

What is the Impact of Below Ankle Amputation upon Quality of Life for Individuals with Type 2 Diabetes Mellitus?

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Table of Contents

Title page	1
Tables.....	8
Figures	9
Copyright Statement	10
Acknowledgements	12
List of Abbreviations	13
Glossary of Terms.....	15
List of Publications.....	17
Contribution to Writing	17
Contribution to the Thesis	17
Abstract.....	18
Prologue.....	19
Motivations to carry out the research, arriving at the Research Question	19
Main Research Question.....	22
Subsidiary Question	22
Research Aims.....	22
Objectives	23
Deciding upon the Data Collection Site.....	23
Researcher Reflexivity, a necessity throughout the research journey.	25
Experiences during the Research: Shaping of the Analysis.	27
Introduction to the Chapters of the Thesis.....	29
Chapter I: Framing the Research	32
Introduction	32
Diabetes and Amputation.....	33
Emergence of Quality of Life Assessment in Health: The Medical Paradigm Shift	36
Defining Quality of life	40
Working Conceptualisation of Quality of Life for this Research	48

Impact of Amputation on Quality of Life	50
Synopsis of Published Article Prior to Data Collection Commencing	50
Subsequent Reading Prior to Data Collection and Analysis Commencing.....	51
Refreshed Literature Review of the Impact of Amputation on Quality of Life	58
Searching for Literature	58
Overview of the Included Studies.....	61
Qualitative Studies	75
Quantitative Studies.....	82
Findings Which Provide Detail on Below Ankle Amputation.....	114
What Information can be Gleaned from the 10 Studies?.....	115
Conclusion of Literature Review: The identification of ‘Body Image’ ‘Physicality’ and ‘Social’ as <i>a priori</i> codes for analysis	117
Overarching Research Question	117
Chapter 2: Research Methodology	119
Introduction to the Methodology Chapter	119
Approach to the Research Question	119
Consideration of Theoretical Position	121
Consideration of Research Methods Adopted	122
Seating the Research within its Method	123
Chapter 3: Method	125
Introduction to the Method Chapter	125
Data Collection Site	125
Permission for Site Access	126
Ethical Issues	126
Informed Consent.....	127
Non-maleficence.....	127
Right to Withdraw	127
Conduct of the Study.....	128
Confidentiality	128
Anonymity	128
Risks to the Researcher	129
Recruitment.....	129
Defining the Population.....	129
Defining Amputation	130

Defining Non-traumatic Amputation.....	133
Inclusion Criteria	134
Exclusion Criteria.....	134
Sample Size.....	135
Recruitment Strategy for the Individual Interviews.....	135
Purposive Sampling.....	135
Participant Recruitment.....	136
Interview Preparation.....	137
Interview Process	141
Data Analysis.....	142
Coding	142
Definition of a Code.....	142
Definition of a Theme	142
Approach to Coding.....	143
Attribute Coding.....	143
Naïve Reading of the Transcripts.....	143
In Vivo Coding.....	144
Interpretative Concept Coding	144
Theme Development	144
Researcher Reflexivity during Data Analysis	145
NVivo 20 for Organisation	146
Thematic analysis via Template Analysis.....	147
Template Analysis Procedural Steps	147
Assessment of the Quality of the Research.....	150
Researcher's Credibility for Undertaking the Project	151
Credibility of the Research Project	152
Credibility of Data Collection	152
Dependability	153
Confirmability & Credibility of the Analysis	153
Transferability.....	154
Chapter Summary and Introduction to the Results Chapter	154
Chapter 4: Findings Exploring Participants and Thematic Analysis.....	155
Introduction to the Findings Chapter.....	155
Attributes of Participants	155

Concluding Thoughts on Demographic Data Presented	167
Exploring the Transcripts: Impact of Below Ankle Amputation on Quality of Life.....	168
Definition of a Code	168
Definition of a Theme	168
Consideration of <i>a priori</i> Codes Body Image, Physicality and Social	171
Template Development: Application to a Further 10 Transcripts	173
Coping with Amputation – Incorporation of Medical Management Theme	175
Consequences of Amputation: –Loss of Spontaneity from Life and Planning for Activity.....	177
Consequences of Amputation: Concern for New Foot Problem	178
Application of the Template to All Transcripts	179
Definitions for Themes	181
Adaptation	181
Am I normal?	181
Attitude to Amputation.....	181
Body Image	182
Concern for a new foot problem	182
Control	182
Dignity, Pride, Persona.....	182
Economic Situation	182
Emotional.....	183
Environmental	183
Getting back to normal	183
Life Perspective.....	183
Medical Management.....	183
Other conditions impacting on QoL	184
Pain.....	184
Photos of amputation	184
Physicality	184
Planning for Activity.....	184
Relationships.....	185
Social	185
Time for Rehab	185
Further Reflection upon Analysis: Creation of Overarching Themes.....	185
Chapter Summary and Introduction to the Findings Chapters	188
Chapter 5: Findings on Acceptance, Coping strategies and Adaptation	189

Introduction to Acceptance Findings	189
Presence of Others within the Interviews.....	190
Acceptance the Amputation Needed to Happen.....	191
Adaptation to Amputation	193
Coping Strategies Identified in Participants Purporting a Worsened Quality of Life	206
Aspects Negatively Impacting upon Adaptation	208
Lack of Information to Prepare.....	208
Inconsistent Post-operative Care	212
Environmental	217
Discussion of New Knowledge Elicited from Exploring Adaptation and Coping Strategies.....	225
Discussion of New Knowledge Exploring Aspects Negatively Impacting upon Adaptation.	233
Chapter 6: Findings on Understanding the impact of amputation upon Quality of Life	238
Introduction to Impact of Amputation Findings.....	238
Self-identity	239
Physicality	240
Emotional Identity.....	248
Economic Identity	252
Body Image	256
Dignity, Pride, Persona.....	259
Social Support	261
Partner relationship.....	262
Family Support	266
Social life	269
Social Isolation.....	271
Environmental.....	272
Other Health Conditions Impacting Quality of Life	273
Summary of Themes Identified	276
Chapter 7: Discussion of Findings relating Impact of Amputation upon Quality of Life	278
Self- identity & Body Image	278
Emotional: Seeking the Positive	283
Social Support	285
The importance of Partner, Family and Friends	285
The importance of medical team support	287

Other Health Conditions Impacting Quality of Life	289
Adaptation and Quality of Life: A Symbiotic Relationship	290
Chapter 8: Synopsis of Findings and Conclusion	294
Precis of the Research Process.....	294
Synopsis of Findings	295
Changes to the Author following the Research Process.....	297
Conclusion.....	298
Implications of the Research	299
Implications for Future Research.....	300
Implications for Practice	300
Continuation of Work.....	303
Work Already Completed	303
Work in Planning	303
References.....	305
Appendices	346
Appendix 1 Application of Hawker et al's Critical Appraisal Tool to Studies Included in the Literature Review	347
Appendix 2 Feedback from Quality of Life Presentation Workshop.....	350
Appendix 3 Documentation Forming Local Research Pack	355
Research Protocol	355
Participant Information Sheet	361
Consent Forms.....	364
Interview Guide	366
Copies of HRA and REC Approval letters.....	368
Certificate of Good Clinical Practice eLearning	376
Promotional Poster for Research	377

Tables

Table 1 Defining and Measuring Quality of Life	42
Table 2 Topics explored relating to patient experience and diabetes related amputation.....	53
Table 3 Search Terms used to Retrieve Research Exploring Impact of Diabetes Related Below Ankle Amputation upon Quality of Life.....	58
Table 4 Included Study Characteristics.....	62
Table 5 Summary of Tools used in Diabetes related Amputation research purporting to determine Quality of Life	83
Table 6 Minor Lower Extremity Amputation Definitions from Published Research.....	130
Table 7 Attributes of Participants.....	156
Table 8 Age Range of Women and Men Interviewed.....	164
Table 9 Level of amputation	165
Table 10 Level of amputation compared to level of deprivation	166
Table 11 Mapping Coping strategies identified in this research to Published Frameworks for Coping and Adaption	229
Table 12 Impact of Aspects identified as negatively impacting upon Adaptation.....	232
Table 13 Application of Hawker et al's (2012) Critical Appraisal Tool to Studies Included in the Literature Review	347

Figures

Figure 1 Hierarchy of Goals of Health Care (adapted from the American Public Health Association 1967)	36
Figure 2 Proposed Conceptual Model of Quality of Life Adapted from Schalock et al. (2016) .	49
Figure 3 PRISMA diagram (Page et al, 2020)	60
Figure 4 Summary of Data Analysis Process	144
Figure 5 Initial Coding Template derived from sub-set of 10 interviewed	170
Figure 6 Change of Coding template when applied to a further 10 transcripts	174
Figure 7 Coding Template when applied to all Transcripts	180
Figure 8 Factors as they relate to Adaptation to amputation and quality of life	187
Figure 9 Active and Passive Coping Strategies Utilised by Participants.....	224
Figure 10 Components of Self-Identity and How this could Impact on QoL.....	239
Figure 11 Aspects Relating to Social Support.....	261
Figure 12 Factors important to Quality of Life for Individuals with Diabetes Related Below Ankle Amputation	277
Figure 13 Conceptualisation of Quality of Life for Individuals with Diabetes after Below Ankle Amputation.....	292

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Dedicated to Cherry and Levers, who lived.

*Live! Live the wonderful life that is in you! Let nothing be
lost upon you. Be always searching for new sensations. Be
afraid of nothing.*

Wilde (2012, p.79)

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List of Abbreviations

Abbreviation	Meaning
BIDQ	Body Image Disturbance Questionnaire
DFS-SF	Diabetic Foot Ulcer Short Form Questionnaire
EQ-5D	European Health-related Quality of Life 5 Dimension Instrument
HADS	Hospital Anxiety and Depression Scale
HRQoL	Health-related Quality of Life
iDEAL	Insights for Diabetes Excellence, Access and Learning
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NRS	Numerical Rating Scale for Pain
NSF	National Service Framework

Abbreviation	Meaning
PAIS	Psychosocial Adjustment to Illness Scale
QoL	Quality of Life
QOLL	Quality of Life Ladder Measure
SF-36	36 Item Short Form Health Survey
SIP	Sickness Impact Profile
TAPES	Trinity Amputation and Prosthesis Experience Scales
WHOQOL-BREF	World Health Organisation Quality of Life Brief Measure

Glossary of Terms

Term	Definition
Active Foot Problem	Specifically related to the diabetic foot. Includes issues such as ulceration, infection, gangrene, Charcot arthropathy or suspicion of Charcot arthropathy.
Amputation	Within the thesis, amputation refers to diabetes-related amputation, unless otherwise stated.
Below ankle amputation	Any amputation occurring distal to the ankle joint.
First Ray amputation	Amputation resulting in removal of the 1 st proximal and distal phalanges, 1 st metatarsal, and medial cuneiform bones.
Foot ulcer	Injury to the skin and/ or underlying tissues below the ankle.
Hallux amputation	Also referred to as the 1 st toe. Believed to have more impact on gait than removal 2 nd , 3 rd , 4 th , or 5 th toes.
Minor Amputation	<p>Amputation below the ankle.</p> <p>Despite this term being widely utilised within published research and reports, the term ‘minor amputation’ has purposely been omitted from research documentation, with the Researcher preferring to use ‘below ankle amputation’ within the thesis and all paperwork pertaining to the study.</p> <p>This decision was for two reasons. Firstly, there is lack of clarity</p>

Term	Definition
	<p>surrounding what level constitutes a ‘minor’ amputation. Secondly, the research was patient facing. If viewed outside of the medial field, minor is defined as unimportant or of little consequence (Oxford English Dictionary, 2019). As individual interviews were undertaken with the public, the use of the term ‘minor amputation’ may have impacted upon the recruitment to the project and of participants sharing their experiences if they perceived the researcher thought their amputation was trivial or had negligible effect.</p>
Toe amputation	Amputation of the phalanges.
Trans met amputation	Amputation across the metatarsal bones.
V wedge amputation	Partial foot amputation, removal of toe and related metatarsal bones.

List of Publications

Levy, N., Gillibrand, W., Kola-Palmer, S. (2017) Minor Amputation and Quality of Life: Is it Time to Give the Patient a Voice? *The Diabetic Foot Journal* 20, 4, 228-234.

Contribution to Writing

Article written by Natasha Levy

Feedback upon the writing provided by PhD Supervisors (Warren Gillibrand and Susanna Kola-Palmer).

Contribution to the Thesis

The article contributes to Chapter 1, specifically the Impact of Amputation Upon Quality of Life section and served as a record of the *a priori* understanding derived from published research prior to data collection and analysis commencing. Prior to submission of the thesis literature searching was refreshed. Additional relevant research published after article was submitted for peer review and subsequent publication has been included within the thesis.

Abstract

The research question arose out of researcher observation of differing practices and patient experiences whilst employed concurrently in two NHS Trusts. The research sought to gain understanding of the impact of diabetes-related below ankle amputation upon quality of life.

Twenty-eight semi-structured individual interviews were undertaken which explored the lived experiences of people who had a below ankle amputation and had been cared for by the same multidisciplinary foot care team. Interviews were analysed using template analysis, a form of thematic analysis which allowed for incorporation of *a priori* knowledge to contribute to the development of codes and themes. NVivo software was used to assist with the organisation of these findings.

The original contribution to knowledge was identified following data analysis. The analysis revealed a variety of perspectives as to the impact of below ankle amputation upon quality of life. This related to an individual's acceptance and adaptation to the amputation, regardless of the level of the amputation experienced. Adaptation, and therefore quality of life was impacted by lack of social support, and by difficulties gaining societal support such as social care and monetary support. A conceptual framework was developed to provide a precis of the new knowledge developed. The conceptual framework presented the interaction of factors impacting upon adaptation and factors subjectively perceived as important to quality of life.

The research developed a suggested set of action points for clinicians working with these individuals, such as providing education upon the amputation journey and rehabilitation, establishing levels of support prior to amputation occurring to identify individuals who may require additional psychological or educational support. Further research was suggested to explore the development of measures which combined adaptation and quality of life to understand the impact of below ankle amputation more clearly for the individual. The author also suggested that the person completing the measure should be able to rank and add factors personally important for it to truly gain insight into individual quality of life.

Prologue

The prologue provides an opportunity to understand my research perspective and includes an account of how the question originated, and the influence of my professional and personal experiences upon my orientation to the research. These elements are made explicit, the reader made aware of the context in which the research was completed, and the subsequent implications this has for perception of the analysis, presentation of findings and conclusions drawn (Braun & Clarke, 2006). Essentially, the prologue provides a reflective lens through which to explore the research. The methods of data collection, data analysis and discussion of the findings presented herein to be seen as intentional decisions made by myself, guided by this underpinning context.

Motivations to carry out the research, arriving at the Research Question

“To study something, we must pay attention to it, notice it, seek it out. Generally, we investigate things that catch our attention, that we are curious about, or that are troublesome. We probe events to better understand them.” (Becker, 1992 p7)

The generation of the question for this research arose due to my reflection within clinical practice. I had qualified as a podiatrist in 1997, at the point where undergraduate teaching was completed through a biomedical lens, focused upon resolving ill health and removing dysfunction (Fish Ragin, 2011). From this perspective, management of the diabetic foot resolved around healing a foot ulcer and preventing recurrence – exploring physiologically based contributing factors and resolving them. However, my clinical experiences, working within a rural community-based NHS Trust, where multidisciplinary teamwork was at arm’s length with

communication via phone and letter, meant I knew these patients' lives, that social, environmental, and psychological elements also needed consideration. As one of two podiatrists who specialised within tissue viability and complex patient management, I was responsible for co-ordinating care, chasing vascular service reviews, and shared patients' frustrations, hopes and fears. Being a member of a small team meant that these patients were known to me personally, the complexity of their problems meaning I saw them at least once a week, over a period of years. This naturally led to deeper working relationships than, for example, people who required a short burst of input to assist with rehabilitation from injury. This led to tensions and reflection upon what my role as a podiatrist was for my patients. If upholding biomedical principles, then success of care would be healing a wound. However, these close working relationships meant I gained understanding of patients' unique situations. For a small holder who was a mechanic working 14 hours a day his priority was not on healing a wound, but on maintaining mobility to work and support the family. The biomedical model of care was at odds with these priorities. I dismissed the biomedical model of health, realising this misaligned with my clinical experiences. Put practically, how could this small holder continue to walk through his fields if in a below knee non-removable cast? How could he continue to live his life, feed his animals? What was the best individualised care for this person? I sought education and guidance through completing a master's degree in 2004.

I chose a masters intentionally designed for all health care practitioners rather than specifically for podiatrists and was exposed to exploring the systemic and holistic impact of diabetes and rheumatological conditions. This encouraged an orientation away from the biomedical model of health and a leaning towards the biopsychosocial model of health (Engel, 1977), incorporating the ideas of physical and psychological wellbeing and subjective assessment. Ensuring the patient voice was heard began to be echoed within guidelines and publications surrounding diabetic foot complications. Clinical guidelines focussed on working in partnership with patients, with shared decision-making regarding care (NICE, 2004). Subsequent publications

emphasised the importance of the patient being placed at the centre of their care; clinical audit also placed importance on the patient voice, determining quality of care, not only by healing rates, but by subjective review of care and exploring impact on quality of life (Department of Health, 2011; Diabetes UK, 2009; Diabetes UK et al., 2011; NICE, 2015). My NHS working environment, guided to be actively supporting the individual patient, exploring their perception of care and quality of life felt in tune with my experiences of working in the acute management of the active diabetic foot.

My question arose when working concurrently for two different NHS Trusts, I was involved within the care of two patients actively asking for toe amputation. These were patients of a similar age and overall health status. At one trust, there was a multidisciplinary meeting around the patient and their family, different management options were discussed, and amputation was organised. The site healed well post-operatively and life continued. At the other Trust, the patient was seen by the vascular surgeon in isolation, amputation was declined with a recommendation to continue with conservative care. Life stopped for this patient, once an active cricket umpire, he became immobile, reliant on hospital transport, only leaving the house for clinical visits. The chronic wound impacted upon his physical and mental health, worsening his quality of life. I was left wondering what the outcome may have been if this patient had been seen by the other trust. This led to a literature search to determine what research had explored quality of life for below ankle amputation and revealed no research had specifically looked at these individuals; amputation was used in studies as a comparator for chronic ulceration, or that mobility issues were less if a smaller amputation was undertaken (Boutoille et al., 2008; Pickwell et al., 2016).

These studies had used questionnaires which had not been validated for this population, this led me to think, where was the patient voice? Did we really understand the impact of below ankle amputation? Subsequent attendance at diabetes conferences compounded my thinking. Below ankle amputation, titled 'minor' amputation was explored as a salvage procedure, with

speakers exploring rates of healing as a successful outcome. There was no patient voice, no consideration as the impact upon life, no experiential understanding of the impact this salvage procedure might have for the individual. The research question and data collection method were shaped by reflection upon all these elements. The question was easily formed as was the decision to undertake individual interviews, where the interview was guided by developing understanding of the lived experiences of below ankle amputation, gaining understanding of what was important to quality of life and the impact below ankle amputation had upon this from the participant's perspective. Once published, this would add new knowledge into the field of diabetes-related below ankle amputation and would enable greater understanding and shaping of care from a biopsychosocial perspective.

Main Research Question

What is the Impact of Below Ankle Amputation upon Quality of Life for Individuals with Type 2 Diabetes Mellitus?

Subsidiary Question

What is Important to Quality of Life for those who have Experienced Below Ankle Amputation as a Consequence of Type 2 Diabetes Mellitus?

Research Aims

The overall aim of the research was to explore what impact below ankle amputation had upon quality of life.

Objectives

In order to explore this, as no previous research had explored quality of life for this specific group the following objectives were formed:

- ♦ To determine what factors were included in the conceptualisation of quality of life for individuals with Type 2 Diabetes Mellitus and below ankle amputation.
- ♦ Exploring the impact below ankle amputation has had upon conceptualisation of quality of life.

Deciding upon the Data Collection Site

I intentionally decided where to approach for data collection. I wanted a multidisciplinary foot clinic which was working to the recommended standards of care at the time of data collection (NICE, 2015), and explored what data was available to me. The Diabetes Foot Care Profiles (Office for Health Improvement & Disparities, 2023) provided an overview of rates of below ankle amputation for clinical commissioning group areas, comparing rates with national averages and areas with similar patient demographics. These profiles are still used to scrutinise care and attempt to reduce higher than national average amputation rates. The multidisciplinary foot team within the Trust I wished to approach had lower than national average below ankle amputation rates, possibly reflective of them leading on research exploring care and management of diabetic foot disease with a focus to providing optimum care close to home. The team led by a consultant diabetologist who was a professor, the clinical director for R&D and clinical trial unit for the Trust and a member of the International Working Group for the Diabetic Foot. I felt that if the research question and the research proposal were of interest

to a lead within the field of diabetes research, an individual who was shaping international recommendations and guidance on the diabetic foot, then it was worthy of continuing with what had developed from my own clinical insights and reflections. I began working upon the research proposal and ethical approval forms required for data collection within the NHS. A successful meeting with the lead consultant diabetologist led to agreement for the study to be hosted by the multidisciplinary clinic. The ethical approval forms were completed and submitted.

In order to gain permission to data collect within the NHS, proportionate review by the Research Ethics Service was required. The panel scrutinise forms and supporting evidence which in part are generated by inputting information onto the Integrated Research Application System (IRAS). The 36-page form, and subsequent forms relating to the relevant health authority are comprised to consider all types of research. As such, they have an empirical, positivistic tone, interviewing is included within the option titled questionnaire/interview or observational study. Questions relating to issues such sample size must be completed, even if at odds with the underpinning principles of the research. In this case I wanted to explore a richness of individual experience to gain insight into the lived experience of below ankle amputation, exploring with the participants what was important to quality of life and how the amputation may have influenced this. For myself, the sample size was slightly irrelevant, as Vasileiou et al (2018) suggest, data adequacy should be key, however the form required completion, so justification of an appropriate sample size was necessary. The application system did not refer to research findings, rather it asked what the 'primary outcomes' were. Despite this tension between chosen study style and the application process, in order to gain permission for the research from proportionate review panel and Health Research Authority I adopted a style and tone reflective of that presented to me within the research documentation. Consequently, proportionate review and HRA agreement for the study was straightforward but had consequences for the tone of work which comprised the local research pack presented in Appendix 3.

Once ethical approvals and permission to be onsite at the clinic was gained, I began to think about how to present myself to the multidisciplinary team. My previous clinical experiences made me familiar with the clinical environment of a busy multidisciplinary clinic, but I was to be there as a researcher, not a clinician. This contrast of roles came within the first morning when data collection commenced. I was introduced by the lead diabetologist to the whole team as a researcher and was invited to move freely between all the consulting rooms. The whole team (nurses, podiatrists, researchers, consultants) were tasked by the lead diabetologist to support the research and identify potential participants. To build upon this and establish an effective relationship I ensured I was a visible presence, attending the clinic on a weekly basis, and gave updates to the team on progression of the study. Once data collection ceased, I presented initial findings at their team review meeting. This support was invaluable and led to the smooth running of the research. The best compliment being their invitation to allow my masters students to come and data collect for any future studies.

Researcher Reflexivity, a necessity throughout the research journey.

No researcher will come to a subject blind, the research question stemmed from my interest in understanding the life world of those who had undergone below ankle amputation. That the research question stemmed from my reflection and wonder, suggests my own experiences and preconceptions led to the question being chosen. Understandably, those perceptions could exert influence upon the interpretation of the gathered data (Langdridge, 2007). We can never be truly separate from our experiences and world view, and should acknowledge these influences,

“If we simply try to forget or ignore what we already “know”, we may find that the presuppositions persistently creep back into our reflections. It is better to make explicit our understandings, beliefs, biases, assumptions, presuppositions, and theories. We try to come to terms with our assumptions, not in order to forget them again, but rather to hold them deliberately at bay and even to turn this knowledge against itself, as it were, thereby exposing its shallow or concealing character” (van Manen, 1990 p 47)

Understandably the consequence of accepting this position is that researcher reflexivity is important for the researcher and the reader. Understanding the impact of precognition and presumption is necessary to understand the context for the research undertaken and the findings. I could not bracket away my experiences whilst data collecting, interpreting the data, or writing the research (Dowling, 2007). These notions were brought into the light, so that I as the researcher, and the reader, by exploring this prologue, are aware of my potential biases and the context of the research (van Manen, 2007). For myself, this exploration enabled a freedom from pre-understanding or pre-judice, to know my preconceptions enabled me to consciously acknowledge them during the data collection, data analysis and writing processes, consciously holding these in balance. In practical terms, I intentionally documented the research journey, exploring prior to data collection any preconceived ideas regarding amputation and quality of life, through publication of a precis of available research exploring below ankle amputation and quality of life (Levy et al., 2017). During the interviews I actively listened to what was being said and maintained a focus to the research question by keeping the interview guide within line of sight (Appendix 3). The interviews were flexible and followed where data relating to the research question led. To explore the explicit and implicit meaning within the interviews I used varying techniques, developed through attending a conference and workshops exploring active listening skills and exploring literature pertaining to qualitative interviewing (Alvesson & Ashcraft, 2012; Kvale & Brinkman, 2009). Some techniques adopted were either repeating back my understanding or exploring more deeply with the participant specific aspects where I had not

gained clarity of their experiences and meaning. In this way they were able to confirm or correct my comprehension of their experiences. Throughout the interview and data analysis process I created memorandums to explore my thoughts and perceptions. Initial analyses were shared with peers to prevent a narrow filter of view. Subsequent interim findings were presented to a health multi-professional audience at a regional conference (Levy, 2018) to gain feedback and explore alternative perceptions and interpretations (Appendix 2).

Experiences during the Research: Shaping of the Analysis.

During the process of competing this PhD life happened. I had a child, returned to work part time, still passionate about exploring the lived world of those who had amputation, but now juggling parenthood, trying to determine what role model I could be for my daughter, this thought competing with 'mum' guilt for having time away from being a mum.

Life rolls on, interviews were completed, and changed me and my perspective to care. By seeing patients in the hospital clinic, I was simultaneously reinserted into a familiar clinical environment, but removed from my previous clinical role. I was there as a researcher, enabling me to step back from the immediacy of a situation and reflect. All seemed much as I had experienced when working in those NHS teams. Busy clinics, a range of emotions and patients – some onboard with care, others disengaged, some patients were not connected with or understood.

During the interview process, being invited into someone's house, their openness to sharing their experiences of amputation and their life with a relative stranger sharpened my perspective that the individual needed to be understood. That patient centred care which the NHS purports to achieve, could in no way be successful without gaining understanding of individual lived experience. Interviewing Frank was like a lightning bolt, in the clinic, although not termed a

difficult patient, conversation was challenging between the clinical team and Frank. Exploring with Frank his life and world perspective changed the perception I had had from observing his treatment in clinic. A highly intelligent man, frustrated with the health care system, a sea of changing professionals not understanding his experiences or his priorities.

During data analysis and thesis write up, my world was changed forever, my husband being diagnosed with inoperable cancer and dying some 15 months after, and my Papa unexpectedly dying some 4 months before my husband passed called a halt to the PhD. Navigating these unwelcomed life changing events changed me. When I returned to relisten to the interviews and analysis, I realised that to gain insight into quality of life, merely reporting factors important or not important to quality of life would be keeping me within the same health silo as those patients reported outcome questionnaires. To gain understanding and insight, I needed to explore the adaptation to amputation journey. Reviewing the transcripts, I realised the interviews were full of this richness. To help me orientate to their experiences I had asked each interviewee to share how their amputation had happened, this led naturally to them exploring adapting, or not, to the amputation and subsequently their life afterwards. Each point of exploring and writing about the transcripts deepened this perception. As Max van Manen had succinctly said,

“To write is to reflect; to write is research, and in writing we may deepen and change ourselves in ways we cannot predict” (van Manen, 2016 p20)

These reflections have led to the construction of the thesis, as it is presented here. The final paragraph of this prologue provides the reader with an introduction to the structure of the thesis and provides a synopsis of the content to be found in each of the chapters herein.

Introduction to the Chapters of the Thesis

The impact of my experiences is reflected within the structure of this thesis. Chapter 1, titled Framing the Research demonstrates for the reader my perception of the necessity for this research. An overview of increasing incidence of diabetes and amputation is presented, identifying that these experiences of amputation are not diminishing, and this research is necessary to explore these events. There is exploration of emergence of quality of life research within the health field, and the fact that quality of life is now an outcome measure to explore foot related events for those with diabetes. There is discussion that there is no standard definition for quality of life. Following this a working conceptualisation of quality of life for this research is presented. A literature review of research exploring quality of life and below ankle amputation is presented, demonstrating to the reader that no previous UK based study has explored for this group the impact of below ankle amputation. I also discuss most research published has used health outcome measures and have not explored quality of life *pe se*, leaving uncertainty as to what we understand about the impact of below ankle amputation on quality of life, thereby demonstrating the necessity for this research to be completed. The knowledge gleaned from studies which reported separate below ankle amputation findings is presented. This knowledge is used to form tentative *a priori* codes used within the chosen data analysis method.

Chapter 2 explores the methodological considerations for the research, explores the approach to the research question, and why a qualitative interview study was necessary to explore the research question. The style of interviewing is explored, with the roles of the researcher and participant discussed.

Chapter 3 presents the methods undertaken to complete the research. The ethical considerations, recruitment process, data collection and data analysis methods are included within this chapter. Template analysis, the chosen form of thematic analysis for the research is

introduced and the steps for data analysis using this technique are explored. The principles guiding the process of coding and data analysis are introduced and finally there is mention of the use of NVivo, a qualitative software data system to assist with organisation of the data analysis process.

The findings are intentionally split between 4 chapters due to the volume of findings. The first findings chapter, Chapter 4 provides the reader with an overview of the participants of the study so that they can consider the characteristics of these participants and how these findings may be applicable to their own field of study and interest. Findings from exploration of the transcripts are presented, the development of the codes and themes through the application to the transcript data is detailed. Definitions of what these codes and themes encapsulate has been presented so that the reader is oriented to the author's perspective. Visual representations of the data analysis work are presented within this chapter. The final organisation of the overarching themes and codes as to what is important to adaptation and quality of life is presented.

