	50
5.5	Future Avenues	51
6	Conclusion.....	51
7	Section B: Abstract.....	61
8	Introduction	62
8.1	Religiosity/Spirituality in Adolescence	63
8.2	Culture and Chronic Physical Illness in Adolescence	63
8.3	Spirituality and Chronic Physical Illness in Adolescence	64
8.4	Chronic Liver Disease in Adolescence.....	64
8.5	Study Aims	65
9	Method.....	66
9.1	Study Design and Epistemological Position.....	66
9.2	Participants.....	66
9.2.1	Inclusion Criteria.....	66

MRP: EXPLORING CULTURE AND ILLNESS

9.2.2	Recruitment	66
9.2.3	Sample.....	67
9.3	Ethical Considerations.....	67
9.4	Procedure	68
9.5	Data Analysis.....	69
9.6	Quality and Validity	69
10	Results.....	70
10.1	Self-report Measures	70
10.2	Qualitative Data Analysis	71
10.3	Theoretical Categories and Sub-categories	72
10.3.1	Summary of Illness Adjustment Model.....	72
10.3.2	SOCIO-CULTURAL CONTEXT (Category 1)	74
10.3.3	HIGHER POWER (Category 2)	79
10.3.4	ILLNESS ADJUSTMENT (Category 3).....	82
10.3.5	PERSONAL DEVELOPMENT (Category 4)	89
11	Discussion.....	93
11.1	Spirituality and Adjustment.....	93
11.2	Families, peers and Adjustment.....	94
11.3	Spiritual Growth and Personal Development from Illness Adjustment	
	95	
11.4	Clinical Implications.....	96
11.5	Limitations.....	97
11.6	Future Work.....	97
12	Conclusion	98

MRP: EXPLORING CULTURE AND ILLNESS

Section A

In what ways does culture influence the experience of living with chronic illness? A review of UK-based studies

1 Section A: Abstract

Aim: A review of theoretical and empirical studies on cultural influences on the experiences and perceptions of chronic illness across patient groups in the UK.

Rationale: Health inequalities continue to persist in the UK between different demographic groups. Exploration of cultural influences on illness may contribute towards improving healthcare services for diverse populations.

Method: A search for empirical studies published since 1998 on cultural influences on chronic illness in the UK was conducted on Canterbury Christ Church University journals, MEDLINE, psycINFO, and psycARTICLES databases. The findings from 18 studies were aggregated and applied to Leventhal's illness frameworks.

Findings: Whilst perceptions and experiences of chronic illness are shaped by cultural beliefs, values and attitudes, these influences appear to be mediated through a range of factors, including health and illness beliefs, family and gender dynamics, coping strategies, cross-cultural interactions with healthcare professionals, linguistics and languages, age and class. Such factors may have led to a plethora of barriers in accessing the full extent of healthcare services available and difficulties in following medical advice given. However, several studies reviewed had methodological shortcomings which raise questions and limit the confidence with which conclusions can be drawn.

Clinical Implications: Culturally-sensitive service delivery requires a person-centred approach which takes into account individual and contextual factors.

Future Directions: Some research is needed on positive cultural influences on adjustment.

2 Introduction

'The way that hide that fell in myself before when I finished the world I feel like a totally different person' (Bache, Bhui, Dein & Korszun, 2012)

2.1 Multi-cultural Britain

For centuries Britain has been the destination of various migrant groups from around the world, largely due to its extensive range of historical and geopolitical links with other nations (Ahmad & Bradby, 2007). The process of 'globalization' of the modern world has fuelled more recent migration as people seek a better quality of life, personal safety, work, education, adventure or, are forcibly trafficked by criminals (Helman, 2007). Helman observes that contemporary migrants prefer to maintain their cultural and religious identity rather than assimilating into the 'host community'.

Britain's rich history, coupled with its ongoing, internationally-influential role, has produced the multi-cultural nation it is today. Below is a brief exploration of how the cultural diversity that exists in contemporary Britain has introduced added complexity to the enormous challenge of meeting the population's healthcare needs.

2.2 Defining Ethnicity and Culture

Zagefka (2008) offers a working definition of ethnicity as a somewhat malleable "social construct" which assumes self-ascription, although is limited by existing constructs in use by others. She suggests that usually members of an ethnic group believe they share a "common culture" and "common descent", and possibly, have a self-

defining association with a specific “geographical territory”. There may be additional “characteristics that coincide with the group delineations, e.g. language and/or religion”. In short, culture is a defining factor of ethnicity.

MacLachlan defines culture as a shared “set of guidelines... for living in the world” which facilitate personal growth. It incorporates styles of self-expression and communication, beliefs, values, attitudes, habits and strategies, which individuals are able to draw upon for guidance in managing the tasks and dilemmas of daily life. As such, culture is “contested, temporal and emergent” (Clifford, 1986). Trompenaars (1996) first presented the widely used “onion model” of culture as shown in Figure 1. The outer layer of the onion represents the observable aspects of a culture such as language, clothing, cuisine and behaviours, whilst the middle layer depicts the norms and values of the group, such as idealised gender roles and attitudes to elders. Finally, the inner core comprises of deeply-rooted, basic assumptions or beliefs held about the world including matters related to health and illness. Kluckhohn and Strodtbeck (1961) argue that cultural differences between groups of people have arisen due to their adoption of different sets of resolutions to universal dilemmas, which may have been partially influenced by their unique environmental and historical contexts.

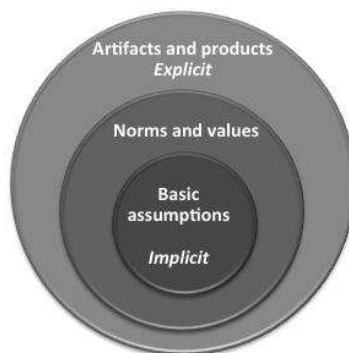


Figure 1: Trompenaars' "Onion Model" of Culture (1996)

2.3 Cultural Influences on Illness Perceptions and Behaviours

In 1977, Engel presented a seminal paper on a biopsychosocial framework of human health and illness which, in addition to biological structures and processes, assumes critical contributions of psychological factors and social context over the lifespan. This triggered a paradigm shift from the purely medical models in existence at that time (Uskul, 2010).

In 1965, Leventhal and Niles conducted a series of experiments to investigate health-seeking behaviours. The predominant behaviourist theories at the time predicted that the reduction of fear would be the primary motivating driver underlying the actions of individuals facing health challenges. Whilst some support for this idea was found by the researchers, such behaviours were short-lived (i.e. up to 48 hours). A new theory was required to explain the more complex behaviours actually observed. Following on from this work, Leventhal, Meyer and Nerenz (1980) went on to develop a highly influential cognitive model of illness perceptions and behaviours as shown in Figure 2 below. They proposed that when faced with illness, individuals act as 'common-sense' problem-solvers and develop an idiosyncratic understanding of their illness. The implication is that individuals actively make sense of illness signs and symptoms, decide how best to respond to them and the associated distressing emotions. They then evaluate whether their chosen response was effective which informs their idiosyncratic model of the illness (Baumann, 2003).

Leventhal, Nerenz and Steele (1984) later proposed an illness representations framework for categorising health beliefs. Petrie & Weinman (1997) summarised the illness representation model as consisting of five stages with corresponding questions: namely, Identity ("What is it?"); Causes ("What caused it?"); Timeline ("How long will it last?"); Consequences ("How will it/has it affected me?"); and Cure/Control ("Can it be

controlled or cured?”). Empirical evidence has been presented which supports this structure across demographic and illness groups, although the content of illness representations may vary between individuals (Petrie & Weinman, 1997, p157). The course of action taken by individuals will be influenced by their illness representations, such as preferred coping strategies and help sources, or indeed whether they would seek help at all (Prins et al., 2008).

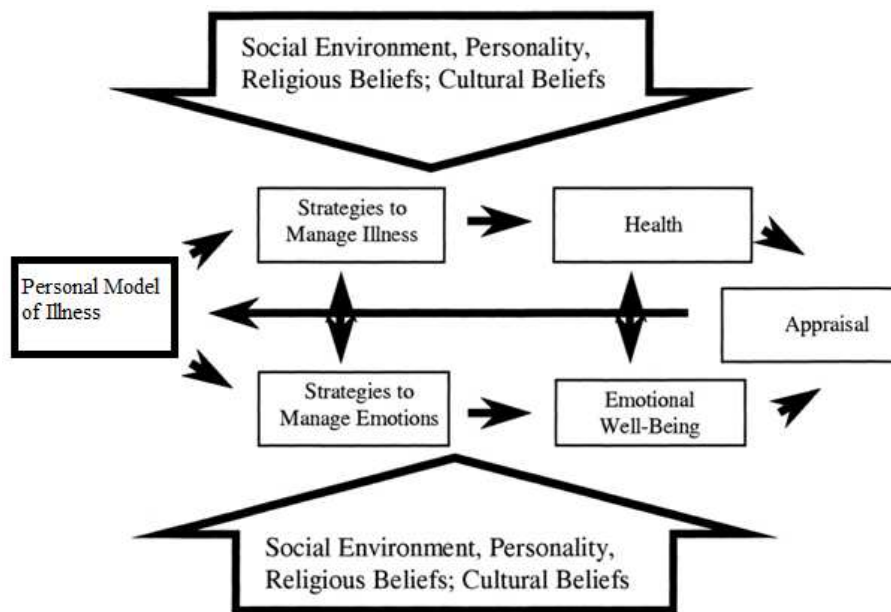


Figure 2: Representation of Self-Regulation Model of Illness (Leventhal et al., 1980, adapted from Bucks et al., 2009)

Crawford (1984) argued that individuals employ the narratives available to them through their cultural frame of reference, which therefore shapes and positions their illness expressions, experiences and meaning-making. Baumann (2003) suggested that cultural beliefs, values and norms can influence the sense-making process at every stage, for example, by contributing possible interpretations of somatic experiences and offering ideas about what to do about them. Taken together, the logical conclusion is

that perceptions of illness (and health) can differ tremendously between different cultural groups, in relation to their respective social contexts (Baumann, 2003, p244).

Turner (1996) was one of a number of writers specifically concerned with cultural and cross-cultural influences on health beliefs and behaviours, illness perceptions and the adjustment process. He contends that in cases where clinicians and patients do not have a shared understanding of health and illness, the treatment process can be significantly impeded. This has been supported by practice-based evidence (e.g. Eshiett & Parry, 2003). Cultural influences on health and illness has attracted the attention of researchers over the past two decades, fuelling a growing evidence base which is largely dominated by qualitative data produced from focus groups and individual interviews (Helman, 2007).

2.4 The UK context

A recent government publication 'Living well for longer' reported that chronic illnesses are the biggest causes of premature death in the UK today (Department of Health, 2013). However, it appears that there is much room for improvement in the British healthcare system with respect to meeting the needs of its ethnically and culturally diverse population. A Better Health paper recently published by the Race Equality Foundation, an original member of the Department of Health's third-sector Strategic Partner Programme, states that "despite the apparent strength of the legislative framework and significant policy-related activity there remains disappointing progress on the ground towards reduced ethnic inequalities in healthcare access, experiences and outcomes" (2014). To back their claims, they cited findings from public inquiries such as the one into the death of David 'Rocky' Bennett, a black

man who's mental and physical health needs went unmet whilst in the care of an NHS trust.

In 2000 the Department of Health published The NHS Plan which included a commitment to reduce health inequalities, yet figures produced over the following decade showed no subsequent decrease (University of Manchester, 2013). For example, illness rates in Bangladeshi and Pakistani women were 10% higher than for White women in 1991, 2001 and 2011, with the difference becoming even more pronounced in older women. Men and women from White travelling communities have the poorest health of all groups, across the lifespan. Outcomes for some ethnic minority groups are poorer, largely due to their reduced access to timely and appropriate healthcare (Szczepura, 2005)

It could be argued that such inequalities in care experiences may be explained by differing perceptions of illness, its causes, treatments and outcomes. Using retrospective data, one British study explored this empirically by examining ethnic differences in response to disease modifying anti-rheumatic drug therapy for patients with rheumatoid arthritis (Helliwell & Ibrahim, 2003). They discovered that patients of South Asian origin terminated their treatment significantly earlier than White Europeans, citing their reasons as lack of efficacy, unpleasant side effects (i.e. skin rashes) or apprehension about potential side effects. However, the reason(s) for the differences in response between the two groups was not firmly established by the authors. They speculated that it may be due to genetic differences in drug metabolism, cultural differences in expectations of the medication or cross-cultural communication difficulties, but an exploration of the exact nature of these differences was beyond the scope of their study.

2.5 Rationale for this Study

The purpose of this review is an attempt to unpack some of the aforementioned complexity in the relationship between illness and culture. Greater understanding of such issues will be required in order to design and deliver a more equitable healthcare system for the diverse populations of the United Kingdom.

3 Method

The focus of this systematic review of theoretical and empirical literature was on the different ways that culture influences the experience of chronic or serious physical illness for people in the United Kingdom. Using the terms shown in Table 1 below Searches were conducted on the abstracts of articles in the Canterbury Christ Church University journals, MEDLINE, psycINFO, and psycARTICLES databases published since 1998, when an independent report on health inequalities was first released (Acheson, 1998), putting a reduction in health inequalities firmly on the NHS agenda as a key tenet of NHS Plan that followed. The focus was placed on cardiovascular diseases, diabetes, HIV and tuberculosis since the prevalence rates for black and minority ethnic groups in the UK is disproportionately high for these conditions, according to Black Health Agency (BHA, 2013), a champion for health and social care equality based on figures published by the British Heart Foundation and the Stroke Association in 2009. After removing duplicates, a total of 607 papers were returned by this search.

AND	NOT
(illness or disease or heart or cardi* or stroke or hypertension or diabetes or tuberculosis or HIV)	(psychiatric or psychosis or psycholog* or depression or postnatal or mental or terminal or end-of-life or palliative)
(culture or cultures or cultural)	(bacter* or blood or immun* or microb* or antibi* or pathogen or vir* or cultured or vivo or tissue or histology or load)
(UK or "United Kingdom" or England or Brit* or Scotland or Wales or "Northern Ireland")	(organis* or organiz* or military)

Table 1: Key search terms

Papers were excluded if they did not explicitly address cultural aspects of patients' own experiences of chronic illness (e.g. if the focus was on carers' perspectives or health professionals' education or practice). Papers were also excluded if they were primarily concerned with medically-unexplained illness or mental health since this area has been much more heavily researched and such work already begun to make an impact on widespread clinical practice (Bhui, Warfa, Edonya, McKenzie, & Bhugra, 2007). Palliative research was also excluded to maintain the focus on clinical populations that were managing chronic illness over the longer term.

The reference lists of the remaining papers were then examined to see if any relevant studies had been missed. In total 587 papers were excluded leaving 18 remaining for the review (see flowchart in Figure 3 below). Of the papers included in the review 17 were empirical qualitative papers written by anthropologists, psychologists, research nurses and general practitioners (GP) and one was a cross-

Cultural Influences on Chronic Illness: A review of UK-based Studies

sectional survey. Drawing on Mays and Pope (2000), attention was paid to the hallmarks of rigorous qualitative research, such as the reporting of reflexivity.

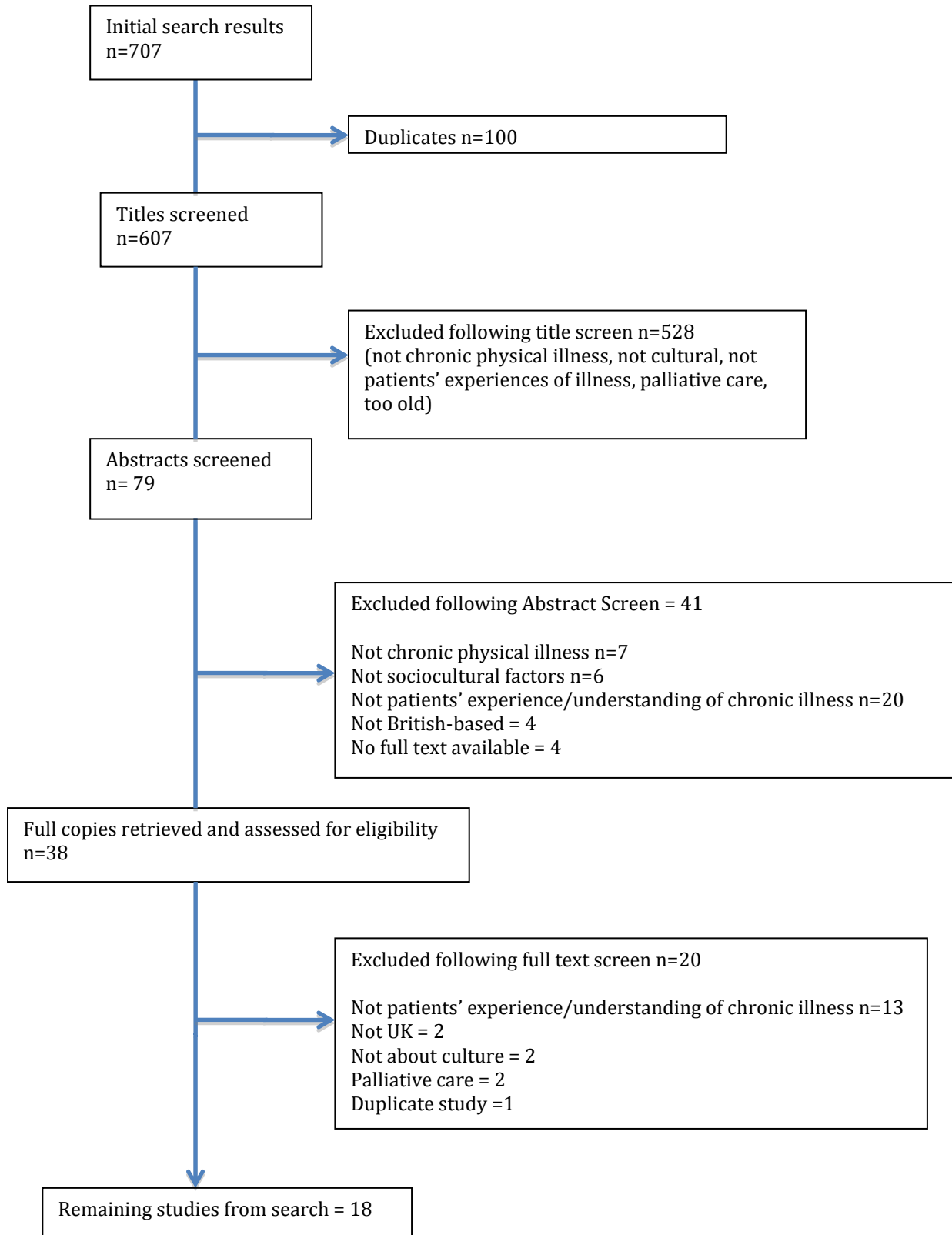


Figure 3: Adapted QUOROM flowchart of study review and selection process.

4 Results

Table 2 is a compilation of key findings extracted from the studies included in the review. Following a similar approach to that taken by Prins, Verhaak, Bensing, van der Meer (2008), the findings were analysed and synthesised by mapping illness beliefs to the structured illness representations model proposed by Leventhal, Nerenz and Steele (1984).

Cultural Influences on Chronic Illness: A review of UK-based Studies

AU	Sample Details	Study Design	Findings	Key Implications
Greenhalgh, Helman & Mu'min-Chowdhury, 1998	40 Bangladeshi and a control group of eight white British and two Afro-Caribbean, all diabetic patients recruited from General Practice surgeries in East London	Construct analysis, Semi-structured interviews, and a novel qualitative approach based on a structured vignette. Responses from both groups compared	Lay sources of information frequently used. Acceptance of God's will jointly held with belief in individual responsibility to follow medical advice. Youth and bodily health synonymous. Larger bodies were viewed as healthy. Culturally specific understanding of physiology and foods. No cultural significance placed on sports or exercise but prayers seen as healthful activity. Dr seen as a busy professional who should not be questioned. Preventative medicine and consultation not valued	Health professionals working with this community who have a greater understanding of their culturally specific beliefs will be better placed to impart acceptable advice.
Richards, Reid & Watt, 2002	15 men and 15 women who had experienced chest pains each from affluent and deprived areas of Glasgow	Qualitative study comparing affluent and deprived participants. Thematic analysis	Residents of the deprived area reported greater perceived vulnerability to heart disease, stemming from greater exposure to heart disease in family members and greater identification with high risk groups and stereotypes of cardiac patients. This greater perceived vulnerability was not associated with more frequent reporting of presenting to a general practitioner.	People from deprived areas are less likely to present to the GP with symptoms of chest pain.

Cultural Influences on Chronic Illness: A review of UK-based Studies

AU	Sample Details	Study Design	Findings	Key Implications
Goberman-Hill, Ayis, & Ebrahim, 2003	24 interviewees with unspecified long-standing illness (11 men and 13 women) aged between 69 and 90 years, a sub-sample of taken from a survey of 999 people over 65 years living in private households in mainland Britain.	Thematic analysis of In-depth interviews	Illness perceptions also fluctuated over time, and diagnoses did not equate to accepted infirmity. Age-related cultural aspects of respondents' perceptions of their long-standing illnesses. Illness accepted as a 'normal' part of aging, but could be worked around to enable people to continue to participate in preferred activities.	Health professionals need to ensure they do not make assumptions about how older adults perceive illness. They need to pay due attention to how they ask questions of older adults' illnesses to ensure they uncover relevant information.
Rhodes, Nocon & Wright, 2003	55 patients diagnosed with diabetes, including 12 Bangladeshi participants aged 43-75 years	Interviews, thematic analysis	Travel plans and language barriers made it particular difficult for the Bangladeshi group to attend appointments, build working relationships with nurse specialists and fully understand the medication regimen. Some patients restricted themselves to unsatisfactory GPs due to expectations of not finding another one who could speak their language.	
Webster, Thompson, Davidson, 2003	35 Gujarati Hindu cardiac patients and their partners	Semi-structured interviews	The Gujarati Hindu cardiac patients interviewed held strong beliefs in God and fate. Some cultural customs made the illness adjustment process more difficult in the first month of recovery. Language difficulties made communications with healthcare professionals more difficult.	Cultural sensitivity and sometimes, extra language support may be needed for when caring for this population

Cultural Influences on Chronic Illness: A review of UK-based Studies

AU	Sample Details	Study Design	Findings	Key Implications
Macaden & Clarke, 2006	Focus group with ethnic health development workers and individual interviews with 20 south Asian older people with diabetes.	Grounded theory study	South Asian patients tended to locate control of the illness externally, i.e. to God or health professionals. They struggled to follow dietary advice due to cultural factors.	Extra resources may be expected and need to be given to support this population, particularly around dietary issues.
Astin, Atkin & Darr, 2007	45 South Asian cardiac patients and 37 carers and 20 White-European cardiac patients and 17 carers. Patients had been admitted to hospital in the past year.	Semi-structured interviews, framework analysis	Language barrier created difficulties in interacting with health service professionals and reduced the occurrence of spouses playing a supportive role in appointments in South Asians compared to White-European patients and increased the likelihood of children acting as mediators, which introduced additional challenges, e.g. passing on information selectively. White Europeans appeared to be better able to adopt dietary changes due to particular cultural family dynamics around food in the South Asian households	Health professionals who are able to converse directly with non-English speaking patients can make a significant difference. Extra support in dietary changes may be helpful for SouthAsian patients
Lawton, Ahmad, Peel, Hollowell, 2007	32 South Asian (23 Pakistanis and 9 Indians) and 32 White British diabetic patients in the Lothian region of Scotland, 33–78 years	Comparative secondary analysis of in-depth interviews on the causation of diabetes and other illnesses	Pakistani and Indian respondents tended to externalise responsibility for the causes of their diabetes with the emphasis on migration-related stressors whilst White British patients were more likely to blame their own lifestyle choices.	It may be helpful to invest some time in understanding patients ideas of the causes of their diabetes and persona values and adapting lifestyle advice accordingly rather than making assumptions about what they believe.