Consideration is given to adaptation to amputation in Chapter 5. Strategies which have led to successful adaptation are explored, as are the experiences and strategies of those who are still struggling to adapt. Direct quotations from the interviews are presented in support of this analysis to enable the reader to explore these experiences. The analysis indicates the importance of a social network for successful adaptation to the amputation. There is discussion of the new knowledge elicited from exploring adaptation. This new knowledge is explored within the context of coping strategies literature, and the findings are mapped against accepted coping measures used within health research and wider conceptualisation of coping and adaptation.

Chapter 6 presents findings relating to understanding the impact of amputation upon quality of life and identifies the importance of social interaction, family, and friends to maintaining quality of life. The chapter also shows that even if an individual has acknowledged limitations

to previous mobility and activity levels, if adaptation is successful, individuals may express no reduction to quality of life following below ankle amputation. The chapter shows that individuals can hold contrasting views, simultaneously acknowledging life is different post-amputation, but also purporting to have good quality of life. The chapter highlights that this complexity surrounding quality of life perception has not been captured by health outcome measures which allow no adaption for the individual and reaffirms the subjective nature of quality of life perception.

Chapter 7 presents a discussion of the findings relating to the impact of amputation upon quality of life and explores the aspects which impact upon quality of life such as self-identity, the importance of a positive attitude, the vital role of a partner, family, and friends to maintaining quality of life, the importance of medical team support, and consideration that other health conditions may impact upon quality of life rather than the amputation itself. Finally, commentary is provided that adaptation and quality of life have a symbiotic relationship. A conceptual diagram, showing the relationship between adaptation and subsequent quality of life perception, essentially a summary of the new knowledge contained within Chapters 4,5,6, and 7, is presented.

Chapter 8 provides the conclusion to the thesis. A precis of the research process is presented, along with a synopsis of the new knowledge. Changes to the author following undertaking the research are documented, exploring the integration of adaptation and exploration of what outcome means from an individual perspective into undergraduate and post graduate education. This is followed by recommendations for future research and recommendations for practice for those involved within care provision for individuals that have experienced below ankle amputation. The timeliness of the findings in terms of current diabetes agenda are explored. Finally concluding thoughts and plans for continuation of the work by the author are explored.

Chapter 1: Framing the Research

Introduction

The cost of diabetes-related lower limb complications has long been discussed in terms of burden to the National Health Service, with data published demonstrating the economic cost savings for preventing ulceration and amputation (Gray & Clarke, 2008; Rajendran et al., 2012). There is scant evidence published about the experiential impact of below ankle amputation for the individual. At time of data collection, only one study had adopted a qualitative design. The USA based study combined the experiences of those with above and below ankle amputation, and themes such as financial anxiety derived from having to fund self-care were not pertinent to the UK (Foster & Lauver, 2014). To current date, four more studies based in Australia, Ghana and the United States have experientially explored the impact of below ankle amputation, again not exploring the experiences of those accessing the UK systems of health and social care support (Amoah et al., 2018; Barg et al., 2017; Crocker et al., 2021; Dillon, Anderson, et al., 2020). There is still a deficit of research exploring quality of life for these individuals within the UK.

Within the UK there has been no conceptual exploration of the impact that below ankle amputation has upon quality of life for individuals with diabetes. In fact, quality of life has not been explored for this group per se. This research project was undertaken to develop new knowledge by exploring the lived experience of people with diabetes mellitus who had undergone below ankle amputation, gaining understanding of what was important to their quality of life, and what impact below ankle amputation had upon this.

Diabetes and Amputation

The consequences of diabetes are of global concern, as the associated complications hold a heavy individual and economic cost (Andersson et al., 2020). These issues are set to increase with forecasts predicting an additional 1 million people being diagnosed with diabetes in the United Kingdom by 2035, current rates being 3,453,748, (NHS Digital, 2022; Public Health England, 2016). Prevalence in the UK has risen from 7.1% in 2020 to 7.3% in 2022, and global projections indicate this will not diminish. Forecasts predict a global rise in diabetes diagnosis from 1 in 11 to 1 in 10 individuals by 2045 (Cho et al., 2018). Landmark longitudinal studies such as the UK Prospective Diabetes Study (1998a, 1998b) and the Diabetes Control and Complications Trial (American Association of Diabetes Educators [AADE], 2002), demonstrated optimised glycaemic and hypertensive control reduced microvascular, macrovascular and neurological complications, and ultimately benefitted the individual and health economy. These benefits have resulted in a proactive approach to diabetes management, with international and national recommendations focussed upon prevention and limitation of complication development (International Diabetes Federation, 2017).

Since the St Vincent Declaration (International Diabetes Federation, 1989) strategies have been developed to reduce preventable complications from occurring. The importance of these screening strategies was re-emphasised by the World Health Organisation Global Report on Diabetes (2016). The rationale being to reduce personal burden and economic impact. Current UK data has demonstrated that non-optimised control results in increased health care costs for each individual, reduced workplace productivity and an economic burden of £2600 million (Bain et al., 2020). Global themes of proactive prevention, screening and staged management are mirrored within national health policies. The World Health Organisation goals to reduce the burden of diabetic disease and improve quality of life are reflected in England's strategy which recommends regular surveillance, timely investigation, and prompt management of

complications to minimise morbidity, mortality, and economic cost (Department of Health, 2001; NICE, 2019; World Health Organisation & International Diabetes Federation, 2020).

Focussing specifically upon the lower limb, complications such as ischaemia, neuropathy and deformity are well established precursors for ulceration and amputation (Edmonds et al., 2021). The global disability burden measure, created by WHO to highlight the hidden impact of conditions, determined that diabetes associated lower limb complications contribute more to the burden of disability than stroke, heart disease or chronic obstructive pulmonary disease (Zhang et al., 2020). Within England, diabetic foot complications extend and increase the cost of hospital stays for those with diabetes, and the total cost of diabetic foot care is responsible for a 1% spend of the overall NHS budget, exceeding that spent for breast, prostate and lung cancer combined (Kerr et al., 2019).

Since the publication of the National Service Framework for Diabetes (2001) and subsequent NICE guidance for the assessment and management of the diabetic foot (2019), effective delivery of care has been determined by annually recording number of foot risk assessments undertaken, foot risk categorisation and exploring amputation rates. The assumption being that effective care reduces amputation. These rates are published annually and were presented by clinical commissioning group (now known as Integrated Care Systems). Areas with similar population demographics were compared, and areas with higher than national average rates of amputation were scrutinised. The latest publication indicated rates of above ankle amputation appeared to be stable, but there was a continued statistically significant increase in rates of below ankle amputation. Below ankle amputation accounting for 26% of all expenditure on diabetic foot disease (Kerr et al., 2019; Office for Health Improvement & Disparities, 2022). Previous technical reports supporting the figures have suggested that this increasing incidence may reflect a policy of limb salvage to prevent larger amputation. Within these reports there is no patient context, or understanding of the impact to the individual, these figures are presented alone (Public Health England, 2017).

Several authors have cautioned the incidence of amputation alone is not sufficient to judge success of care. As early as 2004, Jeffcoate and van Houtum suggested that incidence data required careful interpretation, and that presentation of the figures and a focus to reducing amputation incidence could result in patients' not being offered timely, appropriate intervention. Thereby resulting in inappropriate management of a chronic wound, reduced quality of life and enhanced suffering. This perspective was echoed by Holman et al. (2012), who explored the variation of amputation rates in England and highlighted the importance of exploring the underpinning rationale for amputation. Holman concluded that high incidence of amputation may have indicated effective early intervention rather than deficiencies in care and should not be used to adversely judge the quality of a service in isolation.

Certainly, below ankle amputation has been viewed differently than above ankle amputation by the publishing medical profession. The increasing incidence of below ankle amputation explained as a reflection of a limb salvage culture, to avoid increasing the incidence of above ankle amputation, and to maintain physical function. Vamos et al. (2010) suggested below ankle was undertaken to prevent large limb loss and to enable a patient to maintain physical function, whilst above ankle amputation occurred when no salvage was possible due to devitalised tissue. Rajendran et al. (2012) suggested that the rise in below ankle amputation rates may in part be attributed to better survival of patients with complex co-morbidities, resulting in more necessity for amputation. Rajendran recommended that trends, mortality, and quality of life measures would be better indicators of effective management than amputation rates alone. Throughout the discourse, the patient perspective is missing, the medical field has published the medical perspective on amputation, but the patient is silent. Even when health outcome measures have explored below ankle amputation, this has been a comparator to chronic ulceration, used to support the idea that below ankle amputation is a preferred solution to chronic ulceration, that patients have a better quality of life if below ankle amputation has occurred rather than

continue with a chronic wound (Peters et al, 2001). The impact of below ankle amputation upon quality of life itself being little explored.

Emergence of Quality of Life Assessment in Health: The Medical Paradigm Shift

In 1948 the World Health Organisation defined health as a state of complete mental, physical and social well-being. This could be perceived as an initiator of a global paradigm shift in health care, away from resolution of disease and towards optimisation of health. From the 1950's onwards with the progression of health technology, medical provision was no longer constrained to survival and disease resolution, and prevention of illness became a focus for health provision (Ministry of Health, 1956). This was a global phenomenon, with well-being perceived as the pinnacle of health (see Figure 1). Consequently, long-range health goals were set, with health care focussed upon attaining the best physical and mental health each individual could aspire to, supported by the right social and environmental situation (Surgeon General's Advisory Committee on Urban Health Affairs, 1967).

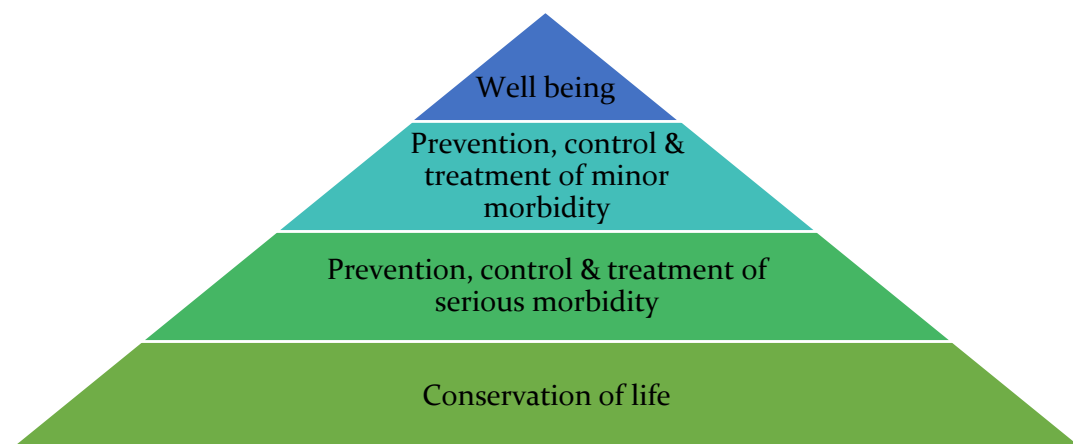


FIGURE 1 HIERARCHY OF GOALS OF HEALTH CARE (ADAPTED FROM THE AMERICAN PUBLIC HEALTH ASSOCIATION 1967)

Within the UK, the 1977 National Health Service Act aimed to secure improvement in physical and mental health, prevent, diagnose, and treat illness. Ethical dilemmas arose, if quality of life would be extremely compromised by medical intervention should intervention occur if life expectancy were extended? What quality was there to this form of extended life? Who and how should quality of life be decided (Scheingraber et al., 2004)? The broadening of health care objectives away from conservation of life and towards establishment of well-being highlighted the narrow focus of health research, previously concerned with treatment evaluation. Objective assessments, reports of mortality and morbidity demonstrated health services ability to conserve life and to prevent, control and treat aspects of illness, but concepts such as well-being or quality of life did not have such tangible objective measures. At this point continuing within the biomedical research paradigm, concerned with determining health by the absence of disease or dysfunction, appeared flawed (Fish Ragin, 2011).

As explored by Kuhn (1996) shifts in paradigms occur when the current view can no longer explain what is being found; in essence, the biomedical approach to health care research was concerned with the absence of disease, but this paradigm was confounded by need for assessment of subjective factors. Reports from Ware (1976) for the Rand Corporation, which later undertook the Medical Outcomes Study, and ultimately the development of the Short-Form 36, a measure designed to benchmark functional health and wellbeing; concluded that objective data in isolation was insufficient to be able to assess the higher levels of the goals of health care and concluded that subjective assessment of health was key. The paradigm shift started, and Engel (1977) echoed Ware's findings and proposed the biopsychosocial approach to medicine which concluded that psychological and social elements were also necessary factors to be incorporated into outcome assessment. Understandably quality of life health research emerged and began to feature within health care to assist with decision making, cost rationalisation and inform patient choice (Bradley et al., 1999; Kind, 1996).

Focussing to diabetes care, the National Service Framework for Diabetes (Department of Health, 2001) reflected the principles explored above, and stated that patient experience and quality of life should be used as outcome measures to determine the success and quality of the care provided. When focussing upon the diabetic foot, the inclusion of subjective evaluation and impact upon quality of life was not initiated until 2009. The Clinical Guidelines for the Diabetic Foot (Hutchinson et al., 2000), audited only objective elements such as number of foot screenings completed and rates of below and above ankle amputation. When updated in 2003, only objective measures of efficacy of treatment were still to be audited, subjective measures exploring the impact for the patient were still absent (Mcintosh et al., 2003). Clinical Guideline 10 (National Institute for Health and Care Excellence [NICE], 2004) explored objective measures such as assessment rates and numbers of ulcerations and below and above ankle amputations. Gaining understanding of the patient experience, understanding their perception of care and health status was first recommended in 2009 by Putting Feet First (Diabetes UK, 2009). At this point the NSF Guidance published by the Patient Reported Outcome Measurement Group (2009) recommended generic and condition specific measures be used to capture the impact of diabetes and interventions for the individual.

Exploring health status, quality of life, psychological well-being, and satisfaction with services are now an integral aspect of review and audit. The generic measure recommended for use alongside disease/condition specific measures for the United Kingdom is the EuroQoL-5D questionnaire designed to explore 5 dimensions of health status. The questions give options for individuals to express the level of the impact a condition has had upon mobility, self-care (washing and dressing ability), usual activities, pain, and anxiety or depression (Clinical Indicators Team, 2016; EuroQol Group, 1990; Patient-Reported Outcome Measurement Group, 2009). This is a rudimentary tool, clearly not exploring factors outside of the sphere of health or capturing the components of health as defined by the World Health Organisation (Bradley, 2001). There are currently no disease specific measures validated to explore life after diabetes

associated amputation (Miller et al., 2021). Literature searching indicates there are few measures which have focussed upon the diabetic foot in any condition.

Those which exist are focussed upon foot function with ulceration, impact of neuropathy, or review the impact of conservative and surgical treatment not related to amputation (Bann et al., 2003; Bennett et al., 1998; Bergin et al., 2009; Kateel et al., 2017; Vileikyte et al., 2003). Published research has reflected this deficit, and studies have utilised generic health outcome measures, anxiety and depression scales, or adjustment to illness scales to explore impact to the patient. This perspective is supported by Ortega-Avila et al. (2019) who conducted a systematic review to identify patient related outcome measures with a focus to foot complications. The review concluded that very few measures had been developed for the diabetic foot and none addressed amputation. The situation is similar for lower extremity amputation regardless of aetiology. A systematic review published in 2021 which explored vascular or diabetes associated above ankle amputation identified that tools designed to determine the impact to the patient focussed upon prosthesis users or wheelchair users, there was no single tool to capture quality of life for all levels of mobility post amputation (Miller et al., 2021). The consequences of the lack of specific measure are clear, it is uncertain if there is truly an understanding of the impact of diabetes associated below ankle amputation upon quality of life.

Defining Quality of Life

“An individual’s perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations and standards and concerns. It is a broad ranging concept affected in a complete way by the person’s physical health, psychological state, level of independence, social relationships, and their relationships to salient features of their environment” (World Health Organisation, 1998 p3)

Quality of life research has become a focus for health, economics and social sciences research (Cummins, 2004). Surprisingly despite the term being widely used throughout NHS guidance documents, no universal definition of quality of life has been presented to clinicians following these frameworks and guidelines. No conceptualisation is referred to explicitly, rather quality of life is alluded to within documents exploring how to measure service quality. At this point, guidance then points to using health outcome measures – the EuroQol-5D (EQ-5D) in combination with an undefined disease/complication specific measure (Patient-Reported Outcome Measurement Group, 2009). This clearly is not exploring quality of life, rather exploring factors focussed upon determining health and functional status.

Although comprehensive, the WHO definition of quality of life is rather nebulous when faced with undertaking research to capture or explore a sense of quality of life and understand the impact of disease related complications. Throughout health and social science publications there is a lack of definition consensus. This lack of clarity has resulted in uncertainty about what is truly being explored in purported quality of life research. A review of quality of life research undertaken by Arnesen and Norheim (2003) identified there was seldom a clear conceptualisation of quality of life prior to the research being undertaken. This raises ethical

and validity issues. Unless the conceptualisation for quality of life is understood for the population in question, then the tools used may not be fit for purpose, invalidating research findings. This position was echoed by later work by Fulton et al. (2012) who perceived that despite quality of life being used as a benchmark to determine outcome of care, the conceptualisation of the term had not been established by researchers, bringing into question what studies had really captured.

The professional background of the researcher, or the particular field in which the research has been undertaken may further limit selection of an appropriate quality of life tool. Barofsky (2012) believed the aim of the researcher altered the quality of life construct utilised. Berntsson and Köhler (2001) suggested that the health-based researcher focussed upon health-related factors, economists to welfare, and social scientist to subjective and objective assessment of wellbeing. Certainly, published health research has used measures for a range of reasons. To determine the financial 'worth' of an intervention, by balancing cost against quality-of-life; to compare the success of multiple interventions, or to assess physical and psychological health. Within this context, quality of life has been relegated to being a generic term, ill-defined and interchanged with happiness, well-being or benchmarked by health outcome measures (Farquhar, 1995; Moons et al., 2006).

Within the sphere of health research there are contrasting perceptions about how to capture a sense of someone's quality of life, and even if quality of life can be measured *per se*. In order to gain understanding the author explored a broad health research literature. Table 1 presents the findings of this exploration into literature attempting to define and measure quality of life.

TABLE 1 DEFINING AND MEASURING QUALITY OF LIFE

Authors Exploring QoL	Defining and Measuring Quality of Life
Goodinson and Singleton (1989)	There should be an identified definition of quality of life prior to measurement. The measurement should be a subjective assessment of a range of dimensions, individuals should be enabled to apply a weighting to those which have significance for them and collected at numerous points over the progression of a change in health status. Quality of life needs to be considered in combination with coping strategies and past illness experiences.
Zhan (1992)	Subjective measure of material and spiritual well-being, how well an individual can participate in the human experience. Impacted upon by personal background, health, social, cultural, and environmental elements.
Gill and Feinstein (1994)	Subjective measurement to replace or supplement expert developed instruments.
Rosenberg (1995)	Subjective understanding of self-reflection, interpretation of events as lived given the context of the individual's own morals and norms.
Farquhar (1995)	Quality of life needs to be defined by the expert and the individual. Authors should state their conceptualisation of quality of life, and not use the term if only exploring health and functional status, this should not be referred to as quality of life, but rather health related quality of life.

Authors Exploring QoL	Defining and Measuring Quality of Life
Ormel et al. (1997)	Quality of life is psychological well-being; this is dependent upon physical and social needs being satisfied. Quality of life can be impeded by limitations in environmental situation, functional opportunities and lack of information.
Rubin and Peyrot (1999)	Individual subjective interpretation of physical, mental and social well-being, exploring individual life satisfaction and happiness.
Haas (1999)	<p>Subjective multifactorial assessment of life contextualised by the environmental situation and the values the community and the individuals hold. Includes exploring wellbeing, physical, psychological, social and spiritual factors.</p> <p>If an individual was unable to relate these aspects, then an objective measure could be used as a proxy to determine quality of life.</p>
Koch (2000)	Current measures reflect the burden of a disease rather than life quality and are not appropriate to capture Quality of Life. Should subjectively explore individual physical, cognitive and social context.
Arnesen and Norheim (2003)	People adapt to change, therefore good health, but shorter life may not equate to a better quality of life than a longer life with poorer health. Quality of life should be captured as a subjective individual perception.

Authors Exploring QoL	Defining and Measuring Quality of Life
Bognar (2005)	Subjective assessment of social welfare should be included in quality of life assessment to capture the importance of elements such as access to services and opportunities to the individual.
Koller et al. (2005)	<p>Should be focussed upon what is achievable by health care and measured in the context of the impact of a disease upon quality of life. Quality of life should be considered alongside:</p> <ol style="list-style-type: none"> 1. Classical Endpoints Survival, complications, clinical health status biochemical parameters 2. Hermeneutic endpoints Quality of life, expectations, coping, negative effect, social stigma 3. Relevance to the clinical situation
Moons et al. (2006)	Quality of life should be determined by a subjective measure of how satisfied an individual is with life as a whole.
Mooney (2006)	Broad concept incorporating environmental, social, economic, and health satisfaction. Questionnaire measures should be used as a start point to assist with individualising care.
Ruta et al. (2007)	Quality of life is the gap between actual and desired capabilities.
Plummer and Molzahn (2009)	Quality of life is an intangible subjective interpretation of individual lived experience.
Speight et al. (2009)	No single measure appropriate for all explorations of quality of life. Need to be clear as to what is wanted to be explored, more

Authors Exploring QoL	Defining and Measuring Quality of Life
	than one measure should be used to attempt to capture the essence of the question being asked.
Sousa Gomes et al. (2010)	Quality of life is the individual perception of their own situation, impacted by the social and environmental situation and how this is perceived by the individual.
Barofsky (2012)	Need to establish how an individual defines quality of life before exploring their perception of their quality of life.
Schalock et al. (2016)	Quality of life is multidimensional, the core focussed upon personal well-being. The domains are Independence (personal development and self-determination), Social Participation (interpersonal relationships, social inclusion and rights), and Well-being (emotional, physical and material well-being)

The table indicates within the health field several authors have attempted to provide a definition for quality of life. All agree that quality of life is multifactorial and can be explored. Consensus fractures as to what these factors are and how these areas should be assessed; whether to record objective outcomes, explore subjective perceptions, or to review both (Sousa Gomes et al., 2010). Debate also exists whether generalised or disease specific measures should be used to capture quality of life. Disease specific measures thought to capture the specific limitations and long-term complications of disease pathology, whilst general measures ascertain and map disease impact when compared to a “healthy” general population. Focusing to diabetes, work comparing the benefits of using disease specific or generalised measures to capture quality of life has been inconclusive, and the recommendation was for both to be used (Huang et al., 2008; Patient-Reported Outcome Measurement Group, 2009).

Authors have explored the style of assessment used to capture a measure of quality of life, a common argument being that tools with pre-determined domains may not capture aspects important for the individual. Ergo, they captured what was perceived to be important to quality of life by the chosen outcome measure rather than what was individually important (Carr & Higginson, 2001). To illustrate this point further, an interview survey of 2000 adults in Great Britain was conducted to explore what was important to quality of life (Bowling, 1995). Participants were asked to explain what was important in their lives. The survey recorded the 5 most important elements as ranked by each participant and resulted in the generation of a list of items most important to life. In ranked order these were family relationships, social relationships, personal health, health of those close to the respondent, finances/ social situation, environment, job satisfaction, ability to work, social and leisure activities, religious or spiritual life, education, and a range of other elements such as happiness and well-being. These aspects are seldom seen in measures such as the EQ-5D, the recommended patient reported outcome measure within the NHS for individuals with long term conditions (NHS Digital Clinical Indicators Team, 2019). A later study which explored how patients with chronic health issues defined health and quality of life also supported the idea that factors perceived may not be included in expert derived health related measures. Thematic analysis of semi-structured interview data identified participants mentioned a broad range of elements important to quality of life, these were related to fundamental human needs such as having good living conditions, participating in leisure activities and hobbies, taking part in culture and having meaningful relationships with family and friends (Fagerlind et al., 2010).

As explored by Skovlund (2005), measures used to explore quality of life should be easy to interpret, provide reliable, appropriate information and be practical within a clinical setting to use. This is perhaps why the EQ-5D has been utilised due to the simplicity of 5 questions and an overall score for health status. However, EQ-5D is not a proxy for individual quality of life perception, it is a health status measure. A critical review of measures used to assess quality of

life in diabetes research determined that only 3 of the 10 measures used by 6085 research studies assessed quality of life. The rest explored health status, satisfaction with treatment, psychological well-being or overall well-being (Speight et al., 2009).

To truly capture and understand individual quality of life, individuals should be enabled to rank or discard elements of assessment tools that are perceived as irrelevant to personal quality of life. Ruta (2007) assessed a capability model of quality of life and proposed individuals should be able to identify what mattered most and consider quality of life in terms of ability to fulfil these goals. Focussing on diabetes, Shillitoe (1988) suggested it was necessary to consider quality of life holistically, rather than focussing upon the impact complications may have upon purely health related issues. Shillitoe discussed diabetes infiltrated all aspects of life, physical, psychological, family and social realms, resulting in adjustment of life goals and quality of life perception. Bradley et al. (1999) refined this argument further and developed the audit of diabetes-dependent quality of life measure, the ADDQoL, an individualised quality of life questionnaire for diabetes which enabled respondents to rate only personally important factors relating to overall diabetes management. Aspects identified as non-applicable were removed from the scoring system, and individuals could rank applicable factors, truly capturing individual perception of quality of life from a questionnaire format useful for the clinical environment. The questionnaire explored elements wider than purely health related factors, enabling participants to reflect upon aspects such as sex life, sporting, holiday or leisure activities, personal motivation and aspects related to management of diabetes.

To date, there is no measure validated for exploring the impact of diabetes related amputation upon quality of life. There is no conceptual framework exploring quality of life as a reference to assist in determining if any of the current measures would be suitable for exploring quality of life for these individuals. Of the research published exploring quality of life and below ankle amputation, none have provided a working conceptualisation of quality of life and only one

study has used a quality of life measure – the WHOQoL-BREF. Unfortunately, the results of this are questionable in terms of understanding the impact of amputation upon quality of life as the full measure was not used – elements relating to social and environmental considerations were not collected (McDonald et al., 2014).

Working Conceptualisation of Quality of Life for this Research

For the purposes of this study, the quality of life working conceptualisation used to frame the research is that written by Schalock et al. (2016), that quality of life is multidimensional, the core focussed upon personal well-being. The working conceptualisation suggested that quality of life was underpinned by a range of factors including an individual's ability to have independence, be able to socially participate as they chose and have emotional, physical and material well-being. Schalock et al. suggested that quality of life could be influenced by personal characteristics and environmental factors, and so could be improved by providing individual support, enabling personal development or increasing individual engagement. Schalock et al's. conceptual framework is summarised in Figure 2.

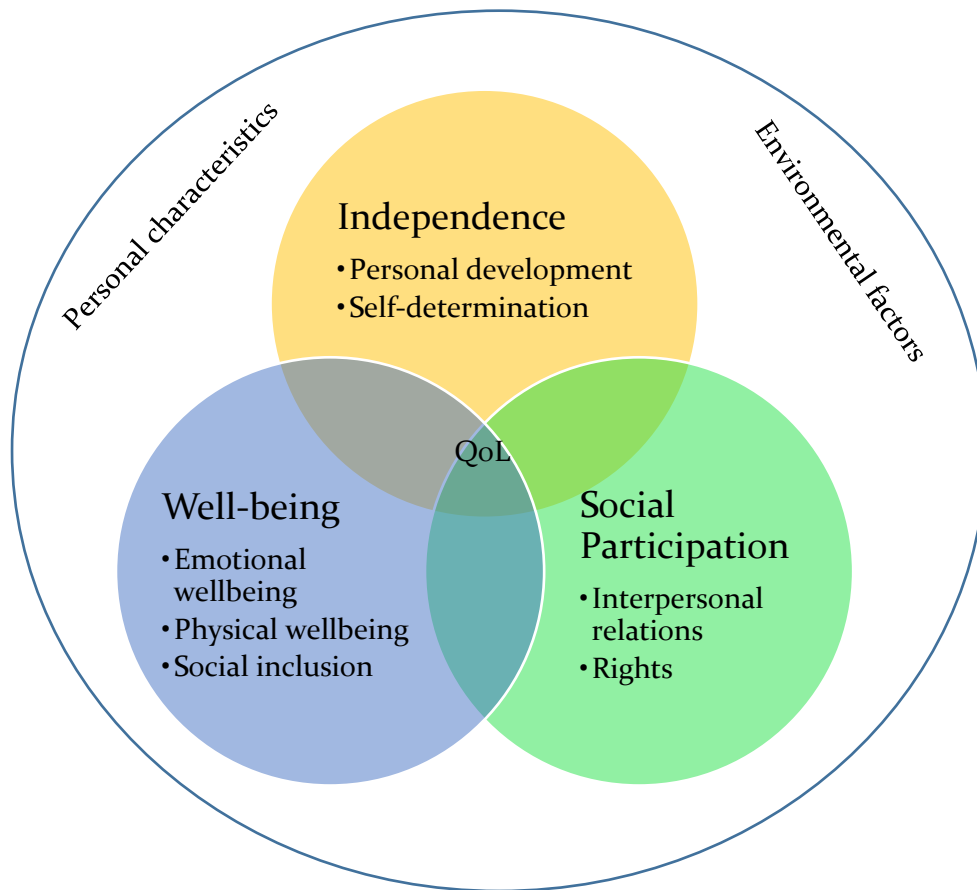


FIGURE 2 PROPOSED CONCEPTUAL MODEL OF QUALITY OF LIFE ADAPTED FROM SCHALOCK ET AL. (2016)

Schalock suggested that over time the conceptualisation of quality of life could shift and alter. This enabled the current author to explore the lived experiences of those who have undergone below ankle amputation, to gain understanding of what is important to individualised quality of life and reflect upon this to present a conceptualisation of quality of life. These aspects are explored within the Results and Findings Chapters.

The following section presents the findings of a literature search undertaken to identify the current understanding of what impact diabetes related below ankle amputation has upon quality of life and presents a summary of the measures which have been utilised. The next section clearly suggests that when viewed against Schalock et al's. definition of quality of life,

the presented research is lacking understanding of quality of life for individuals who had undergone below ankle amputation. Furthermore, that the chosen data collection method of individual interviews was necessary for this research to step back and gain insight into the lived experiences of those who had undergone below ankle amputation in order to be able to understand what was important to quality of life and understand the impact below ankle amputation had upon this.

Impact of Amputation on Quality of Life

Synopsis of Published Article Prior to Data Collection Commencing

An abridged version of the literature review was published in a peer reviewed journal (Levy et al., 2017), capturing the researcher's perception and knowledge prior to data collection and analysis commencing. The paper identified that little was known with regards to the impact of below ankle amputation upon quality of life. At that point in time, no study had below ankle amputation as the main focus of the research. Quantitative studies had utilised questionnaire outcome measures to explore the impact of diabetes-related amputation upon quality of life, namely EQ-5D, HADS, PAIS, SIP, SF-36, and WHOQoL-BREF. Only one of these measures, the WHOQoL-BREF measured quality of life, the rest focussed upon either health related outcomes, adjustment to illness or explored anxiety and depression. Despite using the WHOQoL-BREF, McDonald et al (2014) omitted sections exploring social relationships and environmental factors. These sections would have explored social support, financial situation and social care. Instead, only physical health and emotional quality of life aspects were reviewed. Ergo, none of the quantitative studies explored quality of life per se or gained understanding as to the impact amputation had upon this. The quantitative studies suggested either there was a reduced physical function when amputation occurred, and so an impact to the physical aspect of quality

of life, or there was little impact to life, as determined by the measured utilised (Boutoille et al., 2008; Pickwell et al., 2016; Willrich et al., 2005).

Only one qualitative study was available for review. The study completed by Foster and Lauver (2014) had explored the lived experiences of 15 individuals who had undergone diabetes-associated amputation. The semi-structured interview study identified themes of financial burden, powerlessness, the importance of social support, placing blame upon others for the amputation and uncertainty of the future due to ongoing rehabilitation and adaptation. The theme exploring powerlessness included elements related to the changes in physical abilities as a consequence of the amputation, so may have echoed findings in reduction of physical quality of life found within the quantitative studies completed by Boutoille et al (2008), Peters et al (2001) and Willrich et al (2005). Foster and Lauver's study had been completed within the USA and so some aspects of the findings exploring financial burden relating to the costs of private health care did not resonate with an England based population.

The peer reviewed article concluded that there was no consensus from the published research as to what impact below ankle amputation had upon quality of life and that an explorative UK-based study was necessary to explore the experience of below ankle amputation and gain insight into what was important to quality of life and what impact the amputation had.

Subsequent Reading Prior to Data Collection and Analysis Commencing

The author reviewed this lack of insight from the literature review both in a positive and negative light. On the positive, this gap in knowledge clearly demonstrated the necessity for the completion of the research project to gain insight into the impact of below ankle amputation upon quality of life. Considering the negative, findings were health centred, what effect amputation had to overall quality of life, when viewed from Schalock et al's. (2016)

comprehensive conceptualisation, was unknown. Schalock et al's. conceptualisation determined quality of life to be multidimensional, the core being focussed upon personal well-being with domains of independence, social participation and environmental aspects contributing to overall quality of life. Using this definition, studies using single outcomes measures fell short, and the qualitative study did not capture the lived experiences of those within the UK of individual subjective understanding of quality of life.

When considering commencing data collection and analysis, the author felt this was an insufficient knowledge base from which to be prepared for data collection and analysis. The lack of insight potentially hampering the author who did not have a wider appreciation of the consequences of amputation for the individual. With these limitations in mind, a broader review of diabetes related lower extremity amputation was undertaken. A search of PsycInfo, PsycArticles, CINAHL, Scopus and PubMed was completed using the terms diabetes, lower extremity amputation, adaptation, coping strategies, life satisfaction and self-identity. Articles were included if they were in English, within the last 10 years, and peer reviewed. A hand search was undertaken of the reference section attached to the publications which met the inclusion criteria to widen the scope of literature to be explored.

Although literature searching indicated that no current research had specifically explored below ankle diabetes related amputation, there was research which explored lower extremity amputation in diabetes, the majority exploring participants accessing prosthesis services. Although there was no new knowledge with regards to below ankle amputation, this research provided the author with background knowledge regarding the consequences of diabetes related amputation. Table 2 provides a summary of the research identified, and a commentary upon the insight and understanding gleaned from this is explored after. The search was refreshed prior to thesis completion so the table also includes relevant studies dated from 2018 onwards.

TABLE 2 TOPICS EXPLORED RELATING TO PATIENT EXPERIENCE AND DIABETES RELATED AMPUTATION

Topic	Authors	Study Synopsis	Key Findings
Adaptation, Acceptance & Coping	Imayama et al. (2011)	1147 patients with diabetes and co-morbidities completed surveys to explore personality, lifestyle. HRQoL measured by a single question asking how participants considered health to be.	Personality impacts on coping styles, which can in turn impact upon adjustment and life satisfaction.
	Coffey et al. (2014)	98 patients in a prosthetic rehab programme completed TAPES and WHO disability assessment questionnaires relating to goal pursuit and adjustment.	There was a positive benefit to adaptation for people to adjust their lifestyle or behaviour to maintain their personal goals.
	Ostler et al. (2014)	8 patients who had undergone above ankle amputation participated in semi-structured interviews 2 weeks post-amputation.	Returning to 'normal' life was an important coping strategy. Lack of information about amputation and rehabilitation impacted coping.
	Anderson et al. (2017)	73 participants, interview, and review of records to assess activity levels and social support.	Better social support resulted in better daily function.
	Pedras et al. (2018)	86 participants completed HADS, IES-R, SSSS, WOC and TAPES.	Social support a positive influence on psychosocial adjustment Those anxious or depressed pre amputation were in a similar state post amputation.
	Perreira et al. (2018)	63 people with above and below knee amputations completed Brief COPE scale and Satisfaction with Life Scale.	Better life satisfaction for those using active, planning, religion, acceptance, and humour coping strategies.

Topic	Authors	Study Synopsis	Key Findings
			<p>Women used denial as a short-term coping strategy.</p> <p>Pain had no impact on life satisfaction</p>
	Makai et al. (2019)	29 patients completed questionnaires Beck Depression Inventory, HADS, Connor-Davidson Resilience Scale, Medical Outcomes Study Social Support Survey, Sense of Coherence Scale and Positive and Negative Affect Schedule at 1 month and 6 months post amputation.	Social support bolsters resilience and therefore adaptation Anxiety or depression impact upon resilience and adaptation to amputation.
	Benavent et al. (2020)	61 participants who had undergone amputation completed Prosthesis Evaluation Questionnaire and the socio-demographic details were explored.	<p>Older participants had worsened mobility and recorded more frustration and social burden.</p> <p>Women had appearance scores. Those with better educational levels and social environment had better adaption.</p>
	Zhu et al. (2020)	9 semi-structured interviews exploring amputation before post op wound closure. All participants had experienced below ankle amputation	<p>Adaptation required for physical, emotional, and social changes.</p> <p>Unwelcome judgement and questioning from others led to hiding amputation.</p>
Body Image & Self Identity	Senra et al. (2012)	42 semi-structured interviews exploring emotional impact and adjustment.	Self-identity changes related to body-image, function, biographical self, and future self.

Topic	Authors	Study Synopsis	Key Findings
	Ward Khan et al. (2021)	9 semi-structured interviews with female amputees exploring body image and sexuality.	Findings indicated issues with body-image acceptance, disturbances to sexual relationships and their view of their societal role.

Apart from Zhu et al. (2020) the research all related to above ankle amputation. This is perhaps not surprising as sample populations were recruited from amputation rehabilitation centres (Coffey et al, 2014, Ostler, 2014, Perreira et al, 2018; Senra et al, 2012; Ward Khan et al., 2021) or selected as they had undergone below knee amputation (Anderson et al., 2017; Makai et al. 2019; Pedras et al. 2018). The studies focussed upon a particular aspect of the amputation experiences, either on identifying the impact of coping strategies utilised, or exploring the effect of social support upon adaptation to the amputation. Two studies (Senra et al, 2012; Ward Khan et al, 2021) explored the impact of amputation upon body image perception. None of the research connected these aspects to consequences for quality of life perception.

Research showed that adaption to amputation was influenced by the individual attitude, a participant's social situation and environmental constraints (Benavent et al, 2020). Adaptation was vital to accept changes within physical emotional and social spheres as a result of the amputation (Zhu et al, 2020). Coffey et al. (2014) identified that there was a positive benefit to the individual if there were adjustments to lifestyle or behaviours were adapted to achieve personal goals. Utilising positive, active, planning coping strategies were important to be able to achieve these goals. Unsurprisingly adopting positive strategies was identified to result in improved life satisfaction (Imayama et al., 2011; Perreira et al., 2018). Concerning the role of family, friends and a social network, studies completed by Anderson et al (2017), Pedras et al. (2018), Makai et al (2019) at Zhu et al (2020) all identified the importance of social support for successful adaptation to amputation. Being able to share the amputation experience, having a social network to rely on for support increased resilience and psychosocial adaption to amputation.

Concerning personal acceptance of changes to the physical form, the other theme identified within the studies related to body image. Studies completed by Senra et al (2012) and Ward et al. (2021) identified that amputation led to reflection both upon body-image and in turn this had consequences for self-identity, acceptance of the changes and adaptation. Those struggling

with accepting the changes struggled with the changes to life and referred to life as before and after amputation as two different entities, as though they were two different people (Ward et al, 2021). Showing that the changes as a result of amputation resonate emotionally as well as physically. Zhu et al. (2020) identified participants in the process of adaption hid the amputation to avoid unwanted judgement, to be perceived as normal in the eyes of others.

Impact of Additional Knowledge upon the Author

This additional knowledge from a field outside of quality-of-life research demonstrated the emotional impact of amputation. The physical limitations because of amputation were acknowledged within these studies, but also evidence was presented which demonstrated the influence of amputation upon an individuals' psychosocial functioning. The studies explored coming to terms with the amputation, being able to comprehend what this meant for them as an individual, and through adaptation re-establishing their self-identity. The research provided insight into adaptation, coping theories and body image perception. This new knowledge to be utilised by the author, if relevant, when undertaking the individual interviews and throughout the data analysis process.

Refreshed Literature Review of the Impact of Amputation on Quality of Life

Prior to thesis completion the literature review was refreshed in order to present the current knowledge base and understanding with regards to the impact of below ankle amputation upon quality of life. The sections below outline what information sources were explored, search terms used to retrieve articles and the types of literature included for review. This is then followed by a presentation of the included studies and establishes the need for the current study.

Searching for Literature

Expert opinion was sought from a librarian specialising in health sciences to determine appropriate search terms, appropriate databases and grey literature to explore. A comprehensive database search was preformed of CINAHL, Cochrane, MEDLINE, PsycInfo, PubMed, Science Direct and Scopus, using the key words and exploded terms presented in Table 3. Boolean terms and wildcards appropriate to the individual databases were used to retrieve research pertinent to the topic.

TABLE 3 SEARCH TERMS USED TO RETRIEVE RESEARCH EXPLORING IMPACT OF DIABETES RELATED BELOW ANKLE AMPUTATION UPON QUALITY OF LIFE

Overall Concept to be Explored	Exploded Search Terms Used
Amputation	Lower Extremity Amputation Major Amputation Minor Amputation Below Knee Amputation Below Ankle Amputation

	Lower Limb Amputation
Diabetes	Diabetes Mellitus
Quality of Life	Quality of Life Lived Experience Normality Outcome Patient Reported Outcome

After this process was completed, duplicates were eliminated, titles and abstracts reviewed to ensure pertinence to the research question. A hand search of reference lists of included articles and review of grey literature were completed in order to retrieve any relevant research. Searches were limited to English language and from peer reviewed academic journals. All sources were included regardless of study type to ensure comprehensive exploration, whilst conversational pieces, conference proceedings and book reviews were excluded. The author has chosen to utilise a PRISMA diagram (Figure 3) to assist with summarising the process of searching.

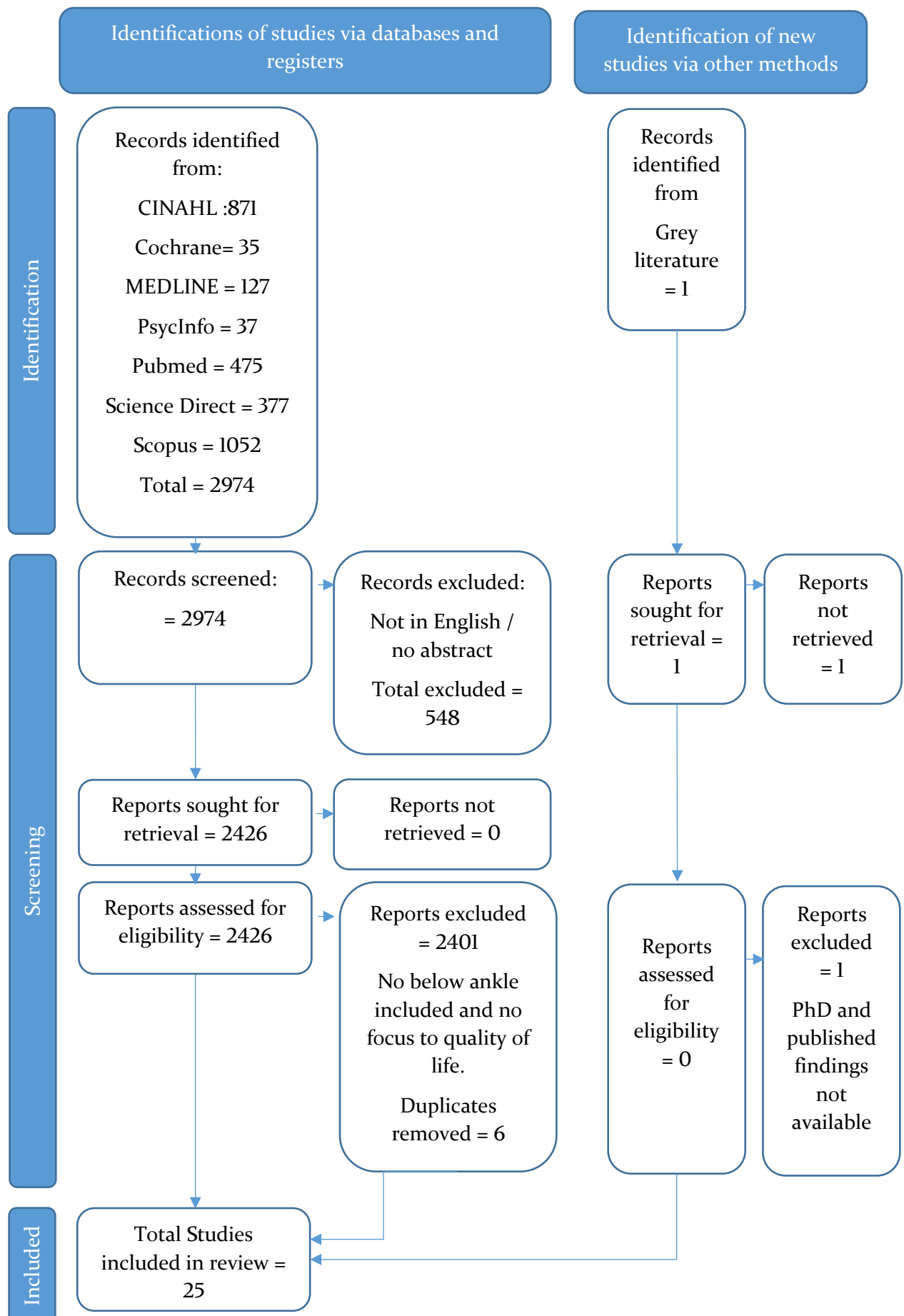


FIGURE 3 PRISMA DIAGRAM (PAGE ET AL, 2020)

Overview of the Included Studies

Following the database searches 2974 citations were identified with an additional registered PhD study identified from exploring the grey literature. A total of 548 citations were removed due to not being in English or providing an abstract. Of the 2426 sources assessed for eligibility to be included in the review, 2401 were excluded due to not including below ankle amputation within the study. The PhD was also excluded as this was not available to review, and further exploration identified no published articles from the PhD. Following this, 6 duplicates were removed to result in a total of 25 studies included in the review. Of the 25 studies included, 20 were questionnaire-based studies utilising an array of measures to explore the impact of amputation. The remaining 5 studies adopted a qualitative semi-structured interview approach. Studies were conducted globally, with the USA having the most studies conducted. Only two were multisite in multiple countries these included sites in Europe and Australia. Due to the range of study styles, the author chose to utilise Hawker et al's. (2002) guidance to be able to systematically review the varied evidence sources and provide a score as to the quality of the evidence itself. The scores are categorised as low, fair or high quality. The studies were either rated as fair or high quality. Those of fair quality provided insufficient details regarding the sampling strategy, did not provide enough information in order for data to be transferable and did not explore research recommendations within the implications. Table 4 provides an overview of the studies included in the review and the quality of the study. Appendix I provides a table showing the calculation of each rating provided by using Hawker et al's critical appraisal tool.

TABLE 4 INCLUDED STUDY CHARACTERISTICS

* Denotes studies with presented below ankle amputation results separately and so can provide insight into the impact of below ankle amputation.

^ Denotes qualitative studies

Study Authors	Abbreviated Title	Study Design	Location of Study	Sample Description	Demographics	Number with Amputation	Below Ankle Findings reported Separately?	Conclusion Issues Raised	Quality Assessment of the Studies (Hawker et al., 2002)
Alva et al. (2014)	Effect of Type 2 Diabetes complications on HRQoL importance of longitudinal data collection	Prospective longitudinal data collection at 7 points over 10 years using EQ-5D	UK	3380 participants completed at least one questionnaire	Age 67.7	150 Not split into above and below ankle	No	HRQoL varies over time, should explore more than once after a complication	High
^Amoah et al. (2018)	Experiences of Diabetes Related Below ankle amputation	Semi-structured interviews with 10 individuals who had undergone amputation	Komfo Anokye Teaching Hospital Ghana	10 participants	40% Female 60% Male 60% aged 40-60	10 Foot Ankle Below knee Above knee Hip	No	2 Themes 1. Physical Adjustment, unable to work, economic loss, loss of physical independence, change in family role. 2. Coping Better than others, god's will for the	Fair

Study Authors	Abbreviated Title	Study Design	Location of Study	Sample Description	Demographics	Number with Amputation	Below Ankle Findings reported Separately?	Conclusion Issues Raised	Quality Assessment of the Studies (Hawker et al., 2002)
								amputation, support of family	
*Aprile et al. (2018)	Pilot Study Exploring the Impact of Type 2 Diabetes Associated First ray amputation on gait and HRQoL	Case-control study using SF-36 for HRQoL, NRS for pain & gait analysis via walking trails and reflective markers for joint position	Italy	6 Control 6 Diabetes 6 Diabetes & 1 st ray amputation	Control 70% Female 30% Male Age 67.5 Diabetes 30% Female 70% Male Age 68.16 Amputation 100% Male Age 75	6	Yes – only 1 st ray amputation	1 st Ray amputation results in reduced physical and social function, and a reduced physical role.	High
^Barg et al. (2017)	Qualitative Interview Study What do individuals with Type 2 Diabetes think and feel about their ulcer or amputation?	Semi-structured interviews exploring educational knowledge of the consequences of diabetes. The concept explored was better education, better prepared.	Philadelphia USA	39 19 foot ulcer 20 Above or below ankle amputation	38% Female 62% Male Age 65.0	4 Transtibial or higher 14 transmetatarsal 2 1 st ray	No	4 themes 1. Disruption Independence altered, using mobility aids altered self-image and judgement by others. 2. Amputees No choice but to have the amputation. 3. Other impacts on health	Fair

Study Authors	Abbreviated Title	Study Design	Location of Study	Sample Description	Demographics	Number with Amputation	Below Ankle Findings reported Separately?	Conclusion Issues Raised	Quality Assessment of the Studies (Hawker et al., 2002)
								Pain or depressive symptoms lead to social withdrawal. 4. Hope important for adaption.	
*Boutoille et al. (2008)	HRQoL for Diabetes Associated amputation compared with chronic ulceration	Comparison those with amputation at least 1 year prior to study and current active ulcer. SF-36 completed once by all participants	Nantes France	9 ulcerations 25 amputations	No Female/ Male information Foot ulcer Age 70 Amputation Age 68	25 6 transtibial, 19 toe or transmet	Yes	Toe or transmet amputation has better physical function and improved pain versus those which chronic ulceration	Fair
Carrington et al. (1996)	Exploring Psychological status of those with Diabetes ulceration or amputation	Age and sex matched control, ulceration and amputation group. HAD, PAIS, Foot Questionnaire and QOLL	Manchester, UK	52 participants 3 Groups Control n= 26 Ulceration n=13 Amputation n=13	31% Female 69% Male Age 42-72	13 12 below knee. No detail of the level of amputation 1 above knee	No	Those with amputation have better life satisfaction than with a current ulceration. Amputees have similar life satisfaction to the control group	Fair
*^Crocker et al. (2021)	Patient perception of the impact of diabetes	Semi-structured individual telephone	Tucson USA	15 Participants	33.3% Female 66.7% Male Age 54.2	8	Yes – quotations from	3 themes 1. Care management	Fair

Study Authors	Abbreviated Title	Study Design	Location of Study	Sample Description	Demographics	Number with Amputation	Below Ankle Findings reported Separately?	Conclusion Issues Raised	Quality Assessment of the Studies (Hawker et al., 2002)
	associated ulceration or amputation on physical, psychosocial and financial situation	interviews exploring the experience of ulceration or amputation. undergone		8 Below ankle amputation 1 Above ankle amputation 6 Ulceration			amputation participants	<p>The importance of family in providing care. The complexity of co-ordinating appointments</p> <p>2. Changes to body image</p> <p>Ashamed of amputation, hiding of amputation site.</p> <p>3. Positive focus to self</p> <p>Active focus upon health improvement</p>	
*^Dillon, Anderson et al (2020)	Lived experience of below ankle then subsequent transtibial amputation. What education is important for informed decisions?	Narrative Semi-structured individual interviews with 10 individuals who had undergone	Hospital Melbourne Australia	10 Participants	20% Female 80% Male Age 52.4 Of the 5 Diabetes related 20% Female	10 5 related to Diabetes	Yes Quotes linked to participant demographics	<p>Presented here are the themes relevant to below ankle amputation.</p> <p>1. Physicality altered with protracted</p>	High

Study Authors	Abbreviated Title	Study Design	Location of Study	Sample Description	Demographics	Number with Amputation	Below Ankle Findings reported Separately?	Conclusion Issues Raised	Quality Assessment of the Studies (Hawker et al., 2002)
		below ankle amputation then subsequent transtibial amputation. Thematic summary presented			80% Male Age 60.8			complications & multiple surgeries impacted upon work and family life. 2. Educational deficit pre below ankle amputation, Need better preparation	
Dillon, Quigley et al. (2020)	HRQoL in People with Partial Foot or Transtibial Amputation	Cross-sectional online study using SF-36 to explore HRQoL, PROMS to look at health status and TAPES used for demographics	America	123 participants 2 Groups Partial Foot amputation n= 42 Transtibial amputation n=81	Partial Foot 33.3% Female 66.7% Male Age 56.3 44.4% had diabetes Transtibial 30.9% Female 69.1% Male Age 54.6 55.6% had diabetes	Partial Foot Toes = 17 Metatarsal = 8 Transmet = 13 Midfoot = 3 Other = 1	Yes Diabetes not reported separately	Level of amputation does not impact HRQoL rather reduced physical function, presence of pain, anxiety or depression negatively impacts HRQoL	High
^Foster and Lauver (2014)	Interview study of the lived experience of diabetes amputation	15 semi-structured interviews with individuals who had	Northeast USA	15 participants	100% Male Age 71.5	15 Above knee, above ankle, below ankle	No	5 themes being a productive member of society. 1. Financial burden	High

Study Authors	Abbreviated Title	Study Design	Location of Study	Sample Description	Demographics	Number with Amputation	Below Ankle Findings reported Separately?	Conclusion Issues Raised	Quality Assessment of the Studies (Hawker et al., 2002)
		undergone above and below ankle amputation explored via thematic analysis						<p>cost of medical care for amputation & and comorbidities</p> <p>2. Powerlessness Loss of body part, inability to complete self-care, immobility, increasing comorbidities loss of independence,</p> <p>3. Social support Family, community, health care professionals, loss lack of support.</p> <p>4. Placing blame Self-blame and regret, wishing care giver did more, grief for loss of body part.</p>	

Study Authors	Abbreviated Title	Study Design	Location of Study	Sample Description	Demographics	Number with Amputation	Below Ankle Findings reported Separately?	Conclusion Issues Raised	Quality Assessment of the Studies (Hawker et al., 2002)
								5. Uncertainty Returning to work, going out with friends, rehabilitation, wound care.	
Hayes et al. (2016)	HRQoL with complications of Type 2 Diabetes	Longitudinal study EQ-5D administered 4 times over 5 years	20 Countries – Australia, Canada, China, Czech Republic, Estonia, France, Germany, Hungary, India, Ireland, Italy, Lithuania, Malaysia, Netherlands, New Zealand Philippines, Poland, Russia, Slovakia, United Kingdom	11,130 participants	43% Female 57% Male Age 65.8	39 Not split into above and below ankle	No	Complications permanently diminished HRQoL, amputation diminishes HRQoL the most out of the complications studied	High
Juzwiszyn et al. (2022)	Acceptance of illness, quality of life perception and nutritional	Questionnaire Study WHOQoL-BREF,	Wroclaw University Hospital Poland	99 patients 6 months after amputation Male = 23	Female age 74.4 (60-90)	Not split into above and below amputation	No	Better quality of life, better acceptance of illness.	High

Study Authors	Abbreviated Title	Study Design	Location of Study	Sample Description	Demographics	Number with Amputation	Below Ankle Findings reported Separately?	Conclusion Issues Raised	Quality Assessment of the Studies (Hawker et al., 2002)
	status after amputation in Type 1 and Type 2 Diabetes	Acceptance of Illness Scale, Nutritional Assessment		Women = 76	Male age 64.3 (55-77)				
McDonald et al. (2014)	Psychosocial Impact of Amputation for Type 1 and Type 2 Diabetes	Questionnaire based study Comparison of 2 groups Completed HADS, WHOQoL-BREF physical & psychological and BIDQ	Sydney Australia	2 Groups Individuals with Diabetes & Amputation (n=50) Control Group Individuals with Diabetes and no amputation (n=240)	Sample With amputation 22% Female 78% Male Age 63.04 Sample Without 33% Female 66% Male Age 64.65 Same geographical areas	3 Below ankle amputations	No	Body Image Disturbance associated with Amputation. Psychosocial aspects such as physical quality of life and depression related to co-morbidities	High
*Nazri et al. (2019)	HRQoL for Diabetes related Below and Above Ankle Amputation	Cross-sectional study patients admitted for amputation January-December 2012. SF-36 used at 6 months to	Tengku Ampuan Afzan Hospital, Kuantan, Malaysia	94 participants	Below Ankle 44.8% Female 55.2 Male Age 53 Above Ankle 44.4% Female 55.6% Male	94 Below ankle = 58 Above ankle = 36	Yes	84.% below ankle able to walk without aid vs. 41.7% above ankle Healing time below ankle 1-5 months All amputation diminishes	Fair

Study Authors	Abbreviated Title	Study Design	Location of Study	Sample Description	Demographics	Number with Amputation	Below Ankle Findings reported Separately?	Conclusion Issues Raised	Quality Assessment of the Studies (Hawker et al., 2002)
		determine HRQoL			Age 56			physical and mental health but Below ankle amputation had statistically significantly better physical function, physical and emotional role, general health and mental health than those with above ankle amputation.	
Pedras et al. (2016)	HRQoL for Patients with Type 2 Diabetes associated Foot ulcer pre and post amputation	Longitudinal study. HRQoL completed pre and 1 month post amputation surgery.	Portugal	108	27.8% Female 72.2% Male Age 65.7	108 – Level not specified	No	Physical and mental QoL post amputation influenced by physical QoL pre-amputation. Physical QoL is diminished post-amputation. No impact on mental component score	High
*Peters et al. (2001)	Impact of Diabetes-Related Lower Limb Amputation upon Health Status	Questionnaire based study comparison of 2 groups – those with amputation and without	Texas, USA	2 Groups Control = 89 Amputation = 35	With Amputation 22.9% Female 77.1% Male Age 56.8 Control 43.8% Female	35 Below Ankle = 26 Above Ankle = 9	Yes	Below ankle amputation impacts physical function.	Fair

Study Authors	Abbreviated Title	Study Design	Location of Study	Sample Description	Demographics	Number with Amputation	Below Ankle Findings reported Separately?	Conclusion Issues Raised	Quality Assessment of the Studies (Hawker et al., 2002)
					56.2% Male Age 52.4				
*Pickwell et al. (2016)	Below ankle amputation does not impact HRQoL in Type 1 and Type 2 Diabetes	Multi-centre prospective cohort study. EQ-5D completed at entry, and at 1 year/ healing/ above ankle amputation	14 Diabetic Foot Centres in 10 Countries Belgium, Czech Republic, Denmark, Germany, Italy, Netherlands, Slovenia, Spain, Sweden, United Kingdom	“ Groups Healed conservatively = 676 Below ankle amputation = 145	Conservative 37.3% Female 62.7% Male Age = 64.3 Below ankle amputation 31% Female 69% Male Age = 64.5	145	Yes – only reviewed below ankle	No negative impact of healing by below ankle amputation. Should be considered a viable treatment option. EQ-5D generic and crude instrument	High
*Quigley et al. (2015)	Pilot study of HRQoL for Diabetes Associated partial foot or transtibial amputation	Postal Cross-sectional study using SF-36	Melbourne Australia	122 posted, 33 fully completed -	Ankle 30% Female 70% Male Age 63 Transtibial 40% Female 60% Male Age 68	23 Trans tibial amputation 1 Toe 5 Forefoot 4 Midfoot	Yes	Those with below ankle amputation had better physical component score than those with trans tibial amputation. However, other aspects such as age, time since diabetes diagnosis and retinopathy impacted upon HRQoL rather than amputation itself.	High

Study Authors	Abbreviated Title	Study Design	Location of Study	Sample Description	Demographics	Number with Amputation	Below Ankle Findings reported Separately?	Conclusion Issues Raised	Quality Assessment of the Studies (Hawker et al., 2002)
*Ragnarson Tenvall & Apelqvist (2000)	Exploring HR QoL in Type 1 and Type 2 Diabetes for those with active and healed by any means foot ulcers	Retrospective & Prospective postal questionnaire EQ-5D sent to all patients seen by 1 MDT 1995-1998	Lund University Hospital Sweden	N= 457 Responders = 310	34.5% Female 65.5% Male Age = 67 (16-98)	52 Below ankle amputations	Yes	Little difference in quality of life for those healed by below ankle amputation or conservative methods. Above ankle significantly reduced quality of life	High
Ribu et al. (2008)	Longitudinal study of Diabetes associated Ulcers and HRQoL	Prospective, observational 1 year follow-up comparison of HRQoL in healed and chronic ulceration SF-36 completed at baseline, 6 months and 1 year.	Oslo Norway	127 at baseline After 12 months 99 left	28% Female 72% Male 61	18 Forefoot = 1 Toes = 10 Transfemoral = 7	No	Healed ulceration led to improve scores in physical function, physical role limitation, general health, social function and mental health	High
*Sothornwit et al. (2018)	Exploring HRQoL for foot ulcer or amputation in Type 1 and Type 2 Diabetes	Cross-sectional study January 2014 – September 2016. One completion of the EQ-5D	Siriraj Hospital, Thailand	Random Sample 254 patients seen at diabetic clinic / foot clinic / dressing room/ eye surgery clinic	56% Female 54% Male Mean age = 65	15	Yes	Amputation does not diminish HRQoL when compared to those which current ulceration	Fair

Study Authors	Abbreviated Title	Study Design	Location of Study	Sample Description	Demographics	Number with Amputation	Below Ankle Findings reported Separately?	Conclusion Issues Raised	Quality Assessment of the Studies (Hawker et al., 2002)
Spanos et al. (2017)	Impact of treatment on Quality of Life for patients with Type 1 diabetes associated foot ulcer	Prospective non-randomised cohort DFS-SF used to determine QoL	Larissa Greece	103 Consecutive patients with ulceration followed for 1 year	33% Female 77% Male Mean age = 69.7	52 (9 /52 went on to have above ankle amputation due to non-healing site)	No	Amputation does not negatively impact on QoL	High
Willrich et al. (2005)	HRQoL, Depression and Cognitive Function in Ulceration or Amputation	Random Sample of those receiving care. SF-36, Mini Mental Exam, Clock Draw Test and Zung Depression Scale	Maywood USA	Neuropathy = 20 Ulcer/ Charcot = 20 Amputation = 20	Neuropathy 30% Female 70% Male Charcot/Ulcer 40% Female 60% Male Amputation 55% Female 45% Male No ages given	20 Toe - Transtibial	No	Amputation impacts on physical function	Fair
Winkley et al. (2009)	HRQoL with a first diabetes associated ulcer	Prospective cohort, participants followed for 18 months with first foot ulcer. SF-36 used for HRQoL	London, UK	253	35.7% Female 64.3% Male Mean age = 62.40	36 – no levels given	No	Amputation does not impact Physical HRQoL.	High
Zhang et al. (2012)	HRQoL for those with Type 2 Diabetes Complications	Cross-sectional review of EQ-5D scores for	USA – California, Hawaii, Indiana,	7327 individuals	53.2% Female 56.8% Male	Unknown – 157 toe or 1 leg amputation	No EQ-5D score 0.70	No insight into the impact of below ankle amputation	Fair

Study Authors	Abbreviated Title	Study Design	Location of Study	Sample Description	Demographics	Number with Amputation	Below Ankle Findings reported Separately?	Conclusion Issues Raised	Quality Assessment of the Studies (Hawker et al., 2002)
		those with diabetes	Michigan, New Jersey, New York, Pennsylvania, Texas		Mean age = 62 (21-100)		Mean Study Population score = 0.80 Perfect health = 1.00	upon quality of life. Above ankle and below combined results indicate detrimental impact to quality of life	

Exploration of the Studies

In order to clearly explore the literature, the author has chosen to present findings from the qualitative and quantitative research initially separately. The qualitative research has been presented first. Each of the 5 pieces of qualitative research undertook semi-structured interviews and employed thematic analysis to explore the experience of amputation. After appraisal of all 5 articles, a summary is provided of the new knowledge gained from the qualitative research.