Cultural Influences on Chronic Illness: A review of UK-based Studies

AU	Sample Details	Study Design	Findings	Key Implications
Fleming, Carter & Pettigrew, 2008	Convenience sample of 5 Gujarati Muslim men with diabetes, and their close associates	Interviews, field observations; topic and analytic coding	This study highlights the complexity of culture, in that perceived and experienced differently depending on other factors such as gender and social class.	Culturally sensitive services need to consider people on an individual basis. Everyone is subject to culture, not just ethnic minorities.
Anderson, Elam, Solarin, Gerver, Fenton & Easterbrook, 2009	Black Caribbean patients (n =25) living with HIV for 9 months to 13 years in South London, England attending a sexually-transmitted disease (STD) clinic. Aged 19-72 years, 10 homosexual men, 5 heterosexual men, 10 heterosexual women.	Qualitative: In-depth interviews; thematic analysis and constant comparison of codes, categories and themes	Cultural values and norms shaped coping strategies, including "black pride" in independent coping in both males and females, reliance on close family ties (perceived to set them apart from White British people), the stigma of carrying virus reduced disclosure, which in some cases had a severe impact on personal relationships and formed a barrier to making use of support groups, submersion of the illness to a greater or lesser extent. Coping and stress levels fluctuate significantly.	Initial awareness of the diagnosis is highly distressing and extra support at this time may be necessary. Specific health workers can sometimes be the only individual who knows of a person's status. Some cultural groups may not readily be able to make use of peer support groups which are helpful for others because they don't want to associate with others who would attend or to discuss the topic they actively avoid. Some patients who take submersion to the extreme may be engaging in very risky behaviours.

Cultural Influences on Chronic Illness: A review of UK-based Studies

AU	Sample Details	Study Design	Findings	Key Implications
Lin, Furze, Spilsbury & Lewin, 2009	Patients with heart disease recruited from a teaching hospital in Taipei, Taiwan (n = 238) and a tertiary cardiothoracic centre in the North of England (n = 204).	Cross-sectional questionnaire-based survey using a descriptive comparative design	Both groups of patients held more maladaptive beliefs about heart disease which may have inhibited them from engaging in helpful activities. However, the Taiwanese patients had misconceptions which were linked to Chinese cultural beliefs whilst the British patient's perspectives were shaped by the westernised biomedical model, probably due to greater access to public health education.	Taiwanese patients may hold Chinese cultural beliefs about illness which could be a barrier to following conventional lifestyle advice given by health professionals working in the medical model
Kirk, 2010	28 children and adolescents, aged 8-19 years needing continued support of medical technology for intravenous medication, feeding, respiration or dialysis. Recruited through Community Children's Nursing Teams in England.	A grounded theory study based on interviews with young patients and their parents	The participants appeared to have a clear sense of a 'peer culture' which prizes vitality, physical strength and sociability, and aspires to independent adult life. Respondents worked very hard to lead a normal life and minimise difference, with the support of their parents. They recognise that medical technology has made both helped and hindered them in achieving this. Some boys deliberately concealed the technology and their condition from all their friends in order to appear normal.	Health professionals need to continue to find ways to provide young people with the least obstructive medical technologies as practicable to enable them to participate in normal activities
				Services need to work harder to find interpreters which would be acceptable to the community

Cultural Influences on Chronic Illness: A review of UK-based Studies

AU	Sample Details	Study Design	Findings	Key Implications
Thompson, Clarke, Newell, Gawkrödger, 2010	7 British women of South Asian decent recruited from NHS clinics in Bradford and Sheffield, UK and The Vitiligo Society U.K.	In-depth semi-structured interviews analysed using the qualitative method of template analysis.	Participants described the experiences of stigmatization and devaluation within their communities. They coped with it by withdrawing socially and concealing their condition. Social support tended to come from outside of the biological family.	Interventions for this and similar populations may need to be made at a community level to dispel myths and reduce stigmatisation, rather than solely focusing on individual therapies.
Graffigna, Vegni, Barello, Olson & Bosio, 2011	Participants with cancer across four studies in England (n=9), Canada, Thailand and Italy	Unstructured interviews, Ethnoscience	Marked differences found in how the four groups of patients experienced fatigue	People who speak different languages may have different experiences of specific symptoms (e.g. cancer-related fatigue)
Dyson, Atkin, Lorraine, Culley, Dyson & Evans, 2011	40 secondary adolescents and young adults (21 female, 19 male) with sickle cell disorder and their parents. Purposive sampling recruited from outpatient clinics	Grounded theory from thematic analysis of In-depth interviews, mapped to Bourdieu's framework of habitus, field and capital.	Young people with sickle-cell sometimes find that the school environment is not supportive of the medical advice they are given to make by their medical team to keep well and avoid sickle cell crises	Health practitioners looking after this group should be mindful of the challenges that they can face in following medical advice when in educational settings, even if the institution has been informed of their medical condition.

Cultural Influences on Chronic Illness: A review of UK-based Studies

AU	Sample Details	Study Design	Findings	Key Implications
Gerrish, Naisby & Ismail, 2012	48 interviews; 4 focus groups each of Somali men and women (56 individuals)	Qualitative: participatory ethnographic approach, purposive 'snowball' sampling, thematic framework data analysis	Some false beliefs about TB widely held in Somali community (e.g. heritable, not fully curable, risk and means of infection.) Patient concerns about reactions to disclosure outside of the family due to perceived stigma and social isolation for TB sufferers within the community. Interpreters viewed with suspicion.	Initiatives required to disseminate more accurate knowledge about TB in the community Ensuring relevant health practitioners are aware of the stigma Strong oral tradition and levels of illiteracy may mean that public health campaigns may need to be more creative in the ways in which information is disseminated
Bache, Bhui, Dein & Korszun, 2012	8 interviews with cancer survivors of African or Black Caribbean origin. (Three men and five women aged between 35 and 81)	Qualitative: thematic framework data analysis	Complex and diverse beliefs about causes reflecting range of cultural influences and the impact of contact with health professionals. Coping strategies included faith and positive thinking/avoidance	Positive thinking/avoidance may underlie unwillingness to initiate diagnostic process. View of NHS care was mostly favourable but some failings of primary care were reported.

Cultural Influences on Chronic Illness: A review of UK-based Studies

AU	Sample Details	Study Design	Findings	Key Implications
Treisman, Jones & Shaw, 2014	12 African women living in the UK, diagnosed with HIV during pregnancy	One-to-one semi- structured interview analyzed using interpretative phenomenological analysis	HIV-related discourses were central to how the participants perceived and responded to HIV. For example, some expressed beliefs about HIV being a punishment for sin or a communication from God, and hence responded by engaging in religious activities. Furthermore, most women highlighted powerful sexual, condemning, and moral discourses associated with HIV in their cultures, and how these influenced views of themselves and decisions related to disclosure. All felt that not breastfeeding was particularly challenging. Some felt this changed the mother-child connection and aroused suspicions from others, particularly given the importance of breastfeeding in African cultures. The women also reported feeling unnatural and not womanly.	The majority also discussed the helpfulness of the social support they experienced from attending HIV specific support groups. These provided opportunities for the women to share a common experience to connect, be inspired, accepted, and unguarded. In contrast, and highlighting the importance of considering individual differences, one woman discussed how such groups acted as a painful reminder of being infected with HIV.

Table 2: Compilation of the findings from reviewed studies

4.1 Beliefs about Causes of Illness

A number of research studies sought to uncover participants' understanding of the causes of their illness. This is important because of their influence on the perception of control of the illness (discussed below in Beliefs about Cure/Control).

4.1.1 Beliefs Linking Illness Lifestyle/Life Stressors

Lawton et al. (2007) compared white British and South Asian patients' causal attributions for their diabetes. Whilst the narratives from both groups were diverse and complex, the researchers found that the White British participants were more likely to be influenced by the media and to blame themselves for their lifestyle choices, which sometimes led to feelings of guilt. In contrast, Lawton et al. found the South Asian participants' accounts of diabetes were commonly bound up with life stressors over which they felt they had had little or no control. For example, one participant thought the cause of his diabetes was shouldering the burden of cultural expectations for him to subjugate his own welfare to fulfil responsibilities for the extended family remarking: "...there's no old people's home in Pakistan". Other migration-specific stresses and strains were cited, particularly the challenges of imparting traditional cultural values in their off-spring who were simultaneously subjected to undesirable "foreign" influences. Interestingly, there is also some research evidence to support the links made by these participants between migration and their chronic illness. Migrants who moved from a low-risk country to a high risk country for cancer, were found to have a significantly increased risk of developing the disease (Parkin, Bray, Ferlay & Pisani, 2005).

In a study comparing maladaptive illness beliefs in Taiwanese and British cardiac patients' Lin, Furze, Spilsbury and Lewin (2008) found evidence of maladaptive beliefs gleaned from their respective cultures. A slight majority of British participants

(52%) and a significantly larger majority of Taiwanese patients (82%) mistakenly believed that stress was the primary cause of their illness, rather than it being a risk factor. The authors drew on previous research studies which have suggested that stress is frequently regarded as a cause for illness in Western cultures. Gerrish et al. (2012) also found beliefs about extreme stress causing tuberculosis among a Somali community, as well as other physical illness such as chest infections.

4.1.2 Supernatural beliefs about Illness

Several studies of ethnic minority participants held supernatural notions of their chronic illness being 'fate' or 'God's will' (e.g. Greenhalgh, Helman, & Chowdhury, 1998; Webster, Thompson & Mayou, 2003; Macaden & Clarke, 2006; Lawton, Ahmad, Peel & Hallowell, 2007). Some participants had rather more negative supernatural beliefs such as the illness being a punishment for past misdemeanours, either by themselves or an ancestor (e.g. Macaden & Clarke, 2006; Bache, Bhui, Dein & Korszun, 2012; Gerrish, Naisby & Ismail (2012); Treisman, Jones & Shaw, 2014). Other researchers reported similar supernatural beliefs were sometimes dually held with biomedical understandings such as the illness being caused by 'genetics' or a 'random occurrence' (Lawton et al., 2007; Bache et al., 2012). For example, Greenhalgh et al. (1998) observed that the Bangladeshi diabetic patients they interviewed jointly held a sense of personal responsibility to follow medical advice received. The writers referenced the work of Airhihenbuwa (1995) who observed that immigrants can sometimes hold dual beliefs, respectively drawn from both their original culture and their host culture, although the latter was less likely to be as deeply-rooted as the former. The research

team concluded that knowledge of such beliefs should be a starting point for the provision of culturally-sensitive health services to this group.

4.2 Timeline

The timeline of a chronic illness is the patient's perception of the duration of their illness. It can change over time if the patient shifts between an acute to a chronic understanding of their illness, and this can be linked to their beliefs about cure/control (Petrie & Weinman, 1997, p 455).

Most of these studies in this review focused on participants with lifelong illnesses. However, where diseases are communicable, timely diagnosis, effective tracing of others at risk and treatment compliance are essential to mitigate the impact of outbreaks. Therefore the health beliefs and behaviours of individuals within the affected communities are a contributory factor to collective outcomes (Gerrish, Naisby & Ismail, 2012). They argue that misguided beliefs about illness and treatment are a recurring problem across groups and diseases and for effective practice, healthcare professionals need to have a good understanding of what they are and the cultural influences underlying them. Gerrish et al. conducted a participatory study which highlighted the impact of false beliefs about tuberculosis (TB), a growing problem amongst the UK-based Somali communities. The authors recognised it to be more than 'just a medical disease to be treated with antibiotic therapy but an entity with historical and cultural roots'.

The Gerrish et al. (2012) study found that misconceptions led some members of a Somali community to believe TB sufferers remain infectious throughout treatment

and that it cannot be fully cured. Drawing on other research, the authors observed that similar beliefs held by other groups where TB is prevalent were difficult to change even with the supply of biomedical information. Interviewees frequently referred to the limited access to effective treatment in Somalia which meant that some people there did not ever get cured of TB. For some, these understandings did not change despite migration to the UK and more readily accessible treatment.

4.3 Consequences

Perceptions of how illness or symptoms will affect an individual are likely to impact on their emotional, cognitive and behavioural responses to it. The findings from the studies below include interesting insights into social constructions of illness, social stigma and other consequences of illness as experienced by young patients.

4.3.1 Cultural Expressions Shaping the Experience of Illness

Graffigna, Vegni, Barelo, Olson and Bosio (2011) hypothesised that since language was the means by which symptoms are socially constructed, patients with the same diagnoses who spoke different languages would experience symptoms differently. The authors looked at linguistic constructions of cancer-related fatigue in English, Canadian, Thai and Italian patients. The results showed marked differences between the four sets of patients, perhaps reflecting their unique languages and cultures. For example, only the Italians reported experiencing fatigue as a relational difficulty. Relative to participants from the other cultures who were much more conscious of the fatigue-related physical limitations of their bodies, the nine English participants

reported far more self-talk and self-reflection and had a more functional view of their bodies. Their expressions of fatigue were in terms of preoccupations with activities they could still do, could no longer do or had to do to compensate.

4.3.2 The Stigma of Illness

Stigma was central to the accounts of a group of seven South Asian women of Pakistani and Indian origin with vitiligo, a chronic skin disease which leaves dark-skinned people with visible white patches (Thompson, Clarke, Newell, & Gawkrödger, 2010). This study set out to understand their psychosocial adjustment to this disfiguring condition and role of culture in this process through a series of semi-structured interviews. These women spoke of the value placed on appearance in their culture and their consequential diminished status within the community, resulting in rejection by others, family shame, low self-esteem and social withdrawal.

According to Gerrish et al. (2012) actual and expected stigmatization can lead to a loss of status, low self-esteem, social isolation and withdrawal which can in turn, inhibit appropriate health-seeking behaviours even when help is available. The researchers found that a diagnosis of TB was associated with a perceived stigma within the Somali community, such that TB resulted in the individual or even their entire family being shunned by the wider community. However, it appeared that individuals who had a biomedical understanding of the disease rather than supernatural causal beliefs (discussed above) carried less stigmatizing attitudes. Interestingly, there was little evidence that TB patients who had disclosed their status to the wider community actually did experience discrimination, and furthermore, it had the positive effect that it

encouraged others to share their own experiences with TB. The writers concluded that more research was needed to test strategies designed to reduce TB-related stigma in the Somali community.

Stigma and self-stigma also appeared in the narratives of the Treisman et al. (2014) study of African mothers living with HIV. Most participants reported pejorative discourses in their cultures assuming immoral activity on the part of people infected with HIV, and how these negatively impacted on their self-image and willingness to disclose. Being unable to breastfeed was especially problematic for them. They reported worrying about whether others might suspect their HIV-status in the light of the importance of breastfeeding in 'African cultures'. They also reported feeling 'unnatural and not womanly' and were concerned about their emotional connection to their baby.

In a study of people of Caribbean origin living in South East London with HIV-AIDS, Anderson et al. (2009) found that the stigma of carrying the virus in the Black community reportedly reduced the likelihood of disclosure to others outside of a handful of trusted individuals, which in some cases had a severe impact on other personal relationships and coping strategies employed (see below).

4.3.3 Childhood/Adolescent Perspectives on Impact of Illness

Pre-adolescence and adolescence are life-stages when conforming to peer sub-cultures has a heightened significance for most individuals. Coping with long-term physical illness in addition to the developmental tasks and cultural expectations characteristic of this period, makes it all the more challenging for young patients.

Dyson, Atkin, Culley, Dyson and Evans (2010) carried out a thematic analysis of 40 interviews with adolescents who had sickle cell disorders, predicated on Bourdieu's

conceptual framework built on the notions of 'habitus', 'field' and 'capital' (see Bourdieu, 1984). Their key finding of relevance to this paper was that the expectations of adolescents within the school 'field' was frequently at odds with medical advice received from the clinic 'field'. The adolescents struggled for normality and in order to accumulate 'cultural capital' (i.e. that which is valued in society's youth such as a good record of school attendance and examination passes). However, schools were reputedly unsupportive of the interviewees with respect to their illness management strategies. The few concessions that were made were often inadequate or disjointed. Significantly, the default expectation that health practitioners have of simply supplying schools with information about the medical condition in the hope of improving the patient's day-to-day environment, made little or no impact, at best, or worsened matters by providing ammunition to unsympathetic peers to be used against the interviewees. Further the writers argued that sickle cell disease erodes the limited 'cultural capital' most highly prized in some young black adolescents (i.e. sporting proficiency). General attendance and participation difficulties left many of the participants feeling devalued.

Research nurse, Susan Kirk (2010) set out to allow children and adolescents dependent on medical technology to voice their experiences which she identified to be a gap in the literature. She positioned childhood as a social construct and young people as 'competent social actors' who held different (and hence, valuable) knowledge to adults. The principle finding of her grounded theory study of 28 participants aged 8-19 years old was that 'living an ordinary life' was at the core of these young people's aspirations. Notions of 'normal' life were culturally-informed rather than dictated by the illness, and future aspirations were set accordingly, such as living independently and having children. In this respect, conflicting perceptions of the technology were reported: seen as both a 'disabler' in the sense of emphasising difference from peers, and an 'enabler',

in that it was life-sustaining and facilitated participation in 'normal' life as much as possible. For example, one interviewee reported attending her friend's birthday party but being the only one not able to stay for the sleepover. This echoed the finding of the Goberman-Hill et al. (2003) study of the older adults, who were also striving to participate as 'normal,' in spite of long-term illness.

4.4 Beliefs about Cure/Control

Beliefs about causes, timelines and consequences of illness all had a direct impact on individuals' conceptions on the strategies they used to manage it.

4.4.1 Beliefs about Control of Illness

Perceptions of control of illness appeared to be culturally-informed.

Goberman-Hill, Ayis & Ebrahim (2003) conducted in-depth interviews with 24 survey respondents over 64 years old, which covered their experiences of long-term illness. Inconsistencies between a survey completed some weeks beforehand and the later interviews were common. The authors discovered that the interviewees' illness perceptions fluctuated over time such that receiving a diagnosis of a long-term illness did not equate to accepting infirmity. Illness perceptions appeared to be associated with the participants' perceived level of control in relation to the illness, through lifestyle choices and a positive attitude. Interestingly, such diagnoses were viewed a 'normal' element of the aging process to be expected and respondents reported working around these illnesses in order to continue to participate in valued activities. The authors inferred that interviewees' perceptions of ageing and illness identities, whether accepted or rejected, "may constitute a key part of their cultural capital". They conclude that the "narratives [of illness] are not merely personal accounts, but reflect wider

social, cultural and historical forces". The implication for healthcare practitioners working with this client group is to ensure they do not make inaccurate assumptions about their illness perceptions and expectations and that due attention is paid to what, how and when questions are asked and the responses given to gather pertinent information.

Webster et al. (2003) found that in their first month post-discharge, Gujarati cardiac patients expressed beliefs that any possibilities for recovery lay entirely in God's hands. For some of these participants the solution to their health problems therefore lay in alternative healing rather than in conventional medicine and lifestyle advice.

Macaden and Clarke (2006) also found a tendency for South Asian diabetic patients to perceive control of their medical condition as being external to themselves. The participants in their study located responsibility for their health in professionals. The authors argued that the South Asian cultures are built on "dependent collectivism" which leads to reduced independent thinking and greater reliance on others, in comparison to the more individualist Western cultures. Reporting similar findings to Macaden and Clarke, Lawton et al. (2007) speculated that the externalised responsibility evident in South Asian cultures with respect to illness may have reflected a more general perception of having limited control over their lives and their more "socio-centric" culture.

4.4.2 Exercise

The idea of exercise appeared to be problematic in some studies included in this review. Greenhalgh, Helman and Mu'min-Chowdhury (1998) used a novel method of enquiry, the structured vignette, to investigate culturally-specific health beliefs of

Bangladeshi diabetic patients originating from the rural farming villages of Sylhet. They found that no cultural significance was attached to the notion of exercise, and as such, no specific translation of the word exists in Sylheti making it difficult for clinicians to promote. However, prayers were seen as a vitality-inducing physical activity.

In the Lin et al. (2008) study comparing Taiwanese and British cardiac patients, a belief widely held by both groups was that any stressful or strenuous activity was dangerous. This frequently led to unhealthy avoidance of exercise and other lifestyle adaptations recommended by their health professionals, increasing the risk of further cardiac events. Furthermore, both groups also reported that it was important to self-monitor before initiating activity which could potentially lead to unhealthy cycles of over-activity on 'good' days and under-activity on 'bad' days.

Investigating family support around cardiac patients, Astin et al. (2007) found that the White-European spouses frequently encouraged their partners to exercise, whilst South Asian children tended to fulfil this role. Whilst walking was the most acceptable form of exercise, South Asian women were discouraged by their families from going out walking alone for fear of physical attack.