The quantitative research is then presented by the measure used. Table 5 presents a summary of each measure utilised within the published research and is presented prior to the exploration of the quantitative studies to orientate the reader as to what each measure records or scores. Exploring research together which has used the same outcome measure has enabled the author to compile an idea of the supporting or contrasting results garnered by the same outcome method. A summary is provided at the end of each outcome measure reviewing what knowledge has been gained regarding the impact of below ankle amputation upon quality of life.

Finally, there is a summary of the findings elicited from reviewing all research, qualitative and quantitative relating to quality of life and below ankle amputation. The author presents the knowledge gleaned from the 10 studies, and how this has been utilised within the current study.

Qualitative Studies

Only one qualitative study was available for exploration prior to data collection commencing for the current research project (Foster & Lauver, 2014). Since data collection began in June 2017, four additional qualitative studies have explored the lived experience of amputation. None have explored the experiences within the UK, and this confirms the timeliness and currency of the research undertaken. The findings of the current research will contribute to the global

understanding of the impact of diabetes related below ankle amputation upon quality of life. The qualitative studies are explored below.

Foster and Lauver

Foster and Lauver (2014) undertook semi-structured interviews exploring the experience-as-lived of 15 patients in a suburban North-East region of the USA who had undergone amputation following chronic ulceration. The study included individuals with above knee, below knee and transmetatarsal or toe amputation who were recruited from 5 hospitals. All were over 40, and were determined to have good levels of education, all were graduates. All participants had medical insurance. Essentially the study explored those who were highly educated, with good socio-economic status rather than gaining insight into those within a poor social-economic situation. The study found the participants were concerned with being productive, when considered from a social and economic perspective. The research identified 5 key themes but did not group these themes into level of amputation. The themes were financial burden, social support, powerlessness, blaming and uncertainty. Some of the themes identified were specific to the United States population such as concerns about the financial burden of health care, however other aspects such as loss of social activity, independence and issues around supporting their family financially may reflect the thoughts of individuals within the UK. The importance of support from both health care professionals and family was identified as being key to recovery during adaptation to the amputation. It could be suggested that the theme identified as 'blame' could be associated with maladaptation to the amputation, unable to accept the change that had happened and either blaming themselves or medical professionals for the amputation. The study concluded that those undergoing amputation needed to have improved knowledge with regards to social and financial support during rehabilitation, and a clearer idea of the rehabilitation process. As the themes were explored for all 15 participants together, the study,

although providing insight into the experiences of those who have undergone diabetes-associated amputation, there is no specific knowledge gained as to the impact of below ankle amputation upon quality of life.

Barg et al.

Barg et al. (2017) undertook 39 individual interviews of people in Philadelphia, USA who either had a foot ulcer or amputation, the results identifying themes surrounding being a social and economic burden echoing Foster and Laver's 2014 United States study. Four individuals had above ankle amputation, 16 had below ankle amputation (14 transmetatarsal, 2 first ray amputation). All procedures had occurred within 4 weeks of enrolment in the study and interviews were completed either in the participants home or via telephone. Telephone interviews may have led to issues such as visual cues being missed by the data collectors, which could result in the interview not fully exploring elements that were important to the individual. The interviews were structured around the concept that improved health literacy would improve self-care. Data analysis identified themes indicating amputation was disruptive to the individual's ability to function and maintain independence, there was change to physical appearance and self-image due to the necessity to use mobility aids such as walking sticks. Changes to role-identity were associated with alterations in ability to function, with participants being more reliant upon family support, feeling a burden to the family both financially and for the care needed post amputation. Concerning any positive events post amputation, participants were more motivated to improve their individual health, some expressed improved social relationships and an appreciation for life. The study provided demographic exploring the age, gender, marital status and educational level of participants. This data is useful to enable comprehension with regards to those who participated within the study. Focussing upon the impact of below ankle, Barg et al. did not present findings by level of amputation, rather those with current ulceration were compared to those who had experienced amputation of any level.

However, the majority of experiential data concerning amputation was derived from below ankle amputation – 16 of the 20 accounts were individuals with either first ray or transmetatarsal amputation. The study therefore does provide some knowledge with regards to the impact of below ankle amputation upon quality of life in terms of body-image perception and provides confirmation that amputation does result in physical functional limitations with consequences to employment and familial role during the first phases of rehabilitation. As participants were not re-interviewed further along the rehabilitation process, there is uncertainty whether aspects expressed by those with amputation, such as loss of independence remain.

Amoah et al

Amoah et al. (2018) undertook an exploratory study of 10 individuals in Ghana who had experienced a range of amputation levels – from toe to hip disarticulation. They interviewed individuals using a semi-structured interview format. The data collection instrument asked participants to explore their amputation experiences focussing upon physical experiences, emotional changes, social support, coping strategies, and the impact upon life. There was no scope within the interviews to explore wider aspects such as environmental situation or exploring the role of the health care team within the amputation experience. Results of all levels of amputation were presented together. The researchers presented two key themes, physical experience and coping strategies. The results explored the difficulties in using physical walking aids, inability to work and more reliance upon immediate family. Coping strategies included thinking they were better off than others with worse ill health or accepting the amputation as god's will. These aspects could be seen to be ways of seeking adaption to the changes wrought by the amputation. Amoah et al. (2018) were surprised to find some participants were happy to have the amputation and attributed this to potential resolution of chronic amputation. No exploratory data has been presented to provide context for why participants expressed happiness for amputation, exploration may have given insight into quality-of-life perception pre

and post amputation. Although those who experienced below ankle amputation were included within the study, it is hard to determine if any of these findings and supporting quotes for the themes identified relate to those with a below ankle amputation as the level of amputation that these 10 participants experienced was not presented either within the body of the article or the additional files, demonstrating that there is still a need for UK based research to explore below ankle amputation for individuals with diabetes mellitus.

Dillon, Anderson et al.

Dillon, Anderson, et al. (2020) explored the experiences of 10 individuals in Australia who had below ankle then subsequent transtibial amputations. Prior to first amputation participants lacked knowledge about the amputation procedures, the potential outcomes and what impact this may have for them. This resulted in lack of ability to make informed decisions and to be prepared for rehabilitation or complications post-surgery. The individuals were recruited from a hospital prosthetics centre in Melbourne, expert patients who inputted into orthotic training courses at La Trobe University or through replying to an advert in an amputee peer support magazine. The narrative enquiry semi-structured interviews captured the experiences of those who had undergone below ankle and subsequent transtibial amputations. Analysis determined all 10 participants had unresolved complications from the below ankle amputation which necessitated further surgery. The study identified participants had little knowledge of the outcomes or risks associated with below ankle amputation prior to the surgery occurring. This was in contrast to more structured education prior to the above ankle amputation. All reported the detrimental impact the complications and unsuccessful surgery had upon family and quality of life; life was on hold until successful revision surgery. The research highlighted the importance of knowledge and education prior to amputation being undertaken to enable individuals to prepare for the life changes and to enable positive adaptation to the amputation.

However, by nature of the study aims and inclusion criteria, these results and insights only relate to those who had experience of unsuccessful below ankle amputation.

Crocker et al.

The study completed by Crocker et al. (2021) explored the impact of either diabetes associated ulceration or amputation upon physical, psychosocial and financial aspects of life in those from disadvantaged socio-economic backgrounds. The study conducted with the USA recruited participants from patients who attended a limb salvage team based at one Medical Centre in Tucson. Eight of the 15 participants had experienced below ankle amputation, one above ankle amputation and the other 6 had a history of ulceration. Semi-structured telephone interviews were conducted by 3 researchers experienced in conducting interviews. The researchers all used an interview guide which focussed to exploring physical and psychosocial and financial impact of amputation or ulceration. The study originally chose a focus group format, but due to Covid, had to alter to a remote interview structure.

The thematically analysed transcripts identified there were physical changes for those who underwent amputation. There was a limitation of activities during the healing process, and this had implications both within the psychosocial and financial realms explored by the study. Reduced mobility occurred in the study due to post-operative recuperation and the ongoing changes to physicality having lost part of a foot. The reduced physicality resulted in participants being unable to work, altering their economic situation. This led to an alteration in their economic situation, and reliance upon family and/or a partner to financially provide. As the study was completed within the USA from those with poor socioeconomic background with substandard medical insurance, the financial impact of the study orientated around the psychological impact of being unable to work and how to pay the medical bills. This is not the

situation within England with regards to provision of medical care. However, the lack of ability to work could have consequences to lifestyle for those within England.

Crocker et al's study recognised the importance of family or partner during these events for both emotional and practical support. Family provided a caring role for participants post-amputation. The study identified that those who had experienced below ankle amputation reported negative body image perception. There was shame or embarrassment due to the loss, and participants chose to hide the amputation to avoid unwelcome observation or conversation with strangers.

The study provides insight into the person experience of amputation, although the population studied does not echo the demographics of an England based study, there are insights gained into the lived experience of amputation such as altered mobility, the importance of family and potential body-image alteration.

Conclusion from the Qualitative Findings: Body image perception may be altered due to the amputation. Changes to physicality may cause alterations to economic situation. Social support is important for rehabilitation.

The 5 qualitative studies have provided detail as to the lived experience of amputation. Of the five qualitative studies, those conducted by Barg et al., Crocker et al. and Dillon, Anderson et al. presented findings from those who had undergone below ankle amputation. These findings suggest that changes to physicality have physical, social and psychological implications. Due to this there is a need for social support from family or partners. The studies also indicated that there may be consequences for how an individual views themselves, amputation resulting being ashamed or hiding the altered physical form, avoiding external judgement.

Quantitative Studies

Of the 25 studies identified as relating to exploring quality of life and amputation, 20 utilised questionnaire-based outcome measures to explore quality of life. Table 5 provides a summary of the outcome measures used by these studies, so the reader is aware of what these tools are designed to measure, and what topics each measure explores. Following this, there is exploration of the quantitative studies by the outcome measure chosen so that the findings of studies using the same outcomes can be reviewed and findings can be compared for commonality or diversity. A summary is provided at the end of each section detailing what conclusions can be drawn as to the impact of below ankle amputation upon quality of life.

TABLE 5 SUMMARY OF TOOLS USED IN DIABETES RELATED AMPUTATION RESEARCH PURPORTING TO DETERMINE QUALITY OF LIFE

Name of Tool	What Measuring	Factors Assessed	How Measured
Diabetic Foot Ulcer Scale Short Form Questionnaire DFS-SF Abetz et al. (2002)	<p>Questionnaire exploring the impact of diabetic foot ulceration and treatment upon quality of life. Focussed upon factors related to foot ulcers.</p> <p>Developed for use within clinical trials.</p>	<p>58 items explored within 11 domains:</p> <ol style="list-style-type: none"> 1. Leisure 2. Physical Health 3. Daily activities 4. Emotions 5. Noncompliance 6. Family 7. Friends 8. Positive attitude 9. Treatment 10. Satisfaction 11. Financial 	<p>Five responses available to comment upon each question within the domains.</p> <p>Responses include, not at all/ a little/ somewhat/ quite a bit/ extremely.</p> <p>The start of each domain focused to the foot ulcer with the opening statement, 'because of your foot ulcer...'</p> <p>Each domain scored from 0-100.</p>

Name of Tool	What Measuring	Factors Assessed	How Measured
			Higher score indicative of better quality of life
EuroQol EQ-5D (EuroQol Group, 1990)	<p>Two-part generic health measure questionnaire</p> <p>The UK recommended tool alongside a measure for a specific health condition for diabetes.</p>	<p>5 dimensions:</p> <ol style="list-style-type: none"> 1. Mobility 2. Self-care 3. Usual activities 4. Pain or discomfort 5. Anxiety or depression <p>Visual analogue Scale rating health on the day of completion 0= worst imaginable health state – 100 = best imaginable health state</p>	<p>The EQ-5D-3L has three response options, the 5 EQ-5D-5L has five response options.</p> <p>All sections scored according to the responses and provide a five number health state indicating the extent to which each dimension is impacted.</p>

Name of Tool	What Measuring	Factors Assessed	How Measured
			A higher score indicates more impact, a lower score, lower impact to the domain in question.
Foot questionnaire (Carrington et al., 1996)	Likert Scale of 12 factors determining how individuals felt about their feet during the last month	12 pairs of opposites: 1. Painful/painless 2. Healthy/unhealthy 3. Weak/strong 4. Comfortable/uncomfortable	Participants asked to put a mark on the 7-point line between the pairs of opposites. These marks were attributed a score.

Name of Tool	What Measuring	Factors Assessed	How Measured
		<ul style="list-style-type: none"> 5. Important to me/ not important to me 6. Worthless to me/ valuable to me, 7. Attractive/ unattractive, 8. Useless / useful 9. Definitely part of me / not really part of me 10. Not worth looking after / worth looking after, 11. Easy to keep clean / difficult to keep clean, 12. Unpleasant / pleasant 	Higher score indicative of a more positive attitude to the feet.

Name of Tool	What Measuring	Factors Assessed	How Measured
Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983)	Questionnaire determining states of anxiety and depression in a non-psychiatric setting	2 subscales assessed by 14 questions to assess anxiety and depression: 1. I feel tense or 'wound up' 2. I still enjoy the things I used to enjoy 3. I get a sort of frightened feeling like something awful is about to happen 4. I can laugh and see the funny side of things 5. I feel cheerful 6. I can sit and ease and feel relaxed 7. I feel as if I am slowed down 8. I get a sort of frightened feeling like 'butterflies in stomach' 9. I have lost interest in my appearance	Four responses available for each question. Differing words used but inferring the amount this feeling arises as definitely/ sometimes/ not often/ very seldom. An overall score produced from scoring each item identifies if individuals are normal, borderline or have a clinical 'caseness' of anxiety or depression.

Name of Tool	What Measuring	Factors Assessed	How Measured
		<p>10. I feel restless as if I have to be on the move</p> <p>11. I look forward with enjoyment to things</p> <p>12. I get sudden feelings of panic</p>	
Psychosocial Adjustment to Illness Scale (PAIS) (Derogatis, 1986)	Semi-structured interview or self-completed scale determining psychological adjustment to current illness	46 questions measuring 7 domains of adjustment to illness: <ol style="list-style-type: none"> 1. Health care orientation 2. Vocational environment 3. Domestic environment 4. Sexual relationships 5. Extended family relationships 6. Social environment 7. Psychological stress 	Four responses available for each question Same as before / slight / moderate / significant Higher rating indicative of poorer adjustment to illness.

Name of Tool	What Measuring	Factors Assessed	How Measured
Quality of Life Ladder (QOLL) (Carrington et al., 1996)	Scale Measurement of current life satisfaction	0-10 scale measuring worst possible life to best possible life	<p>Participant to imagine own personal best and worst life and then mark on the ladder where current life satisfaction is.</p> <p>Higher score indicative of greater life satisfaction.</p> <p>Mean score for whole population is 6.6</p>
The Medical Outcomes Study 36-item Short Form Health Survey (SF-36) (Tarlov et al., 1989)	Health Survey exploring health concepts related to functional status and well-being	36 questions covering 8 domains: <ol style="list-style-type: none"> 1. Physical functioning 2. Role-limitation physical 3. Bodily pain 4. General health 	All question responses are scored. A combination of question scores are combined to provide a score for the 8 domains. A range

Name of Tool	What Measuring	Factors Assessed	How Measured
		<ul style="list-style-type: none"> 5. Vitality 6. Social functioning 7. Role limitation -emotional 8. Mental health 	<p>of responses for each section all aiming to capture either worsened, same or improved status.</p> <p>Two summary scores for physical & mental health summary can be calculated.</p> <p>These can be compared to normal population scores to explore how health and wellbeing is impacted.</p> <p>A higher score indicates better functional status and well-being.</p>

Name of Tool	What Measuring	Factors Assessed	How Measured
Sickness Impact Profile (SIP) (Bergner et al., 1981)	Perceived health status measure exploring the impact of illness /alteration in health upon behaviour	136 questions, 3 sections covering 12 dimensions: <ol style="list-style-type: none"> 1. Independent sleep and rest, eating, work, home management, recreation & pastimes 2. Physical ambulation, mobility, body care & movement 3. Psychosocial social interaction, alertness behaviour, emotional behaviour, communication 	Yes/no response to all questions. Each answer has an assigned value. These are added to provide a health status score for a score for psychosocial, physical or other impairment. An overall score can be calculated ranging from 0-100. A lower score indicating better health and less impact of the illness or alteration to health.

Name of Tool	What Measuring	Factors Assessed	How Measured
			A score of 100 would indicate poor health and large impact upon behaviour.
Trinity Amputation and Prosthesis Experience Scales (TAPES) (Gallagher & MacLachlan, 2000a)	Questionnaire exploring the physical and psychosocial adjustment to a prosthetic limb	Self-administered Questionnaire exploring 5 aspects: <ol style="list-style-type: none"> 1. Psychosocial adjustment General adjustment, social adjustment, adjustment to limitation 2. Activity restriction Functional, social, athletic 3. Prosthetic satisfaction Functional, aesthetic, weight 4. Limb pain 	Separate scores are produced for each of the sections. For the psychosocial domain, a higher score indicates better adjustment For activity restriction, a higher score indicates more restrictions.

Name of Tool	What Measuring	Factors Assessed	How Measured
		<p>5. Other medical conditions</p> <p>Plus, rating general health and physical capabilities</p>	<p>For the Prosthesis satisfaction section, a higher score indicates better satisfaction with the prosthesis.</p> <p>Pain is explored by asking type/ duration/ frequency/ level and impact to life.</p> <p>Finally general health and physical capabilities are rated on a scale ranging from poor to very good.</p>
World Health Organisation Quality of Life- Brief (WHOQOL-BREF)	<p>Quality of Life Measure designed to gather individual perception of their life</p>	<p>26 items explored within 4 domains:</p> <p>1. Physical health</p>	<p>Each domain rated on a 5-point scale. The responses include not at all/ a little /</p>

Name of Tool	What Measuring	Factors Assessed	How Measured
(World Health Organisation, 1997)	incorporates wider issues such as societal position and environment.	<p>activities of daily living, dependence on medicinal substances and medical aids, energy and fatigue, mobility, pain and discomfort, sleep and rest, work capacity</p> <p>2. Psychological</p> <p>bodily image and appearance, negative feelings, positive feelings, self-esteem, spirituality/ religion/ personal beliefs, thinking learning memory and concentration</p> <p>3. Social Relationships</p> <p>personal relationships, social support, sexual activity</p> <p>4. Environment</p>	<p>moderately /mostly / extremely.</p> <p>A score is calculated for each domain which provides an individual quality of life profile. A higher score indicates a better quality of life.</p> <p>The Summary questions provide perception of quality of life and health.</p> <p>Respondents can reply either very poor / poor /</p>

Name of Tool	What Measuring	Factors Assessed	How Measured
		<p>Financial resources, freedom physical safety and security, health, and social care: accessibility and quality, home environment</p> <p>Summary questions asking overall perception of quality of life and overall perception of health</p>	<p>neither poor nor good / good / very good.</p>

Adapted and updated from (Levy et al., 2017)

DFS-SF- Determining Quality of Life related to Diabetic Foot Ulceration

Spanos et al. (2017) identified active ulceration was worse for quality of life than an ulcer healed by amputation or conservative methods. The study also identified that quality of life was not impacted by the method of healing. The prospective, central Greece based cohort study of 103 individuals explored the impact of diabetic foot ulceration and treatment upon quality of life by using the DFS-SF at recruitment to the study and at 12 months. Fifty-two individuals experienced below ankle amputation, this was related to a deeper wound and presence of neuropathy. Following healing, improvements were identified within the quality-of-life domains exploring leisure, negative emotions, physical health, daily life dependency and treatment satisfaction. However, data was reported collectively for all types of healing, so no exploration into the separate domain scores or comparison between conservative, minor or major amputation was possible. The study provided a wide range of demographic data to enable comparison with other studies, however, this was the only study to explore quality of life by using the DFS-SF and so is hard to compare to studies which have more frequently utilised measures such as the EQ-5D or the SF-36. The diabetic foot ulcer scale was developed and validated for exploring life with ulceration, exploring how much a foot ulcer has limited activities, pain, the limitation of usual activities. The questions are focussed to issues that the foot ulceration may cause rather than exploring aspects such as environmental or economic aspects. The questionnaire is very health orientated and so may not be fully exploring quality of life as defined by Schalock (2016).

Conclusion from DFS-SF findings: Amputation does not deteriorate Quality of Life.

Spanos et al. (2017) provided insight individuals with healed ulceration, resolved by conservative or surgical means have a better quality of life than those with chronic ulceration.

Below ankle amputation was not presented separately, so there is no insight specifically into the impact of below ankle amputation upon quality of life.

EQ-5D – Determining Health Status

Ragnarson Tennvall and Apelqvist (2000) also identified that active ulceration was worse for quality of life than ulceration healed by amputation by using the Swedish version of EQ-5D. The researchers justified the use of the health status measure as a specific diabetic foot related quality of life tool was not available at the time of their research. The research aimed to determine what the impact of ulceration was on HRQoL and whether EQ-5D was sensitive enough to determine differences in HRQoL between current foot ulceration, primarily healed ulceration and those who had undergone below or above ankle amputation. Purposive sampling was used send a postal questionnaire to all patients between 1995-1998 who had been treated by a multidisciplinary foot care team at one hospital location in Sweden (n=440). The study found that patients with active ulceration rated overall HRQoL worse than individuals with healed ulceration or healed below ankle amputation. Scores for usual activities, mobility, self-care, pain, anxiety, and health state were also worse for those with active ulceration. The results show that HRQoL for those with below ankle amputation was not dissimilar to healed ulceration (0.61 and 0.60 respectively) but was dramatically different for those with current active ulceration (0.44), but all states are diminished from the general population of 0.89. Ragnarson Tennvall and Apelqvist explored that the EQ-5D was only one health outcome measure that could have been used. They explored that additional quality of life measures could have been utilised, but this may have reduced the response rate. Those with below ankle amputation accounted for 17% of all respondents. One of the strengths of the study is that the subscales of EQ-5D were presented for those with current ulcer, healed, below ankle and above

ankle amputation so that each component is available for exploration. For the 5 scales, 71.2% had some problems with mobility, 73.1% expressed no issues with self-care, 48.1% and 30.8% reported no problems or some problems with usual activities respectively and 71.2% reported no pain. Exploring health state, 24.4% reported health was better, and 57.4% much the same. The study essentially highlighted that a healed foot represented a better health related quality of life than one with chronic ulceration if healed by conservative methods or below ankle amputation. The study highlights that individual who have undergone below ankle amputation may need to adapt their expectations of completing normal activities and may require support to assist with employing adaptation strategies.

The USA based Translating Research into Action for Diabetes (TRIAD) multicentre prospective study by Zhang et al. (2012) explored HRQoL for 7,327 individuals with Type 2 diabetes who paid into 10 specific health plans. Participants were from a range of USA locations, but all had private health care insurance, thereby omitting to explore those who did not have insurance and may have therefore be expected to have less effective medical management. The study determined that those with a diabetes related complication had lower EQ-5D scores than those with just a diagnosis of diabetes. Of the 7327 participants, 157 had 1 leg or toe amputated. The lowest scores were for individuals with either amputation of 1 toe or leg (0.70) or bilateral leg amputation (0.67), indicating that amputation could be of detriment to health status. However, the results for below and above ankle have been presented together, so the picture for the impact of below ankle amputation lacks clarity. As the overall health utility score is presented, rather than the results of the 5 subscales there is no data to explore to determine which aspects of the 5 domains explored by EQ-5D have been impacted or if there is indeed an impact from below ankle amputation at all. The study by Zhang et al does not provide any additional context or understanding as to the impact of below ankle amputation upon quality of life.

Alva et al. (2014) confirm Zhang's findings that amputation impacts more severely on health status than other cardiovascular events. Data was collected as part of the UKPDS study with the

EQ-5D was administered at seven points over 10 years to explore the impact of complications upon HRQoL. Analysis was performed on 11,614 questionnaires and indicated that patients who had one complication or more during the time period reported a reduced quality of life, but there was no further reduction in HRQoL over the subsequent 10 years. The study confirmed that amputation had the most impact upon HRQoL when compared to stroke, heart attack, blindness or ischaemic heart disease and that over time, quality of life did not improve. The study also demonstrated the validity of capturing a measure of health status in the acute first year and this being comparable to longer term. However, the level of amputation was not defined within this study, and the subset of the 5 EQ-5D aspects are not presented so there is no ability to explore what impact below ankle amputation has upon quality of life.

The ADVANCE study Hayes et al. (2016) confirmed Alva and Zhang's findings that amputation reduced health status. The multi-centre, multi-country longitudinal study explored the impact complications had by administering the EQ-5D at four points over a 5-year period to 11,130 individuals from 20 countries throughout Australasia, Asia, Europe, and North America. Within the UK there were 22 data collection sites. The study included any individual diagnosed with diabetes when 30 or older, was over 55 years of age when entering the study and had a history of macrovascular disease or a risk factor for macrovascular disease. The utility scores determined that amputation was most detrimental out of the 7 macrovascular complications studied (amputation, blindness, heart failure, ischaemic heart disease, myocardial infarction, renal failure, and stroke) to health status. The UK overall average score was 86, those at beginning of the study had a mean score of 82, indicating the detrimental impact of diabetes and a history of macrovascular disease. For amputation after 5 years this was significantly reduced by 0.122. As the overall utility score was reported by the study, there was no data to determine which of the 5 domains assessed by the administered EQ-5D-3L were impacted. Although the overall sample size was large, amputation was only experienced by 39 individuals, some 0.3% of the study population. There was no data presented exploring the split between

the 20 countries, nor between above and below ankle amputation. The authors were contacted, but no data was available to review to explore the potential UK population of those with amputation. This leaves uncertainty with regards to the impact of below ankle amputation upon quality of life for the UK population.

Pickwell et al. (2016) completed a prospective cohort multicentre study of 14 diabetic foot centres in 10 European countries, 2 data collection sites were based within England. The study explored the impact below ankle amputation had when compared to conservative treatment for ulceration. The results indicated that minor amputation did not negatively affect health status. Pickwell et al concluded that minor amputation should cease to be viewed as a failure of care, but as a viable treatment option. The multicentre study prospectively followed 1088 individuals who attended one of the 14 participating centres during the period 2003-2004 who completed the EQ-5D-3L at the start and end of the study. Of the 1088 recruited to the study, 70 died, 50 underwent major amputation, 145 minor amputations, 131 were not healed within the year and 16 individuals had data missing regarding their amputation status. Pickwell et al defined minor amputation as any amputation from toes to midfoot and so this means the results are not entirely comparable with research where minor amputation had included all amputation below the ankle. The results show, perhaps unsurprisingly, that those who underwent amputation had more complex ulcerations, possibly leading to the decision to amputate. The ulcerations were larger, deeper, and more associated with peripheral arterial disease and infection. When healing rates were 6 months or longer, patients who healed by amputation had a statistically significant improved anxiety/ depression scores than those who had healed by conservative methods. Pickwell et al suggested that this may be due to these patients anticipating that major amputation may be a possibility so healing following minor amputation may have reduced their anxiety levels more. Considering the suitability of the EQ-5D, Pickwell et al concluded that this was a “generic and rather crude HRQoL tool which is not specific for diabetic foot disease” (Pickwell et al 2016 p 5) and concluded that a randomised control trial was necessary to further

explore the impact of below ankle amputation upon quality of life. This study provides the current research with an indicator of the fact that toe and midfoot amputation does not impact HRQoL as measured by EQ-5D. The study presented the change in the EQ-5D individual scores. These indicated an improvement in all scores - mobility, self-care, usual activities, pain, and anxiety and depression when compared to those who receiving conservative care. However, data collection was only over 1 year, or when epithelial tissue was intact. When considering the stages of healing following this, there is still organisation and maturation of these sites, so a longer data collection window may have altered final scores. However, this study does provide insight that when compared to ongoing wound care, those who had healed amputation report improvement in all aspects of HRQoL as measured by EQ-5D. If the WHOQoL-BREF had been utilised insight would have been gained into quality of life per se.

The Thailand based study of 254 patients completed by Sothornwit et al. (2018) identified that any foot related complication resulted in a worse health-related quality of life that individuals with diabetes complications such as retinopathy, renal disease or coronary artery disease or no complications. The study also identified quality of life was not significantly different between those who had current ulceration or had undergone amputation. Only 15 below and 28 above ankle amputations were included within the study, Sothornwit et al. (2018) did explore small sample size could be a rationale for no significant difference to quality of life identified between other diabetes complications and those with no complications (coronary artery disease n=27 utility 0.889, end stage renal disease n=28 utility 0.898, without complication n=31 utility 0.961). It is possible this could also be the case for exploring if quality of life for those with differing foot complications. The supplementary information provided with the publication presented the utility scores for below ankle amputation (0.823), above ankle amputation (0.717), current ulceration (0.681). This data suggests, albeit not significantly, that those with a below ankle amputation had better quality of life that individuals with either major amputation or current foot ulceration. The EQ-5D subscales are not presented, so there is no opportunity

to explore in more detail where the differences to quality of life are. The authors also agree with Pickwell et al. (2016) that the EQ-5D was a generic instrument, not specific to the sample population and concluded this may have which may have biased the results. This commentary from Pickwell et al. (2016) and Sothornwit et al. (2018) highlights issues with generic health outcome measures and for the necessity of understanding conceptualisation of quality of life for groups to be researched prior to selecting an assessment tool. The study identifies that there may be no impact upon quality of life if compared to having a current ulceration.

Conclusion from EQ-5D findings: Below ankle amputation does not diminish Quality of Life

Only 3 of the 6 research studies utilising EQ-5D as a health outcome measure explored below ankle findings separately. These studies were completed by Pickwell et al. (2016), Sothornwit et al. (2018) and Tennvall Ragnarson and Apelqvist (2000). These studies indicated that quality of life was not diminished by below ankle amputation when assessed using the EQ-5D measure.

PAIS – Determining Adjustment to Amputation

Carrington et al. (1996) explored the psychological aspects of QoL for people with or without diabetes associated lower limb complications within a UK population and determined that chronic ulceration was more detrimental than healed amputation. This age and sex matched study compared 13 consecutive patients with a chronic foot ulceration to individuals with either diabetes related unilateral below knee or above knee amputation (all prosthesis users) or with a diagnosis of diabetes and no history of lower limb complications. Structured interviews were completed for all participants and comprised of completion of a range of tools aimed at capturing factors related to QoL (psychosocial adjustment to illness scale, hospital anxiety and depression scale, foot questionnaire and QoL ladder). Individuals with healed amputation were

found to have a better QoL and a positive attitude to their feet than those with chronic ulceration. This was comparable to the control group. Those with amputation or ulceration were more depressed and had worse psychological adjustment to illness than those with no lower limb complications. The study also highlighted amputees expressed worse health care orientation through assessment with the PAIS. This highlights the lack of information and preparation necessary prior to amputation occurring. The study did not express what level of below knee amputation was preformed, so there were no conclusive findings exploring the impact of below ankle amputation. The sample sizes of 13 for amputation and 26 for control is small for this style of study, a larger cohort would be necessary to determine that accuracy of the findings. Also, there are questions over the validity of the Foot questionnaire, which was developed for the study to explore participant attitude to their feet. However, there was no information presented as to how the set of 12 dichotomies regarding attitude to feet was developed or validated. There is uncertainty as whether patients were involved within the questionnaire creation. The validity of results is questionable, there is no certainty if the foot questionnaire was exploring the correct aspects to be able to determine how an individual with diabetes feels about their feet. The author has identified there is no additional published papers which explore the testing, validity and reliability of the Foot questionnaire.

Conclusion from PAIS findings: No commentary on below ankle amputation

There was no separation of findings with respect to the level of amputation, therefore no new insight is available from this study as to the impact of below ankle amputation upon quality of life.

SIP – Determining Impact of Disease on Functional Status

Peters et al. (2001) found that the greater the extent of amputation, the larger the hindrance to physical status as assessed by the SIP. The results of the case control study of 124 patients who had undergone either below ankle or above ankle amputation revealed that patients who had undergone a toe or midfoot amputation did not report a significantly higher total impairment score than patients who had not undergone amputation. Amputation appeared to not impact psychosocial function. Peters et al (2001) concluded that more foot salvage procedures should be undertaken prior to considering major amputation. However, a further study would be required to explore this further as the SIP was unable to differentiate a difference between psychosocial functioning scores between those with or without amputation. This may have been a true reflection upon the impact of amputation but may highlight the tool's insensitivity to identify status change for amputees. Also, the study identified that those who had undergone amputation also presented with other confounding issues, a longer duration of diabetes, inability to palpate a pulse, and sensation loss, all indicative of systemic changes. The other consequences of diabetes were not reported; however, these may have confounded the findings. Peters et al. did recognise the need for further research to be undertaken to confirm the findings, more recent studies exploring diabetes related amputation have not utilised SIP.

Conclusion from SIP findings: Below ankle amputation reduces physical function.

Below ankle amputation impacts physical function, but not psychosocial function.

SF-36 – Determining Health Status Relating to Function and Well-being

Willrich et al. (2005) determined a reduction in functional status post-amputation of any level. The study aimed to develop a screening system which would enable practitioners to be able to compare health status and well-being for those who had either a chronic ulceration/ Charcot arthropathy or had undergone amputation. The USA based study explored cognitive function by using the clock drawing test and mini mental exam, and the SF-36 to determine health status and well-being. Willrich recruited a control group of individuals with diabetes and peripheral neuropathy. Why this complication was chosen is not clear within the study report. The study indicated that any complication did not negatively impact upon cognitive function, and there were no indications that those with any diabetes related foot issues had a greater element of depression than the overall diabetes population. However, there were reductions in perceived functional status and overall health status for ulceration, Charcot arthropathy and amputation when compared to those with only neuropathy. Both below and above ankle amputations were included in the study, and results were not separated by level of amputation, making it difficult to ascertain the impact of below ankle amputation per se. There was a small sample size, only 20 participants within each of the groups and the only demographics presented within the findings were the percentage of women and men participating within the subgroups. There was no exploration of age, other complications, duration of diabetes, making it difficult to compare to other study populations in research exploring amputation and hard to generalise to a wider audience.

Boutoille et al.'s (2008) retrospective study based in France identified that those who had undergone below ankle amputation had a statistically significant better physical function score than individuals with chronic ulceration, as determined by the SF-36. The study also indicated that the more minor the amputation, the more minor the impact upon physical functioning scores. This supports the findings from Peters et al.'s (2001) study, however the researchers

commented that there was wide variation within individual subscales of the SF-36 for both physical functioning and emotional domains. This could be attributed to the small sample size, The study included 9 individuals who had chronic ulceration and 25 amputees (19 of whom had undergone below ankle amputation). The study also recruited amputees between the years 2002-2004 who were at least a year-post amputation and presumably healed as they were not current patients at the hospital setting where current ulceration patients were recruited from. These details were not included within the body of the publication. Although some demographics are presented, such as HbA1c, age, there is no mention of males and females within the study, nor are the demographics regarding other diabetes complications, cardiovascular factors and smoking history. All of these were collected and if published would have enabled the reader to be able to explore the population in more detail and explore across published studies more easily.

Ribu et al. (2008) completed a longitudinal study with 127 patients with foot ulceration who attended outpatient clinics in Oslo, Norway and determined those with a non-healing ulceration became increasingly more socially isolated than those with healed ulceration. The SF-36 was used at baseline, 6 months and 1 year. Eighteen individuals underwent amputation (2 transfemoral, 5 below knee, 1 forefoot, 10 toe amputations). Due to the low levels of amputation, these participants were excluded from the calculations to explore changes over time. Data was therefore not available to assess the long-term impact of amputation compared to chronic or healed ulceration from this study or to determine what impact, if any amputation had upon health outcomes as measured by the SF-36. It would have been interesting to be able to explore the impact of amputation upon social functioning had the sample size for amputation been large enough for errors not to occur in calculations.

The finding of health status deteriorating in the presence of unhealed ulceration and being improved in those with healed was also confirmed in a prospective study undertaken by Winkley et al. (2009). In this England-based prospective cohort study, 253 people with diabetes

and first foot ulceration were followed for 18 months, mapping the outcome of the ulceration and determining the impact on health outcomes by using the SF-36. All individuals with ulceration and critical limb ischaemia or calcified arteries were excluded from the study. Therefore, rates of amputation presented in this paper may be lower than present in the actual population. At 18 months 15.5% of the population had undergone amputation. Although the researchers did not explore minor and major amputation separately, there was no significant deterioration in summary physical functioning score for those who had undergone amputation compared with the baseline measures. For the mental health component of the SF-36 there was a non-significant deterioration for those who had undergone amputation. This finding may indicate a psychological impact related to amputation, but as amputation data was presented as a whole it is uncertain if this was for individuals with below or above ankle amputation.

Pedras et al. (2016) completed a longitudinal study exploring the impact of amputation surgery for 108 Portuguese patients and found, perhaps unsurprisingly, that physical function was diminished after surgery, but there was no apparent impact upon mental domains. The study also found that the physical function and emotional health as measured by the SF-36 was predicted by the physicality and emotional status of the participants prior to surgery occurring. Those who underwent re-amputation surgery had worsened physical function. This is understandable as subsequent procedures removed more of a limb, impacting upon an individual's physical function. The level of amputation undertaken was not defined within the study, this may have an important relevance to the findings as previous studies by authors such as RagnarsonTennvall and Apelqvist (2000) and Peters et al (2001) demonstrated the more distal the amputation, the less impact upon physical functioning. Had the findings been explored by level of amputation then this would have identified the potential impact of below ankle amputation upon quality of life. The limitations of the findings were that post-surgical impact was only assessed up to 1 month following surgery, and individuals were likely to still be rehabilitating and naturally during this process physical function would be limited. It would be

of benefit for future longitudinal studies to follow patients for a longer period to see once healed what impact amputation may have upon the physical functioning.

The case-control study of 18 individuals within the USA echoed Pedras et al.'s findings of worsened physical function post-amputation (Aprile et al., 2018). The study explored the impact of first ray amputation on gait and quality of life and identified worsened physical function and diminished social function as assessed by the SF-36. Amputation had occurred between 1 and 11 years prior to the study commencing, so positively this study was able to explore the consequences of amputation to HRQoL after healing of the amputation had occurred. However, the results are presented together, as there were only 6 individuals who had undergone amputation it would have been possible to present this data for review. Each of the domains of SF-36 are presented in addition to the composite scores for physical and mental health. These reveal those who had undergone amputation had a reduced physical role, physical and emotional function, bodily pain and an overall significantly reduced physical composite score. The overall difference for the composite mental health score was not significant. The gait analysis undertaken in the study provides explanation for the reported reduced physical function. Those who had undergone amputation had a slower walking speed, which would link to the self-reported changes to physicality. The SF-36 finding of increased bodily pain likely relates to the higher incidence of neuropathy within the amputation group. Neuropathy was present in 3 of the diabetes and amputation group, as opposed to 1 of the 6 individuals within the diabetes group, and none of the non-diabetes participants. Aprile et al. did not explore the rationale behind the diminished social function in the write up, so there is little understanding as to what this meant for an individual's life, however, this study does provide insight into the impact of below ankle amputation upon HRQoL as measured by the SF-36.

The pilot postal study undertaken by Quigley et al. (2015) explored the different impact below ankle or transtibial amputation had for 33 individuals in Australia who had amputation due to diabetes and an underlying vascular compromise. The results indicated that amputation,

regardless of level appeared to have negligible impact upon mental and physical component scores. Rather, quality of life was negatively affected by time with a diabetes diagnosis, age and systemic diabetes -related complications rather than amputation. The study used the SF-36v2 to explore health related quality of life and the Trinity Amputation and Prosthesis Experience Scale to gather demographic data (Gallagher & MacLachlan, 2004). The pilot study posted versions of the SF-36 and revised TAPES to 33 individuals, 10 whom had undergone partial foot amputation (1 toes, 5 forefoot or 4 midfoot), 23 had transtibial amputation. The study did not provide the separate scores for all aspects of HRQoL that the SF-36 collected for review, instead overall component scores were presented. This identified that mental health scores were similar to population norms, Quigley et al suggested that the lack of impact on mental domains following amputation may be due to goal adjustment in the face of amputation and concluded that a larger study would be required to corroborate the findings. This research identified the complexity of quality of life, and that comorbidities have a role to play within quality of life. The study also demonstrated that measurement by one tool may not be sufficient to grasp and explore what is important to quality of life. Explorative studies would gain more insight.

The Malaysian based cross-sectional study completed by Nazri et al. (2019) explored quality of life with 94 participants who had experienced below or above ankle amputation. As with research completed by Peters et al. (2001) and Ragnarson Tennvall and Apelqvist (2000), the study determined those with a lesser level of amputation had improved physical function. Nazri et al also identified that those with below ankle amputation were more independent, walked without the use of aids, and had better emotional role, mental health and general health scores than those who had undergone above ankle amputation. The study did find those with major amputation experienced less pain and had better social functioning. The author's unsubstantiated suggestion was this may be due to the extended healing times and complications of healing within the minor amputation cases. The increased dependence of participants with major amputation may have led to increased need for socialisation to gain

support. However, these unresolved findings highlight the limitations of questionnaire-based research and highlight the benefits of exploratory research exploring the lived experiences of participants. The study does have limitations, no baseline measures of HRQoL were taken prior to the surgery occurring, so there is no comparison as to the impact of the surgery for the individual. All that can be ascertained is that HRQoL as measured by the SF-36 was better for those with below ankle amputation rather than above ankle amputation. The measures used to explore independence and walking ability were not validated, and the detail of these questionnaires was not provided in the published study, so the reliability of this can be questioned. The population norms for either healthy individuals or individuals with diabetes but no complications have not been provided so exploration of the impact of below ankle amputation upon quality of life cannot be substantiated. All that can be concluded from the study is that those with above ankle amputation have a worse quality of life than those with a below ankle amputation as measured by the SF-36.

A later USA study conducted by 2 of the lead authors of the Quigley et al 2015 study explored the impact of either transtibial or partial foot amputation with a larger sample (Dillon, Quigley, et al., 2020). The study comprised of 123 individuals, recruited over a period of 2 years, 42 with below ankle amputation, 81 with transtibial. The study population were predominantly middle-aged white males with an amputation which had occurred 10 years previously. The study included amputation associated with diabetes, vascular disease, trauma or cancer. Of the 123 individuals included, 61 had diabetes; 63 attributed the amputation to diabetes or vascular disease. The SF-36 scores study were not reported separately for cause of amputation, only for level of amputation, so the impact of diabetes related below ankle amputation cannot be fully explored from this research. The research identified that the level of amputation was not important to quality of life, rather a complex interaction of multiple factors including time since amputation, reduced physical function, fatigue, pain, anxiety or depression negatively impacted

upon quality of life. Due to these findings the research recommended ongoing long-term holistic support was necessary.

Conclusion from SF-36 findings: Below ankle amputation reduces physical quality of life, or it is the co-morbidities and advancing age that impact quality of life rather than the amputation.

The findings from studies using SF-36 are not coherent. Studies which have presented the findings for below ankle amputation separately have either identified that there were physical changes impacting quality of life, as identified by the studies completed by Aprille et al. (2018) and Boutoille et al. (2008). Or that above ankle amputation is more of a detriment to quality of life than below ankle amputation (Nazri et al, 2019). Whereas Quigley et al. (2015) determined that age, time since diagnosis and diabetes related complications such as retinopathy, indicative of systemic disease, were of detriment to quality of life rather than amputation itself.

WHOQoL-BREF Generic Quality of Life Measure

A study of Australian individuals with diabetes found that amputation had little the impact upon quality of life, when assessed using HADS and the physical and psychological subscales of the World Health Organisation Quality of Life Brief measure (WHOQOL-BREF) (McDonald et al., 2014). The study used a control group and undertook multivariate analysis to control for demographic and medical variables such as time since diagnosis, severity of diabetes, number of additional diabetes related micro or macrovascular complications and medical co-morbidities. The findings demonstrated a difference in body image perception for those who had undergone amputation. Data was presented collectively for all those who had undergone amputation, only 3 participants had undergone below ankle amputation, insufficient for

statistical analysis to find anything of significance to present in the findings if analysed separately.

The demographics questionnaire revealed that those who had undergone amputation had a greater range of micro and macrovascular complications, and the multivariate analysis indicated that changes to physical QoL and depression or anxiety were related to this overall deterioration in health rather than the amputation itself. It is not surprising that the amputation group had a greater range of diabetes and medically related complications as it has been well established that a triad of microvascular, macrovascular and trauma elements result in lower limb complications such as ulceration and ultimately amputation (Adler, Boyko, et al., 1999). The findings suggested a wider approach to exploring quality of life is necessary, and that aspects cannot be explored in isolation.

Interestingly, although the authors stated the main aim of the research was to explore the psychosocial impact of amputation, the summary questions from the WHOQOL-BREF which ask a participant's perception of their overall health and overall quality of life and the domains pertaining to social relationships and environment were not utilised within this study. There was no discussion as to why the complete WHOQOL-BREF was not used. The study appears to support the idea that amputation does not have a negative effect upon quality of life, but as the full QoL measure was not used, the findings of this research could be questioned as to whether complete QoL was accurately captured. The study also recruited participants from the same geographical area of Sydney, by an invitation sent to members of diabetes and amputee organisations. The importance of social networks and connecting to those with similar experiences has been established to be of importance to successful adaptation to change (Rybarczyk et al., 2004). Therefore, findings that there was no alteration to physical or emotional quality of life in response to the amputation may not be reflective of those not accessing social support or participating with support groups.

A study published by Juzwyszyn et al. (2022) explored quality of life, illness acceptance and nutritional status for 99 individuals with diabetes associated amputation in Poland identified those with better nutritional status had a quality of life and better acceptance of their illness. The study explored quality of life for 99 patients, 42 of whom had a below ankle amputation using the WHOQOL-BREF and collected data on nutritional status and acceptance of illness for patients who had undergone diabetes related amputation in Poland. Data analysis identified that participants had higher quality of life in the social domains and reduced physical quality of life. Participants with higher quality of life scores in social, environmental and physical domains had a better the level of acceptance to their health status, indicating there may be a relationship between acceptance of illness and quality of life perception. The study recruited from one hospital site, and participants completed the questionnaires 6 months post-amputation. There was no rationale provided as to how participants were sampled and no exploration of participants current situation, whether they were healed or still part of a rehabilitation process. This means there is uncertainty as to whether the results explore life post-amputation or life during the process of healing. There was no mention of sample size calculation within the study writeup so the author is unable to determine if the findings of the inferential statistics presented accurately capture the real situation and the conclusion of the study can be generalised to other populations.

Conclusion from WHOQoL-BREF Findings: Amputation negatively impacts body image perception. Social network, good access to health and social care and good physicality are important to quality of life. In turn, if these aspects are good, there is better acceptance in changed health status.

Although research completed by McDonald et al and Juzwyszyn et al. have both utilised the WHOQoL-BREF, due to the omission of using the social domains and environment by McDonald et al, only one study has explored quality of life per se. The study by Juzwyszyn did not separate findings into above and below ankle amputation. However, 44 of the 99

participants completing the WHOQoL-BREF did have below ankle amputation. The findings illustrated the importance of a social network, good environmental support systems and good physicality were aspects important for good quality of life perception. Also, if these aspects were present then there was better acceptance of the changes wrought by amputation. These findings could be tentatively used to add to the knowledge base for amputation.

The use of HADS by McDonald et al. revealed that there may be a potential impact to body image perception post amputation. Below and Above ankle amputation were not expressively separated within the findings, and as only 3 of 50 amputees had below ankle amputation it is uncertain if there were changes to body image perception for this group. All that can be concluded is that diabetes related amputation in total may negatively impact body image perception.

Findings Which Provide Detail on Below Ankle Amputation

Of the 25 studies explored, only 10, those completed by Aprille et al. (2018), Boutoille et al. (2008), Crocker et al. (2021), Dillon, Anderson et al. (2020), Nazri et al. (2019), Quigley et al. (2015), Peters et al. (2001), Ragnarson Tennvall and Apelqvist (2000), Pickwell et al. (2016) and Sothornwit et al. (2018), provide separate commentary upon the impact of below ankle amputation upon quality of life. The eight quantitative studies utilised health outcome measures, namely EQ-5D, SIP and SF-36. None explored quality of life per se, exploring the multidimensional conceptualisation of quality of life, suggest by Schalock et al. (2016) and adopted as the working definition of quality of life for this study. The quantitative studies provide no definitive understanding gained as to what impact of below ankle amputation has upon quality of life from these studies.

The two qualitative studies providing insight into below ankle amputation both used a semi-structured interview format. Dillon, Anderson et al. (2020) focussed upon those who had below ankle then subsequent transtibial amputation. So, the experiential insight gained from this study is focussed upon those who have experienced failed below ankle amputation. There is no insight into the lived experience of those who have a resolved below ankle amputation. Essentially, the perspective from this study will be skewed considering the intended study focus. The study completed by Crocker et al. (2021) explored physical, psychosocial and financial consequences of amputation. The study does not purport to explore quality of life in toto, and as such provides insight into impact of reduced physicality, such as changed financial status due to the inability to work, and the altered role of family or partner to provide financial and personal assistance to the amputee. Crocker et al. also identified that physical changes led to psychological alteration, the study identified those with below ankle amputation reported negative changes to body-image, hiding the amputation to avoid unwelcomed judgement.

What Information can be Gleaned from the 10 Studies?

The 10 studies were conducted in Australia, France, Italy, Malaysia, Multi-country including the UK, Sweden, Thailand and the USA. Studies, appraised by Hawker et al's. (2002) guidance, were rated to be either high or fair quality. The 5 rated as fair quality had a lack of detail within their sampling strategy, making it unrepeatable, or provided insufficient demographic data to enable transferability of the findings and did not provide recommendations for further research. There were some commonalities within the findings of the ten studies, and these are explored below:

Healed Amputation is better for Quality of Life than Chronic Ulceration

Four quantitative studies identified an improvement to quality of life related to aspects such as having an improved social network, or that the resolution of a chronic wound by amputation resulted in improvement to physical functioning and improved anxiety or depression scores than those who still had an active ulceration (Boutoille et al, 2008; Pickwell et al, 2016; Sothornwit et al, 2017; Ragnarson Tennvall & Apelqvist, 2000). Essentially healed amputation being less disruptive to life than a chronic wound requiring ongoing management.

Alterations to Body-Image Perception

Participants explored changes to body-image because of the below ankle amputation, reporting feeling incomplete due to the amputation. Crocker et al. (2021) identified participants chose to hide the amputation to prevent unwanted external judgement.

Alterations to Physicality & the importance of Family

The idea of there being physical consequences as a result of the below ankle amputation was supported by both quantitative and qualitative study findings. Exploration of the qualitative research findings provided more detail as to the implications of this changed physical functioning. The interview participants expressed there was reduced mobility whilst rehabilitating from the amputation. Dillon, Anderson et al. (2020) and Crocker et al. (2021) explored that individuals were unable to continue in physically demanding jobs and so there were financial consequences to changed physicality, and this naturally led to reliance upon family support. Any ongoing alterations to physical function had consequences for their economic situation and altered familial relationships.

Conclusion of Literature Review: The identification of 'Body Image' 'Physicality' and 'Social' as *a priori* codes for analysis

The findings from these studies provide a platform for this current research. The review of literature has determined that there was no published research which explored the impact of below ankle amputation upon quality of life in its entirety, as defined for the current study. This has confirmed the necessity of the current study completion. The review has provided some insight into the potential impact of below ankle amputation, namely there may be alteration to physicality and body image perception for the individual. The studies have also demonstrated the importance of a social network to those who have undergone below ankle amputation. Considering this, the author has chosen to incorporate this knowledge within the data analysis process. To tentatively use codes called 'physicality', 'body image' and 'social' to encapsulate the knowledge gained from review of the current literature. These codes only to be accepted into the understanding of what is important to quality of life if explored by study participants within the individual interviews and upon data analysis.

Overarching Research Question

Review of the literature identified that no study had completely explored the experiences of below ankle amputation upon quality of life, nor had identified the impact of amputation upon quality of life. Naturally this led to the formulation of questions - an overarching question:

What is the Impact of Below Ankle Amputation upon Quality of Life for Individuals with Type 2 Diabetes Mellitus?

To be able to answer this question, a subsidiary question required exploration:

What is Important to Quality of Life for those who have experienced Below Ankle Amputation as a Consequence of Type 2 Diabetes Mellitus?

Research Aims

The overall aim of the research was to explore what impact below ankle amputation had upon quality of life.

Objectives

In order to explore this, as no previous research had explored quality of life for this specific group the following objectives were formed:

- ♦ To determine what factors were included in the conceptualisation of quality of life for individuals with Type 2 Diabetes Mellitus and below ankle amputation.
- ♦ Exploring the impact below ankle amputation has had upon conceptualisation of quality of life.

Chapter 2: Research Methodology

Introduction to the Methodology Chapter

The Methodology chapter provides the reader with insight into the methodological choices made to answer the research question. The chapter also explores the rationale for the choice of data collection methods chosen, elucidating why individual interviews were the most appropriate means to explore the lived experience of below ankle amputation to gain understanding as to what was important to quality of life and ultimately explore what impact amputation had upon participants quality of life perception.

Approach to the Research Question

A qualitative approach has been chosen to answer the research question. Qualitative research design deemed to be appropriate for studies which wish to explore a phenomenon, seeking understanding, rather than measuring outcomes (Green & Thorogood, 2018). By exploring words as data rather than numbers, qualitative research can provide contextual understanding to quantitative findings, capturing an individual perspective and exploring the world as lived by the participants (Braun & Clarke, 2013; Denzin & Lincoln, 2003).

Within health research, there has been tension with regards to the inclusion and acceptance of the quality of findings derived from qualitative research methods. As explored within Chapter 1, the origins of quality of life research developed in response to a paradigm shift, from a biomedical to a biopsychosocial model of health care (Engle, 1977). If health research is explored from a theoretical perspective, then research framed within the biomedical approach to health was undertaken from a positivist position, with numerical data and inferential statistics utilised to derive answers to questions and inform health care practices (Crotty, 1998).

Research completed within this objective, realist ontological position, fundamentally believing that the phenomena in question could be studied, recorded, and objectively explained, can still be seen to hold favour. The hierarchy of evidence, designed to assist those working in health to determine best practice to assist patients and enhance care, still presents findings from qualitative research alongside expert opinion at the bottom of this hierarchy (Liamputtong, 2010; Murad, 2016). Qualitative research findings being perceived as a lower level of evidence to inform care than that derived from quantitative methods. However, if the biopsychosocial model of care is adopted, as appears to be the case within diabetes management (NICE, 2019), then preferentially using research findings from studies adopting a positivistic stance potentially ignores the impact of individually determined elements such as psychological, social and environmental impacts of life changes, such as amputation, upon quality of life. The subjective impact of these aspects requires consideration, this naturally aligns with a constructivist-interpretivist position. That meaning is derived from how individuals interact with the world, this in turn influenced by social position and the historical situation (Crotty, 1998). A qualitative research approach should be utilised to capture these insights.

Researchers are guided to select appropriate research methodology and methods which answer the research question itself (Williams et al, 2019). When focussing to this research study's phenomena of interest, the impact of below ankle amputation upon quality of life, the literature review presented in Chapter 1 identified 10 studies which included separate results exploring below ankle amputation. Two studies had a qualitative, explorative methodology, neither study was based within the UK, or focussed upon exploring below ankle amputation per se (Crocker et al, 2021; Dillion, Anderson et al, 2020). The remaining 8 studies had utilised closed-question outcome measures to explore the impact of amputation upon quality of life (Aprille et al., 2018; Boutoille et al., 2008; Nazri et al., 2019; Quigley et al., 2015; Peters et al., 2001; Ragnarson Tennvall & Apelqvist, 2000; Pickwell et al., 2016; Sothornvit et al., 2018).

The limitations of health outcome measures have been recognised by other authors. Bowling (1997) explored that many health outcomes measures should be approached with caution, those derived from health professional conceptualisation of quality of life rather than from those who have experienced the phenomena being unlikely to provide insight into quality of life itself. Bradley et al. (1999) presented an argument for patient derived measures, in which participants were able to manipulate the measure to provide an individualized response. At this point in time, no individualised measure exists to explore the impact of below ankle amputation upon quality of life. Currently the EQ-5D, a generic measure of health status, is the approved health outcome measure used within the NHS to explore quality of life, and although recommendations were made to have a condition specific measure (Patient Reported Outcome Measurement Group, 2009), there is no condition specific measure exploring below ankle amputation (Millner et al, 2021). With no published research exploring what elements are important to quality of life for those with below ankle amputation, logically a condition specific measure cannot exist at present time. Foundational research is required to establish what is important to quality of life for those who have experienced below ankle amputation, and to determine what impact amputation has had upon quality of life. The current study is addressing these issues and should be seen as the foundations of future work. The current study should explore the subjective individual lived experience of below ankle amputation, to gain insight and understanding of what is important to quality of life and how below ankle amputation may have impacted upon this.