4.4.3 Dietary Beliefs and Experiences

Attitudes to food consumption reported in some studies diverged from conventional biomedical advice given to patients with chronic illnesses. Greenhalgh et al. (1998) found a commonly shared 'humoral' understanding of human physiology in Bangladeshi culture which assumes a correct balance between the environment, the body, its intake and secretions for the maintenance of optimal health. Aligned to this was a knowledge of 'strong' versus 'weak', and 'digestible' versus 'indigestible' foods,

whilst larger bodies were associated with greater health, possibly reflecting a heritage in which body fat is associated with affluence and well-being.

According to Macaden and Clarke (2006) hospitality and visiting is particularly important to South Asian cultures, which can include partaking in rich, sugary or fatty delicacies. Refusal could be perceived as impolite and in such social situations patients reported weighing up the risks of embarrassment against contravening their medically-restricted diets.

Astin et al. (2007) observed that South Asian households tended to be larger, which contrary to expectations, led to difficulties in prioritising the patients' dietary needs. They discovered that White-European couples tended to share shopping and cooking, and therefore, the responsibility for dietary changes which they appeared to manage relatively successfully. By contrast, most grocery shopping was undertaken by South Asian males, sometimes with their offspring, whilst the cooking was done by a female, e.g. the wife, or if she found the task too strenuous after her cardiac event, the eldest daughter. In the cases of extended family households, the daughters-in-law had primary responsibility for food preparation. In some cases, this meant that the person who was responsible for the patient's diet had no direct contact with a health professional. Notably, the extent to which dietary changes were adopted by the rest of the family appeared to be dependent on the gender of the patient. Where the patient was male, the general expectation was that the whole household would adjust to the new healthier diet, but for female patients the required dietary changes were frequently deemed unpalatable and consequently, they cooked separate meals for themselves, or attempted to eat smaller portions of the original diet. This echoed earlier findings by Macaden and Clarke (2006) and Webster et al. (2003).

4.4.4 Managing illness with Social Support?

The importance of social support was commonly reported across studies. Thompson et al. (2010) found that for Asian women suffering from vitiligo, social support tended to come from a husband or friend, or someone outside of the immediate biological family because they were often ashamed of the patient (see Stigma of illness). Webster et al. (2003) identified the significance of strong family support for South Asian cardiac patients but noted that married couples did not appear united in tackling the medical condition. This research team observed that the word “we” was rarely used and wives did not participate in discussions with their husbands about the future. Of note also, was the burden placed on convalescing patients and their spouses in hosting the culturally-prescribed influx of well-meaning visitors.

People of Caribbean origin living in South East London with HIV-AIDS reported that their cultural values and norms shaped their coping strategies, including the notion of "black pride" (Anderson et al., 2009) This meant either being able to cope with life's challenges independently, or relying solely on close family ties (which they believed culturally differentiated them from White British people). Interestingly, perceptions of their coping capacity and stress levels appeared to fluctuate, even during the course of one interview. The stigma reported by this group (discussed above) formed a barrier against the use of support groups which have been effective for other clinical populations. Participants did not wish to associate with what they considered to be stereotypical HIV-carriers or to discuss the very topic they actively avoided. This finding was mirrored by one respondent in a recent study of African women who had been diagnosed with HIV in pregnancy (Treisman et al., 2014). However, the majority of their participants really valued their attending a support group where they felt completely accepted, and were able to share and be inspired by others.

The key implications of the Anderson et al. (2009) study were that receiving this diagnosis was extremely distressing for participants and extra support on diagnosis may be necessary, particularly where patients are unlikely to be able to access it from family, friends or support groups if they think that this is necessary to avoid stigmatization in their community. In some cases, specific health-workers could be the only other person who knows their status.

When the medical technology was not visible, some participants also reported being very selective about who they disclosed their illness to (Kirk, 2010). In the case of several boys, they concealed their use of the technology and sometimes, their medical condition from all of their friends. This served the purpose of 'fitting in' with the peer cultural norms and thereby supports their identity development. Kirk remarked "Children negotiated living with medical technology by actively engaging in work to incorporate the technology into their lives and bodies. This work appeared to be driven by a desire to 'normalise' their bodies and their lives."

4.4.5 Other Coping Strategies and Solutions

Interviewees in the Thompson et al, (2010) study on vitiligo in Asian women reported using special camouflaging cosmetics or having iatrogenic de-pigmentation which removes all remaining pigmentation from the skin to create a more even appearance. Some believed this to be a positive step because of the value attached to fair-skinned people within their culture whilst others saw it a loss of visible ethnic identity (e.g. being mistaken for an Italian rather than an Indian).

Bache et al. (2012) interviewed 18 British-based patients of West African and Caribbean origin recruited from a cancer charity support group about their illness

perceptions, their coping strategies and their care experiences within the National Health Service (NHS). Whilst respondents held complex and diverse beliefs about the causes of their illness, their coping strategies appeared to be more convergent.

Commonly reported was the role of faith for acceptance of their situation and for supplying spiritual and human support and reassurance, reflecting the strong Christian traditions of the former British colonies (see Pulis, 1999). Positive thinking was also frequently reported and seemed to underlie some unwillingness to initiate or engage with diagnoses.

A commonly employed strategy reported in the Anderson et al. (2009) study was 'submersion' of the illness to some degree. Some participants thought and behaved as if it they did not have HIV status at all or convinced themselves that their medication was for another condition (e.g. epilepsy). Some participants who took submersion to the extreme seemed to be engaging in very risky behaviours, and perhaps were exposing others to infection.

4.4.6 Alternative Healing

Alternative causal beliefs of illness in some participants pointed to alternative solutions. For example, some African women diagnosed with HIV in pregnancy, reported responding to 'God's punishment' for them by engaging in compensatory religious activities (Treisman et al., 2014).

Several participants reported that they had consulted mediums or priests about their current circumstances or intended to do so in the Webster et al. (2003) study of cardiac patients. A respondent in the Rhodes et al. (2003) study reported consulting a religious healer on an extended trip to Bangladesh, to ward off the black magic that she

believed had caused her symptoms. In Bangladesh, this is the only practicable solution for many people who cannot access conventional medicine due to financial and geographical limitations.

Fleming, Carter and Pettigrew (2007) attempted to explore the more subjective, embodied and dynamic aspects of cultural influences on health-related behaviours in a small sample of diabetic Gujarati Muslim men. They found that mediating factors in Gujarati diabetic participants such as gender, socioeconomic status and personal history led to different self-management behaviours, including the adjunctive use of traditional healers. Respondents who originally came from lower socio-economic backgrounds trusted alternative healers more because of their previous contact and knowledge of them in India. Those from the more affluent backgrounds had access to conventional doctors in India and therefore were more reliant on them in the UK. The writers argued that the commonly adopted formulaic approaches to researching culture and developing culturally sensitive services are reductionist and due consideration should be paid to understanding individual perceptions and needs which could include class differences.

4.4.7 Class Influences on Control Perceptions and Health Service Expectations

Studies reported a number of interesting factors which appeared to be underlying differences in expectations between participants. For example, doctors were seen as busy, omniscient professionals who should not be questioned by Bangladeshi diabetic patients, contrary to the views of White British and Afro-Caribbean patients (Greenhalgh et al., 1998).

Cultural Influences on Chronic Illness: A review of UK-based Studies

Richards, Reid and Watt (2002) compared differences between responses to chest pain in participants living in affluent and deprived areas of Glasgow, within their social and cultural context. The affluent group appeared to view cardiac problems within their family history as isolated incidents. They believed genetic risk could be countered with healthy lifestyle choices. They distanced themselves from the cardiac patient stereotypes (i.e. being 'red and bloated'). In sharp contrast, Richards et al. (2002) discovered that respondents from deprived areas personally identified with this stereotype and tended to blame themselves for their ill-health. They had lower expectations of their health status and were more likely to relate their symptoms to their family histories. However, this group was less likely to report symptoms to their GP for due to fear of being blamed for engaging in risk behaviours, concerns about being seen to waste the doctor's time or negative past experiences of health care services.

Making reference to Bourdieu's concept of an individual's culturally-informed 'habitus', Goberman-Hill et al. (2003) suggested that social class influences the perception of health status in the same way that it shapes self-image and modes of self-expression, and by inference, how the individual navigates the 'field' or clinic/medical setting (see Bourdieu, 1984).

4.4.8 Cross-Cultural Challenges Difficulties Accessing Health Services

Perceptions of help available are directly linked to perceptions of control. Several studies reported experiences of specific cultural groups when accessing health services.

Rhodes, Nocon and Wright (2003) interviewed 12 diabetic patients of Bangladeshi origin as part of a wider study in the Bradford area to understand more

about their access to health services. Thematic analysis revealed that frequently missed appointments by this community was as a result of reconnecting with relatives 'back home' on extended journeys by the patient or by the relative who normally accompanies a female patient to go out in public and attend the appointment.

Clinicians and patients not sharing a common language was a recurring difficulty reported across many studies (e.g. Lawton et al., 2007; Webster et al., 2003; Rhodes et al., 2003). One patient in the Webster et al. study commented on the benefit of having a Gujarati-speaking nurse on the ward whilst Rhodes et al. found that non-English speaking diabetic patients reported remaining with an unsatisfactory GP simply because they did not expect to find another one who spoke their language, thus negating the possibility of having choice. Furthermore, some patients reported that their cases had been prematurely transferred back to the GP from a hospital specialist solely due to language difficulties. Non-English speaking diabetic patients were also found to be disadvantaged since language barriers prevented them from developing the sorts of close working relationships with the nurse specialists seen with the English-speaking patients and they were less able to make use of telephone contact provision. Rhodes et al. found that this group consulted lay persons for health advice rather than professionals, mirroring earlier findings by Greenhalgh et al. These language barriers may have been linked to the greater number of medical complaints and symptoms reported by this group of South Asian patients.

Astin et al. (2008) found that limited English language skills in their South Asian patient group reduced the occurrences of spouses playing a supportive role, in clinic appointments or at home, compared to White-European patients. It also increased the likelihood of children acting as mediators and interpreters in the Asian families, which introduced additional dynamics (e.g. the patient or child withholding information to

avoid upsetting the other). Furthermore, Rhodes et al. (2003) found that when English-speaking relatives were unavailable to accompany patients, appointments tended to be missed, since non-related members of the community were generally not trusted as interpreters with sensitive information.

However, difficulties arise when clinicians depend upon interpreters to convey essential medical information patients, according to Lawton et al. (2007). Based on earlier work, they argued that often, interpreters over-simplify or misrepresent nuanced communication, also corroborated by Rhodes et al. (2003). In one case, an interviewee reported that her medication regimen had been dangerously misunderstood due to translation difficulties.

5 Discussion

5.1 Discussion of Findings

This review has supported assertions by Baumann (2003) and others that culture can be considered to be one of many factors that contribute to illness perceptions, health-seeking behaviours and the lived experience of illness and treatment. Returning to Leventhal et al.'s (1984) illness representation model, it was found that beliefs about 'Causes' of illness appeared to be quite similar across cultural groups and diseases. The causal beliefs reported fell into three main categories: biomedical (e.g. genetics), psychosomatic (e.g. stress) and supernatural (e.g. fate or divine punishment). Notably, these beliefs were not necessarily held mutually exclusively (Greenhalgh et al., 1998).

However, even when causal beliefs were similar, individual 'Control/Cure' perceptions differed which, in turn, led to a range of responses. The variations were

accounted for by mediating factors, such as cultural histories and leanings (e.g. Greenhalgh et al.; Lawton et al., 2007); social class (e.g. Richards et al., 2002; Fleming et al., 2007); gender and family dynamics (e.g. Macaden & Clark, 2006; Astin et al., 2007) and actual agency in the social context (e.g. Dyson et al., 2011). Perceived stigma was a 'Consequence' of illness perception reported by participants across several studies (e.g. Anderson et al., 2009; Thompson et al., (2010) and Treisman et al., 2014). There were limited 'TimeLine' beliefs reported due to the long-term nature of the majority of illnesses covered by the review. However, it was demonstrated that tightly-held beliefs imported by migrants from their country of origin could persist even if not applicable to the 'host' country (Gerrish et al., 2012).

5.2 Critique

Due to space limitations, an exhaustive critique of each of the studies included in this review was not possible but significant limitations will be highlighted below with reference to quality assurance guidelines set out by Mays and Pope (2000) and the wider literature on cultural research (Appendix M).

Gerrish et al. (2012) provided a model for the participatory approach to research, but a significant limitation of this study was the absence of reference to the powerful inter-clan dynamics that exists within the Somali community (Hopkins, 2006) and how that might have influenced the 'snowballing' recruitment or the findings presented. In this respect, the study fails to meet the Mays and Pope standards for adequate sampling. It is important for researchers to be mindful of heterogeneity within various communities, and therefore, the scope and applicability of emergent findings. The omission of significant clan delineations reported in this study is an example of the

inconsistencies in defining groups identified by Smaje (1995) which makes it difficult for secondary researchers to make accurate comparisons.

Lambert and Sevak (1996) raised the issues of the importance of researchers providing ethical justification for studying one group but not another, as seen in the decision taken by Webster et al. (2003) to study Gujarati Hindu cardiac patients. No explanation or reasoning was supplied for why exclusive focus on this group by this study was appropriate. Therefore, it could be argued that the context was not sufficiently described for the reader to make a secure assessment of how relatable these findings were to other settings, as suggested by Mays and Pope.

Morgan (1996) advocated for due consideration of cultural dynamics between researchers and participants but few studies reported on this, with some notable exceptions including Webster et al. (2003), Fleming et al. (2007), Lawton et al. (2007) and Treisman et al. (2014). Focusing on the Bache et al. (2012) study in particular, the interviewer was reported as a 'young, White, male medical student'. It appears that the writers struggled to understand some participants' contributions. For example, without any supporting explanation, the following verbatim statement was attributed to a Jamaican woman: "The way that hide that fell in myself before when I finished the world I feel like a totally different person [sic]". This apparent lack of understanding was compounded by reporting the birthplaces of two black participants as 'England' which completely obscured their non-British cultural influences. Within this migrant population, it is common for siblings to be born in different countries but raised together in one family (Ahmad & Bradby, 2007). Shortcomings of this nature are likely to compromise the integrity of the findings and demonstrate the case for the inclusion of 'reflexivity' in the Mays and Pope quality guidelines.

Cultural Influences on Chronic Illness: A review of UK-based Studies

By contrast, Fleming et al. (2007) attempted to mitigate the risk of erroneous cross-cultural interpretations with multi-layered data collection and analysis strategies. They reflected on how the professional status of the interviewer could bias the data collected. However, Lawton and colleagues went even further and set out to reflect on how the cultural background of researchers shaped their interpretations of cultural research data. They believed that the ethnic mix of their research team, which matched the participant sample, made for more complete understandings with which to contextualise the data set. They contended that this enabled them to produce a richer account of respondents' experiences by integrating both the micro-context (personal history) and the unspoken macro-context (socio-cultural milieu), rather than privileging one or the other, a common artefact of cultural research dependent on their own cultural background. The integral element of 'reflexivity' in the data analysis stage of this work went above and beyond the standard proposed by Mays and Pope (2000).

Bache et al. also frequently reported comparisons to findings from their study of black people in the UK to various African-Americans studies, although there was no justification supplied for this seemingly superficial comparison. The writers acknowledged that whilst racial discrimination experienced by these two groups could possibly be comparable, their respective cultures, socio-economic contexts and migration histories are really quite different (Ahmad & Bradby, 2007). Unsurprisingly, there were several noteworthy differences found. To offer up some explanations for the identified health inequalities present in the UK as the writers had originally intended, it may have been more useful to draw comparisons between their sample and white British patients instead. Therefore, the standard 'Appropriateness of the design to the question,' as suggested by Mays and Pope was not met in this study.

5.3 Limitations of This Review

This review captured just a small sub-set of studies which could be labelled as 'British cultural research' in chronic illness by only including studies where culture was expressly stated as the primary focus and participants were actually ill.

'Anti-racist' writers such as Ahmad (1996) argue that the study of culture, race and ethnicity in relation to health and other topics of similar political interest, runs the risk of reinforcing divisions, indulging voyeuristic curiosity in the exotic 'otherness' of minority groups, 'victim-blaming' or pathologising cultural difference, all of which would detract from perhaps, more important contextual factors such as individual differences, ethnicity, class and gender power differentials, marginalisation, socio-economic status, oppression and discrimination by the dominant groups, all known to have potent effects on health. Kelleher (1996) argues that behaviours should be considered as a function of both structure (e.g. culture) and agency (e.g. personal choices and actions). For these reasons cultural beliefs and practices cannot and should not be used solely to explain an individual's response to health matters.

5.4 Implications for Research and Practice

Cultural (and, idiosyncratic) influences on health and illness are applicable to everyone, and not just minorities. Furthermore, this review has demonstrated that responses to cultural influences can differ between individuals within the same cultural group for a variety of reasons. This thinking has led writers such as Fleming et al. (2007) to the conclusion that formulaic approaches to culturally-sensitive healthcare provision are not particularly helpful.

In the final analysis, cultural-sensitivity in healthcare equates to person-centred care, demanding a holistic understanding of individuals and their medical conditions within their socio-cultural contexts, as originally intended by Engel (1977). However, Leventhal's framework of illness representations provides a useful means of conceptualising culturally-informed illness beliefs and is applicable across demographic groups and diseases.

5.5 Future Avenues

The generation of more research in under-researched areas (e.g. recent migrant groups) with explicit consideration for cultural influences will continue to yield valuable insights. However, more cross-group and cross-disease exploration may produce more widely applicable findings. Also, greater focus on positive cultural influences on illness perception and adjustment would add a helpful dimension to the existing evidence base.

6 Conclusion

This review of studies of cultural influences on the experience of and responses to a range of chronic illnesses and treatment has suggested that they can be mediated through a range of factors, including beliefs about health and illness, family and gender dynamics, coping strategies, cross-cultural interactions with healthcare professionals, linguistics and languages, age and class. The studies suggest that these have led to a plethora of barriers in accessing the full extent of healthcare services available or difficulties in following medical advice, which practitioners should hold in mind. It must be noted however, that methodological and quality issues limit the conclusions that can

be drawn from this small evidence base. The Leventhal et al. model of illness representations (1984) has provided a useful framework with which to conceptualise the processes by which cultural influences can lead to different illness perceptions and health-seeking behaviours.

References

- Acheson, D. (1998). Inequalities in health: Report on inequalities in health did give priority for steps to be tackled. *British Medical Journal*, 317(7173), 1659.
- Ahmad, W. I. U. (1996). The trouble with culture. In D. Kelleher & S. Hillier (Eds.) *Researching cultural differences in health* (pp. 190-219). London: Routledge
- Ahmad, W. I. & Bradby, H. (2007). Locating ethnicity and health: Exploring concepts and contexts. *Sociology of Health & Illness*, 29(6), 795-810.
- Airhihenbuwa, C.O. (1995). *Health and culture: Beyond the western paradigm*. Thousand Oaks, California: Sage Publications.
- Anderson, M., Elam, G., Solarin, I., Gerver, S., Fenton, K. & Easterbrook, P. (2009). Coping with HIV: Caribbean people in the United Kingdom. *Qualitative Health Research*, 19(8), 1060-1075.
- Astin, F., Atkin, K., & Darr, A. (2008). Family support and cardiac rehabilitation: A comparative study of the experiences of South Asian and White-European patients and their carer's living in the United Kingdom. *European Journal of Cardiovascular Nursing*, 7(1), 43-51.
- Bache, R. A., Bhui, K. S., Dein, S. & Korszun, A. (2012). African and Black Caribbean origin cancer survivors: A qualitative study of the narratives of causes, coping and care experiences. *Ethnicity & Health*, 17(1-2), 187-201.
- Baumann, L. C. (2003). Culture and illness representation. In L. D. Cameron & H. Leventhal (Eds.), *The self-regulation of health and illness behaviour* (pp. 242-254). London and New York: Routledge.
- BHA. (2013). State of health: Black and other minority groups. Retrieved from http://thebha.org.uk/files/jsna_report_single_page.pdf

Cultural Influences on Chronic Illness: A review of UK-based Studies

- Bhui, K., Warfa, N., Edonya, P., McKenzie, K., & Bhugra, D. (2007). Cultural competence in mental health care: a review of model evaluations. *BMC Health Services Research*, 7, 15-15.
- Blair, A. (1993). Social class and the contextualization of illness experience. In A. Radley (Ed.), *Worlds of illness: Biographical and cultural perspectives on health and disease*, 27-48.
- Bourdieu, P. (1984). *Distinction: A social critique of the judgement of taste*. Cambridge, MA: Harvard University Press.
- Clifford, J. (1986) Introduction: Partial truths. In Clifford, J. and Marcus, G.E. (Eds.) *Writing culture: The poetics and politics of ethnography*. Berkeley: University of California Press.
- Crawford, R. (1984). A cultural account of 'health': Control, release and the social body. In McKinlay, J.B. (Ed.) *Issues in the Political Economy of Health Care*. London: Tavistock.
- Department of Health. (2013). Living well for longer. Retrieved from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/181103/Living_well_for_longer.pdf
- Dyson, S. M., Atkin K., Culley, L.A., Dyson, S.E. & Evans, H. (2011). Sickle cell, habitual dyspositions and fragile dispositions: Young people with sickle cell at school. *Sociology of Health & Illness*, 33(3), 465-483.
- Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science*, 196(4286), 129-136.
- Eshiett, M. U. & Parry, E. H. (2003). Migrants and health: A cultural dilemma. *Clinical Medicine*, 3(3), 229-31.
- Fleming, E., Carter, B., & Pettigrew, J. (2008). The influence of culture on diabetes self-management: Perspectives of Gujarati Muslim men who reside in northwest England. *Journal of Clinical Nursing*, 17(5a), 51-59.

Cultural Influences on Chronic Illness: A review of UK-based Studies

- Gerrish, K., Naisby, A., Ismail, M. (2012). The meaning and consequences of tuberculosis among Somali people in the United Kingdom. *Journal of Advanced Nursing*, 68(12), 2654-63.
- Gooberman-Hill, R., Ayis, S. & Ebrahim S. (2003). Understanding long-standing illness among older people. *Social Science & Medicine*, 56(12), 2555-64.
- Greenhalgh, T., Helman, C., & Chowdhury, A. M. M. (1998). Health beliefs and folk models of diabetes in British Bangladeshis: a qualitative study. *British Medical Journal*, 316(7136), 978-983.
- Graffigna, G., Vegni, E., Barelo, S., Olson, K., Bosio, C.A. (2011). Studying the social construction of cancer-related fatigue experience: The heuristic value of Ethnoscience. *Patient Education & Counseling*, 82(3), 402-9.
- Helliwell, P. S. (2003). Ethnic differences in responses to disease modifying drugs. *Rheumatology*, 42(10), 1197-1201
- Helman, C. G. (2007). *Culture, health and illness*. London: Butterworth-Heinemann.
- Hopkins, G. (2006). Somali community organizations in London and Toronto: Collaboration and effectiveness. *Journal of Refugee Studies*, 19(3), 361-380.
- Kelleher, D., & Hillier, S. M. (1996). *Researching cultural differences in health*. London: Routledge.
- Kirk, S. (2010). How children and young people construct and negotiate living with medical technology. *Social Science & Medicine*, 71(10), 1796-803.
- Kluckhohn, C. & Strodtbeck, F. (1961). *Variations in value orientations*. Evanston, IL: Row, Peterson.
- Lawton, J., Ahmad, N., Peel, E. & Hallowell, N. (2007). Contextualising accounts of illness: Notions of responsibility and blame in white and South Asian respondents' accounts of diabetes causation. *Sociology of Health & Illness*, 29(6): 891-906.

Cultural Influences on Chronic Illness: A review of UK-based Studies

- Lambert, H., & Sevak, L. (1996). Is 'cultural difference' a useful concept?: Perceptions of health and the sources of ill health among Londoners of South Asian origin. In D. Kelleher & S. Hillier (Eds.), *Researching cultural differences in health*. (pp. 124-59). London: Routledge.
- Leventhal, H., & Niles, P. (1965). Persistence of influence for varying durations of exposure to threat stimuli. *Psychological Reports*, 16(1), 223-233.
- Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common sense representation of illness danger. *Contributions to Medical Psychology*, 2, 7-30.
- Leventhal, H., Nerenz, D. R., & Steele, D. J. (1984). Illness representation and coping with health threats. In A. Baum, S. E. Taylor, & J. E. Singer (Eds.), *Handbook of psychology and health* (pp. 219- 252). Hillsdale, NJ: Lawrence Erlbaum Associates.
- Lin, Y. P., Furze, G., Spilsbury, K., & Lewin, R. J. (2009). Misconceived and maladaptive beliefs about heart disease: A comparison between Taiwan and Britain. *Journal of Clinical Nursing*, 18(1), 46-55.
- Macaden, L., & Clarke, C. L. (2006). Risk perception among older South Asian people in the UK with type 2 diabetes. *International Journal of Older People Nursing*, 1(3), 177-181.
- MacLachlan, M. (2006). *Culture and health: A critical perspective towards global health*. Chichester, West Sussex: John Wiley & Sons.
- Mays, N. & Pope, C. (2000). Assessing quality in qualitative research. *British Medical Journal*, 320(7226), 50-52.
- Morgan (1996). The meanings of high blood pressure among Afro-Caribbean and white patients. In D. Kelleher & S. Hillier (Eds.), *Researching cultural differences in health*. (pp. 124-59). London: Routledge.
- Parkin, D. M., Bray, F., Ferlay, J., & Pisani, P. (2005). Global cancer statistics, 2002. *CA: A Cancer Journal for Clinicians*, 55(2), 74-108.

- Petrie, K. J., & Weinman, J. (1997). *Perceptions of health and illness: Current research and applications*. Taylor & Francis.
- Prins, M. A., Verhaak, P. F., Bensing, J. M., & Van der Meer, K. (2008). Health beliefs and perceived need for mental health care of anxiety and depression: The patients' perspective explored. *Clinical Psychology Review, 28*(6), 1038-1058.
- Pulis, J. (1999). Religion, diaspora and cultural identity: An introduction. In J. Pulis (Ed.), *Religion, diaspora and cultural identity: A reader in the anglophone Caribbean* (pp. 1-12). London: Taylor & Francis.
- Rhodes, P., Nocon, A., & Wright, J. (2003). Access to diabetes services: The experiences of Bangladeshi people in Bradford, UK. *Ethnicity & health, 8*(3), 171-188.
- Richards, H. M., Reid, M. E., & Watt, G. C. M. (2002). Socioeconomic variations in responses to chest pain: Qualitative study. *British Medical Journal, 324*(7349), 1308.
- Smaje, C. (1995). *Health, 'race', and ethnicity: Making sense of the evidence*. London: King's Fund Institute.
- Szczepura, A. (2005). Access to health care for ethnic minority populations. *Postgraduate Medical Journal, 81*, 141-147.
- Thompson, A. R., Clarke, S. A., Newell, R. J., & Gawkrödger, D. J. (2010). Vitiligo linked to stigmatization in British South Asian women: A qualitative study of the experiences of living with vitiligo. *British Journal of Dermatology, 163*(3), 481-486.
- Treisman, K., Jones, F. W., & Shaw, E. (2014). The experiences and coping strategies of United Kingdom-based African women following an HIV diagnosis during pregnancy. *Journal of the Association of Nurses in AIDS Care, 25*(2), 145-157.
- Trompenaars, F. (1996). Resolving international conflict: Culture and business strategy. *Business Strategy Review, 7*(3), 51-63.

University of Manchester. (2013). Dynamics of diversity: Evidence from the 2011 census.

Retrieved from <http://www.ethnicity.ac.uk/medialibrary/briefingsupdated/which-ethnic-groups-have-the-poorest-health.pdf>

Turner, D. C. (1996). The role of culture in chronic illness. *American Behavioral Scientist*, 39(6), 717–728.

Uskul, A. K. (2010). Socio-cultural aspects of health and illness. In D. French, A. Kaptein, K. Vedhara, & J. Weinman, (Eds.). *Health psychology*. Oxford: Blackwell Publishing.

Webster, R. A., Thompson, D. R., & Davidson, P. M. (2003). The first 12 weeks following discharge from hospital: The experience of Gujarati South Asian survivors of acute myocardial infarction and their families. *Contemporary Nurse*, 15(3), 288-299.

Zagefka, H. (2009). The concept of ethnicity in social psychological research: Definitional issues. *International Journal of Intercultural Relations*, 33(3), 228-241.

Section B

A qualitative exploration of the impact of culture and faith on illness-perception and adjustment in adolescents with liver disease*

*All names have been replaced with pseudonyms. Some data has been changed to preserve the anonymity of the participants.

7 Section B: Abstract

Purpose: Treatment non-adherence in adolescent liver transplant recipients ranges between 17-53%, increasing the risks of medical complications. Whilst spiritual matters have been shown impacts on illness perceptions and behaviours of adolescents with other diseases. The aim of this study was to explore cultural and spiritual influences on adolescents' adjustment to liver disease.

Methods: Ten semi-structured interviews were conducted with 16-24 years olds, recruited from a British regional liver clinic. Half were liver transplant recipients.

Results: Some participants reported an illness-related spiritual or socio-cultural crisis, which resulted in non-adherence. This seemed to lead to a turning point, followed by adjustment and personal development. However, illness adjustment was sometimes transitory, and as such, appeared to be a cyclical process, entangled with universal adolescent developmental tasks.

Conclusions: Practitioners this population must take into account socio-cultural and spiritual influences to promote treatment adherence and overall functioning when working with some adolescents with liver disease.

Key words: Liver disease, adolescents, adjustment, spirituality, culture

Implications and Contribution:

Evidence shows high treatment non-adherence rates and reduced levels of psychosocial wellbeing and functioning in adolescent liver transplant recipients. This study indicates that in the wider population of youths with liver disease, spiritual and socio-cultural matters can underlie illness adjustment difficulties which may need to be addressed by their clinicians.

8 Introduction

Culture has been described as an “inherited lens” through which individuals learn ways to perceive and experience the world, to relate to others and to supernatural forces or gods (Helman, 2007, p2). Indeed, religion has been defined as an “institution of culturally patterned interaction with a culturally postulated superhuman being” (Spiro, 1966, cited by Pargament, 2001). Whilst there is ongoing debate about the distinctions between these concepts, in this paper the term religiosity/spirituality (R/S) is used interchangeably with faith in the broadest sense, meaning “a search for significance in ways related to the sacred”, embracing both institutionalised pathways, and individualised relationships with a “transcendent force” (Pargament, 2001).

Adolescence spans the transition between childhood and adulthood, commencing with pubertal changes and ending with culture-specific social changes (Herbert, 2003, p. 164). Shaw (2001) sets out the developmental tasks of adolescence, namely, separation-individuation from parents, physical and cognitive development, and social identity formation (i.e. peer conformity). Advances in brain imaging technology have revealed non-linear, neurological development throughout adolescence which appears to underlie specific reasoning patterns characteristic of the life-stage (Blakemore & Robbins, 2012). Notably, adolescents can be prone to exercising poor judgement in relation to high-risk behaviours, including substance abuse. In particular, the UK has been classified as a high prevalence country for drinking in adolescence in a recent European-wide survey (Healey, Rahman, Faizal & Kinderman, 2014).

8.1 Religiosity/Spirituality in Adolescence

Whilst the principal developmental task of adolescence is the establishment a coherent identity (Eriksson, 1968), empirical evidence demonstrates that adolescence can also be a critical period for spiritual maturation, when individuals shift from institutionally-oriented R/S to a more personalised form (Good, Willoughby & Busseri, 2010). The Positive Youth Development (PYD) framework suggests that R/S can guide the adolescent towards healthy identity formation and personal development into functional individuals who can think outside of themselves and make a positive contribution to their immediate social context and the wider society (Lerner, Albers, Anderson & Dowling, 2006, p61). The writers referred to this development as 'transcendence'. In a multi-cultural region of Northern England, it was found that 30% of adolescents aged between 11 and 16 years attended religious gatherings and 40% prayed more than once a month (Village, Francis, & Brockett, 2011).

8.2 Culture and Chronic Physical Illness in Adolescence

Health and illness are amongst the numerous aspects of human life viewed by individuals through a 'cultural lens'. Cultural beliefs, assumptions and discourses influence the perceptions and somatic experiences of illness and provide a framework for solving illness-related problems (Baumann, 2003). Cross-cultural differences between adolescent patients and their clinicians in understanding the causes, treatment and management of illness, can lead to adherence difficulties and adverse outcomes (Turner, 1996). Further, generational differences in illness perception between immigrants and their children can generate psychosocial difficulties and, potentially,

introduce complexities into the young person's illness adjustment experiences and behaviours (Turner, 1996).

8.3 Spirituality and Chronic Physical Illness in Adolescence

The link between R/S and chronic illness in adolescents is also worthy of attention for improved psychosocial outcomes. The extant evidence is complex and suggests that R/S can be both adaptive and detrimental for adolescents' illness perceptions and coping strategies for chronic physical illness (Pargament et al., 1998). More recently, Reynolds, Mrug, Hensler, Guion and Madan-Swain (2014) identified positive and negative R/S coping pathways in younger adolescents with an average age of 14.7 years diagnosed with cystic fibrosis or diabetes. Positive spiritual coping strategies such as beliefs that God was helping them, were associated with fewer depressive symptoms. Greater depressive symptoms predicted maladaptive spiritual cognitions which they termed 'negative spiritual coping', such as thoughts that God was punishing them. Reynolds, Mrug and Guion (2013) also concluded that optimistic attribution styles eventuated in positive spiritual coping with fewer internalising and externalising problems, whilst life-threatening illnesses were associated with more maladaptive spiritual cognitions and more conduct problems.

8.4 Chronic Liver Disease in Adolescence

According to the Children's Liver Disease Foundation (2014) at least two children in the UK are diagnosed with a liver disease every day. Treatment will usually require lifelong adherence to medical care, including clinical monitoring, medication and lifestyle management, such as avoiding alcohol consumption. However, in American adolescents with liver transplants, treatment non-adherence rates range from 17% to

53%, 4 times higher than non-adherence in adults (Fredericks, 2009). Moreover, adolescent liver transplant recipients are known to be particularly vulnerable to reduced adherence when transitioning from paediatric to adult healthcare services, increasing the risk of poorer medical outcomes and a consequential reduced quality of life (Annunziato, 2007). Compared to healthy controls, adolescent liver transplant recipients are known to have reduced levels of overall, psychosocial, school and physical functioning (Fredericks, Zelikovsky, Aujoulat, Hames & Wray, 2014). Shaw (2001) argues that treatment adherence and adjustment to illness in adolescence should be considered in the light of life-stage developmental tasks and processes, in addition to the socio-cultural context.

8.5 Study Aims

There are large gaps in evidence-base for the adjustment of adolescents diagnosed with chronic liver disease in the UK context, and especially so for non-transplant recipients. Also, the few studies which investigate culture and religious beliefs in relation to this clinical population are specifically focused on the transplantation process (Maloney, Clay & Robinson, 2005; Oliver, Woywodt, Ahmed & Saif, 2010). Interestingly, there is a tendency within Anglosphere research to position culture 'as only belonging to and being problematic in relation to people from minority (usually non-white) ethnic groups' (Fleming, Carter & Pettigrew, 2008).

Therefore this study seeks to answer the following question:

How does culture and spirituality appear to influence illness perception and adjustment to chronic liver disease in a diverse sample of young people, including non-transplant recipients?

9 Method

9.1 Study Design and Epistemological Position

Extant literature of cultural and R/S influences on adolescents with physical illnesses is minimal. This calls for a qualitative approach which is able to capture the richness and complexity of participants' beliefs, meanings and subjective experiences without preconceptions. The social-constructionist approach to the grounded theory method (GTM) informed by Charmaz (2006) enables the researcher to go beyond a mere description of the participants' accounts to co-construct an emergent, interpretative model of salient structures and processes grounded in their data.

9.2 Participants

9.2.1 Inclusion Criteria

Participants were English-speaking, adolescents and young adults who had been diagnosed with a chronic liver disease (CLD) and attended hepatologist clinics at a hospital covering a large region of the UK. Participants were not required to have any particular spiritual interests.

9.2.2 Recruitment

Initially, patients selected by the clinic team who met the criteria were sent invitation letters and study information packs. A revision was later made to the recruitment procedure, such that clinic attendees were approached by a member of the research team whilst in the waiting area prior to their clinic appointment. Information packs with contact details were given to patients who showed an interest in taking part.

9.2.3 Sample

A total of twelve patients agreed to participate initially. Two patients withdrew before interview, with one giving the reason that the subject matter was not relevant to them and the other giving no reason. The final sample of ten participants consisted of six males and four females, ranging in age from 16 to 24 years. Further demographic information has been reported in Table 1. Ages have been banded and some ethnicities have been changed to preserve anonymity. Participants will be referred to by pseudonyms reflecting their cultural heritage for the remainder of the paper.

Table 1
Study participant demographics

Pseudonym	Age Band (years)	Ethnicity	Religion	Age at diagnosis (years)	Liver Transplant Recipient
'Adesuwa'	20+	Black African	Christian	7-10	Yes
'Chloe'	<20	White British	Christian	<7	Yes
'Farouk'	20+	Asian	Muslim	11+	Yes
'Jamal'	<20	Black African	Muslim	<7	No
'Justin'	<20	White British	None	11+	No
'Khadijah'	<20	Asian	Muslim	11+	No
'Nathaniel'	<20	Black Caribbean	Christian	<7	Yes
'Ollie'	<20	White British	None	<7	No
'Remi'	20+	Black African	Christian	11+	No
'Tom'	20+	White British	None	11	Yes

9.3 Ethical Considerations

Approval for this study, and the later revision to the recruitment process, was granted by both the NHS Research Ethics Committee and the Research and Development Office of the hospital trust from which participants were recruited. Each participant was given a participant information sheet and study invitation letter at least 24 hours before interviews took place (Appendix A). Before each interview began,

participants were invited to ask questions and sign a consent form to confirm their agreement to take part (Appendix B). A small payment was given to cover expenses.

9.4 Procedure

Each session began with two self-report questionnaires on medication adherence (Appendix C) and religiosity/spirituality (Brief Multi-dimensional Measure of Religiosity and Spirituality, BMMRS, Appendix D). The questionnaires were used for descriptive purposes only: to give insight into their regular practices and to provide a basis for comparison between participants. The medication adherence questionnaire was an adapted version of an unpublished measure which had been developed by the hospital and provides a rating for how closely medication is taken as prescribed, in terms of dosage and timing. The BMMRS has been found to have acceptable reliability and validity properties when used with adolescent populations (Harris et al., 2008). For this study a cumulative composite score was calculated based on the individual BMMRS index scores for each participant.

The study was based on one-to-one semi-structured interviews conducted by one researcher and recorded with the participants' consent. The interview durations ranged from 30 minutes to 1 hour, with the majority over 45 minutes long. Interviews were conducted at the hospital where the participants were recruited or at their home. The original interview schedule largely consisted of open questions designed to elicit rich narratives (Appendix E). In keeping with the general principles of GTM, the interview audios were transcribed and analysed in order, whilst data collection continued. As such, the interview schedule was progressively modified to enable the researcher to cross-check emergent concepts from earlier interviews.

9.5 Data Analysis

A research journal was maintained throughout the project (Appendix F) and brief memos were made following each interview, noting salient points and impressions (Appendix G) to provide an audit trail of conceptual developments.

Informed by Charmaz (1990), initial codes were generated with line-by-line open coding of the first four transcripts in Nvivo 10, with the focus on actions, processes, assumptions, strategies and consequences. (Appendix H shows an example). At the end of the open coding apparent duplicates were combined.

Diagrams were created early on to visualise the relationships between the initial codes and to select the focused codes to be used for the remaining transcripts (Appendix I). To produce the model relationships between the emergent sub-categories were explored with the use of memo-writing and constant comparisons between data, focused codes, sub-categories and cases to identify patterns of similarities and differences. The codes and sub-categories underwent several splits, mergers and reconfigurations as the analysis progressed. It was also necessary to revisit some of the earlier transcripts to recode larger sections of data, once the sub-categories had become more firmly established (Appendix J). In line with Charmaz (1990) the base model continued to develop during the process of drafting this report.

9.6 Quality and Validity

Reference was made to Mays and Pope (2000) to monitor quality in this study. The researcher was a parent to adolescents and a practicing Christian from an ethnic

Cultural and spiritual influences on adolescents with liver disease: A qualitative study minority group. This background is likely to have introduced both insight and bias into the data collection and the analysis stages. Annotations were made on transcripts when the researcher was conscious of these influences shaping follow-up questions during interviews. The researcher had previously worked with this clinical group as a psychology assistant which initiated her interest.

Initial and focused coding was conducted with guidance from a research supervisor experienced in GTM. A densely coded segment of one transcript was also coded by a research colleague and reviewed to identify notable differences in interpretation.

The models produced were presented for verification to two clinical psychologists working extensively with this clinical population.

10 Results

10.1 Self-report Measures

The scores obtained from the medication adherence and the religiosity/spirituality (BMMRS) measures are reported in Table 2 below. The BMMRS scores ranged from 141 for Remi, who reported being a lifelong Christian, down to 39 for Ollie who had no religion. The minimum possible score was 34 and the maximum was 178. Khadijah reported the lowest medication adherence score of 59 out of a possible total of 100, whilst the highest scores of 95 were reported by Ollie and Jamal. Farouk declined to complete the medication adherence questionnaire.

Table 2

Scores obtained from self-report measures

Pseudonym	BMMRS* Score	Medication Adherence Total
'Adesuwa'	113	80
'Chloe'	128	76
'Farouk'	66	-
'Jamal'	132	95
'Justin'	54	92
'Khadijah'	117	59
'Nathaniel'	120	69
'Ollie'	39	95
'Remi'	141	77
'Tom'	60	74

* Compounded indices score derived from Brief Multi-Dimensional Measure of Religiosity and Spirituality (Fetzer Institute, 1999)

10.2 Qualitative Data Analysis

The coding stages yielded a final total of 210 initial codes and 48 focused codes (Appendix K), which fell into one of four high-level theoretical categories. These focused codes were later subsumed by 16 sub-categories. A collection of memos showing how initial codes, focused codes and sub-categories were developed is shown in Appendix G.

A model was produced which covers the full range of focused codes generated, with the emphasis on the 'illness adjustment' theoretical category (Figure 1). This model will be discussed below, with THEORETICAL CATEGORIES shown in CAPITALS, **sub-categories** in **bold** and participants' *quotes* in *italics*.

10.3 Theoretical Categories and Sub-categories

10.3.1 Summary of Illness Adjustment Model

The participants were all embedded within their respective SOCIO-CULTURAL CONTEXT, some of which incorporated spiritual beliefs in a HIGHER POWER.

Participants reported very personal journeys through the ILLNESS ADJUSTMENT process which were influenced by their SOCIO_CULTURAL CONTEXT, and critically, by trusted individuals within their social network. The experiences and challenges of the adjustment process led to PERSONAL DEVELOPMENT and, in some cases, spiritual growth.