Consideration of Theoretical Position

The research has been approached from the ontological perspective of relativism, in that reality and interpretation of reality is shaped by mental construction. There is not one single objective

reality, rather reality is individually constructed, and this is influenced by historical and social constraints, essentially when and where an individual is situated (Moon & Blackman, 2014). Perception of reality is not fixed, rather as an individual alters, reality alters accordingly (Crotty, 1998). Accepting this individualised construction of reality leads to consideration of a constructivist epistemology. Individuals constructing knowledge of a phenomena based upon their own perceptions. Understandably an individual's environmental situation, their societal, cultural and historical constraints influence how individuals construct meaning around a phenomenon (Braun & Clarke, 2013). When the ontological and epistemological positions are applied to the research question, exploring what the impact of below ankle amputation upon quality of life for individuals with type 2 diabetes mellitus is, the necessity for an explorative qualitative research approach can be clearly seen, providing contextual understanding and insight.

Consideration of Research Methods Adopted

The characteristics of qualitative research have been explored by numerous authors. Qualitative research is defined as that in which data is derived from a real setting, gaining participants perception of a phenomenon, and exploring with participants the understanding developed. (Miles & Huberman, 1994). Within a qualitative enquiry there are multiple interpretations of the data collected, the researcher is not removed and distant from this process, rather the researcher is part of the contextual situation in which the research has been conducted. The researcher's perspective and insight contribute to the data that is presented. This subjectivity is openly conveyed to the reader, the researcher adopting self-reflection and reflexivity for the reader to be aware of the situational context of the research (Braun & Clarke, 2013). Within the context of this thesis, the author's life perspective, professional background, precognition, and

preconception – essentially the author's subjectivity has been presented within the Prologue and Chapter 1 so that the reader is aware of the context in which the data has been explored.

Seating the Research within its Method

A qualitative interview study approach was chosen as little was known around the subject area and the researcher was seeking a deep understanding of the experiences of people who had undergone below ankle amputation (Bassett, 2004; Becker, 1992; Todres & Wheeler, 2001). The role of the qualitative researcher being to gain understanding and insight as to the effect below ankle amputation had upon quality of life, resulting in better understanding of the phenomenon for those working with patients experiencing amputation (Spinelli, 2005).

Individual interviews were chosen as the most appropriate way to explore lived experience in rich detail. The interviews were completed with two intentions, firstly, to gather individual experiential narratives to gain a richer, deeper understanding of the phenomena studied, and secondly, to enable the researcher to converse with the participant about the meaning of the experience, generating deeper understanding (Arksey & Knight, 1999).

There are multiple methods of how to undertake interviews, and careful consideration was given as to the overarching research question, aims and objectives to ensure that the style of interview chosen would provide insight into the impact of below ankle amputation upon quality of life. An interview is a conversation, and the actions of the researcher, how they present themselves within that context can impact upon the knowledge gained (Fontana & Frey, 2003). As explored within Chapter 3, the researcher chose a semi-structured approach to interviewing. Semi-structured being defined as the phenomena in question being the focus of the interview, but with the flexibility to ask additional questions and explore topics as they emerged within the

interview itself (Kvale & Brinkman, 2009). This approach was seen as advantageous by the author to gain a detailed insight into the lived world of those who had undergone below ankle amputation. This would also ensure that presumption and precognition would not constrain the interview or topics explored. The participant essential to enabling the author to explore the phenomena from their perspective. An interview guide was created by the author (Appendix 3), this was to enable the research question to remain the focus of the interview, to act as an *aide memoire*, to ensure key aspects were explored. The guide also included examples of probes to encourage the author to seek for clarity and depth of understanding, revealing the participants perspective (Grey, 2003).

The considerations towards the attitude and approach towards the interview itself, essentially, considered as where, who, when, why, how, what and whatever have been included within the subsequent Method Chapter of the thesis. Chapter 3 provides detail upon how the author built a rapport and developed trust with the participants, utilised active listening skills to consider the points participants were expressing and deciding upon appropriate choice of wording from prompts to capture detailed data exploring below ankle amputation and quality of life. Essentially the interview needed to be undertaken from the position of equality, a collaborative event (Braun & Clarke, 2013). The participant contributing to the construction of knowledge about the impact of below ankle amputation upon quality of life. The researcher enabled to clarify their perception and interpretation of the experiences the participants were conveying, developing insight into the phenomena. The participants both providing their lived world experiences, enabling the researcher to gain insight, and by providing feedback upon the researcher's perception of their accounts, correcting or confirming the researcher's interpretation.

The following method chapter explores the intentional choices for data collection site, choices made with regards to purposive sampling, interview preparation, the interview process itself, what was transcribed for analysis and the chosen method of data analysis.

Chapter 3: Method

Introduction to the Method Chapter

This chapter explores the methods utilised within the study, exploring the rationale for the chosen data collection site, access to the participants, recruitment strategy and the methods of data collection and data analysis chosen. Consideration is also given to considering the quality of the data collected, the trustworthiness of the data collected in relation to answering the research question.

Data Collection Site

As no previous study in the United Kingdom had explored from a qualitative perspective the impact of below ankle amputation upon quality of life, the choice of data collection site was carefully considered. The NHS multidisciplinary diabetic foot clinic chosen as the data collection site met the then current recommendations for management of the diabetic foot (NICE, 2015). The clinic provided the full complement of clinicians with skills in diabetology, podiatry, specialist nursing, vascular surgery, orthopaedic surgery, microbiology, wound care, casting, biomechanics, orthoses, and radiology. The research was therefore gathering the lived experiences of those who had received optimal care. The clinic selected also served the entire population of a county – both city and rural communities, and had telemedicine outreach links, enabling the researcher to access a diversity of individuals who had undergone below ankle amputation.

This clinical setting was also chosen due to the support for research available. The lead consultant being director of research and development and head of the clinical trials unit for the Trust in addition to being a contributing author and subgroup chair for the International

Working Group for the Diabetic Foot. The clinic was actively involved in research projects focussed upon patient care. Research nurses and research podiatrists were well established, actively participating within the daily clinics. This combination of factors meant the process of recruitment and data collection was well supported by the immediate care team and research clinicians working within the department. In addition, patients were familiar with research being undertaken by the clinic, so there were high levels of willingness to participate within the research project. This support enabled purposive recruitment and interviews to be completed within 20 weeks.

Permission for Site Access

Ethical approval was sought and granted for the project from the School of Human and Health Research and Ethics Committee. Following internal approval, meetings were held with the lead consultant to explore the research proposal and ensure local support. Ethical approval was gained from REC and HRA (Appendix 3) with only one amendment, amputation to be referred to as “below ankle” rather than “minor”, as it is titled within the annual national foot audits (Public Health England, 2019), as minor may have been perceived by potential participants as the researcher thinking their amputation as insignificant, causing a barrier to participation.

Ethical Issues

During the process of gaining ethical approval potential ethical issues were explored within the context of Beauchamp and Childress (2019) ethical principles. Documented below is how these were addressed.

Informed Consent

Participants were fully informed of the nature of the research. This was attained by the participant information sheet being provided to all interested in participating and the researcher discussing any queries prior to the consent form being completed (Appendix 3).

Non-maleficence

There was the potential that participants may have found discussing their amputation experience upsetting, although many found it a positive experience to talk through their amputation. No on-going distress was caused to any of the participants; however, preparations were made so that participants could have been offered the details of psychological support and advised to request referral via their GP. Some did become emotional during the interview, participants were assessed individually and asked if they wished to pause or terminate the interview. This was the participant's decision to make.

Right to Withdraw

Participants had the right to withdraw from the interview at any point. The consent clearly explained that data gathered to that point would be used unless the participant expressed the wish for the previously collected data to be withdrawn from the study (Appendix 3). The consent also explained that pseudonymised quotations from the interviews would be used for write-up and publication. No participants requested to withdraw.

Conduct of the Study

Participant information sheets gave contact details of individuals who could be contacted if there were any concerns about the conduct of the study (Appendix 3).

Confidentiality

Members of the direct care and hospital research teams were aware of the potential participants for the study due to dispensing and discussing the information sheets with patients interested in participating in the interviews. Likewise, for interviews which occurred on NHS premises, the direct care team were aware of participation in the study, but data gathered was not divulged to the team.

Confidentiality for the content of the audio recorded interview was maintained by participants being allocated a pseudonym during transcription. Audio recordings were uploaded to a secure university server and stored as MP3 files under the pseudonymised name. Once uploaded, the original recording was erased from the portable recorder. All electronic information was password protected and stored on a secure server. Hard copies of documents, such as consent forms, contact details for participants, were kept in locked drawers within a locked office. Only the researcher had access to this data. All data will be destroyed 10 years after completion of the research in line with University Guidelines (University of Huddersfield, 2019).

Anonymity

The identity of research participants was only known to the researcher. All participant names were replaced with pseudonyms.

Risks to the Researcher

Interviews took place during normal working hours in a mix of home and hospital locations. When interviews occurred at home, colleagues were informed of the times and dates on the interviews. The researcher contacted the designated colleague after completion of the interview.

Recruitment

As proposed by Robinson (2014), there were 4 elements which required careful consideration prior to commencing upon the study, namely, defining the population, sample size, sampling strategy and recruitment. These aspects are explored below.

Defining the Population

Within the UK 90% of those diagnosed with diabetes present with Type 2 Diabetes, Type 1 accounting for 8% of the UK population, the remaining 2% attributed to gestational, monogenic or associated with rare syndromes (Diabetes UK, 2023). The most recently published research comparing Type 1 and Type 2 lower limb amputation rates in England determined incidence was higher in those with Type 2 Diabetes (Vamos et al, 2010). Exploration of the impact of below ankle amputation upon quality of life for those with Type 2 diabetes was decided upon due to the factors explored above and the ability to be able to identify 30 willing participants within the chosen data collection site within timeframes imposed by undertaking the research as part of doctoral level studies. Work exploring quality of life for those with below ankle amputation and Type 1 diabetes to be considered as potential post-doctoral research. Within the NHS, data regarding disease diagnosis and procedures undertaken are collected using a standardised coding system (NHS Digital, 2020; World Health Organisation, 2018). It was possible to identify

individuals with Type 2 diabetes mellitus who had undergone non-traumatic below ankle amputation.

Defining Amputation

Across literature and coding systems lower extremity amputation is referred to by a range of terms. Within the UK, lower extremity amputation is referred to as major or minor amputation (Public Health England, 2019), however, there is no global definition for what range of procedures or level of amputation constitutes minor amputation. The level of amputation presented as “minor” varies within published research, as explored within the Table.

TABLE 6 MINOR LOWER EXTREMITY AMPUTATION DEFINITIONS FROM PUBLISHED RESEARCH

Author	Definition of Minor Lower Extremity Amputation	Comments
Abdelgadir et al. (2009)	No definition	Looking at lower extremity amputation reported on above and below knee.
Coffey et al. (2009)	No definition	Recruited patients from Prosthesis/ Limb centres identified individuals with trans tibial or above knee amputation

Author	Definition of Minor Lower Extremity Amputation	Comments
RagnarsonTennvall and Apelqvist (2000)	No definition	Separated out major and minor amputation despite no definition of these terms
Aydin et al. (2010)	No explicit definition of minor amputation, due to how they have defined major amputation can infer minor to be below ankle.	Defined Major amputation as Symes (through tibia and fibula removing malleoli), above knee and below knee.
Lavery et al. (1999)	Amputation defined in levels: Foot – everything below the ankle Leg – ankle to through-knee Thigh – proximal to through-knee	Major and minor not explicitly defined.
Dawes et al. (2010)	Amputation defined in levels: Toe/ metatarsal/ ankle Transtibial (Symes) Transfemoral / knee Unclassified/ pelvic	Major and minor not explicitly defined.
Amoah et al. (2018)	Amputation defined in levels: Foot (toes or partial foot) Ankle (ankle disarticulation) Below knee (knee disarticulation)	Major and minor not explicitly defined.

Author	Definition of Minor Lower Extremity Amputation	Comments
	Above knee (trans femoral) Hip (Hip disarticulation)	
Canavan et al. (2008)	Toes to the tarsometatarsal joint	Defined in research design
Ribu et al. (2008)	Toes to and including forefoot	Major defined as trans femoral and above Reported in results section, not explicitly defined in method
Quigley et al. (2015)	Toes to midfoot	Used the term partial foot amputation rather than minor
Pickwell et al. (2016)	Toes to and including forefoot	Definition included in the methods section
Hämäläinen et al. (1999)	Amputations referred to as below or above ankle	Major and minor not explicitly defined.
Vamos et al. (2010)	Below ankle	Defined in study methods
López-de-Andrés et al. (2011)	Below ankle	Major defined as through or above the ankle joint.
van Battum et al. (2011)	Below ankle	Defined in study methods Sub categorised into hallux, toes 2-5, metatarsal and midfoot
Rajendran et al. (2012)	Below ankle	Major defined as below or above knee

Author	Definition of Minor Lower Extremity Amputation	Comments
Public Health England (2019)	Below ankle	Major defined as above the ankle
Nazri et al. (2019)	Level of ankle joint and below	Major above the ankle Defined within introduction section
Adler, Ahroni, et al. (1999)	Distal to below knee amputation	Detail of minor presented in results, not stated in research design; includes an above ankle amputation procedure.

To ensure the results of this study were comparable to previous work, an individual was included if they had undergone *any amputation distal to the ankle joint*. Concisely referred to herein as *below ankle amputation*.

Defining Non-traumatic Amputation

Within the context of this study, the definition of non-traumatic amputation was related not to the experiential impact to the individual, rather a reflection of the aetiology resulting in the amputation occurring. To date, research exploring amputation occurring because of reduced tissue viability as a consequence of diabetes associated complications, such as peripheral arterial disease, does identify this type of amputation as “non-traumatic” (Creager et al, 2021, Davies et al, 2019, Geiss et al, 2019). It is within this context that the inclusion criteria, the ethical approval forms and research protocol (Appendix 3) were written. Non-traumatic amputation identifying

those for whom amputation had arisen because of the long-term complications of diabetes, rather than occurring as a result of accidental injury not related to the diagnosis and consequences of diabetes.

Inclusion Criteria

- ♦ Diagnosis of Type 2 diabetes mellitus
- ♦ Non-traumatic diabetes-associated below ankle amputation
- ♦ Over 18 years of age
- ♦ English speaking

Exclusion Criteria

- ♦ No diagnosis of Type 2 diabetes mellitus
- ♦ Trauma induced below ankle amputation (not related to diabetes aetiology)
- ♦ Under 18 years of age
- ♦ Individuals unable to understand English
- ♦ Impaired capacity to provide informed consent

Patients with co-morbidities were not excluded, as the association of co-morbidities such as ischaemia, foot deformity and neuropathy result in ulceration and potentially amputation (Oyibo et al., 2002). Demographic information for each participant was also collected.

Sample Size

A fixed sample size was not appropriate for this research exploring the lived experiences of those who had undergone below ankle amputation. However, during the design process and submission of ethical approval forms, consideration of resources and timeline planning required some thought to sample size (Robinson, 2014). As Vasileiou et al. (2018) suggest, data adequacy should be the foremost consideration. In essence, that the data is of sufficient quality to answer the research question. In real terms, as this was the first UK based research exploring the lived experience of below ankle amputation and the impact to quality of life, consideration was required to ensure the sample size was sufficient to enable diverse amputation experiences to be explored. The richness of the experiential data focussed upon answering the research question, gaining insight into the lived experiences of those who had undergone amputation and exploring the impact this had upon quality of life. A minimum of 10 participants were sought. Data collection, transcription and analysis occurred simultaneously, thereby enabling the researcher to explore similarities and dichotomies within participants lived experiences. Although each experience was unique, by keeping focus to the research question, a richness of data was developed centred upon adaptation and quality of life. A total of 28 individual interviews were completed. Tables 7 through 10 in Chapter 4 explore the diversity of the participants in terms of age, sex, level of amputation and index of social deprivation.

Recruitment Strategy for the Individual Interviews

Purposive Sampling

A purposive sample was taken from the defined population, to ensure information rich data was derived from the interviews (Patton, 2002). The research aimed to explore all levels of below ankle amputation, intentionally exploring a diverse range of experiences to gain insight into the

lived experiences. The range of experiences and opinions expressed by research participants is summarised within Table 7 in Chapter 4. The chosen data analysis method, template analysis also recommended exploring a range of experiences to explore the phenomena. Guidance upon template analysis by Brooks et al (2015) recommended the first subset of data to be explored should have divergent views and experience.

Participant Recruitment

The research was advertised by promotional poster approved by REC within the waiting room for the Diabetic Foot Clinic (Appendix 3). All staff involved within direct care and research were informed of the study by the researcher and lead consultant and asked to promote the study to patients who met the inclusion criteria.

The researcher was present at the Diabetic Foot Clinic every week during the data collection process, on a day when the full MDT was present for case review. The researcher used this opportunity to liaise with the team, updating them on the number recruited and interviewed, ensuring recruitment was optimised. The researcher was given permission to freely access any of the treatment rooms and treating clinicians would invite the researcher into treatment rooms to discuss the research with patients they had identified as meeting the inclusion criteria.

The clinic ran daily, and so when the researcher was not on site, research clinicians and members of the direct care team actively looked to recruit participants to the study. Potential participants were either approached or could approach a member of the team for a participant information sheet and the project was discussed (Appendix 3). If the researcher was not on site, a Permission for Researcher Contact Form (Appendix 3) was completed detailing contact details for those potentially interested in participating. The researcher contacted these individuals directly to answer any further questions about the research either when on site or via telephone. If they wished to proceed, then a suitable location and time were arranged for the interview.

The location and time were chosen by the participant. Locations included private consultation rooms, dialysis wards and homes of the interviewees.

Prior to commencing with the interview, the researcher reminded the participants of the information contained within the Participant Information Sheet, ensured there were no further questions, and following this, consent was read through with each participant and signed on the day of the interview (Appendix 3). The consent for interview (Appendix 3) detailed that the interview would be recorded and transcribed, a pseudonym created to protect the participants identity and direct quotations could be used within the research. Participants were also advised that they could withdraw from the study at any point, and this would not impact upon the care received. Participants also gave consent for the interview recordings to being securely stored for 10 years, in accordance with university guidelines, and original personal data would only be accessed by the researcher. Interviews were then completed. Careful consideration was given as to how to conduct a qualitative interview, and guidance sought from authors providing instruction upon qualitative interview techniques. This is considered below.

Interview Preparation

Preparation for the individual interviews was considered from van Manen's (2016) approach to qualitative interviewing, namely exploring where, who, when, why, how, what and whatever. Conceptually, there are parallels to Kvale and Brinkmann (2009) and King et al's. (2019) guides to qualitative interviewing. Outlined below is how these were considered for this research.

Where

Interviews were conducted within a location and time chosen by the participant; in many cases this was within the participants own home. This gave the opportunity for the conversation to

be held in a private environment without a time constraint being placed upon the location. This personal environment allowed participants to have control over an element of the interview process, and to start the interview on equal terms with the researcher. In some cases, the participant chose to conduct their interview within the presence of a family member, partner, or nurse. Some of the participants invited the family member or partner to contribute to the interview, the amputation seen as a shared event for them. The importance of these relationships for adaptation and good quality of life perception is explored within Chapters 5 and 6. It was important to the researcher that the interview process was focused upon the sharing of information, and that the participant was comfortable exploring their experience of below ankle amputation and was eased into reflecting upon their experiences for the researcher to gain understanding of their experience-as-lived of below ankle amputation and what was important to their quality of life.

Of the 28 interviews undertaken, all took place at the location the participant preferred, the majority within the participant's home, two preferred the dialysis unit. This enabled the researcher to gain understanding of their life and to have insight into what was important to them. Examples of these insights include observing a well-tended and loved garden, this gave context to the desire to mobilise and the importance of being outdoors in relation to freedom. Other examples include visiting a participant who had newly moved into a bungalow from a 3-storey house. There were a range of feelings expressed, sadness about leaving the house in which the immediate family was raised, but positive thoughts about the ability to mobilise post amputation and being closer to their social network. This insight would have been difficult to achieve if interviewing in the NHS private consultation room.

Who

The researcher gave careful thought about how to establish a relationship with the participant, aiming to be viewed as personable to gain confidence and encourage openness within the interview. Attending the data collection site weekly was a conscious decision as it meant most of the initial introductions were completed within the clinical environment. By being able to begin a conversation within the clinic the researcher was aware of the current foot health status – whether there was a new ulceration, or if the amputation site was intact or deteriorating. This allowed for an easier flow into the interview itself by being familiar with the individual participant's current situation.

The approach to how to commence the interview was carefully considered. Beginning with an account of how the amputation happened gave the researcher understanding of their lived experience and how they reacted to the amputation.

When

A maximum of 2 interviews were booked into one day, with the participant selecting a time convenient to them. This was intentional so that the interviews were not rushed, enabling the participant an opportunity of time to open up to explore their lived experience of below ankle amputation. This also enabled the researcher time to document initial thoughts and impressions regarding each interview concerning what was important to quality of life and the impact the amputation had upon this.

Why

By preparing and having a copy of the interview outline visible during each interview ensured that the interview kept focus to answering the research questions. Additional questions were asked to gain understanding of experiences.

How

van Manen (2016) recommends that interviews are recorded so that there is the opportunity to explore and revisit the experiences. Focussing upon the interview itself, a flexible approach was suggested, posing questions in a language and manner specific to each participant and using examples to assist with gaining full understanding. The researcher was able to use their active listening skills during the participant sharing their amputation experience at the start of the interview to focus in upon their choice of language and colloquialisms, to develop an idea of how to phrase the subsequent questions.

What

The lived experience of below ankle amputation was explored with each participant, the researcher asked additional questions around the interview guide to ensure an understanding of their perspective.

Whatever

van Manen (2016) councils to allow silence within the interview; enabling the participant a moment to gather their thoughts, rather than immediately stepping in with a question to fill the void. This enables an individual to reflect upon their previous answers. Tactics such as forming the last sentence into an open-ended question were also recommended to encourage

the participant to continue exploring the experiences. These recommendations have been utilised throughout the interview process.

Interview Process

The interview guide (Appendix 3) was reviewed by the researcher prior to commencing every interview. The guide structure based upon Kvale's (1996) typology, ensured a depth and richness of data was generated during the interviews. The guide was taken into each interview and left in the researcher's eye line to ensure that the interview was focussed upon the research question. The interviews were semi-structured in which the overall topics to explore were identified, but there was flexibility for the researcher in how and when these were approached (Kvale & Brinkmann, 2009; Robson, 2011). This gave a consistency throughout the 28 interviews undertaken, ensuring the research question was answered. Being enabled to ask additional unplanned questions meant factors important to quality of life which the researcher was naïve could be fully explored to gain new understanding and insight (Langdridge, 2007).

All interviews were audio recorded. Notes were taken by the researcher immediately after each interview of key ideas that emerged during the interview process. Audio files were uploaded onto a secure server and the original data file on portable Dictaphone erased. Each participant and the subsequently created data were assigned a pseudonym. Credibility of the data was maintained by the audio recordings being transcribed verbatim by the researcher to accurately capture the participants lived experience. This ensured that no superficial decisions were made, or vital data discarded without the process of coding being applied to each transcript.

As transcription and initial analysis were conducted in parallel with data collection, the researcher recognised repetition in the themes explored by the interview participants. Data collection ceased when 28 interviews were completed due to this repetition.

Data Analysis

Coding

The researcher has pragmatically used coding as a means to an end, namely, to condense and explore all interview data, revealing the similarities and dichotomies regarding the impact of below ankle amputation on quality of life.

Definition of a Code

A code is a word or phrase which encapsulates the researcher interpreted meaning of a section of data. Within the analysis process the researcher maintained a working dictionary clearly defining what each code incorporated. This was reviewed prior to any analysis work being undertaken to ensure the researcher was firmly focussed upon the research. Amendments to codes were documented with memos throughout the analysis process.

Definition of a Theme

A theme is a word or phrase developed following analysis of the coding to act as an overarching header, or umbrella under which codes which related to a particular idea could be brought together. In essence, the researcher stepping back and interpretively exploring what was being expressed. For example, individuals commented upon their monetary situation, some exploring their inability to work post amputation and the difficulty of gaining benefit support. Others explored their reluctance to use benefits. All these aspects were considered by the researcher to be codes relating to economic situation. A theme titled 'Economic Situation' was created. The researcher maintained a working database of theme definitions and which codes were

incorporated under this. A conceptual diagram was created to provide an overview of this work for the researcher to be able to explore when undertaking theme and conceptual analysis.

Approach to Coding

To ensure all data was considered equally, the following phenomenological method of analysis was undertaken for each transcript, a blend of the qualitative analyses' methods explored by Saldaña (2016) and van Manen's (2016) approach to data.

Attribute Coding

A record of the socio-demographic data of all participants was collated. For each individual this included age, sex, level of amputation, time since amputation and index of multiple deprivation rank and decile.

Naïve Reading of the Transcripts

To re-orientate the researcher to the data, each transcript was re-read and memos of the initial thoughts the researcher had immediately following the interview were reviewed. Following this a naïve reading was undertaken, discovering what quality of life meant for each participant and how the experience of minor amputation may have impacted upon this. These initial impressions were captured within a memo.

In Vivo Coding

Saldaña (2016) recommends this as a method which prioritises and respects the participants voice, enabling the researcher to capture the inherent meaning of the data. Key phrases pertinent to understanding the lived experience of below ankle amputation and quality of life were identified using direct quotations. These were used subsequently within what van Manen describes as interpretative analysis, and Saldana as concept coding.

Interpretative Concept Coding

Within this phase, the researcher approached the data from an analytical deductive stance, the in vivo coding used as a base upon which to begin conceptual coding, exploring the essence of what was being said. Conceptual codes were created, and definitions were developed of what the researcher assigned codes meant and incorporated into the developing coding template.

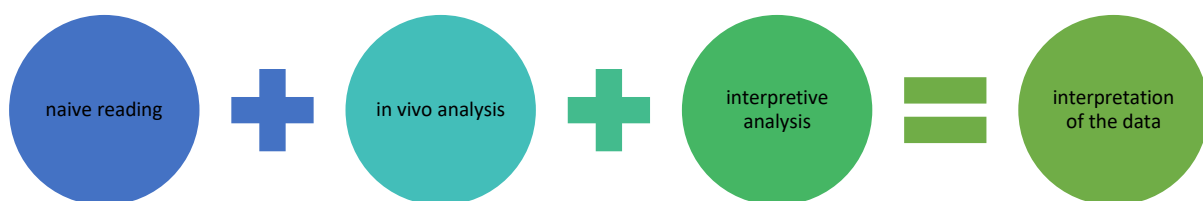


FIGURE 4 SUMMARY OF DATA ANALYSIS PROCESS

Theme Development

Theme development required multiple transcripts to be explored, the researcher building clusters of codes around conceptual themes. For example, a range of views were expressed

surrounding social life, for some social life had dwindled, for others the amputation made no impact, some now had a supportive but smaller friendship group, others were completely isolated by the consequences of the below ankle amputation. All were gathered under a theme entitled “social life.”

Researcher Reflexivity during Data Analysis

Research memos were kept throughout the data collection and analysis phases of the research process. These included initial ideas of the key themes explored within the interview, memos defining what a theme meant, how a code was defined, rationale for new codes being added into the template and rationale for changes to the initial template. A summary of researcher beliefs, knowledge and potential biases prior to data analysis began was recorded, the researcher used this during the analysis process to assist with being aware of preconceptions and potential bias (Levy et al., 2017). The researcher reflexivity has been presented as a Prologue for the thesis. As part of this, the researcher also stepped back from the process of analysis to be critical of the data analysis process itself. The following elements were considered at the end of each coding step.

1. Does the code answer the question?

Did the codes assist in gaining understanding of the experience-as-lived? Saldaña (2016) cautions against a deluge of coding everything in case it is of potential significance. The research question and aims remained in clear focus during the coding process.

2. Use selected codes repeatedly

The researcher had to remain in control of the coding, were there sufficient codes to capture the essence of the data in rich detail whilst not being overwhelmed with extraneous codes? King (2017) cautions against bending the data to fit a code. Analytic memos were created to ensure clear definitions of what each code meant as a memo, so data was not forced to fit an irrelevant code.

3. Review and revise codes

Incorporating a date stamp for when a code was created and for any subsequent redefining of codes ensured the researcher was using and developing codes to assist with answering the research question rather than creating a code for the sake of capturing irrelevant data.

NVivo 20 for Organisation

Nvivo (version 20) was selected to assist with the organisation of data analysis. All interviews were pseudomysed, transcribed, checked for accuracy, and uploaded to Nvivo. Memos were created for each participant, summarising the initial thoughts of the researcher immediately after the interview, and immediately after initial reading of the transcript. These memos were reviewed during the simple and conceptual analysis process. This was to maintain a conversation with the living data, the interview and participant, rather than too strong a focus on the transcription of the lived word. During the transcription process time stamps were placed as key points were made so that the researcher could easily revisit the spoken, lived words rather than fixed words to ensure the context was not misconstrued.

Thematic analysis via Template Analysis

Template analysis was selected as it enabled the researcher to acknowledge their prior knowledge of diabetes, amputation and the literature pertaining to this subject area. As explored within the Chapter 1, published research determined that below ankle amputation may alter body image perception and physical mobility (McDonald et al., 2014; Peters et al., 2001; Willrich et al., 2005). Both body image perception and physicality were included as *a priori* codes within the initial template developed. Subsequent analysis, explored within the results and discussion chapters, has reviewed, and refined these concepts.

Template analysis enabled the researcher to organise, analyse and reveal links between the lived experiences of those who had undergone below ankle amputation (Brooks et al., 2015; King & Brooks, 2017). The organisation of data in a hierarchical schema provided a simplified representation of the analysis. This was important for two reasons, firstly to enable the researcher to keep a tight focus to the overall aim of the research, namely exploring the lived experience of those who had undergone below ankle amputation, gaining understanding of the impact on their quality of life (King, 2017). Secondly, this schema assisted others to navigate through the qualitative research, giving a key to enable them to see the researcher's perspective and the development of the conceptual analysis herein.