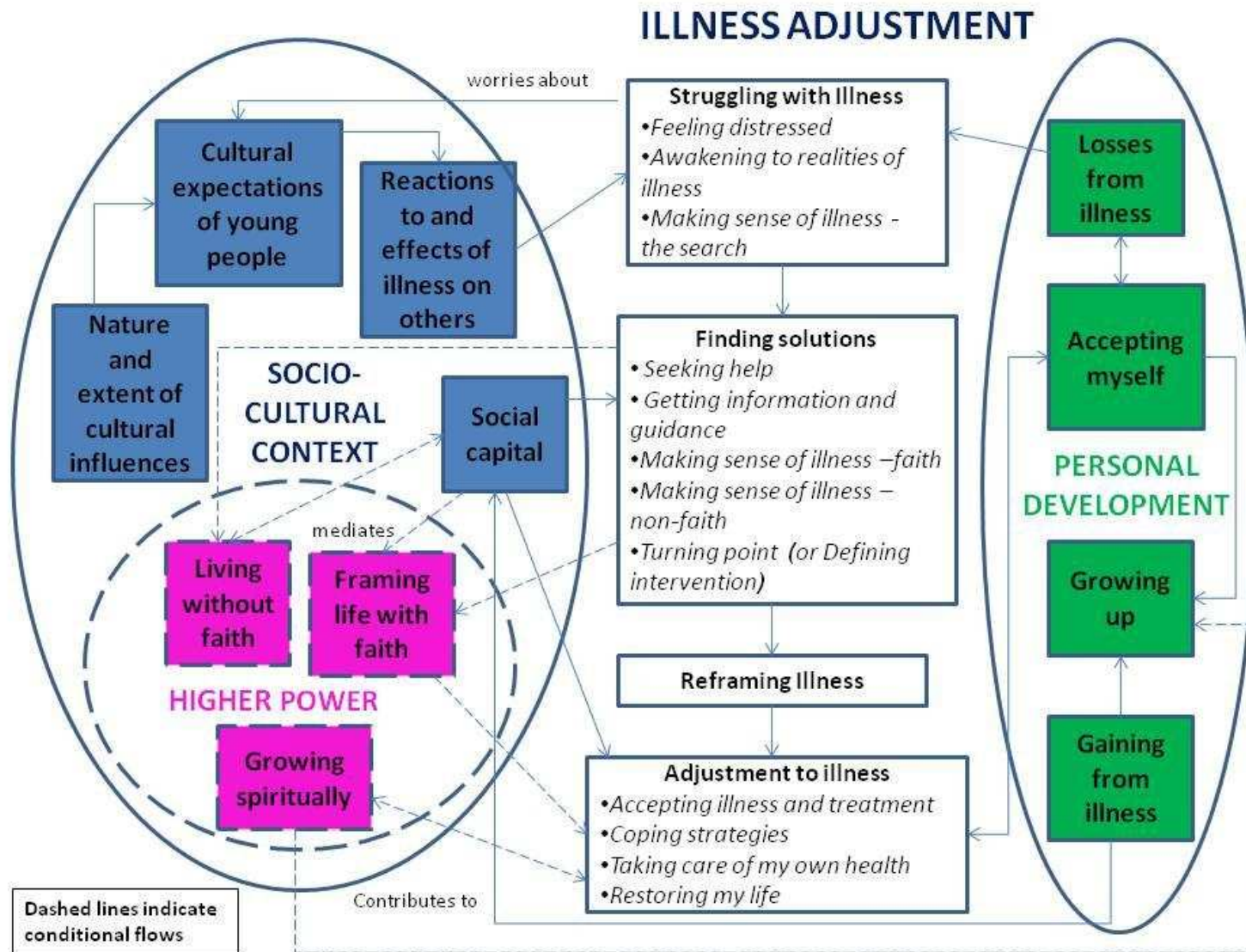


Figure 4: Cultural and Spiritual influences on adjustment to chronic liver disease in adolescents and young adults

10.3.2 SOCIO-CULTURAL CONTEXT (Category 1)

The sub-categories capture the key influences emanating from the participants' cultures and social networks which appeared to impact on their experience of illness and their adjustment to it.

Nature and extent of cultural influences

Participants identified a broad range of cultural traditions, beliefs and attitudes which seemed to pass down through generations and across between peers. Several participants recognised that beliefs in a HIGHER POWER were woven through the fabric of their cultures, whilst cultural ideas surrounding family and community life seemed to frame participants' experiences of themselves.

Khadijah: "I think my cultural and religious beliefs are like influenced by everyone you are with as well."

Farouk once overheard an imam talking to his parents about illness.

Farouk: "If your son is very sick, it is because of what you have done in the past."

Adesuwa: "..when I was sick...they'd say, 'Oh, it's witchcraft'"

Some cultural positions on illness reported impacted on participants' ILLNESS ADJUSTMENT. Justin reflected on attitudes to the sick. He decided not to tell other students at his school about his condition.

Justin: "But people can never get rid of that, kind of, treating someone different because of it [CLD]. Whether they know they're doing it or not, they're always going to do it."

Participants made both positive and negative observations about their cultures in relation to their illness management. Tom who also suffered from depression, perceived British culture to be quite understanding of mental health problems, perhaps more so than other cultures. As liver patients who are advised not to drink, Tom and Farouk made contrasting comments about their respective cultures which reflected differing attitudes to alcohol. Tom's ILLNESS ADJUSTMENT strategy meant challenging an element of British youth culture.

Tom: "But I do think there's a pressure in the culture in general. If you don't go out and have a good time and don't have a drink or get so drunk that you can't stand up, you're boring. That's a really wrong thing. The pressure is immense."

Farouk: "We are not allowed to drink alcohol...Yeah, that's very good... I love this part of my religion. So I think, it is helping me."

Participants also discussed cross-cultural differences and health professionals. Adesuwa said she did not allow her spiritual beliefs to obstruct her medical care but recalled her acute embarrassment when her mother regularly pronounced "God is the physician!" in front of doctors at her hospital bedside. However, Farouk was forthright in his expectations for culturally-sensitive care.

Farouk: "They have to. I'm here and if I say something they don't understand, then [they should] ask...I am not ashamed. I'm not afraid. I am open to talking, if it's related."

Cultural expectations of young people

Participants reported various culturally-mandated social pressures and the strategies they used to navigate them. Farouk complied with expectations for him to fulfil his father's wishes, which meant going to university just to stay on par with his cousins. Farouk was so determined he described vomiting blood on the way to an exam on one occasion. By contrast, Tom chose to challenge his culture, referring to generational differences between him and his father in their attitudes to work and illness.

Tom: "You've got my dad who's a different generation who goes to work no matter what, even if he's feeling terrible. Whereas me, in the past I've not been to work because I literally have no energy to get up and that's frowned upon by my dad because he's like "Well why aren't you here, you should be here."

Remi had grown up in a culture where respect and deference to elders is expected. However, she recalled having to disassociate from a well-meaning 'Uncle' who was blaming her lack of faith for her failure to recover. Despite seeming to reject this conception of her illness, her unilateral decision to stop taking her prescribed medication at one point, appears to illustrate the pull of this cultural framing of her

illness. Abandoning her uncle's interpretation of God's 'healing' power was part of Remi's ILLNESS ADJUSTMENT journey.

Social Capital

Participants reported the intrinsic value in being part of their social networks in the ILLNESS ADJUSTMENT. They unanimously referred to the social support received from family, peers and healthcare professionals.

Nathaniel: "It will get to nine o'clock and one of my friends will say ['Nathaniel'], what you doing here? Get out of here! Time to take your medicine!' Or something like that."

Tom: "I've got a big, big group of people here [at hospital] who I feel comfortable to talk to about everything. Which is good. I mean to have those people makes it a lot easier to be here sometimes."

Ollie noticed that having like-minded friends made it easier for him not to drink on his weekly nights out. However, social support was not always adaptive. Farouk migrated to the UK as a young adolescent and thus, experienced a monumental shift in his SOCIO-CULTURAL CONTEXT. He was extremely distressed at the onset of his illness, and he needed support, but he was away from childhood friends back in his home country and was isolated from healthy peers at his British school. He described having left a highly controlled state, and finding himself exposed to an unrestrained internet sub-culture which he felt had a very damaging effect on his well-being and spirituality. He described having to be 'rescued' by college friends later who helped him to restore his faith.

Farouk: "I was angry. But then it slowly...I came to this conclusion..., here, when you're in this place, and I guess the cause of it is too much internet... Because, I keep reading and you know, you get fed basically...Censorship doesn't exist here."

Some participants expressed a wish to give back to their social contexts because of the help they had received, suggestive of their PERSONAL DEVELOPMENT resulting from ILLNESS ADJUSTMENT. Although Khadijah normally treated her illness as a private matter, she declared her willingness to disclose it if she felt it might help others.

Khadijah: "If someone asked me about it, I would tell them. Because for all I know they might need kind of help or something"

Reactions and effects of illness on others

Reflections on the negative impact of illness on interviewee's families featured in several narratives. For instance, Remi described the unwelcome change in her role at home brought about by her illness and how hard this was on her widowed mother.

Remi: "She said that immediately the illness came, it was loads for her to handle because she didn't have a helping hand anymore. And I was like now I was another... I was being taken care of by my brother and sister."

Participants also cited a range of unhelpful responses from others, mostly outside of the immediate family circle, who were less inclined to empathise with them, such as schoolmates, teachers and employers. Typical responses included lacking understanding, worries about getting infected or falling sick too, and outright disbelief.

Tom: "You've got people there like my supervisor at my old job who used to get very, very annoyed when I used to take days off, he just thought I was faking"

In spite of the difficulties, participants also reported positive effects of their illness on others. Chloe believed that the experience of having to support her through her challenges has also strengthened her parents.

Chloe: "...they have had to watch me have blood tests and stuff, which isn't nice. But I think it's kind of, has made them stronger as well"

10.3.3 HIGHER POWER (Category 2)

For most participants, faith played a key role in their ILLNESS ADJUSTMENT, usually leading to significant changes in their faith.

Living without Faith

Several participants recounted their early adolescent years as being a period of questioning or complete disinterest in spiritual matters. This appeared to have been part of the normal developmental tasks of adolescence.

Adesuwa: "Well, when I was growing up it did mean a lot to me. Then once I hit, like, I think 13, 14 it didn't really mean anything to me...I'd be going to church because my mum said I had to"

At other times, negative spiritual cognitions were triggered by the distress and pain bound up in **Struggling with Illness**.

Adesuwa: "Sometimes it wasn't even praying for complete healing. It was just to get rid of the pain that I was in at that time, just for a minute, just give me a day off maybe, but He [God] just didn't and I felt, like, okay, why am I praying? I don't get it. I don't want to pray anymore"

Chloe: "I think when I get angry or got angry I would start to question it all and be like "Well, you don't love me, God"

However, Justin relinquished entirely the Christian R/S beliefs he acquired at primary school in an angry response to being diagnosed with CLD. Justin, his mother and father all had conflicting perspectives on spirituality so unlike the other participants with faith beliefs he had no relatives or peers to reinforce his faith in the face of this challenge.

Justin: "When I was first diagnosed with it I completely lost faith"

Framing life with faith and Growing spiritually

The majority of participants professed varying degrees of faith at interview which they had inherited from their families (see Table 2). They expressed their understanding of God's characteristics and intentions, as learned from parents, siblings, cousins, peers and their place of worship. Jamal believed that his illness was part of God's plan for him, a belief expressed by various people at his mosque after his recovery from CLD.

Jamal: "Yes, yes, almost anything that happens in my life I feel is part of God's plan."

Interviewees were able to articulate their spiritual identity and even differentiate between religion and spirituality, which may be an indication of spiritual maturation. Tom had not grown up in a religious household but his spirituality had grown over the course of his illness, with input from a Catholic aunt.

Tom: "I mean I do pray sometimes. But I wouldn't say I have a particular faith or religion."

Several participants reported later spiritual growth and a strengthened commitment, following periods of grappling with faith due to the general turbulence of early adolescence or triggered when **Struggling with Illness** during the ILLNESS ADJUSTMENT process.

Khadijah: "I'm stronger in my faith now, I feel closer to God"

Jamal: "I never used to pray a lot, I just ... couldn't be bothered, but like now I make the effort to pray five times a day"

Some participants reported spiritual growth leading to their PERSONAL DEVELOPMENT. Spiritual coping strategies developed through Khadijah's illness were used to relieve ordinary social difficulties, whilst Tom demonstrated considerations which extended beyond his personal needs.

Tom: "I believe praying for things that are going to make me better doesn't just help me. It helps my family. It helps my friends ... and everything. So in an unselfish way that's why I do it."

10.3.4 ILLNESS ADJUSTMENT (Category 3)

This category maps participants' journeys through the adjustment process.

Chronicling illness (not shown in Figure 1)

Participants fell into two camps: those who were diagnosed as babies or young children who had stayed relatively well throughout adolescence and those who became ill in adolescence, who had all experienced bouts of debilitating illness, including two who reported being gravely ill immediately before transplantation.

Adesuwa: "I remember a few weeks before my liver transplant they were like, 'Oh, we can't find a liver'...and that my mum should call a priest"

For participants diagnosed in early childhood, their understanding of their medical condition as mediated by their families, was recounted in largely positive terms. Chloe and Nathaniel conveyed a clear sense of being made to feel special. On the other hand, Ollie felt he was treated normally, an approach taken by his family on the advice of his doctors, which was immensely important to his sense of self.

Ollie: "I'd be a very similar person [without CLD]...[My family] treated me exactly the same."

Initially, some participants diagnosed in adolescence also reported very limited understanding of their medical condition. In the cases of Remi and Adesuwa, it appears

that their mothers had made concerted efforts to minimise the impact of the diagnosis had on them.

Remi: "She doesn't make things big but she also makes things fun. So like in the time when it was happening she was always like "Let's go and do something ..." So it wasn't like it was all associated with bad memories and bad things. It was merged in with good things"

Struggling with illness

All interviewees reported difficulties at some point after being diagnosed, ranging from body image or control worries, emotional distress and physical pain, which was hard to bear. Emotions included anger, confusion and disappointment: with God, others and even themselves.

For the participants with a minimal early understanding of their illness, difficulties eventually materialised as the illness worsened or the limitations mounted.

Chloe: "Then as you grow older and my transplant started to affect my life more, as I got to secondary school ... When I was little... I could just sort of brush it off and not really think about it."

For others, their later diagnoses presented them with immediate difficulties.

Khadijah: "I was just like, angry at everyone and everything"

Farouk: "I just wanted to die. I didn't like the idea of living at all because I was being tortured...So there was a big, big change in my body, how it looks, how it works. I didn't like myself at all"

The distress of illness triggered negative spiritual cognitions (see **Living without Faith**). Some participants were aware that negative perceptions of their illness circulated within their respective communities (see **Nature and extent of cultural influences** and **Cultural expectations of young people**). Whilst the participants claimed not to subscribe to these views, there were also indications that some participants may have been somewhat influenced by them in their own sense-making.

Farouk: "What did I do? What did I do? I didn't do anything wrong."

Remi: "And I do almost feel sometimes like it's a lack of faith to the reason why I'm not healed."

Finding Solutions

The distress and challenges of illness, as described above, channelled some participants into actively seeking help from trusted individuals or information sources.

Chloe: I remember going to [a Christian]camp this year and speaking to one of the leaders about drinking and getting drunk and stuff

Justin: "...researching did help because it, like, helped me let go of this, 'this is my fault'"

Khadijah: "I didn't know how to control it. So I used to get really mad about it and one day she [her sister] sat me down and she was like 'You need to understand that everything that happens to you, like, whether it's illness or anything, that's God testing you.'"

At some point, whether through their own thought processes or an intervention from a trusted individual, participants reported making some kind of sense of their

illness. Chloe and Nathaniel had similar medical histories and faith beliefs but very different ideas about why they had their illness.

Chloe: "...in some form or another, it is part of a big plan"

Nathaniel: "Personally I think it's random because one, like, there's no other traces of it in my family of anybody else having it"

Some participants dually held faith and non-faith beliefs about their illness. Jamal reported feeling 80-90% certain that his illness was test from God, but he also wondered also whether it was just random. In Justin's case, his understanding of his illness switched from being faith-based to a non-faith explanation.

Justin: "I felt like maybe I'd done something and I was being punished for it or, like, I'd do something in the future and this is punishment for something I was going to do."

Justin: "And, then as you learn the other side and just, like, science and stuff and that God... there's no real proof. I just, kind of, okay, God doesn't exist. This is genetics. It's science. I'm not being punished for anything."

Notably, four interviewees expressly absolved their parents of any blame for their illness.

Nathaniel: "...the way I see it is the only people that I can blame is my mum and my dad, and I can't...my mum or my dad doesn't have a liver condition, so it's not to say that I've got it from any of them."

For most participants, after a period of distress or sense-making, there seem to be a turning point which informed their acceptance of their illness and preferred coping

Cultural and spiritual influences on adolescents with liver disease: A qualitative study strategies. For many participants who had interpreted their illness as part of God's plan for them, this resulted in a significant growth in their spirituality (i.e. HIGHER POWER).

Jamal: "When I went to hospital I was very weak and the doctors were doubting whether I would stay alive and whatsoever, but I did and since then I just, like, yes, believe in God a lot."

For Tom and Justin, a new-found gratitude for their survival and their health not being worse was instrumental in their transition from their earlier period of struggle. Tom had buckled under the pressure of wanting to fit in but made himself extremely ill in the process. He was told he had four months to live unless he was willing to adhere to treatment.

Tom: "I went through a stage that year where I didn't take my tablets because I thought: I'm fine. I was the healthiest I've been for a long time, I looked healthy, I felt healthy and I went out there and I drunk every single day, all day, all night. I regret that now because I now realise how much of a gift I've got."

Reframing illness

Ollie was adamant that there was no positive aspect to having his medical condition. By contrast, all other participants found benefits in their illness, such as bringing the family closer together or closer to God.

Tom: "So yeah it's a blessing really in a very weird disguise. It's brought us [the extended family] all a lot, lot closer which is good, very good."

Khadijah: "Because if I didn't get ill, God knows I could have been, I wouldn't have been praying, anything could have happened to me. Even though that happened I gained something as well. I'm stronger in my faith now, I feel closer to God, I feel closer to my sisters now that we all pray and we stopped arguing that much."

Adjusting to illness

Interviewees looked back at the difficult process of accepting their condition and managing the treatment. Farouk had undergone extensive surgery that would affect him for the rest of his life.

Farouk: "It took some time for me to, I would say after eight months then I could talk about it...I have adapted to it."

Justin: "At first it's difficult, but then it, kind of, drums into your daily routine and you just, like, get up, take your pills, brush your teeth, get dressed, go to school..."

Coping strategies varied between participants. Those who were non-religious relied on ignoring the illness as much as possible. Notably, this was made possible because the impact of the illness on their lives was comparatively minor.

Ollie: "Just ignore it. Ignore the unknown."

An essential part of this strategy was highly selective disclosure, such that very few people outside of their families were aware of their condition. In this way, life could continue as closely to life without CLD.

Religious participants were much more reliant on faith-based strategies such as prayer and trusting in God (i.e. their HIGHER POWER). This group also included all the participants with the most severe health problems, in terms of having been transplanted or having been close to death.

Remi (on her faith): "Yeah, there's no question about that. I think I would definitely have gone crazy."

Tom considered himself to be spiritually aware although he was not from a religious SOCIO-CULTURAL CONTEXT. At times of distress or isolation that were part and parcel of his frequent hospitalisations, he also resorted to prayer for cathartic release.

Tom: "Just having the feeling of someone else listening to you. When I've been here and I haven't had people come to see me, or I haven't been able to speak to the family as much as I would like. In a way it's another release of emotion and hope and sadness I suppose"

As participants were growing older, it was important for them to start taking over the responsibility for their medical care from their parents. Nathaniel discussed attending more recent appointments with his mother.

Nathaniel: "she's been leaving me, like, kind of, independent to give over my own information, so I have to learn"

Every participant in this small sample expressed a desire to reclaim their lives and their identities following illness. A recurring theme was a dread of the inevitable pity that followed disclosure of their illness and their wish to be treated normally by others. Adesuwa explained that she wanted to make decisions for herself regarding what she was physically unable to do, and not have others deciding for her. The interviewees did not want to be seen as a diagnosis, but just wanted to get on with their lives.

Khadijah: "I'm fine and it made no difference to me. I still am who I am. I'm still 'Khadijah'"

Adesuwa: "Take me off the bat of who I am, don't...see 'Adesuwa' first, instead of liver disease or the operation first."

Adesuwa: "I still study. As soon as I came out of intensive care I went back to uni...I want to know that I tried, even if I don't make it, even if I'm not here by the end of this year."

10.3.5 PERSONAL DEVELOPMENT (Category 4)

Despite the losses suffered due to illness, participant reported some gains and experienced personal growth directly as a result of their ILLNESS ADJUSTMENT.

Losses from illness

Some participants contrasted their current circumstances with life before their illness to convey the scale of their losses to it.

Khadijah: "I was 13...I barely took life seriously. Then I've been given something that I'm going to have for the rest of my life"

Most respondents recounted the past setbacks they have suffered due to the illness and their current lives being hampered by it. This ranged from difficulties with friendships, social status, education, employment, travel plans and even their own personal development itself.

Remi: "Let's get to a really good university'. I was on track to that, I was at a grammar school and I was doing well, then I got ill and that changed dramatically."

This was a particularly strong theme for the older interviewees (i.e. over 20 years old). Adesuwa stopped planning ahead because of past disappointments when her medical condition had not improved as fast as she had been led to believe by doctors. Tom attributed his bouts of depression to his inability to work due to his illness.

Tom: "I mean I've found it really impossible to keep a job because of my illness. That's a big pressure not having any money to go and do anything because you can't work"

Travel restrictions for medical reasons were also mentioned by a few participants. For those from immigrant families, this was especially problematic because, at a time when they were forging their identities, they were unable to reconnect with their home country. In Adesuwa's case, her illness meant holding her family back from travelling too.

Adesuwa: "They want to go on holiday, but they don't want to, like, leave me behind and I can't go"

Accepting myself

The participants each appeared to be developing a sense of self in general. For example, they were able to clearly differentiate themselves from others according to their general principles and ways of life, in addition to matters of illness. From an early age, Chloe was acutely aware that her transplant made her different to her peers.

Chloe: "...it was this thing that made me different from everybody else"

Self-acceptance, in particular, emerged as a significant by-product of the ILLNESS ADJUSTMENT process. Farouk reflected on how his illness had hindered his academic work and the need, therefore, to set his own standards.

Farouk: "You just don't achieve the same result as everyone else no matter how hard you try."

Growing up

Many young people in this sample reported periods of turbulence, questioning and experimentation while in early adolescence. Jamal hinted at the reasons for his faith waning during his high school years.

Jamal: "Just like, you know, the usual teenager temptations, yes. I don't really think I need to expand. I think you know what I mean [chuckle]"

However, having a chronic illness appears to have brought added complexities to the process, and appears to have shaped some participants' views on wider matters. Khadijah believed that her illness was God's test for her, but extended that notion to other areas of her life.

Khadijah: "That's what I remember, life's a test...Everything in life is a test."

Most participants reported their future plans and steps they were taking towards them. Some career aspirations had been specifically influenced by their experiences of illness. Justin and Jamal both expressed an interest in medicine because they thought they would make empathic doctors.

Jamal: "I feel like it would be good to be a doctor because I would have been in, like, the other person's shoes as a patient, so I would know how it feels"

Gaining from illness

In spite of the challenges of illness, participants reported some personal benefits of having been through the experience. Remi realised that she was admired within her SOCIO-CULTURAL CONTEXT for her courage and determination.

Remi: "I know a lot of people have been very encouraged by the way that I live and it's not in a big headed way"

Nathaniel attended a skiing trip organised by the hospital when he was younger. He won a prize for his tenacity and he vividly recalled his parents being overcome with emotion at the time. He believed that tenacity was still one of his best qualities.

Nathaniel: "...that made me realise, like, how much of an important child I am because my mum and my dad started crying... because of this condition I have been able to win this award and it felt good"

11 Discussion

This study sought to gain some understanding of how culture and spirituality influenced the illness perceptions and adjustment to living with chronic liver disease in a sample of adolescents and young adults living in the UK. Attention was also paid to the roles of their families and peers, as well as the resultant effects on their faith.

Spirituality, culture and families/peers will be discussed in relation to adjustment.

11.1 Spirituality and Adjustment

As shown in Figure 1, the participants in this sample were embedded within their respective socio-cultural contexts, where for most, religion played a central role. As discussed by Shaw (2001), several participants demonstrated expected adolescent development such as thinking more independently and questioning previously taken-for-granted R/S beliefs.

All participants reported struggling with a range of difficulties with their illness at some point. These difficulties were most commonly triggered by a near-death episode of illness or an inability to reconcile their R/S beliefs with the tragedy of their illness. The combination of struggles with illness and the more general questioning of spiritual beliefs described above, may underlie the maladaptive spiritual cognitions or 'negative spiritual coping' reported such as "You don't love me, God" (Reynolds et al., 2013).

These struggles fuelled a need for the participants to make sense of the illness and why it had happened to them, leading to a turning point and reframing, which later informed their respective avenues to acceptance of the illness (including differences from peers) and their preferred coping strategies. Several participants reported a new-found gratitude for their survival: for the medical care and/or donor organ they had received, but most frequently, that their illness was not worse.

For other participants, trusted individuals (often family members) played a key role in assisting these adolescents in their adjustment to the illness by being a role model, or by introducing or reinforcing spiritual beliefs to help them make sense of the illness or cope with the treatment. As a result, some participants renewed and strengthened their faith commitments. Some described a more intimate and personalised relationship with the Divine which extended beyond illness-related matters, reflecting both the 'positive spiritual coping' as described by Reynolds et al. (2013) and the trajectory of spiritual growth reported by Good et al. (2010). This was especially true of all those participants who had been transplanted or had been gravely ill. In the only case where direct social support in spiritual meaning-making did not occur, R/S beliefs were abandoned altogether in favour of medical information found through a process of self-directed research.

The participants in this sample who reported negative spiritual cognitions or 'negative spiritual coping' such as 'I do almost feel sometimes like it's a lack of faith', reported abandoning them eventually in favour of more adaptive coping strategies. Interestingly, in two cases, it appears that the seeds of these negative R/S beliefs originated from distal community members rather than the participants themselves or their immediate families.

11.2 Families, peers and Adjustment

As shown in Figure 1, participants' illnesses impacted on their social networks of relatives, friends, teachers and employers. Responses ranged from the helpful to the unhelpful, including unqualified support; fear of getting sick too; unwelcome pity; mistrust; and intense frustration with them for being unable to meet the social, educational and employment and even, spiritual demands.

In line with findings reported by Fredericks et al. (2014), all participants in the sample expressed a wish for a 'normal' life, which often meant the, sometimes, challenging task of managing their own or other people's culturally-mandated expectations of them. However, as discussed in Shaw (2001) chronic illness can hinder the typical course of adolescent development. Older participants recounted considerably more turbulent narratives. This group reported learning from the consequences of past mistakes which compromised their health, such as taking on too much work or drinking excess alcohol, in a bid to meet expectations in the British 'get up and go...culture,' as described by one participant. Some participants were simultaneously subjected to pressure from their African communities to turn to (sometimes conflicting) Christian or traditional solutions for healing. For older participants, it appeared that adjustment to illness in their respective socio-cultural contexts was a dynamic and difficult process, intermingled with the usual physical, cognitive and social development which occurs in adolescence and beyond.

11.3 Spiritual Growth and Personal Development from Illness Adjustment

Successful adjustment to illness and the acceptance of 'difference' from peers, reportedly led to personal development and positive gains for most participants. Some also experienced spiritual growth which appeared to create a secondary pathway to personal growth. For example, one participant who did not subscribe to a particular faith reported learning to pray unselfishly for his family and friends rather than himself. Personal development included confidence about meeting other challenges, caring for others and a greater self-awareness and self-efficacy, to the benefit of their social networks. In this respect participants reported varying degrees of 'transcendence' of the

Cultural and spiritual influences on adolescents with liver disease: A qualitative study type described by Lerner et al. (2006), with most thinking wider than their immediate social circle. Many participants reported their aspirations to help and encourage others, some by becoming doctors or by sharing their experiences, such as their decision to participate in this research. However, no clear relationship emerged between 'transcendence' and spirituality in this sample as was found in their research.

11.4 Clinical Implications

The findings from this study suggest that in some cases it may be helpful for practitioners working with this group to explore cultural and spiritual matters, rather than treat them merely as basic demographic data to be routinely collected. In particular, attention needs to be paid to spiritual or socio-cultural crises which could trigger non-adherence. When multiple beliefs about illness are held, practitioners may need to provide support to strengthen the more helpful ones. Also, it may be necessary to identify individuals who may be influencing the adjustment process, and support the young person to inform or challenge them, as appropriate.

Peer support forums may be beneficial to assist in the adjustment process. Several participants expressed a keen interest in sharing their experiences with others, which may be an important component of their own adjustment journey. Such groups may be especially helpful for recent immigrants who have not built up their own support networks, and may be more vulnerable to resorting to maladaptive coping. Self-esteem building activities may give young patients opportunities to have their parents witness them making positive achievements not available in the wider culture geared for healthy peers. Such an initiative was a crucial juncture in one participant's adjustment journey, and the development of his positive self-image.

11.5 Limitations

Time and recruitment constraints resulted in opportune sampling rather than purposive sampling, limiting the study to 'theoretical sufficiency' rather than purist 'theoretical saturation' (Dey, 1999). A non-religious participant with severe or disruptive illness or who had been transplanted would have been an important negative case but was missing from this sample. Therefore, this study has been unable to shed any light on how such young people may cope.

Further insights may have been made with multiple interviews to build trust and capture possible fluctuations (Charmaz, 1990). Attempts to re-contact participants for respondent validation were unsuccessful, whilst triangulation might have been achieved by also interviewing parents (Mays & Pope, 2000). Finally, it is not understood how this sample might have differed from non-participating patients. For instance, it may be the case that this sample of participants had more satisfactory illness adjustment experiences which they were more willing and able to discuss.

11.6 Future Work

Research into cultural and spiritual influences on illness is still in its infancy across diseases. More research of a narrower scope is needed into adherence, overall functioning, and psychosocial well-being in adolescent patients diagnosed with CLD, including non-transplant recipients, which takes account of cultural, spiritual and other relevant contextual influences. In particular, further investigations (e.g. longitudinal studies) are warranted into the life-cycles of positive and negative spiritual cognitions, and their role in adjustment could be especially informative for health practitioners and

families, given the central role they played in supporting these young people in their adjustment to CLD.

12 Conclusion

Using the grounded theory method, this qualitative study found that a range of cultural and spiritual influences impacted on the adjustment to chronic liver disease in a sample of adolescents and young adults.

Positive spiritual coping influences were typically mediated by a significant individual close to the religious participants. Non-religious participants relied on ignoring their illness and maintaining a grateful, positive outlook.

Participants faced various challenges in managing culturally-mandated expectations placed upon them by themselves and others. Older participants and those with the most severe illness seemed to have suffered greater difficulties relative to their healthy peers. Managing employment, education and social lives (e.g. participation and coping with alcohol) were particular concerns. Grappling with the various challenges of illness sometimes seemed to result in lessons learned, personal development and spiritual growth, to the benefit of other aspects of participants' lives and their respective social networks.

Importantly, it appears that acceptance of illness is not on a simplistic linear path, but is a transitory state, within a dynamic, cyclical process of adjustment, entangled with the universal developmental tasks of adolescence.

This preliminary model can form a starting point for future work.

References

- Annunziato, R. A., Emre, S., Shneider, B., Barton, C., Dugan, C. A., & Shemesh, E. (2007). Adherence and medical outcomes in pediatric liver transplant recipients who transition to adult services. *Pediatric Transplantation, 11*(6), 608-614.
- Baumann, L. C. (2003). Culture and illness representation. In L. D. Cameron & H. Leventhal (Eds.), *The self-regulation of health and illness behaviour* (pp. 242-254). London and New York: Routledge.
- Blakemore, S. J., & Robbins, T. W. (2012). Decision-making in the adolescent brain. *Nature Neuroscience, 15*(9), 1184-1191.
- Charmaz, K. (1990). 'Discovering' chronic illness: Using grounded theory. *Social Science & Medicine, 30*(11), 1161-1172.
- Charmaz, K. (2006). *Constructing grounded theory. A practical guide through qualitative analysis*. London: Sage.
- Children's Liver Disease Foundation (2014). I've just found out my child has Liver Disease: Support series. Retrieved from http://www.childliverdisease.org/file_download.aspx?id=7160
- Dey, I. (1999). *Grounding grounded theory guidelines for qualitative inquiry*. San Diego: Academic Press.
- Erikson, E. H. (1968). *Identity: Youth and crisis*. New York: Norton.
- Fleming, E., Carter, B., & Pettigrew, J. (2008). The influence of culture on diabetes self-management: Perspectives of Gujarati Muslim men who reside in northwest England. *Journal of Clinical Nursing, 17*(5a), 51-59.
- Fredericks, E. M. (2009). Nonadherence and the transition to adulthood. *Liver Transplantation, 15*(2), 63-69.

- Fredericks, E. M., Zelikovsky, N., Aujoulat, I., Hames, A., & Wray, J. (2014). Post-transplant adjustment–The later years. *Pediatric Transplantation, 18*(7), 675-688.
- Good, M., Willoughby, T., & Busseri, M. A. (2011). Stability and change in adolescent spirituality/religiosity: A person-centered approach. *Developmental Psychology, 47*(2), 538.
- Harris, S. K., Sherritt, L. R., Holder, D. W., Kulig, J., Shrier, L. A., & Knight, J. R. (2008). Reliability and validity of the brief multidimensional measure of religiousness/spirituality among adolescents. *Journal of Religion and Health, 47*(4), 438-457.
- Healey, C., Rahman, A., Faizal, M., & Kinderman, P. (2014). Underage drinking in the UK: Changing trends, impact and interventions. A rapid evidence synthesis. *International Journal of Drug Policy, 25*(1), 124-132.
- Helman, C. G. (2007). *Culture, health and illness*. London: Butterworth-Heinemann.
- Herbert, M. (2003). *Typical and atypical development: From conception to adolescence*. Oxford: Blackwell Publishing.
- Lerner, R. M., Alberts, A. E., Anderson, P. M., & Dowling, E. M. (2006). On making humans human: Spirituality and the promotion of positive youth development. In E. C. Roehlkepartain, P. E. King, L. Wagener, & P. L. Benson (Eds.), *Handbook of spiritual development in childhood and adolescence* (pp. 60-72). Thousand Oaks, CA: Sage Publications.
- Maloney, R., Clay, D. L., & Robinson, J. (2005). Sociocultural issues in pediatric transplantation: A conceptual model. *Journal of Pediatric Psychology, 30*(3), 235-246.

- Mays, N. & Pope, C. (2000). Assessing quality in qualitative research. *British Medical Journal*, 320(7226), 50-52.
- Oliver, M., Woywodt, A., Ahmed, A., Saif, I. (2011). Organ donation, transplantation and religion. *Nephrology Dialysis Transplantation*, 26(2), 437-444.
- Pargament, K. I., Smith, B. W., Koenig, H. G., & Perez, L. (1998). Patterns of positive and negative religious coping with major life stressors. *Journal for the Scientific Study of Religion*, 37(4), 710-724.
- Pargament, K. I. (2001). *The psychology of religion and coping: Theory, research, practice*. New York: The Guilford Press.
- Reynolds, N., Mrug, S., & Guion, K. (2013). Spiritual coping and psychosocial adjustment of adolescents with chronic illness: The role of cognitive attributions, age, and disease group. *The Journal of Adolescent Health*, 52(5), 559-565.
- Reynolds, N., Mrug, S., Hensler, M., Guion, K., & Madan-Swain, A. (2014). Spiritual Coping and Adjustment in Adolescents with Chronic Illness: A 2-Year Prospective Study. *Journal of Pediatric Psychology*, 39(5), 542-551.
- Shaw, R. J. (2001). Treatment adherence in adolescents: Development and psychopathology. *Clinical Child Psychology and Psychiatry*, 6(1), 137-150.
- Turner, D. C. (1996). The role of culture in chronic illness. *American Behavioral Scientist*, 39(6), 717-728.
- Village, A., Francis, L. J., & Brockett, A. (2011). Religious affect among adolescents in a multi-faith society: The role of personality and religious identity. *Journal of Beliefs & Values*, 32(3), 295-301.

Section C

List of Appendices

Appendix A: Participant information sheet & study invitation letter

Appendix B: Participant consent form

Appendix C: Medication adherence self-report questionnaire

Appendix D: Brief Multi-dimensional Measure of Religiosity and Spirituality

Appendix E: Interview schedule

Appendix F: Abridged Research journal

Appendix G: A collection of memos showing post-interview notes and development of categories and sub-categories development

Appendix H: line-by-line coded transcript

Appendix I: Diagrams of initial code groupings and early models

Appendix J: Nvivo v10 screen-shots showing progression of category development from an open code

Appendix K: Table of categories, sub-categories, focused codes, and quotes

Appendix L: Participant Journeys through ILLNESS ADJUSTMENT model

Appendix M: Mays & Pope Qualitative Study Guidelines

Appendix N: NRES approval and amendment letters

Appendix O: R &D approval and amendment letters

Appendix P: NRES study summary letter

Appendix Q: End of study report for participants

Appendix R: Author guideline notes for chosen journal

Appendix A



Study Title: Young People with Liver Disease: Culture & Faith

REC Reference Number: 14/SC/0099 PR

We would like to invite you to take part in a research study. This information sheet provides some details about the research, why it is being carried out and how you can participate. Before you decide we would like you to understand why the research is being done and what it would involve for you. Sonia Fihosy, who is carrying out the research, will go through this information sheet and answer any questions you might have. Talk to others about the study if you wish.

What is the research study about?

We would like to understand the issues faced by young people who have liver disease. Spiritual beliefs play an important part in some young people's lives, whilst we are all influenced by the culture around us. We would like to understand how culture and faith affect the way young people view and cope with their illness and treatment.

Do I have to take part?

It is up to you to decide to participate in this study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. Choosing not to take part will not disadvantage you or affect the treatment that you receive in any way.

Why is this study being done?

For most people, being 16-24 years old is a time of change and challenges. We would like to understand more about what it is like to be a young person managing a long-term condition during this time of your life; and in particular what makes things easier or more complicated in managing the illness with respect to your culture and/or faith. Having this knowledge may help liver health professionals to support young people from different cultures and faiths in future.

Why have I been invited? We would like to interview up to 20 young people aged 16-24 years who attend Young Adult Liver clinics at [REDACTED] and particularly those who identify with a faith or consider themselves to be spiritual. If that describes you, we would be interested in hearing from you. However, we may not be able to interview everyone who

contacts us. If you do not want to participate, you do not have to, and you are free to withdraw at any time without giving a reason.

What will happen if I take part?

If you agree to take part, the researcher will arrange a mutually convenient time to interview you. This might be at [REDACTED] Hospital or we can come and visit you at home. Alternatively, the interview could be done remotely by telephone or Skype if this is more convenient for you. The interview will take up to one and a half hours. You will be asked to sign a consent form indicating that you have read and understood this information sheet and that you are willing to participate. The interview may perhaps be on the same day you attend a routine clinic appointment, if you wish. You will be asked about your religion, spirituality and culture in relation to your illness. The interview will be recorded. You do not have to answer any questions you are not comfortable with. There is also a possibility that you may be invited back to do a follow-up interview. However, if this happens, you are not under any obligation to agree.

Who is carrying out the study?

The study is being carried out by Sonia Fihosy, Trainee Clinical Psychologist, as part of a Doctoral qualification in Clinical Psychology undertaken at Canterbury Christ Church University. The study is supervised by Dr. [REDACTED] Clinical Psychologist at the Liver Transition Service, and Dr. [REDACTED], Clinical Psychologist at Canterbury Christ Church University. Dr. [REDACTED], Paediatric Hepatology Consultant is also involved in the project. Neither participation nor withdrawal from the study will affect your routine clinical care.

Will my taking part in the study and my responses be kept confidential?

The information collected in this study will be kept securely in compliance with the Data Protection Act (1998). The data will only be accessible to the researcher and not shared with anyone outside of the research team. Some interviews may be transcribed by a third party, however the recordings will be completely anonymised before being handed over for transcription services (e.g. all identifying names, places and organisations will be edited out).

What is the benefit to you of taking part?

Participation in the study is entirely voluntary and whether or not you take part will not affect your treatment in any way. Participation in the study may help us understand more about how to help young people with liver conditions in the future, but is unlikely to have any direct benefits for you. There is a possibility that you may find it upsetting to talking to the researcher about your illness. If this happens, and you wanted, you could be offered support by a clinical psychologist in the [REDACTED] Liver Transition team or the hospital chaplaincy service.

What if I change my mind after I have agreed to take part?

You may withdraw from the study at any time before, during or after the interview without having to give any reason, just by letting us know you wish to do so by email on sf277@canterbury.ac.uk or tel.: [REDACTED]. If you have already completed questionnaires or done an interview, your data will be removed from the results and securely destroyed.

What will happen with the results of the study when it is completed?

The results will be written up in a thesis and stored at the University. A version of the report may be published in a scientific journal. The written reports will contain anonymous quotes from the interviews or feedback given. It will not be possible for anyone to identify you or any other participant in the reports.

Expenses and payment

All participants who complete the study will receive £10 towards their travel expenses.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the National Research Ethics Service - Committee South Central (Hampshire B).

Questions / concerns

If you have any further questions about the research, please feel free to contact the researcher via email, details of which are below, or in person. In the unlikely event that participating in this research has caused you distress in some way, please contact your clinician.

Contact details of the researcher

Please contact Sonia Fihosy if you are interested in taking part in the study.
Email: sf277@canterbury.ac.uk tel.: 07466 447320

Thank you for taking time to read this information sheet.



Dear _____,

As a service providing care for young people with liver condition we are keen to find out more about your experiences of living with a liver condition. In order to do so, we are wondering if you would be interested in participating in one of the research studies we are currently running? Enclosed you will find a sheet with some more detailed information.

Please note that participation in the study is entirely voluntary. If you do not want to participate, you do not have to, and you are free to withdraw at any time without giving a reason. Choosing not to take part will not disadvantage you, or affect the treatment that you receive, in any way. If you decide to participate, none of the information you provide will be shared with your doctors or the other members of the clinical team.

The researcher, Sonia Fihosy, is carrying out this study as part of a qualification in clinical psychology (DClinpsy). The researcher may approach you at the hospital when you come in for your next clinic appointment, to discuss the study with you.

Please take a moment to read the research information sheet enclosed. If you think you would like to participate please contact Sonia by telephone on _____, or by email sf277@canterbury.ac.uk. Please also feel free to contact Sonia if you have any questions as you are making up your mind. Alternatively, you may speak with Dr. _____ Clinical Psychologist (_____), if you have study-related questions or problems.

Thank you for your consideration.

Yours sincerely,

Dr _____
Consultant _____

Centre Number: ██████████

Study Number: ██████████

Patient Identification Number:

CONSENT FORM

Project Title: Young People with Liver Disease: Culture & Faith

Researcher: Sonia Fihosy

Please initial all boxes

I confirm that I have read and understand the Participant Information Sheet (dated 09-09-2014, version 2.6) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that participation is voluntary and I can withdraw from the study at any time at all, even if I previously agreed to participate. If I withdraw, all of my data will be permanently destroyed and will not be included in the results. I understand that if I do not wish to take any part in the study, my medical treatment or legal rights will not be affected.

I understand that I will complete some brief questionnaires about my health, my culture and religious/ spiritual beliefs. I understand may then be interviewed for up to one and a half hours and if so, that the interview will be recorded. I may later be invited back for a shorter follow-up interview, which I can decline if I wish.

I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from Salomons Centre for Applied Psychology (Canterbury Christ Church University), from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records

I understand that my data will be used and stored anonymously. I agree that quotes from my interview(s) may be included in a published report but any information that could reveal my identity will be removed.

I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Person taking consent.

Date

Signature

Tick this box to receive a results information sheet when this study is completed.

Appendices C-D

These have been removed from the electronic copy.

Appendix E: Interview Schedule

The questions will be flexible, to allow for probing and clarification, as the participants' stories unfold in accordance with the protocol of Grounded Theory (Charmaz, 2002). Examples of the sorts of questions that will be asked are shown below:

Initial Questions

What is culture?

Tell me about how you see your culture. (*If relevant, both inside and outside your family*).

What is religion/faith/spirituality and what do you identify with?

Tell me about what religion or spirituality or having a faith means to you.

How does your view of your culture and compare to your family and friends' views?

What does your religion say about physical illness (*and transplant, if relevant*)?

What does having a serious physical illness mean in your culture?

Intermediate Questions

Looking back on the time when you first realised you had this illness, did having a faith influence you in those early days?

Has your religion or spiritual beliefs affected your view of your illness? (If so, could you describe how?)

Has being spiritual or having a faith helped you cope with having an illness? (If so, could tell me about your thoughts and feelings about it?)

Has being spiritual or having a faith helped you cope with treatment? (If so, what aspects of it help you manage?)

How has your family reacted to your illness? (*If relevant*)

Do you have friends who know about your illness? (If so, how did they know and how have your they reacted to your illness?)

Ending Questions

Has your relationship to religion/spirituality changed over the time you have been ill?

What advice would you give to a young person in your (*place of worship*) or culture who found themselves with a similar illness to you?

Do you think that your illness would affect people from other cultures differently?

Do you think you would you mention cultural matters related to your health* to medical professionals? (If so, how do you think they would respond. If not, why not?)

*examples would be given if requested by participant (e.g. non-disclosure to parents of alcohol use or sexual activity; cultural celebrations conflicting with clinic appointments or medication schedules)

Reference

Charmaz, K. (2002). "Qualitative interviewing and grounded theory analysis". In: Gubrium, J.F. & Holstein, J.A. (eds.), *Handbook of Interview Research: Context & Method*, pp. 675-694. London: Sage.

Appendices F-H

These have been removed from the electronic copy.