Template Analysis Procedural Steps

Guidance has been provided by the creators of template analysis (Brooks & King, 2014; Brooks et al., 2015; King, 2012; King & Brooks, 2017), the sequence of 7 steps regarded as a fluid rather than rigid process, the researcher encouraged to move from inductive to deductive analysis, gaining a rich and deep understanding of the lived experience. Explored below is how the researcher utilised the steps within the data analysis process.

1. Definition of physicality and body image perception as *a priori* codes

Literature review completed prior to data collection identified that little research existed exploring the impact below ankle amputation had upon quality of life. Aside from one study (Foster & Lauver, 2014), quality of life was explored via generic health questionnaires and concluded either no change to quality of life, or a detrimental change to physical mobility and body image perception (McDonald et al., 2014; Peters et al., 2001; Willrich et al., 2005). Physical mobility and body image perception were chosen as *a priori* codes for the initial template.

2. Familiarity with the data

The researcher personally transcribed all interviews and reviewed each transcript for accuracy against the original audio recording. Prior to beginning analysis, the researcher read each transcript and listened to the recordings to gain familiarity with the data.

3. Preliminary coding on a sub-set of data

A subset of 10 was chosen for development of preliminary coding (Brooks et al., 2015). The group were chosen to have divergent views and experiences. Each transcript and audio file were approached in a systematic way, as outlined in the approach to coding section. Codes were created to capture the essence of the data. Definitions were created as to what each code word meant. This was to ensure no merging or confusing of ideas, to capture understanding of the experience-as-lived of the interviewees. Material which explored the *a priori* codes of physical mobility and body perception was also identified.

4. Organisation of the codes into clusters and development of 'Themes'

Clusters of codes emerged; the researcher developed Themes around these clusters to encapsulate the essence of what these related to. These themes were used to develop the initial template, and a visual representation of these themes and related codes was developed by the researcher to explore the hierarchical and longitudinal nature of these themes (see Figure 5). Some major topic areas, such as acceptance of amputation, were determined to be an integrative theme, underpinning ideas such as positive mental attitude, amputation having no effect on quality of life and return to normal.

5. Development of initial coding template

The initial coding template was developed by exploring how themes and clusters connected. Figure 5 presented within Chapter 4 provides a visual representation of the Theme and code development work. The author has chosen to present the coding template in this fashion to enable all of the themes and codes to be seen together, rather than as a list which would have spread over two or three pages and would be harder to explore and understand.

6. Template development

This initial template was applied, revised, and reapplied to another 10 transcripts, as recommended by Brooks et al. (2015). As the template was not fixed, this enabled the creation of new codes to document any new insights gained into the lived experience of those who had undergone below ankle amputation.

7. Finalise and apply to full data set

King (2017) elucidates that no template is ever fully finalised, instead it should capture elements which answer the research question, rather than diverging into interesting, but non-pertinent lived experiences. Researcher reflexivity, being aware of *a priori* knowledge, biases and assumptions throughout data collection and analysis was vital.

Assessment of the Quality of the Research

The intention of the researcher was to provide insight into the lived experience of those who had undergone below ankle amputation, generating new knowledge regarding what was important to quality of life and what impact the amputation had upon it. The care and management of an individual with an active diabetic foot problems being clearly seated within organised health care systems and a multidisciplinary team. This is a globally recognised key aspect of management of complex issues such as amputation (NICE, 2019; Schaper et al, 2020). This knowledge led the author to consider how research would be received by those working within the field of diabetes care. As touched upon in the Prologue and Chapter 2, within health there is a history of a biomedical approach to care, and a positivistic, empirical stance within health research. Logically this position results in scrutiny of research findings in terms of quality of the findings to influence change in health care practices. A hierarchy of evidence being used to indicate the importance of study findings (Murad et al, 2016). Within health there is an undercurrent that qualitative research is considered less important in the hierarchy of research. Randomised controlled trials are held in the highest esteem and qualitative research considered alongside expert opinion, held in low esteem, and deemed to be lower quality (Green & Thorogood, 2018; Liamputtong, 2010). Considering this undercurrent, and the expectation of

this audience to be orientated towards expecting commentary upon quality, the author has chosen to explore the trustworthiness of this research.

If adopting the position of authors such as Guba and Lincoln (1989), who responded to the positivistic demand for assessment of quality of qualitative findings (and developed the parallel quality criteria), then for research findings to be relevant, the reader must be assured of the quality of the findings. Qualitative research findings are derived not from numerical data, as in the case in quantitative research, but from naturalistic inquiry and experiential description. The aims of qualitative research differ from quantitative research, aiming to recognise the subjectivity of the data and explore interpretation of the findings. It is therefore natural to extend the argument, as several authors have (Denzin, 1988, Seale, 1999), that quality assessment measures used within the sphere of quantitative research such as internal validity, generalisability, reliability, and objectivity are not relevant to qualitative research. Positivistic terms relating to quantitative research assessment do not reflect the nature of naturalistic enquiry (Adler, 2022, Symon & Cassell, 2012). To recognise the subjectivity and interpretation, Guba and Lincoln (1985) proposed exploring the quality of qualitative research by assessing the trustworthiness of the findings. Trustworthiness of qualitative research findings being determined by exploring credibility, dependability, confirmability, and transferability (Guba, 1981, Guba and Lincoln, 2001, Lincoln and Guba, 1985, Symon and Cassell, 2012). How these aspects are met by the current research are discussed below.

Researcher's Credibility for Undertaking the Project

The researcher has 13 years of clinical experience working both in diabetic foot multidisciplinary teams and as the lead link within rural isolated environments. There is a subsequent 10 years of Senior Lecturer experience, leading undergraduate and post graduate modules focused upon high-risk patient management. Academically, the researcher completed a master's degree

focussed upon diabetes, rheumatology, tissue viability, wound care, and attended a post graduate conference exploring skills such as active listening, essential within qualitative interviewing. This demonstrates the researcher's credibility for undertaking the research and conducting the interviews.

Credibility of the Research Project

The research proposal was examined and passed by both the School of Human and Health Sciences Ethics Committee and, due to data collection occurring within the NHS, a Research Ethics Committee Proportionate Review. Annual reports were completed for the Research Ethics Committee and the local Trust Research Board for progress on the project to be reviewed. During the planning of the project, quality was incorporated into the planning of the data collection and analysis methods, consideration was given to utilising a typology for the interview script to ensure a rich depth to data collection, and qualitative interview techniques were also studied to support this (Alvesson & Ashcraft, 2012; King et al., 2019; Kvale & Brinkmann, 2009).

Credibility of Data Collection

Prior to data collection, the researcher spent every Wednesday within the diabetic foot clinic, staff and potential participants became familiar with the researcher's presence. A relationship was developed prior to the interview commencing with the researcher being aware of the medical history of each participant and the current state of foot health. This enabled the researcher to establish a relationship with the participants so that an open exchange was possible during the interview itself.

Dependability

Immediately after each interview the researcher documented the initial reflections of what impact below ankle amputation had upon quality of life for each participant. Interviews were transcribed verbatim by the researcher within the same week to prevent omission of any data which may later be perceived to be important to answering the research question. During the data analysis process, coding definitions and any additions to themes were documented. The transformation of the template during the stages of template analysis are presented within the results chapter.

Confirmability & Credibility of the Analysis

There was peer review of in vivo and conceptual coding of the sub-set of 10 identified to create the initial template by a health psychology researcher who was a member of the supervisory team. This ensured the researcher remained open and not limited by own thoughts and focus.

Subsequently, the initial ideas exploring the impact of below ankle amputation upon quality of life were presented at a Diabetes UK Study Day. The presentation workshop was attended by a range of health professionals working within the sphere of diabetes. They were invited to explore the concept of quality of life (photographs of their work are included within Appendix 2). These perceptions were also cross-referenced to the initial template development to ensure there was not a narrow focus based upon the researcher's preconceptions. As analysis and data collection occurred in parallel, this led to the researcher exploring some emerging themes with the participants. An illustration of this was the importance of a positive attitude to successful adjustment to the amputation.

Transferability

The research context, design and data collection methodology and analysis are clearly documented within the thesis and will be within future publications. Within the results section, demographic data for all participants is presented to enable those reading the research to explore how these findings might echo their own location and context.

Chapter Summary and Introduction to the Results Chapter

This method chapter has detailed how the research was undertaken, documenting research design, ethical approval, recruitment, data collection, ethical issues, and data analysis. The chapter also addressed how the underpinning methodological stance of hermeneutic phenomenology as explored by van Manen (2016) was applied during these processes.

The following Results Chapter presents the attributes of the research participants, a key summary of their individual interviews and documents the thematic analysis process. Excerpts of the interviews are presented here to demonstrate the context from which the coding was undertaken. The results chapter also presents the template analysis process, from initial coding through to the finalised template, all focussed upon answering the research question, determining the impact diabetes associated below ankle amputation has had upon quality of life.

Chapter 4: Findings Exploring Participants and Thematic Analysis

Introduction to the Findings Chapter

This chapter presents the characteristics of those interviewed, along with excerpts of the interviews demonstrating the contrasting experiences participants have from the below ankle amputation. The initial thematic analysis template and the final product of the template analysis process are presented. This template of conceptual and in vivo codes was not the final product of this research, rather, the coding hierarchy was a navigation tool, to enable the researcher and reader to be guided through the rich data derived from the 28 interviews exploring the impact below ankle amputation has had upon quality of life. These findings are discussed within Chapters 5 and 6.

Attributes of Participants

A total of 28 interviews were conducted from June 2017 to January 2018. The table presented on the following pages summarises the attribute coding data collected for each interviewee and the key commentary about each participant. Subsequent tables are presented to focus upon aspects such as level of amputation and social deprivation index.

TABLE 7 ATTRIBUTES OF PARTICIPANTS

Pseudonym	Age	Index of multiple deprivation rank	How deprived	Level of amputation	Key Commentary
Rowan *	69	11040	30%-40%	3 rd Toe	No change to quality of life since amputation, no mobility issues subsequently.
Angela *	71	15939	40%-50%	5 th Toe	Positive attitude, 21 months in a wheelchair rehabilitating. Very conscious of following medical advice.
Clive*	51	15302	40%-50%	5 th Toe	3 children, divorced, work focus until amputation. Amputation happened for 'the right reasons'.
Annie*	54	1627	10% most deprived	3 rd , 4 th , 5 th toe	Unable to work since amputation. Social life diminished, reliance on scooter.
Dianne*	72	8068	20%-30%	4 th toe then subsequent 1 st toe	Was a dancer, had 2 separate amputation experiences. Life was not altered when the 4 th toe was removed, the 1 st toe amputation altered mobility and social life.

Pseudonym	Age	Index of multiple deprivation rank	How deprived	Level of amputation	Key Commentary
Guy*	76	12621	30%-40%	3 rd toe removed then tips of 2 nd and 3 rd toes, bone out of 1 st .	Pragmatic about amputation, was requesting amputation for a year prior to the event, 'get rid of it'. Chronic ulceration impacted walking, amputation does not.
Andrew*	55	27685	80%-90%	2 nd 3 rd met V section	Ex-military, pragmatic about amputation. Quality of life remains unchanged; amputation has not impacted this. New ulcer healing means current reduction in activity.
Sam *	54	6362	10%- 20%	Trans met	Pride from working, feels the benefit support system is very judgemental and did not consider his work ethic. Smaller social group since amputation.
Keith*	61	9754	20%-30%	Trans met	Without family and partner would have been unable to continue as a Publican. Pub is a 'Hospital hotel' all openly share experiences.

Pseudonym	Age	Index of multiple deprivation rank	How deprived	Level of amputation	Key Commentary
Sandy*	64	15922	40%-50%	Trans met	Footwear changes led to change of appearance and choice of clothing limited. Kidney dialysis also limiting life.
Bill	60	128	10% most deprived	1 st toe	Opened to accept help, thinking about adjusting working role so can maintain independence. Strong, proud father.
Frank	62	11839	30%-40%	1 st toe	Pragmatic: demands intelligence from health care workers, disappointed at lack of joined up care.
Gerry	58	18130	50%-60%	1 st toe	Positive attitude, self-reliant as little support available, could be viewed as challenging rather than assertive in conversations with medical practitioners.
John	73	28077	80%-90%	1 st autoamputated then other 1 st amputated	Amputation has not impacted upon quality of life, issues from other medical conditions have. Wife's support vital.

Pseudonym	Age	Index of multiple deprivation rank	How deprived	Level of amputation	Key Commentary
Tom**	52	20258	60%-70%	1 st toe, other leg amputated	Positive attitude, big not small goals. Work accommodated changes needed. Jokes about amputations, has acted as expert patient talking to others about amputation.
Steve**	57	4929	10%-20%	1 st toe, other leg amputated	Specialist holiday guide prior to kidney issues. Dialysis limiting life choices not the amputation.
Albert	61	6770	20% - 30%	2 nd Toe	Can still ride motorbike. Vital for freedom and self-sufficiency, lives alone.
Charles	67	6669	20%-30%	2 nd toe	Acceptance of amputation, but healing and resting impacting upon social choices.
Judy	85	18256	50%- 60%	2 nd Toe	Footwear and fashion changes post amputation. Social life centred around her religious beliefs. Technology vital to maintain social connections.

Pseudonym	Age	Index of multiple deprivation rank	How deprived	Level of amputation	Key Commentary
Nathan	44	766	10% most deprived	5 th toe	Toe not an issue, other health problems cause the limitation to quality of life. Wheelchair user awaiting adaptations to home environment.
Richard	60	11611	30% - 40%	Right 1 st Left 3 rd , 4 th , 5 th	On sick from work 2 years post amputations, location of house limits mobility, over 20 steps to entrance, therefore social life has become limited.
Ted	65	15502	40%-50%	2 nd , 3 rd , 4 th , 5 th Toes	Family vital to rehab, own business means working was a possibility even during healing.
Louisa	65	17767	50% - 60%	2 nd , 3 rd , 4 th , 5 th toes	Fearful for left foot, misses being able to drive the car. Respect for medical profession involved within her care.
Gary	58	24990	70%-80%	3 rd , 4 th , 5 th toes	Other medical conditions impacting upon life. Stents, angioplasty, and pain from ischaemia. Had to move to a

Pseudonym	Age	Index of multiple deprivation rank	How deprived	Level of amputation	Key Commentary
					new house as house was tied to job. Had 32 months non-weightbearing for amputation to heal.
Bob	63	28162	80% - 90%	Right 2 nd , 3 rd , 4 th toes	Wide social network not impacted by amputation. Health in focus – lost 3 stone post amputation.
David	67	9064	20%-30%	3 rd , 4 th toes and 5 th toe and shaft V section	Positive attitude to rehabilitation, photos used as a benchmark of progress towards healing and as a motivation to continue with choice of limited mobility now for quicker healing.
Derek	78	4374	10%-20%	3 rd , 4 th , 5 th trans met	Obesity limits mobility not amputation, family visits daily.
Alison	70	5708	10%-20%	Trans Met amputation	Support of family, grandchildren have more of a caring role now. Reduced social activity due to mobility and other health issues. 'Glad it's gone,' extreme pain prior to amputation.

*These participants were included in the subset of 10 to develop the initial template

**These participants have had below ankle amputation on one foot, and a below knee amputation on the other leg. These were both diabetes related, non-traumatic amputations.

Table 7 overleaf provides a full summary of the attribute data for each participant. Age, the index of multiple deprivation rank and how deprived the area is in which the participant resides, level of amputation and key commentary, a synopsis following initial transcription and naïve reading of each transcript are all presented. The index of multiple deprivation ranks all areas in England from those which are most deprived to the least deprived area (Ministry of Housing, 2019). The most deprived is ranked as number 1, the least deprived is 32,844. These indices are derived from a combination of elements which contribute to deprivation, namely, income, employment, education, health and disability, crime, barriers to housing and services, and living environment deprivation. The deprivation rank is not calculated upon an individual basis but highlights the level of deprivation for the area in which participants reside. The table demonstrates that participants were from a wide range of levels of deprivation from the 10% most deprived to those in areas 80-90% least deprived, thereby potential social and environmental impacts upon quality of life were also able to be explored within the interviews.

The first 10 Individuals highlighted by the asterix formed the original subset from which the preliminary coding and initial coding template was developed. These ten were chosen for their diversity of age, level of amputation, area deprivation and perspective to below ankle amputation.

TABLE 8 AGE RANGE OF WOMEN AND MEN INTERVIEWED

Age of participant	Number of Women	Number of Men
40-49	0	1
50-59	1	7
60-69	2	10
70-79	3	3
80-89	1	0
Total	7	21

Seven women and twenty-one men were interviewed for the research. The table above shows the age range of individuals who participated within the research, specifically the youngest participant was Nathan aged 44, the oldest was Judy aged 85 (please see Table 7 for amputation details and key commentary). Clearly more men than women participated within the interviews, the numbers equate to 25% of women and 75% of men being part of this research. This was perhaps to be expected and mirrors published incidence data which found men accounted for between 73.2% - 88% of diabetes related below ankle amputation, and the average age of amputation being 67 ± 9 years (Cascini et al., 2020; National Cardiovascular Intelligence Network, 2021; Rajendran et al., 2012).

TABLE 9 LEVEL OF AMPUTATION

Level of Amputation	Women		Men		Total /33
	First Amputation	Subsequent Amputation	First Amputation	Subsequent Amputation	
Hallux (1st toe)	0	1	7	1	9
1 Lesser toe (2,3,4,5)	3	0	6	0	9
Toes	2	0	4	2	8
V section metatarsal	0	0	2	0	2
Trans metatarsal	2	0	3	0	5

Table 9 shows the level of amputation which had occurred for men and women. As can be seen, there was a wide range of level of amputation for both men and women, and some of the participants had further amputation after the initial procedure (Dianne, Guy, and Richard). As seen in Table 7, Dianne's subsequent hallux amputation impacted upon her social life, Richard's amputations in combination with his house having 20 steps to navigate limited his mobility, and ergo, social life. Guy, by contrast, found ulceration prior to amputation limited his life rather than the amputations.

TABLE 10 LEVEL OF AMPUTATION COMPARED TO LEVEL OF DEPRIVATION

Level of amputation	Level of deprivation / %								
	10 most deprived	10-20	20-30	30-40	40-50	50-60	60-70	70-80	80-90
Hallux (1 st)	1	1	1	3	-	1	1	-	1
Lesser Toe (2,3,4,5)	1	-	3	2	2	1	-	-	-
Toes	1	-	1	2	1	1	-	1	1
V section metatarsal	-	-	1	-	-	-	-	-	1
Trans metatarsal	-	3	1	-	1	-	-	-	-
Total amputations per how deprived	3	4	7	7	4	3	1	1	3

Table 10 shows the level of deprivation, number and level of amputations performed for research participants. As can be seen above, more amputations in total were undertaken in individuals in the most deprived areas. More invasive amputation has occurred for those residing in more deprived situations. There were 25 amputations within the 0-50% most

deprived compared to 8 in the 50-90% less deprived. These findings are supported by previous studies, Fejfarová et al. (2014) found those who had undergone amputation had lower standards of living, Stevens et al. (2014) identified high incidence of diabetes related amputation related to lower-income urban and rural areas. Two studies based within Scotland identified disproportionately higher levels of amputation in more deprived areas (Hurst et al., 2020; Hurst et al., 2021).

Concluding Thoughts on Demographic Data Presented

The tables indicate the similarities of participants within the current study to previously published research. This is in respect to levels of amputation and social deprivation. This enables the reader to be confident of the comparable nature of the research population to the published research. However, this previously published research was of a quantitative nature, with no exploration of the impact the below ankle amputation had for the individual. The following data analysis results explore the thematic analysis with regards to understanding the impact of below ankle amputation upon quality of life.

Exploring the Transcripts: Impact of Below Ankle Amputation on Quality of Life

The 28 individual interviews generated transcripts with over 110,000 words to review. As explored within the method chapter, template analysis, a form of thematic analysis, was chosen to explore the transcripts and audio recordings of the interviews. The focus of the analysis was upon gaining understanding of the impact below ankle amputation had upon quality of life, and subsequently conceptualisation of quality of life. Guidance on template analysis (King and Brooks, 2017), suggests that an initial subset of data with a diverse range of experiences are used to shape an initial hierarchical template, codes reviewed and clustered together into relevant themes. The researcher's *a priori* knowledge incorporated only if the data supported this.

Definition of a Code

A code is a word or phrase which encapsulates the researcher interpreted meaning of a section of data.

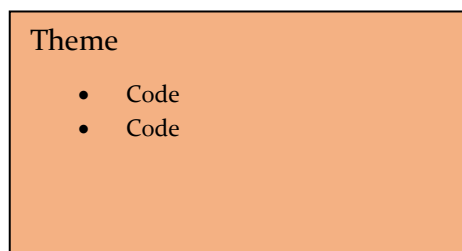
Definition of a Theme

A theme is a word or phrase developed following analysis of the coding to act as an umbrella concept under which codes which related to a particular idea could be brought together.

Following transcription by the researcher alone, each transcript was read, in vivo and conceptually coded to capture data which explored what impact below ankle amputation

had upon quality of life. Following the guidance by Brooks and King (2014) on thematic analysis template development, the initial template was derived from a combination of the *a priori* codes of body image, physicality and social, identified from previous research in the field, and new codes derived from the transcript analysis of 10 diverse experiences of amputation. The new codes were developed by adopting a blend of qualitative analysis methods described by Saldaña (2016) and van Manen(2016) to capture the consequences of amputation, exploring intra-personal, inter-personal and external factors impacting upon quality of life.

The hierarchy of codes and themes after reviewing the initial subset of data has been presented in Figure 5. The 10 transcripts of Rowan, Angela, Clive, Annie, Dianne, Guy, Andrew, Sam, Keith, and Sandy. Themes identified related to the consequences of amputation and the impact upon quality of life. These themes were titled by the researcher physicality, time for rehab, emotional, social, economic situation, body image, pain, dignity and pride, relationships, am I normal, getting back to normal, attitude to amputation, control, life perspective, no change to quality of life and photos of amputation. Rather than create a long list of Themes and the codes which are encapsulated into a theme, the researcher has chosen to include a visual summary of the thematic analysis so that the reader can explore all the themes and related codes on a single page. Each colour block represents a separate Theme, the phrase at the top denotes the title of the Theme, the bulleted list denotes the codes incorporated into the theme, as illustrated below:



The initial template is shown overleaf.



FIGURE 5 INITIAL CODING TEMPLATE DERIVED FROM SUB-SET OF 10 INTERVIEWED

Consideration of *a priori* Codes Body Image, Physicality and Social

The *a priori* code of Body Image was found to be resonant with those interviewed, much of this was centred upon forced alteration of footwear to orthopaedic shoes, and ergo, loss of choice for clothing, changes to physical appearance and alteration of self-identity. Body image was accepted into the continued analysis.

“As I say my big thing at the moment is about the shoes, I’ve always been a shoe person you see as well, but I’ll get there with them. You want to, you know, I mean I don’t always want dress trousers. I have worn trousers a lot of the time, tracky bottoms when I come here because I don’t want to ruin decent trousers, but I wore skirts as well, like I say, I was a bit of a shoe person, it was the first thing I went to in a shop, shoes, and, but, I know they can’t be fantastic, but there’s got to be some better designs you can get. I’ll wait and see, this is my first lot then I’ll talk to them about having some more, I even don’t mind paying for them, I’ve got no objection to that, but it needs to be better designed. Yes, so that it fits with your clothes it doesn’t look horrible with the clothes that you are wearing. I don’t think it’s too much to ask. I don’t even want shoes with heels on, but something that looks decent, not booty.”

Sandy (Trans met amputation) p 23

Concerning the *a priori* code physicality, relating to physical mobility, expression of limitation of movement was related to whilst the amputation site was healing and once this had resolved. Physicality was expressed by participants unprompted within the interviews and so was accepted to be a code within the development of the template.

“I think the first couple of days I couldn’t move. I was stuck upstairs, but eventually I found myself coming downstairs on my bum, sitting where Nigel is, with a zimmer frame with a vacuum pump attached to it with a pipe attached to

my foot to suck the rubbish out and suck the flesh back to the front. And I think I was like that from the early mid-September way through into the February-March, wasn't it? February, March I've got a picture of it on my phone at foot clinic and it is graining nicely, and it is about that size (holds hands up to 50p size) and that was mid-February. I don't think I went into a shoe, a proper shoe, until the June or July. With a prosthetic in."

Keith (trans met amputation) p 8

"And it and it just devastated me absolutely. I just went about in the wheelchair everywhere I couldn't walk; I couldn't do anything because they were frightened if I did walk. You see, being an abscess, it needs to heal from the inside out. They couldn't do anything with it, couldn't pack it, they couldn't stitch it. And I think, really, I really did very well to be honest, but it was absolutely devastating. Being pushed around and on buses and, oh dear it really did for me to be honest. But I came through it and now I'm fine. I mean, we go about shopping every day and occasionally we go for a little walk along the canal. Holidays, I've gone all round Norfolk, all over, yes, yes. It's, we love Norfolk it's a nice place."

Angela (5th toe amputated) p 11

"In actual fact the strange thing is I didn't notice any difference. There was no difference to my gait, there was no difference in walking or anything else. It was basically normal. But what he said was because it's the middle toe it wouldn't have that effect. If it had been any of the other toes it would have had an effect. But because it was that one, you know, the other toes compensated for it. So, I never had a problem at all. And I've never had a problem since."

Rowan (3rd toe amputated) p 2

Data analysis identified that the *a priori* code Social should be included within the template development. Participant expressed the importance of a social network, both for adaptation and ongoing quality of life. They explored relationships with partners, family and friends.

“I am involved with Sports clubs, football and cricket and I have been able to carry on that. I am a secretary of a semi-pro football club, so I am quite busy, both in the office and at the grounds and whatever. My quality of life has not gone backwards at all really. It’s not stopping me from doing anything.

I’m a fairly positive person, I’m a social person, I’ve got lots of friends, do a lot of networking so I am lucky in that respect. Yes, I could understand it if you were a bit of a person who didn’t have many friends or hadn’t got a good family it could drag you down a bit, but I haven’t allowed it to drag me down. I am positive, as I say.”

Bob (Right 2nd, 3rd, 4th toes amputated) p 3

“The support of your family, it’s paramount. Luckily, I’m married, lucky that I have kids and grandkids and it all helped that little bit.”

Ted (2nd, 3rd, 4th, and 5th toes amputated) p 15

Template Development: Application to a Further 10 Transcripts

As recommended by Brooks and King (2014) and Brooks et al. (2015) the template was then applied to a further 10 transcripts. As the ethos of template analysis is to allow fluidity throughout data analysis, other subcodes and themes were incorporated within the template. New themes were concerned with exploring the relationships participants had with their medical team, planning for activities and concern for future foot problems. The rationale for inclusion of these factors is explored after Figure 6.

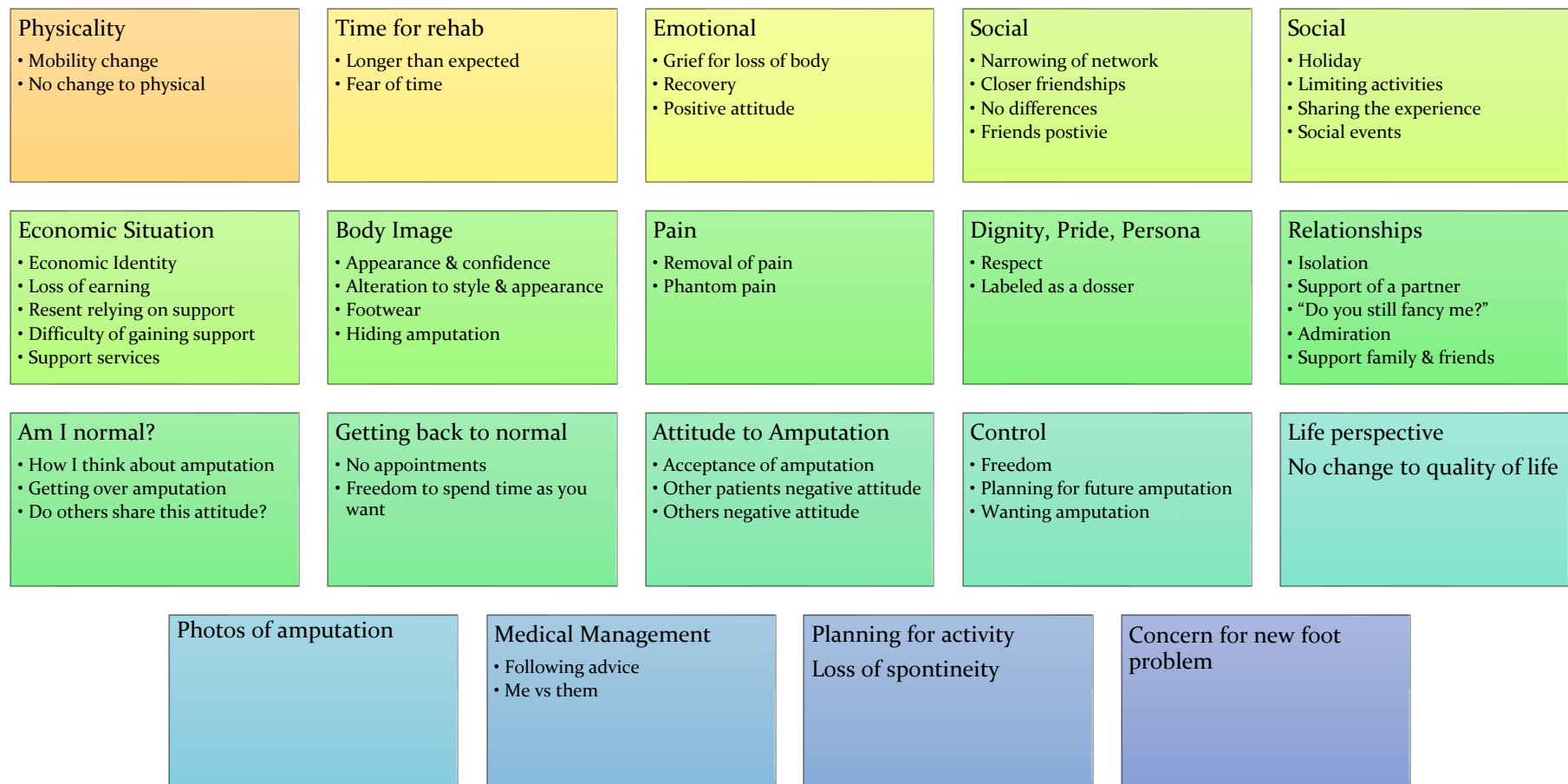


FIGURE 6 CHANGE OF CODING TEMPLATE WHEN APPLIED TO A FURTHER 10 TRANSCRIPTS

Coping with Amputation – Incorporation of Medical Management Theme

Medical management was added as a theme to capture the conceptualisation of the medical profession being vital to adaptation and acceptance of amputation. Individuals chose to incorporate the medical team into their social support network, using them as part of their coping strategies, gaining knowledge, and undertaking goal-related activities to plan for a successful rehabilitation. For some participants, such as Angela, this trust and professional relationship was successful, and was recounted as being essential to their adaptation to the amputation. For others, such as Gerry and Frank, some of these professional relationships were not as successful. Gerry has anger, the medical treatment goals and management plans are askew from his own set of priorities to maintain his own perception of his self-identity. For Frank, he has contempt for “professionals” with a lack of knowledge and skill. In both instances these discordant relationships have delayed their personally set goals. Rather than passively accepting this, they were able to use this as a driver for self-care and re-establishment of independence.