Appendix I

Earlier models of sub-categories and categories

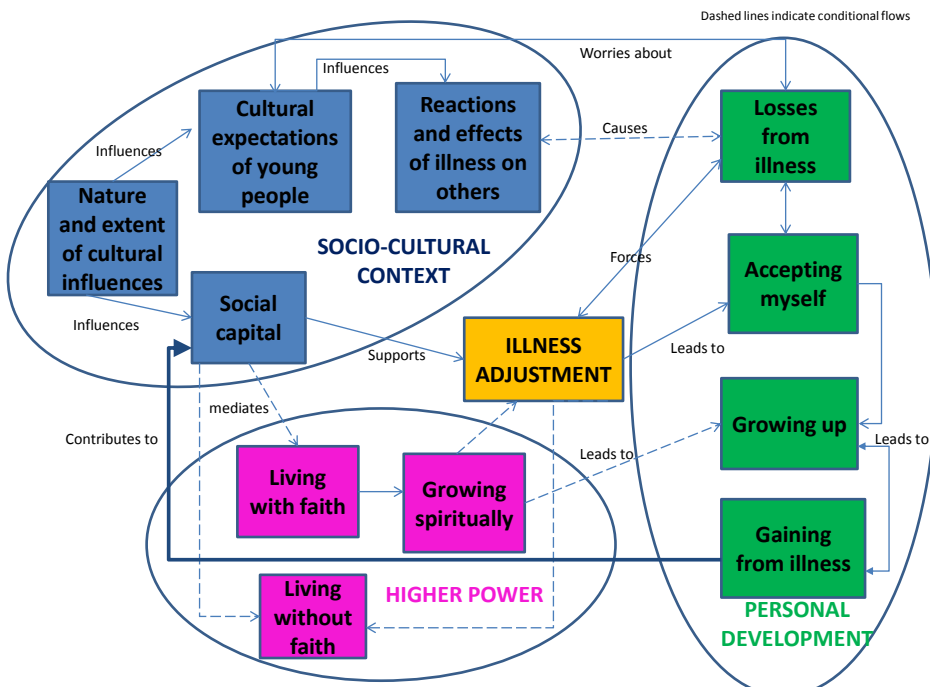
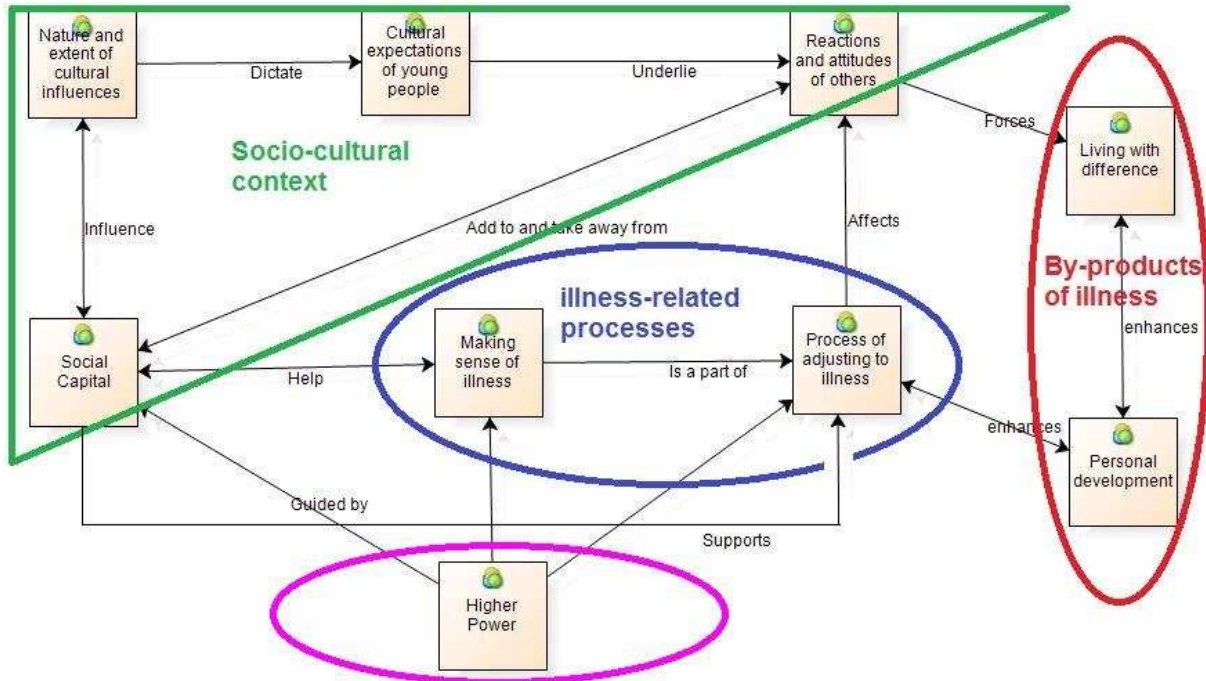
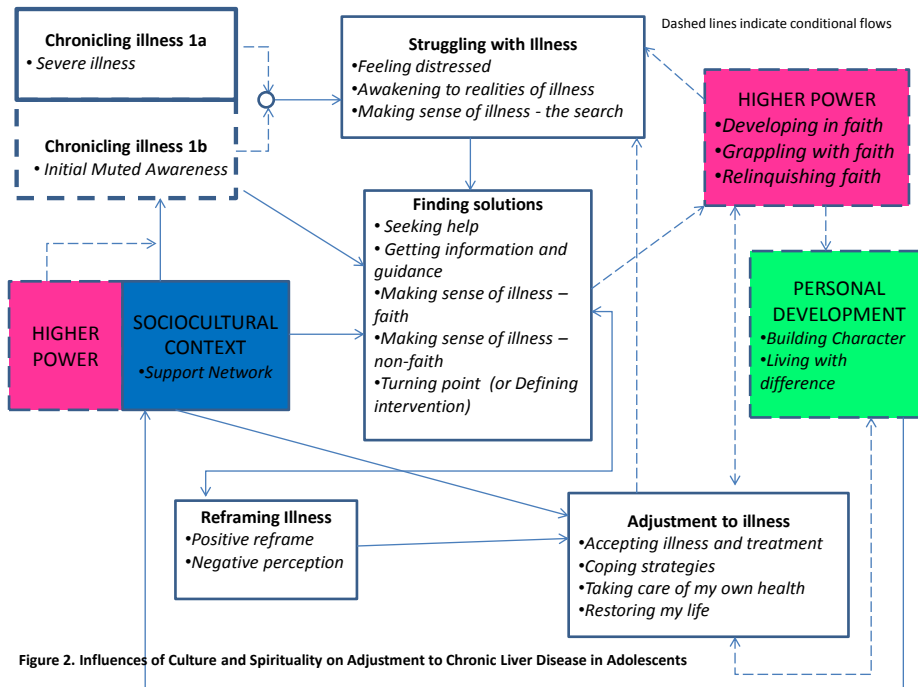


Figure 1 Overarching Model of Cultural and R/S influences on adolescents living with chronic liver disease



Appendix J: Nvivo v10 screen-shots showing progression of category development from an open code

Category: ADJUSTMENT

Sub-Category: Adjusting to illness and Treatment

Focused Code: Restoring my life

Open Code: *Rejecting Sympathy*

BackUp 201503292042.nvp - NVivo

File Home Create External Data Analyze Query Explore Layout View

Look for: Search In: Nodes Find Now Clear Advanced Find X

Name	Sources	Referenc	Created On	Created	Modified On	Modified
Realising seriousness of illness and mortality	3	15	19/03/2015 09:	SF	29/03/2015 17:	SF
Realities of living with illness	3	8	19/03/2015 18:	SF	29/03/2015 17:	SF
Receiving guidance	3	16	19/03/2015 09:	SF	29/03/2015 20:	SF
Reclaiming identity	2	9	19/03/2015 15:	SF	29/03/2015 17:	SF
Reduced importance of people at place of worship	2	5	23/03/2015 08:	SF	29/03/2015 17:	SF
Referring to all-encompassing nature of culture	1	1	21/03/2015 18:	SF	29/03/2015 17:	SF
Rejecting sympathy	1	3	19/03/2015 16:	SF	29/03/2015 17:	SF
Relating culture to religion	2	5	19/03/2015 19:	SF	29/03/2015 17:	SF
Relationship between health and state of mind	1	2	22/03/2015 12:	SF	29/03/2015 17:	SF
Seeing the benefits of illness	2	8	19/03/2015 13:	SF	29/03/2015 17:	SF
Seeking a way out through prayer	2	2	19/03/2015 13:	SF	29/03/2015 17:	SF
Seeking cathartic release of distressing emotions	2	2	20/03/2015 11:	SF	29/03/2015 17:	SF
Seeking guidance	2	8	17/03/2015 21:	SF	29/03/2015 17:	SF
Seeking power beyond your own	1	2	20/03/2015 11:	SF	29/03/2015 17:	SF
Seeking social support from another avenue	1	4	20/03/2015 11:	SF	29/03/2015 17:	SF
Seeking support	1	3	20/03/2015 15:	SF	29/03/2015 17:	SF
Seeking understanding	3	9	19/03/2015 09:	SF	29/03/2015 17:	SF
Selective Disclosure	3	13	19/03/2015 15:	SF	29/03/2015 17:	SF
Setbacks due to illness	1	2	22/03/2015 22:	SF	29/03/2015 17:	SF
Shifting away from and challenging upbringing	1	1	21/03/2015 19:	SF	29/03/2015 17:	SF
Social support from family and friends	3	21	19/03/2015 15:	SF	29/03/2015 17:	SF
Speculation of others' expectations	1	1	22/03/2015 21:	SF	29/03/2015 17:	SF
Struggling to make sense of the illness	1	14	19/03/2015 09:	SF	29/03/2015 17:	SF
Struggling with God's answers	1	6	22/03/2015 12:	SF	29/03/2015 17:	SF
Taking a pragmatic approach	1	4	22/03/2015 18:	SF	29/03/2015 17:	SF
Taking faith seriously	2	15	17/03/2015 21:	SF	29/03/2015 17:	SF
Taking stock of resources	3	9	19/03/2015 12:	SF	29/03/2015 17:	SF
Taking stock of the negatives	3	23	19/03/2015 09:	SF	29/03/2015 17:	SF
Telling one's story	3	32	17/03/2015 21:	SF	29/03/2015 17:	SF

Sources

Nodes

SF 155 Items

Notes: The original open coding was kept in a completely flat structure. Reclaiming identity and Rejecting sympathy are shown in their early stages. ADJUSTMENT later renamed ILLNESS ADJUSTMENT

Codes sorted.nvp - NVivo

File Home Create External Data Analyze Query Explore Layout View

1 2 3

Nodes

- Nodes
 - ADJUSTMENT 5 -15
 - Adjusting to illness and treatment
 - Accepting illness and treatment
 - Coping Strategies
 - Restoring my life
 - Taking care of own health
 - Chronicling illness
 - Finding solutions
 - Reframing illness
 - Struggling with illness
 - HIGHER POWER 3-6
 - Growing spiritually
 - Living with faith
 - Living without faith
 - PERSONAL DEVELOPMENT 4-9
 - Accepting myself
 - Gaining from illness
 - Growing up
 - Losses from illness
 - SOCIOCULTURAL CONTEXT 4 - 13
 - Cultural expectations of young people
 - Challenging the Culture
 - Complying with expectations
 - Navigating the culture
 - Nature and extent of cultural influences
 - Reactions and impact on others
 - Social Capital
 - Relationships
 - Node Matrices

Look for: Search In Restoring my life Find Now Clear Advanced

Restoring my life

Name	Sources	Reference	Created On	Created B	Modified On	Modified B
Wanting to be 'normal'	7	20	20/03/2015 16:37	SF	17/04/2015 11:5	SF
RESTORING MY LIFE	4	9	04/04/2015 18:07	SF	12/04/2015 21:3	SF
Rejecting sympathy	4	6	19/03/2015 16:50	SF	16/04/2015 05:0	SF
Reclaiming identity	2	9	19/03/2015 15:10	SF	16/04/2015 05:0	SF
Living well with illness	2	2	23/03/2015 06:54	SF	14/04/2015 13:4	SF
Deserving a break from the rules	2	4	20/03/2015 17:41	SF	17/04/2015 11:5	SF
Adjusting to illness and treatment	0	0	22/03/2015 19:30	SF	10/04/2015 11:3	SF

After Justin GENERATIONAL CULTURE Reclaiming identity Rejecting sympathy

<Internals\Adesuwa 9\Adesuwa 9> - § 1 reference coded [0.24% Coverage]

Reference 1 - 0.24% Coverage

I don't really tell everybody because I don't like the, oh, aspect of it. I don't, I just hate that, oh...

<Internals\Justin 7\Justin 7> - § 1 reference coded [0.78% Coverage]

Reference 1 - 0.78% Coverage

just because when you initially tell them they, kind of, have a look of pity and I don't like that look. So, I tend not to tell them, so that I don't get treated differently.

<Internals\Khadijah 1\Khadijah 1> - § 3 references coded [0.76% Coverage]

Reference 1 - 0.18% Coverage

but other than that I don't tell people because people when they hear about it they go awwwww

In Nodes Code At

SF 7 Items Sources: 4 References: 6 Unfiltered 100%

Note: The original Open "Adjusting to illness and treatment" was raised to a sub-category and the references re-coded with finer granularity.

THEORETICAL CATEGORY	Sub-category	Focused codes	Number of participants	Example Quotes
SOCIOCULTURAL CONTEXT	Nature and extent of cultural influences	Cultural Capital	4	<p>Remi: "There have been periods where I have not taken my medicines because I have been like "I'm trusting in god" and I'm like "He will heal me," and those periods sometimes they've worked. Sometimes I've been fine and then sometimes, I've been not fine."</p> <p>Farouk: "Back home they all prayed for me together, just for me. "</p> <p>Justin: "But people can never get rid of that, kind of, treating someone different because of it. Whether they know they're doing it or not, they're always going to do it. "</p> <p>Khadijah: "I think my cultural and religious beliefs are like influenced by everyone you are with as well."</p> <p>Tom: "Culture is different religion's way of living really."</p>
SOCIOCULTURAL CONTEXT	Cultural expectations of young people	Challenging the culture	4	<p>Adesuwa: "I just don't believe it. There were times before my mum used to say, oh, 'It's witchcraft' and stuff like that... My mum used to say it because people used to feed it to her, so she used to turn it to me. After that I'm not part of it, like, if that's what you want to do that's your thing."</p> <p>Tom: "and they've been like "Oh you're boring aren't you?" and I'm like "No I'm just not allowed to drink too much."</p> <p>Tom: "you've got my dad who's a different generation who goes to work no matter what even if he's feeling terrible. Whereas me, in the past I've not been to work because I literally have no energy to get up and that's frowned upon by my dad because he's like 'Well why aren't you here, you should be here.'"</p>
SOCIOCULTURAL CONTEXT	Cultural expectations of young people	Navigating the culture	4	<p>Khadijah: "If I were to get married one day obviously before I get married to a guy he's going to have to know about it. "</p> <p>Chloe: "people are like "What? You're not drinking?!" And kind of question that. But then because I almost have an excuse not to "</p> <p>Ollie: "Sometimes I have one drink, but, yes, definitely not on the scale as my friends."</p>
SOCIOCULTURAL CONTEXT	Cultural expectations of young people	Complying with expectations	4	<p>Farouk: "As I was saying I just went to university to because of my dad. Because, I want to be what he wants me to be"</p> <p>Nathaniel: "The reason I say it's not for me is because the way I've been brought up is basically you do that and you're going to suffer and I've tried to not even step into the bad books."</p> <p>Khadijah: "so when I started praying a few weeks later my sister, the 18-year-old she started praying with me, and then after that one by one, everyone kind of prays now on a regular basis."</p>
SOCIOCULTURAL CONTEXT	Nature and extent of cultural influences	Cultural sources and acquisition	5	<p>Nathaniel: "They've influenced me in terms of, like, respecting elders, because where my mum and dad come from it is very important to respect elders and to listen to them because they are, like, more wise"</p>
SOCIOCULTURAL CONTEXT	Nature and extent of cultural influences	Cross-culturally interactions	3	<p>Remi: "...but then I also call not just people who are nigerian I have a few white people and Asian people in my church that I call aunty and uncle as well. I don't know its just a term of respect"</p> <p>Farouk: "I am not ashamed. I'm not afraid. I am open to talking, if it's related."</p>

SOCIOCULTURAL CONTEXT	Nature and extent of cultural influences	Making value judgements of culture	3	Farouk: "We are not allowed to drink alcohol. That is very good. Yeah, That's very good... I love this part of my religion. So I think, it is helping me, it's helping me." Tom: "But I do think there's a pressure in the culture in general. If you don't go out and have a good time and don't have a drink or get so drunk that you can't stand up, you're boring. That's a really wrong thing. The pressure is immense. " Tom: "Sometimes you don't realise how much what I've got wrong with me affects my extended family. " Tom: "I wouldn't be able to sit there and talk to him about what I'm going through because more for his sake than mine." Remi: "I feel it is too much for most people to deal with because its just depressing"
SOCIOCULTURAL CONTEXT	Reactions and effects of illness on others	Negative impact of illness on others	4	Khadijah: "Then everyone kind of accepted it, got used to it, each one"
SOCIOCULTURAL CONTEXT	Reactions and effects of illness on others	Others getting used to my illness	2	
SOCIOCULTURAL CONTEXT	Reactions and effects of illness on others	Positive impact of illness on others	4	Tom: "Its bought the family closer in all respects. I've got cousins who I didn't know I had until about five years ago and they are amazing as well they come and see us all the time. So yeah it's a blessing really in a very weird disguise." Chloe(on her parents): "I think it has been hard on them and also the implications that have come from that, they have had to watch me have blood tests and stuff, which isn't nice. But I think it's kind of, has made them stronger as well"
SOCIOCULTURAL CONTEXT	Reactions and effects of illness on others	Unhelpful Reactions	5	Tom: "[friend] won't ask questions or ask how I am because he's scared of the answer. " Tom: "There's one of them who gets really, really grumpy when I say I can't come out because I don't feel very well, they think I'm just kind of fobbing them off. " Tom: "You've got people there like my supervisor at my old job who used to get very, very annoyed when I used to take days off, he just thought I was faking" Remi: "he believed entirely that we should be healed entirely and he kind of believed as well that it was a lack of faith " Farouk: "But teachers they don't really want to know. School people, school staff, they don't know want to think, they don't wanna discuss it." Adesuwa: "Treat me and tell me to do things that normal people do and not just, 'Oh, no, she can't do that because...'"
SOCIOCULTURAL CONTEXT	Social Capital	Helping others	4	Khadijah: "Because obviously because once people know that your religious beliefs do have an impact on it I think people will take their religion more seriously. If someone is like a Christian or a Hindu but they don't take their religion seriously like I did, but once they read this information or something like oh it does actually help" Farouk (on the support he received when he was very ill): "It made me feel responsible, like how am I going to return that, all of this kindness to them."

SOCIOCULTURAL CONTEXT	Social Capital	Social support	9	<p>Tom: "I've got a big, big group of people here [at hospital] who I feel comfortable to talk to about everything. Which is good. I mean to have those people makes it a lot easier to be here sometimes."</p> <p>Nathaniel: "My mum and my dad they were there all the way."</p> <p>Nathaniel: "friends I've grown up with since primary school some will play nice jokes, for instance, it will get to nine o'clock and one of my friends will say 'Nathaniel' what you doing here, get out of here, time to take your medicine or something like that. "</p> <p>Farouk: "Because I think they deserve it too. They don't deserve, all of the things that they have done for me too, a lot of other mothers and fathers, because I had this very difficult illness. They worry more, They have worried more, they cared more"</p> <p>Farouk: "No I was angry. Then it slowly began to come to this conclusion. The cause is too much internet you keep reading and you know you get fed by it."</p> <p>Justin: "It was very reassuring that people were behind me"</p> <p>Ollie: "My parents are probably the reason why I ignore it so much."</p>
SOCIOCULTURAL CONTEXT	Social Capital	Strength in numbers	6	<p>Farouk: "So it's very important for them to know that everyone's like that who has got the same thing is like that. They are not the only ones."</p> <p>Ollie: "It's not that big of a deal to them because, you know, I've got some friends who don't really drink at all, "</p> <p>Farouk: "I identify myself as being a Shia. I love it, I don't see anything wrong with it but..."</p> <p>Jamal: "Well, I am more religious than the majority of them"</p>
PERSONAL DEVELOPMENT	Accepting myself	Knowing who I am	7	<p>Ollie: "But, then I started to hang out with people outside the private school I realised how many people actually did do drugs"</p> <p>Adesuwa: "Whatever the hell you want to do. Get the chicken [witchcraft antidote]. That's your problem, but it's not me. I'm not, I'm not, you know...it's nothing to do with me."</p> <p>Khadijah: "If I want to get married I don't know if he's going to be able to put up with me constantly being at hospitals..., ... nurses knocking on my door at certain times."</p>
PERSONAL DEVELOPMENT	Accepting myself	Living with difference	5	<p>Chloe: "but it was this thing that made me different from everybody else"</p> <p>Jamal: "it's happened also because of the fact that you know that, like, whether you're upset about it or not you are not going to be able to do it so there is no point on, like, dwelling on it"</p>
PERSONAL DEVELOPMENT	Gaining from illness	Building Character	8	<p>Remi: "I think it's been a very strong growth factor. Because when one's life is plain sailing they have nothing much to think or meditate about I think and so it's definitely given me more to think about, more to ponder on"</p> <p>Jamal: "It's [the illness] made me more serious about my education, yes. I don't know why that is, but it just has."</p> <p>Chloe: "it kind of proves...how strong I can be"</p> <p>Adesuwa: "I had to grow up really fast when I got sick. Maybe that's a good thing because I've been able to help my mum a lot. I've been able to do a lot of things that people my age haven't even caught up to. "</p> <p>Tom: "I believe praying for things that are going to make me better doesn't just help me. It helps my family. It helps my friends and my sisters and everything. So in an unselfish way that's why I do it."</p>

PERSONAL DEVELOPMENT	Gaining from illness	Feeling good about self	3	<p>Tom: "I don't mean this in a big headed way but if it wasn't for me and the things that I've done, all the things that I've been through he [Dad] wouldn't have done that [started coaching a local football team], because he wouldn't have realised how important life is."</p> <p>Remi: "I know a lot of people have been very encouraged by the way that I live and it's not in a big headed way "</p> <p>Chloe: "I think it really changed for me. When I was smaller I thought of it as it's amazing that I'm alive and therefore it is a gift from God, my life means something."</p> <p>Farouk: "I went through all of these difficulties and I survived "</p> <p>Farouk: "I feel very special and important"</p> <p>Nathaniel: "that's one of the things that I'll always remember and I'll feel like basically this condition has done this for me, like, because of this condition I have been able to win this award and it felt good."</p> <p>Nathaniel: "when my mum and dad tell me stories about the whole liver transplant procedure the look that they have on their face I can see that they're happy and that I am their special child in a way"</p> <p>Khadijah: "but now that I have that I have responsibility I have to take action for my own life, I need to control... Like no one's going to be there for me, I'm going to have to stand on my own two feet and go forward on my own. So I've started taking responsibility now."</p>
PERSONAL DEVELOPMENT	Growing up	Making my own choices	4	<p>Adesuwa: "When I'm in hospital, like, I remember sometimes my mum used to be like "Oh, God is the physician!"and...some of the doctors used to be like...So, it made it awkward, so I wouldn't really say things like that,...'You don't need to touch me, I'm healed, see this bible here.'"</p> <p>Chloe: "My views on my religion and stuff I often keep to myself because I find it a much more personal thing. And I don't really think that people need to know that about me. "</p>
PERSONAL DEVELOPMENT	Growing up	Making positive strides	4	<p>Khadijah: "I have to take action for my own life, I need to control... Like no one's going to be there for me, I'm going to have to stand on my own two feet and go forward on my own. So I've started taking responsibility now."</p> <p>Remi: "So I think I just came to a point where I was like "No. OK I think I'm going to let things go now and do more that I want to do"</p> <p>Chloe: "I have survived so much already I can carry on going."</p> <p>Jamal: "I feel like it would be good to be a doctor because I would have been in, like, the other person's shoes as a patient, so I would know how it feels"</p> <p>Justin: "I think it's affected what I want to do because, well, I want to be a doctor, so I think because I've been in that environment and because I have it I'd be able to understand people who are diagnosed with it a lot better because I'd be able to help them."</p> <p>Khadijah: "Thats what I remember, life's a test, life's a test, everything in life is a test."</p>
PERSONAL DEVELOPMENT	Growing up	Making sense of life	4	<p>Tom: "You can see their beliefs are right like most of their beliefs are right to me and vice versa, and also sometimes I think they are wrong and sometimes they think I'm wrong. "</p> <p>Jamal: "Just like, you know, the usual teenager temptations, yes. I don't really think I need to expand. I think you know what I mean [chuckle]"</p>

PERSONAL DEVELOPMENT	Losses from illness	Making sense of life	3	<p>Tom: "I mean I've found it really impossible to keep a job because of my illness."</p> <p>Chloe: "we had somebody talking to us about Gap years the other day and thinking about going away for six months to a different country or something like that. I was like but I'd need at least two blood tests within that time so would I be able to go?"</p> <p>Jamal: "before my medical condition was diagnosed I used to play football and do loads of sports and be very active, but since then, since I've had my major operation, because I have got a scar across my stomach and it is dangerous, I can't play football as much."</p> <p>Adesuwa: "Yes, they want to go on holiday, but they don't want to, like, leave me behind and I can't go so, it's a bit..."</p> <p>Adesuwa: "when I first had my liver transplant they said they were going to close me up three months after, five months after and they didn't. And, I built myself up, I thought okay after this I'm going to do this, I'm going to do that and I the more I built myself up the more the diagnosis came, the more complications came, the more things have been.... So, I found like I built myself to fall down all the time and it will always crush you. Every time is like, oh, no, you can't do this."</p> <p>Khadijah: "I used to be in triple science but because I missed a lot of school they dropped me to double and then because I missed I still couldn't really understand, my attendance was still really bad they dropped me to foundation. Then because I was in foundation I lost my motivation"</p> <p>Remi: "So I think the people taking care of me thing definitely made me regress because I wasn't being taken care of before. I was taking care of other people. "</p>
PERSONAL DEVELOPMENT	Losses from illness	Setbacks due to illness	5	<p>Remi: "Let's get to a really good university'. I was on track to that, I was at a grammar school and I was doing well, then I got ill and that changed dramatically."</p> <p>Remi: "...they used to make jokes like "Oh 'Remi', the sick one!"</p> <p>Remi: "there have been moments that haven't been so easy and they haven't been as fun, like coming to terms with the fact that I am 21 and just starting university"</p> <p>Tom: "OK I was 18 but I hadn't had the chance to grow up like other people had so that was my first chance to go and do the things that people had been doing for the last two years."</p> <p>Khadijah: "I barely took life seriously"</p> <p>Remi: "Like my mum even says a lot that I, before the illness came I was such a helping hand to her, like I used to do so much for her and with her, I was almost like the mum kind of and she was like the dad. "</p>
PERSONAL DEVELOPMENT	Losses from illness	Before illness	7	<p>Justin: "so I was brought up on the idea that God exists and, so I think up until that point...and at 11 I didn't really have an idea of life outside of God existing, so I just assumed there was a God."</p> <p>Adesuwa: "I visited once maybe in 2011 before I got really sick. It's nice I loved it there. I thought when I went there...my mum always used to say 'I'm going to send you back to Nigeria!' I was thinking if I only knew it was this good I would have just gone."</p>

Illness Adjustment	Adjusting to Illness	Coping Strategies	7	<p>Remi: "Yeah, there's no question about that [faith helping]. I think I would definitely have gone crazy."</p> <p>Chloe: "Although, there are points when it [faith] makes it easier because there are points when I am going through treatment and I find it difficult and I know I can pray and talk to God."</p> <p>Justin: "I don't tend to tell people about it"</p> <p>Ollie: "Just ignore it. Ignore the unknown."</p> <p>Adesuwa: "You're thinking above it, so you're in a calm collective place... take yourself out of that situation...Where I used to be in pain here my mum used to put me in the wheelchair and we used to just stroll me around like outside and the fresh air...you never used to think of the pain because you're seeing different things and you're not just seeing four walls of this hospital... you just forget about the pain. The pain might still be there, but it won't be so severe."</p> <p>Khadijah: "I hate it more than anything taking my medicine I hate it. But it's something I've learnt to do. Rather than saying I hate it I've accepted it"</p> <p>Remi: "I think it was just realising that this is probably going to stay with me for all of my life"</p> <p>Farouk: "So there was a big, big change in my body, how it looks, how it works. I didn't like myself at all, it took some time for me to, I would say after eight months then I could talk about it...I have adapted to it."</p>
Illness Adjustment	Adjusting to Illness	Accepting illness and treatment	3	<p>Chloe: "just sort of brush it off and not really think about it"</p> <p>Justin: "At first it's difficult, but then it, kind of, drums into your daily routine and you just, like, get up take your pills, brush your teeth, get dressed, go to school..."</p> <p>Tom: "But then again when I was here in a coma and waking up from that and realising how lucky I am to be here I guess that has changed my point of view on a lot of things like drinking and like going out and the pressures of doing that."</p>
Illness Adjustment	Adjusting to Illness	Restoring mylife	7	<p>Khadijah: "I'm fine and it made no difference to me. I still am who I am. I'm still 'Khadijah'"</p> <p>Justin: "just because when you initially tell them they, kind of, have a look of pity and I don't like that look. So, I tend not to tell them, so that I don't get treated differently."</p> <p>Ollie: "so if I tell it to someone it sounds a lot worse than it is. And, then I guess you get that sense of pity and, you know, that sort of...then they sort of treat you differently, so I guess I don't really like that"</p> <p>Adesuwa: "Take me off the bat of who I am, don't...see 'Adesuwa' first, instead of liver disease or the operation first."</p> <p>Adesuwa: "I still study. As soon as I came out of intensive care I went back to uni...I want to know that I tried, even if I don't make it, even if I'm not here by the end of this year."</p> <p>Nathaniel: "And, I never feel..., that I'm not treated the same. "</p>
Illness Adjustment	Adjusting to Illness	Taking care of own health	6	<p>Remi: "And I had to come slowly to the realisation that I needed to do more to help myself"</p> <p>Jamal: "Yes, it's not easy at all, but what kept me taking it was because, like, if I've decided to stop taking it for a bit or whatsoever, like, I would not want to have another, how do I say it, like, episode of my illness again."</p> <p>Nathaniel: "She's [Mum's] been leaving me, like, kind of, independent to give over my own information, so I have to learn, kind of, but, yes, it's great knowing"</p>

Illness Adjustment	Chronicling illness	Initial Muted Awareness	3	<p>Remi: "I didn't realise, as well I think, how big it was as well."</p> <p>Remi: "she doesn't make things big but she also makes things fun. so like in the time when it was happening she was always like well lets go and something, or lets go and do something, so it wasn't like it was all associated with bad memories and bad things it was merged in with good things"</p> <p>Farouk: "I was angry."</p> <p>Justin: "I lost faith. I blamed God, myself for what had happened"</p> <p>Adesuwa: "I was in hospital all the time"</p> <p>Adesuwa:"I remember a few weeks before my liver transplant they were like, oh, we can't find a liver, blah, blah, blah and that my mum should call a priest"</p>
Illness Adjustment	Chronicling illness	Critical Illness	5	<p>Tom: "when I got really bad and literally within seconds there were tents and doctors around me trying to pump stuff in to me. "</p> <p>Jamal:"one time I had a very bad experience with it and I lost a lot of blood. When I went to hospital I was very weak and the doctors were doubting whether I would stay alive"</p>
Illness Adjustment	Chronicling illness	Turning Point	10	<p>Tom: "But then again when I was here in a coma and waking up from that and realising how lucky I am to be here I guess that has changed my point of view on a lot of things like drinking and like going out and the pressures of doing that."</p> <p>Farouk: "Yeah some of my friends...From college... people who talked to me and calmed me down. Again, it didn't happen immediately, but it took it's time.</p> <p>Jamal: "When I went to hospital I was very weak and the doctors were doubting whether I would stay alive and whatsoever, but I did and since then I just, like, yes, believe in God a lot. "</p> <p>Ollie: "And, that's the one thing the doctors always said to us, you know, don't worry about the future, take it day by day."</p>
Illness Adjustment	Finding solutions	Getting Information and guidance	7	<p>Khadijah: "My sister said to me 'Whenever you are wondering where God is and you're angry just remember a teacher is always quiet during a test.'"</p> <p>Tom: "My auntie who is a Christian says that what I have got wrong with me is because of God, but he's done it to make me a stronger person. For me, I believe that in a certain way"</p> <p>Jamal: "When I had my major operation that was more or less solved the problem, when I go to the mosque and speak to relatives or close friends or whatsoever they would say that my recovery was due to my strong faith in God. They say that even though, like, it's a test and stuff they say that if you weren't religious and praying and doing this during the time then you might not have made it through"</p> <p>Ollie: "that's the one thing the doctors always said to us, you know, don't worry about the future, take it day by day"</p>
Illness Adjustment	Finding solutions	Seeking help and information	4	<p>Chloe: "I remember going to camp this year and speaking to one of the leaders about drinking and getting drunk and stuff "</p> <p>Justin: "Yes, by the fact...researching did help because it, like, helped me let go of this, this is my fault, but no one else is to blame"</p>

Illness Adjustment	Finding solutions	Making sense of illness - faith	5	<p>Chloe: "I started thinking about it as a plan"</p> <p>Farouk: "God is testing you to see how strong your beliefs. So they said 'Maybe your test is more difficult, just make sure you come out of it proud. You don't go off, don't go off the track.'"</p> <p>Justin: "I felt like maybe I'd done something and I was being punished for it or, like, I'd do something in the future and this is punishment for something I was going to do."</p> <p>Tom: "that upset him because the reason I've got what I've got wrong with me comes from his side of the family so he blames himself for it. Which he shouldn't but he does, as any parent would I suppose. "</p> <p>Justin: "No, I don't feel like I was given it for a reason, like, I was given it because it's in my genes and I'm just going to have to deal with it, yes."</p> <p>Nathaniel: "Personally I think it's random because one, like, there's no other traces of it in my family of anybody else having it"</p> <p>Jamal: "It just might be a horrible illness, like, people get ill every now and then."</p> <p>[Interviewer: "Would you say that there are any good things about the fact that you've had this? Anything positive that's come out of it in any way?"] Ollie: "Not really, no."</p>
Illness Adjustment	Finding solutions	Making sense of illness - non-faith	5	
Illness Adjustment	Reframing illness	Negative perception	1	
Illness Adjustment	Reframing illness	Positive reframe	9	<p>Tom: "So yeah it's a blessing really in a very weird disguise. It's brought us all a lot, lot closer which is good, very good."</p> <p>Adesuwa: "In some way I am a bit happy God put me in this situation not that it happened, not that I'm happy it happened, but he put me in that situation because maybe I wouldn't have got closer to God."</p> <p>Khadijah: "Because if I didn't get ill, God knows I could have been, I wouldn't have been praying, anything could have happened to me. Even though that happened I gained something as well. I'm stronger in my faith now, I feel closer to god, I feel closer to my sisters now that we all pray and we stopped arguing that much"</p> <p>Khadijah: "This is your liver, this is one of the organs you need to function your body and when you don't have that you could die."</p>
Illness Adjustment	Struggling with illness	Awakening to realities of illness	4	<p>Tom: "I was very like 'Well, I'm better now so why can't I do the things I want to do?' OK I was 18 but I hadn't had the chance to grow up like other people had so that was my first chance to go and do the things that people had been doing for the last two years."</p> <p>Remi: "As time went on and things started getting more and more difficult thats when, that's when I started struggling a bit"</p> <p>Farouk: "So there was a big, big change in my body, how it looks, how it works. I didn't like myself at all"</p>

Illness Adjustment	Struggling with illness	Feeling distressed	7	<p>Khadijah: "I was just like, angry at everyone and everything"</p> <p>Tom: "So it affects a lot more than just having to come to hospital or anything like that. It affects literally everything, every aspect of life that you wouldn't even think about."</p> <p>Chloe: I think it fluctuates so much. There are points where I am totally rocking this, and then there are points where I am at rock bottom. So I think it comes and goes to be honest.</p> <p>Ollie: "there are sometimes where, obviously, I've wished I didn't have it because...I guess the only thing that really annoys me is that when I was growing up obviously my liver was a lot bigger and it was really massive and so it used to make my tummy pop out and it used to give me a, sort of...and I still have a bit of a weird figure, like, on the top half of my body."</p> <p>Farouk: "I just wanted to die. I didn't, like the idea of living at all because I was being tortured."</p> <p>Khadijah: "...but then the liver disease came so it was just like another cycle because I went back to the angry phase. then I was in that angry phase for a long time."</p>
Illness Adjustment	Struggling with illness	Making sense of illness - the search	7	<p>Tom: "Because when you are younger I don't think it makes sense anyway. Even for adults it doesn't make sense sometimes, so I mean now it doesn't make sense."</p> <p>Chloe: "Yeah. I think also if you added in different people's opinions to it, as well it gets even more confusing."</p> <p>Justin: "So, when I was diagnosed I was, kind of, like, why am I going through this? "</p> <p>Adesuwa: "...when I was sick is that they'd say, oh, it's witchcraft"</p> <p>Farouk: "Basically there are stupid people in this world, stupid people with no brain, they pretend that they are religious. When I was very little I used to hear the imams that said if you have, make a big sin in your life god is allowed to take it back in your life. So one of the things is, ' if your son is very sick it is because of what you have done in the past.' So that's one of the things that we, I have heard before"</p>
HIGHER POWER	Growing spiritually	Constructing a faith identity	2	<p>Tom: "I mean I do pray sometimes. But I wouldn't say I have a particular faith or religion."</p> <p>Remi: "I do find it a bit hard in the sense like, well slavery and so many things were done in the name of Christianity"</p> <p>Khadijah: "I'm stronger in my faith now, I feel closer to God"</p>
HIGHER POWER	Growing spiritually	Developing in faith	6	<p>Jamal: "I never used to pray a lot, I just used to, like, couldn't be bothered, but like now I make the effort to pray five times a day"</p> <p>Adesuwa: "But, I think that it just, like, for me now, God is, like, my friend"</p>

HIGHER POWER	Growing spiritually	Grappling with faith	4	<p>Remi: "I've come to a point where it's like 'Let me do what I need to do to operate now and if it is that my faith is weak, grow my faith, but don't mess about with my life because then I am just wasting it away, kind of, by not taking my medicines and keep on testing it out.' Because I still don't know entirely if it is faith. "</p> <p>Chloe: "And also if I think about it too hard, if I really start thinking about my faith and then I think about my transplant and I try and fit the two together it gets difficult because they don't match, at all, and that makes it difficult, as well."</p> <p>Farouk: "So I said, "Ok, there is no God. Definitely. At all."But then that started to fade away, and then I changed my belief "</p> <p>Adesuwa: "but nothing was changing. I felt like it was even getting worse the more they prayed, so I just didn't."</p> <p>Adesuwa: "They were trying to control my bile obstruction then that cut of supply to my liver and my liver was doing bad anyway, so it made it worse. Then I had to have my second liver transplant and at that point I just stopped praying. I stopped completely."</p> <p>Khadijah: "because I know that God tests those that he loves and I know that, I strongly feel that he is watching me and he is testing me. "</p>
HIGHER POWER	Framing life with faith	Making Divine Attributions	4	<p>Chloe: "I believe that God loves everything, he does everything with the best intentions even if it doesn't seem that way, you have to look. "</p> <p>Farouk: "God is testing you"</p> <p>Jamal: "Yes, yes, almost anything that happens in my life I feel is part of God's plan."</p> <p>Tom: "to believe in something else and to be able to put whats going on in your life through that instead of family and friends. It's just another release if that makes sense."</p>
HIGHER POWER	Framing life with faith	Requesting Divine Interventions	5	<p>Khadijah: "You know if you ask God for forgiveness or you want something, or you say 'Thank you', I, kind of, just literally, the second after I finish my prayer, I feel better. I feel that cleared my mind. That actually helped me, I needed that. Its kind of like that. That little positive attitude. It impacts on me."</p> <p>Farouk: "I was, I had nothing to do with religion since I would say eight to thirteen years old. I didn't know anything about religion. I was just living my life."</p>
HIGHER POWER	Living without faith	Not believing	2	<p>Jamal: "I wasn't religious at this time"</p> <p>Justin: "God doesn't exist this is genetics. It's science. "</p>
HIGHER POWER	Living without faith	Dormant Faith	2	<p>Adesuwa:"Well, when I was growing up it did mean a lot to me. Then once I hit, like, I think 13, 14 it didn't really mean anything to me. I would go to church, but I'd be going to church because my mum said I had to"</p> <p>Khadijah: "Yeah that was before I had this disease. I was always that kind of person. I only used to pray when I felt bad or when... I never used to pray, I'm not going to lie I never used to"</p>
HIGHER POWER	Living without faith	Relinquishing faith	1	<p>Justin: "when I was first diagnosed with it I completely lost faith "</p>

APPENDIX L

Participant Journeys through ILLNESS ADJUSTMENT model

	'Tom' Example Quotes	'Adesuwa' Example Quotes
Socio Cultural Context	"and they've been like "Oh you're boring aren't you?" and I'm like "No I'm just not allowed to drink too much."	"I just don't believe it. There were times before my mum used to say, oh, 'It's witchcraft' and stuff like that... My mum used to say it because people used to feed it to her, so she used to turn it to me. After that I'm not part of it, like, if that's what you want to do that's your thing."
Higher Power Influences	"But I wouldn't say I have a particular faith or religion. I'm quite aware of Christianity because I went to a Church of England school, but I wouldn't say that I do have a religion."	"When I changed my whole perspective, like, that's when I just start going to church because my mum said I really had to go to church"
Struggles (->Grappling with faith)	"OK I was 18 but I hadn't had the chance to grow up like other people had so that was my first chance to go and do the things that people had been doing for the last two years. I shouldn't have done it but I did"	Yes, 2012 and then in 2013 I got even worse with my liver. They were trying to control my bile obstruction then that cut of supply to my liver and my liver was doing bad anyway, so it made it worse. Then I had to have my second liver transplant and at that point I just stopped praying. I stopped completely.
Finding Solution/Turning point	"I regret that now because I now realise how much of a gift I've got" "But then again when I was here in a	"I've never been scared of death. Maybe because I've been hit with so many things I've just never been scared. But, then my mum was really sad and

	<p>coma and waking up from that and realising how lucky I am to be here I guess that has changed my point of view on a lot of things like drinking and like going out and the pressures of doing that.”</p>	<p>the only thing I prayed for was for them to not be sad. I don't want them to be sad. I didn't really care that much about myself and I just don't want them to be sad.”</p> <p>“At that time I prayed and I prayed and I prayed ... just put me in a situation where they won't be sad anymore.”</p>
Reframing	<p>“So yeah it's a blessing really in a very weird disguise. It's brought us all a lot, lot closer which is good, very good.”</p>	<p>“In some way I am a bit happy God put me in this situation not that it happened, not that I'm happy it happened, but he put me in that situation because maybe I wouldn't have got closer to God. Maybe I would be living a whole different life and have a whole different perspective. I had to grow up really fast when I got sick. Maybe that's a good thing because I've been able to help my mum a lot.”</p>
Adjustment	<p>“I want to work. I love to work. I hate sitting at home doing nothing but I just know that there's no point because every time over the last four years that I've started a job I've got very ill, and I've got to the point where I think well there's no point in me going around in circles. I might as well stick at one thing get myself better and then go and find a job instead of taking four steps forward and ten steps back.”</p>	<p>“...do you know in fact I don't even think five years into the future because I've learnt that sometimes...because when I first had my liver transplant they said they were going to close me up three months after, five months after and they didn't. And, I built myself up, I thought okay after this I'm going to do this, I'm going to do that and I the more I built myself up the more the diagnosis came, the more complications came, the more things have been.... So, I found like I built myself to fall down all the time and it will always crush you. Every time is like, oh, no, you can't do this. “</p>

<p>Personal Development</p>	<p>“I believe praying for things that are going to make me better doesn’t just help me. It helps my family. It helps my friends and my sisters and everything. So in an unselfish way that's why I do it.”</p> <p>“Because if you do things that make you ill it doesn’t just affect yourself it affects your family and everyone else.”</p>	<p>"Some people milk the situation, like, when I was in hospital for [long period of time] and there was people, like, just sat there and just let the disease take over them, but sometimes you just have to move on, like. It’s hard. It’s not easy. I’m definitely not going to sit here and be like, oh, it’s okay, but you just have to deal with it and don’t let it take you over because it will put you in a state of really sad, like, sad, sadness and then you just get in a rut of doing the same thing every single day and that’s boring."</p>
<p>Spiritual Development</p>	<p>“I’ve sat there and thought well if god does exist and he’s done it to make me stronger its worked, and spoken to him through praying and stuff and that connection sometimes is there for me. so yeah in a way I do think that it does have a lot to do with things but to me more when things aren't' going well. “</p>	<p>“I think that it just, like, for me now, God is, like, my friend”</p>

Appendices M-R

These have been removed from the electronic copy.