“Anyway, I got through that, and the top of the thing was Doctor, as she was then, she’s professor now, she looked one day and she said, right, we’ll have a look at this and did it up and said ‘I think I’ll try and let you walk. Just try and walk 20 minutes a day. If it’s too much, walk for 10 minutes and stand for 10 minutes, stand at your kitchen sink, and watch the flowers and the birds.’ Right, so I did this, and I managed 20 minutes, but I knew I had done 20 minutes walking, my leg had gone thin, it was wasted muscle you see Natasha. So, I did exactly to the letter, I followed her instructions, and every day I increased it by another minute. It doesn’t sound a lot, but to me it was a lot. Another minute, another minute, another minute, till I was walking for the best part of the day really. Gradually I increased it, and I went to her one day and she had a look at it, and she said, ‘Yes it’s doing marvellous now, you’ve got your strength back and all the rest of it.’ Well, I said Dr, there is no point my coming to you and you’re telling me “don’t do this and you must do that”, and my going home and

doing exactly the opposite, padding around the flat there's no point to it. She said, 'I just wish all my patients thought like that.' I feel that I feel better in myself as well as my foot being better yes really, I do feel better yes, yes.

Angela (5th toe amputated) p 3-4

"Next thing I had an air cast boot on, but I sprayed it black so I could go on a motorbike. Then I came off the bike, with it on. Then I was back in front of Dr again and she said, 'you're not going anywhere this time, you'll stay in bed and do as you're told.' I was in Ward 407, down the bottom, and on dialysis. It was alright, you just can't get out. This place, they are like the Gestapo, every time you go round a corner, 'you're not going, you're not going out, you're not doing this, you're not doing that.' Hard place to get out of this place. I bought a scooter, a 600cc scooter, lift the seat up and you can get anywhere. Beats the system, I mean beats the system, you have to beat the system. When the renal team come round 'you can't do this, that' I'll show you, I do what I want to do."

Gerry (1st toe amputated) p 1-2

"From my perspective I'm a very hardy individual, I'll go "ok." From pretty much after I came out of the hospital, I was doing my own dressings to save time, I got peed off going down to the surgery and waiting for 2 hours, what is the point? I said at the hospital, I do this myself. They said, as long as you get it checked by a professional at least once a week. It was every couple of days; for a fortnight I had the district nurses coming round and after that it was every second day down at the hospital or down at my local surgery. Hospital appointments are kept because you are seeing the professor or the consultant, but the in-between I said, look I can do this better myself, so I ended up doing it myself. I decided to go every second week to my local surgery. The clinic, but the in-between times I just did it myself. But like I say, you get people slate you, perhaps not so broad minded, or perhaps not so unmoved by injury, illness as such that makes you struggle profusely with the problems I've had. I probably swore at people, but I

don't care I just look at it all and say, 'what?' It's just me, but I have no problem saying to a consultant "you're an idiot" and I will say it if that's what I'm thinking."

Frank (1st toe amputated) 26

Consequences of Amputation: –Loss of Spontaneity from Life and Planning for Activity

Other codes added explored the changes that amputation had made to lifestyle, exploring the loss of spontaneity, that activities had to now be planned.

If like Albert says "Oh, you coming to so-and-so with me?" I said yes, I will do, I can't say that now, I think where am I going? How long are we going to be? So I have to take something with me for my diabetes, I've always got something in my bag anyway, but I've always got to plan more or less, I just can't nip in the car and go somewhere I don't know where were going, I can't do that I can't, I've got to make sure I can get round where we're going, is my chair in the back? Which it always is, but I always say that don't I? "Is my chair in the back"? You've got that many things in front of you to think about before you even set foot out of the door, or plan to set foot out of the door."

Alison (trans met amputation) p 9

"I'm going out with the girls tomorrow night around the town. I don't know I'm a bit, I don't know, nervous, I'm really looking forward to it but I'm thinking, am I going to be able to have a little dance if they have a dance? I don't want to be just sat at the table having a drink. It's alright when you go out for the meal. But when there's a bit of music and I love dancing, I'm thinking am I going to be able to do it? But I thought if I don't go, I'm never going to know and at least I'll be with some friends and have a laugh. I'm not nervous, I am looking forward to it but it's like I don't want them to compensate for me. Because obviously I

won't be as fast as they are. But I think I'll be fine so I'm looking forward to that. But it's not nice."

Annie (2,3,4 toes amputated) p 8

Consequences of Amputation: Concern for New Foot Problem

Reflecting upon the event that led to the original amputation led others to be concerned for a future where more amputation may occur. For Albert, the level of amputation was a concern, that this may impact upon his independence and lifestyle. For Bob, there was fear that there may be a recurrence of amputation. David chose to adapt his lifestyle, reducing self-perceived risky activities to try to prevent a recurrence of amputation.

"Yes, it is a worry, a constant worry about losing my foot. If they take just my foot, then I wouldn't be able to ride again. If they take it off below the knee then I would be able to get a prosthetic leg and then I can get round it by getting a thumb break for the bike, even though it costs over £400 for one."

Albert (2nd toe amputated) p 4

"I just hope nothing else because you do hear. I've bumped into a couple of people in hospital and get talking and they say, "that's how I started and now I've lost mine to the knee". That's the last thing you want to hear when you have had 3 toes off, but touch wood, I've had nothing else, no issues going wrong apart from these ulcers."

Bob (2nd, 3rd, 4th toes amputated) p 12

“Got to be careful, as for cooking a meal I wouldn’t take the gamble now. Might sound silly to some people, might be the be all and end all to some people, but for us, as we are, we can get by with it. As for doing it on your own I’d certainly think twice, you’ve got to as you might end up with more, flipping injured. You’re looking out for what might happen, sort of thing, never used to think.”

David (3rd 4th 5th toes amputated and V amputation to shafts) p 13-14

Application of the Template to All Transcripts

Review of the final 8 transcripts lead to more sub-codes being introduced to areas such as attitude to amputation, relationships, and medical management and environmental. New main themes were created; adaptation to amputation, with included codes relating to coping strategies for amputation, and other conditions impacting on quality of life to fully capture the depth and richness of the data (King & Brooks, 2017). This is represented within figure 7.

Physicality <ul style="list-style-type: none"> • Mobility change • No change to physical • Balance 	Time for rehab <ul style="list-style-type: none"> • Longer than expected • Fear of time 	Emotional <ul style="list-style-type: none"> • Grief for loss of body • Recovery • Positive mental attitude 	Social <ul style="list-style-type: none"> • Narrowing of network • Closer friendships • No differences • Friends positive 	Social <ul style="list-style-type: none"> • Holiday • Limiting activities • Sharing the experience • Social events
Economic Situation <ul style="list-style-type: none"> • Economic Identity • Loss of earning • Resent relying on support • Difficulty of gaining support • Support services 	Economic Situation <ul style="list-style-type: none"> • Financial situation 	Body Image <ul style="list-style-type: none"> • Appearance & confidence • Alteration to style and appearance • Footwear • Hiding amputation 	Pain <ul style="list-style-type: none"> • Pain post-op • Removal of pain • Phantom pain 	Dignity, Pride, Persona <ul style="list-style-type: none"> • Respect • Labeled as a dossier • Others judgement
Relationships <ul style="list-style-type: none"> • Isolation • Support of a partner • “Do you still fancy me?” • Admiration • Support of family & friends 	Relationships <ul style="list-style-type: none"> • Concerned limiting partner’s QoL • No partner • Partner’s concern for patient • Reliance on partner as carer 	Am I normal? <ul style="list-style-type: none"> • How I think about amputation • Getting over amputation • Do others share this attitude? 	Getting back to normal <ul style="list-style-type: none"> • No appointments • Freedom to spend time as you want 	Attitude to Amputation <ul style="list-style-type: none"> • Acceptance of amputation • Other patients negative attitude • Others negative attitude • Inspiration of others to motivate rehab
Attitude to Amputation <ul style="list-style-type: none"> • Involved in the decision making • Others not understanding acceptance of amputation • Suddenly aware of seriousness 	Control <ul style="list-style-type: none"> • Freedom • Health control • Planning for future amputation • Self care wound • Wanting amputation 	Life perspective <ul style="list-style-type: none"> • No change to quality of life • Moving forwards • Partner’s perspective 	Photos of amputation	Medical Management <ul style="list-style-type: none"> • Following advice • Me vs them • Respect for medical team • Trust • Compromise now for quicker rehab
Planning for activity <ul style="list-style-type: none"> • Loss of spontaneity 	Concern for new foot problem	Adaptation <ul style="list-style-type: none"> • Coping strategies for amputation • Minor viewed differently to major 	Other conditions impacting on QoL	Environmental <ul style="list-style-type: none"> • Societal issues

FIGURE 7 CODING TEMPLATE WHEN APPLIED TO ALL TRANSCRIPTS

Definitions for Themes

The definitions for themes and codes were recorded by the researcher within Nvivo and were referred to prior to any analysis work occurring. The following paragraphs provide the researcher developed definition for the themes presented so that the reader can be orientated to the researcher's perspective and analysis. These have been presented alphabetically, not by order of importance.

Adaptation

The ability to adapt to the changes necessary as a result of the below ankle amputation. Explores coping strategies utilised by participants.

Am I normal?

Theme incorporating participants questioning of the researcher, exploring if their experiences were similar to others interviewed. This links to themes exploring control and highlighted a lack of support from those with similar experiences.

Attitude to Amputation

Exploration of own and others perspective with regards to the amputation. Includes aspects such as the participant having accepted and adapted to the amputation, but the judgement of family and friends perceiving this as a terrible event when the amputee had made the amputation decision and have couched this as a successful event. Also explores the idea of positive attitude and observation of other individuals who were not successfully adapting to the amputation.

Body Image

Defined as thoughts exploring body image perception. The adjustment of self, the forced alterations to clothing and footwear altering persona presented to the world. The exploration of being able to hide the amputation.

Concern for a new foot problem

Exploring the worry that a new foot problem may hamper quality of life.

Control

Someone's ability to control their life - including having the freedom to make decisions, both around their health and their life itself.

Dignity, Pride, Persona

Exploring impact upon self-identity of changes in abilities and activity levels. Persona included to define the judgement of others about the individual post amputation. A loss of respect and the importance of this to self-perception.

Economic Situation

Incorporating data pertaining to feelings about their economic identity, the consequences of being unable to work, the grief for loss of working, and the worry of financial issues arising. Also incorporates elements surrounding frustration or lack of knowledge in accessing support services, and disability support system battles to attain support.

Emotional

Theme exploring the emotional impact of the below ankle amputation. Incorporating codes relating to the importance of a positive mental attitude, the emotional experience of recovery from the events leading to amputation and post amputation healing. Grief for the loss of a body part and the emotional adjustment also incorporated within this theme.

Environmental

This was to relate to the environment in which the participants resided within, considering the wider social issues that confounded them, for example the benefits system.

Getting back to normal

To be interpreted as a desire for normality. Including the idea of no appointments and freedom to spend time as you want.

Life Perspective

Exploring the importance of how the individual considers their quality of life. Ties into the overarching theme of adaptation to amputation.

Medical Management

Theme exploring the importance of the patient-medical team relationship. Incorporates the participant's attitude to the medical team, the trust and reliance upon them for education to enable self-care and management.

Other conditions impacting on QoL

Theme created in response to participants vocalising that the amputation did not impact quality of life, rather other medical conditions were responsible for diminishing this.

Pain

Relating to the resolution of pain post-amputation, the pain during the healing process or the frustration of ongoing phantom pain compromising quality of life.

Photos of amputation

Benchmarking progress, as part of a strategy to share the amputation journey with family and friends. Part of the positive coping strategy to enable adaptation to the amputation.

Physicality

Overarching idea incorporating codes which link to data exploring positive and negative aspects relating to physical life. This incorporates codes relating to changes of mobility, no changes to physical activity and to reported balance issues post-amputation.

Planning for Activity

Exploring the changes to quality of life, with regards to activities once spontaneously completed now requiring planning.

Relationships

Exploring the importance of support of partner, family or friends in relation to adaptation and ongoing care needed for the amputation. Also includes the expressed guilt at reliance upon these relationships and the forced alteration of relationships, and the necessity for those partners, family and friends to adopt a caring role.

Social

Exploring the importance of a social network. The social network being defined as including partner, friends, family and social events, activities and the importance of holidays.

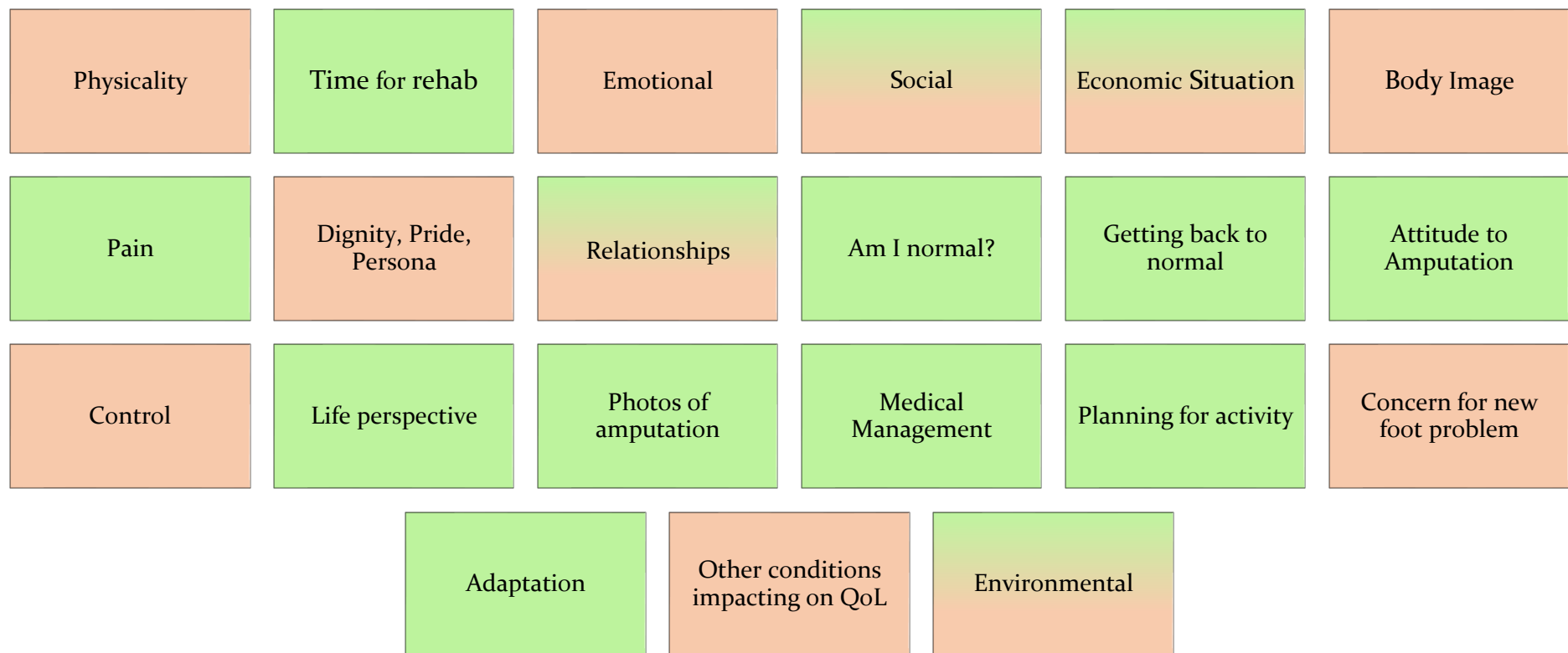
Time for Rehab

Theme exploring the surprise at the length of time for rehabilitation to be successful, and the impact this had upon the adaptation journey. Can be seen to link to the Medical Management Theme in terms of acceptance of rehab time and also to Control, and adaptation.

Further Reflection upon Analysis: Creation of Overarching Themes

There was further review of all the transcripts, considering how the coding matched the overriding question of what impact below ankle amputation had upon quality of life. This resulted in revision and reflection, an amalgamation of a priori, in vivo, and conceptual coding. An overarching conceptual idea was formed, that adaptation impacted upon quality of life, and quality of life could not be considered in isolation. There were similarities between participants in what elements were important to quality of life, such as physical mobility, emotional wellbeing, social network, and economic situation, however, the perception of the effect the amputation had upon quality of life varied. A range of views were expressed, some found

improvements to quality of life – the resolution of a chronic wound resulted in removal of pain, reduction in hospital and outpatient visits, and a return to higher activity levels. Others found no difference to quality of life, and for some there was a worsened quality of life post amputation, the amputation triggering changes to their social and economic situations. Participants shared their experiences of being unable to continue in their previous roles, difficulties in achieving the level of support that was now required or becoming socially isolated due to physical limitation. However, this was not related to the level of amputation preformed, Annie, who had 3 toes removed, reported a worsened quality of life. Keith, with a trans met amputation, expressed there were life changes due to reduction in mobility, but this had not impaired his life quality. The participants perception of their quality of life was related to their acceptance and adaptation to the amputation. Illustrated in Figure 8 is the final development of the template derived from the thematic analysis process, identifying factors coded to the overarching themes of adaptation to amputation and quality of life.



Key

- Adaptation to amputation factors
- Quality of life factors
- Factors important to Adaptation and Quality of Life

FIGURE 8 FACTORS AS THEY RELATE TO ADAPTATION TO AMPUTATION AND QUALITY OF LIFE

Chapter Summary and Introduction to the Findings Chapters

The results chapter has presented the attributes of the study participants, development of the analysis of the data and themes that related to adaptation and quality of life derived from data analysis. The subsequent chapters discuss the new knowledge and factors shown in Figure 8. Chapter 5 explores acceptance, adaptation and coping strategies used to adapt to a life with below ankle amputation. Chapter 6 explores the subsequent impact upon quality of life, and ergo, factors important to quality of life. A visual summary of the new knowledge is finally presented in a Chapter 7 within a conceptual framework of quality of life for below ankle amputation.

Chapter 5: Findings on Acceptance, Coping strategies and Adaptation

Introduction to Acceptance Findings

The Results chapter presented the attributes of the 28 interview participants. The data demonstrated the similarities between the current study participants and previous amputation research in terms of amputation aetiology, incidence data and that those residing in more deprived areas had larger areas of the foot amputated (Hurst et al., 2020; National Cardiovascular Intelligence Network, 2021; Ugwu et al., 2019).

The Results chapter also presented the thematic analysis process and provided visual representations of how the procedural steps for Template Analysis contributed to the production of a coding template, perceived by the researcher as a way to encapsulate the key aspects of the lived experiences of those who had undergone below ankle amputation. Analysis provided insight that quality of life could not be viewed in isolation, rather the lived experiences of the participants identified that adaptation to the amputation was an important factor contributing to overall appreciation of quality of life. Chapter 4 finally presented Figure 8 which explored the new knowledge derived from the data relating to adaptation and factors important to quality of life. This current chapter explores acceptance, and coping strategies and adaptation to below ankle amputation.

To address the overall aims of the research, namely, to explore the impact of diabetes related amputation upon quality of life, it was important to establish how the participants adapted to the amputation. The findings of this research indicate that successful adaptation and acceptance of amputation resulted in participants expressing there was little alteration to their quality of life. By contrast, those still adapting to the reality of being an amputee expressed worsened

quality of life. Exploring these dichotomies of views and the coping strategies utilised ultimately gave insight into factors important to quality of life.

The paragraphs below explore the experiences of amputation in terms of acceptance and coping strategies adopted to adjust to this life change. Once these findings have been explored, and a new base of knowledge established for acceptance and coping strategies adopted by those with below ankle amputation, the subsequent findings chapter will present what was important to quality of life and the impact below ankle amputation had upon quality of life. The combination of this new knowledge is finally presented as a conceptualisation of quality of life for individuals with diabetes related below ankle amputation.

Presence of Others within the Interviews

Of the 28 interviews conducted, 11 individuals did this whilst a partner, family member or nurse was present within the location they chose. One of the 11, Gerry, completed the interview whilst undergoing dialysis, and drew a nurse into the conversation to explore the lack of communication between teams and the necessity for his self-sufficiency. Gerry's interaction is explored within the adaptation to interview section below.

The other 10 participants, namely Alison, Andrew, Charles, David, Gary, John, Keith, Louisa, Ted and Tom chose to participate within the interview at their home. Their partners, or in the case of Keith, his brother, were present within the home, and were invited by the participants to comment upon answering "How did the amputation happen?" Enabling the participants to recollect aspects of this experience or confirming their perceptions. This, on reflection, confirms the importance of having an established social network, both for successful adaptation to amputation, and as is discussed within Chapter 6, for maintaining a 'good' quality of life

perception. Where relevant to explore a particular theme, the researcher has included quotations which show the importance of these relationships.

Acceptance the Amputation Needed to Happen

All who were interviewed saw the necessity for amputation, some were aware amputation would happen as the ulceration was not responding to treatment. For others, who had emergency admittance to hospital due to spreading infection, there was little time to be prepared, but they were aware of the seriousness of their situation and the inevitability of amputation.

“Yes, entirely, having some knowledge, I know that if I’d looked at a tooth socket and it had looked how my toe had looked, and how it smelt, it was awful, because when I was coming here initially, I was redressing it myself, and I was thinking this just isn’t getting better, so it was already in my mind. What was going to need to be done, so I think I had already prepared myself to have it done, or to be told that it needed doing before the surgeon even brought the subject up. In fact, I asked him about it first, but I was conscious that I didn’t want to do that as it was almost disrespectful; to the fact that they were trying to treat it with antibiotics and I didn’t want him to think I was some sort of blasé idiot who was happy to be mutilated, but I’d sort of reconciled myself to losing it.”

Clive (5th toe amputated) p 2

“I knew exactly what was happening and I had already realised that I was going to end up having an amputation, so I was quite chilled about it to be honest. I realised obviously I had an infection in it, and it was going bad, so it didn’t really phase me out or anything.”

Bob (2nd, 3rd, 4th toes amputated) p 2

“They sort of were letting you make the decision, and I’m thinking well they should be saying we ought to take this off.”

John (1st autoamputated then other 1st amputated) p. 6

“I mean I knew deep down it was gangrene and it needed to come off, but you don’t like to admit it to yourself.”

Gary (3rd, 4th, 5th, toes amputated) p. 8

“It was the only option, have it off or die.”

Derek (3rd, 4th, 5th trans met) p. 3

“They told me about it, I was already here, I came to the accident and emergency. They examined me and said we’ve got to take this toe off, one toe off. Then they had to take another one, and then I went down to have a vac pump put on, and they said, they decided to take the rest off as they weren’t looking good. It wasn’t my decision it was the doctors. He said that I had gangrene in my foot, my toe it had to come off, it was the only way really otherwise I would have lost the leg. They were brilliant they were, you couldn’t put them down, couldn’t fault them. Like the doctor said, when they were going to put a vac pump on, but he said we decided to take the rest of them off just, to cut a long story short, because you’re risking the infection going up your leg. Yes, I was glad they did it. I still did nearly lose my leg, luckily I didn’t.”

Sam (trans met amputation) pp. 2 & 11

Adaptation to Amputation

Individuals adopted multiple strategies simultaneously, the majority ultimately adopting coping strategies that best enabled them to manage the situations they faced. The following list comprises a summary of the coping strategies, aimed at acceptance of the amputation identified within the thematic analysis of the transcripts.

Coping Strategies Identified in Participants Purporting Same or Improved Quality of Life

- ♦ Determination to have a positive attitude to amputation
- ♦ Compare self as more fortunate than others both emotionally and physically
- ♦ Pragmatic acceptance
- ♦ Social network – aka relationships friends, family, partner, and medics involved in care
- ♦ Laugh about the changes
- ♦ Drive to regain physical and emotional independence
- ♦ Photographs for self-motivation

Determination to have a Positive Attitude to Amputation

Recurrently those interviewed expressed the importance of a positive mental attitude to the amputation. This was key to the rehabilitation and re-mobilisation process.

“I try and see the good in every situation, because it keeps me going, if you get depressed and upset about things, what’s the point? So, I always try to see the best in a situation. Positive? Yes, you’ve got to be. One of my favourite sayings is “if you didn’t laugh, you’d cry” and I think it’s really true. I try to remain positive about whatever’s happening. I try to take some good out of it and that’s what

keeps me going for sure. I do occasionally have down days where I get upset about things, but I go to bed, have a sleep, wake up next morning and I'm ready to go."

Steve (1st toe amputated) p. 2

"I'm glad I stuck with it although it was a bit painful because I've not been on my feet for 21 months. I'm glad I stuck at it I could have easily given up and thought I can't do this, I can't walk, no, no good to me this, I can't walk me, I'll just sit in the wheelchair and get pushed around. But I'm just so glad that I stuck with it really otherwise, well, the alternative would be that I'm still in the wheelchair and that. I think it's a question of what's in your mind you know how you feel about it it's your mind really isn't it? I could have so easily just sat back and let things go on as they were, but I didn't want to be like that, I didn't want to be an invalid do you know what I mean? I wanted to be independent to get up and walk and get going and get back to my old self really."

Angela (5th toe amputated) p. 21

"You've got to have that because if you don't you'd go down, and if you're going down there is nothing at the end of it."

David (3rd, 4th toes and 5th toes and met shaft V section amputation) p. 12

"No, no I thought it's only next to my little one, it's not like it's my big one you know, just get on with it. I've got a very positive attitude and I firmly believe if you are positive you get better quicker. So I just, it's only next to the little toe, ok you've lost it, just get on with it, you know, and it didn't make any difference to my quality of life at all. I went dancing again and I was fine."

Dianne (4th toe then subsequent 1st toe amputation) p. 7

Compare self as more fortunate than others both emotionally and physically

Interestingly, for those who stated that a positive attitude was vital, there was comparison to other patients they had observed who they perceived to be in a worse situation than themselves. They formed a clear distinction between themselves, and ‘not being like them,’ and illustrated the differences with examples of negative expressions of emotion and maladaptation such as moaning, being aggressive with the medical staff, elements which were not conducive to acceptance, adaptation, or good quality of life.

“But I think your attitude when you go into these hospitals, if you’re sort of, you know, if you’re not a whinger, you’re not whinging at everything – nurse I want a bedpan, nurse I want this, nurse I want that, nurse I can’t eat this breakfast. And you do get them like that really. I think if you’re sort of, you have a laugh with them, and you’re quite happy and jolly with them, they’re alright with you and I think that is part of the battle.

Yes, I think it’s all in your mind isn’t it really? I don’t know, I suppose some people are different some people are happy to be you know, sitting about and not doing anything. I’ve never been like that, I had twins at 37, yes I did, two little boys to bring up, identical boys and they born 3 minutes apart. So I’ve always been active, I’ve always been busy.”

Angela (5th toe amputated) pp. 5 & 21

“If you get yourself into a depression it just pulls you down. I’ve seen it with other people, I’m not like that normally before I’m ill or anything, so I’m not going to do it now, I’ve got to keep going. I’m not saying I don’t have times when I have a cry, but I think everybody does, but I have to say to myself “pull yourself together, have your cry” my husband will say to me, have your cry, let it be done with and start again. I’ve never really been depressed, depressed, just a bit fed up with how things are going and want it to happen quicker, so impatience rather than anything.”

For others, like Tom, the observation of others physical restriction acted as motivation to regain mobility during the rehabilitation process.

“Otherwise it would beat you wouldn’t it? There are people out there. When I went to the clinic, a lot of them were older people, in wheelchairs and I used to sit and think I’m not going there. I had a few months when I came out of hospital and I hated it, absolutely hated it, I think that was another thing that spurred me to get on with it. Because people will say “you can have one of these scooters, why don’t you have one of them?” No, not while I can still walk round, do you know what I mean?”

Tom (1st toe amputated) p. 25

Pragmatic Acceptance of Amputation

Several expressed the view that amputation was necessary and accepted it quickly. Guy, Andrew, and Steve all had experience of chronic foot ulceration and saw a wound as a limitation of their lifestyle, and amputation as a solution.

“My attitude was then, it’s such a bother it’s stopping me doing a, b, and c, let’s get rid of it. Because I’d had 2 years of antibiotics, it was ok for a little bit then it would break down. And that is how that came about, which, I’d lost, I mean that toe I’ve lost before, and I’ve lost off the tip of another couple with this infection and the toe is quite bent but it doesn’t bother me now.”

Guy (3rd toe removed, then tips of 2nd 3rd, bone out of 1st amputation) p. 3

“The amputation’s not bothered me which most people can’t understand, just one of them things. I’d rather just be happy about it than, what’s the point of being miserable, you only pull yourself down if you are. I can understand people who had had large amputation who get depressed. But it’s just one of them things.”

Andrew (2nd 3rd met V section amputation) p. 11

“Yes, if I hadn’t got this problem, I would be fine because I can walk round no problem because I’d got my balance back. If it hadn’t been for that I would be walking the dog, cycling and all sorts, but now I’m in the same situation where it’s, I need to keep the weight off it so I’m not doing nothing. This is actually more problem than this.”

Steve (1st toe, other leg amputated) commenting on current wound p. 2

Others, who had additional medical conditions drew upon these experiences to identify the successful coping strategies to adjust to the amputation,

“Well, I think, I think I just learned to cope with everything because I’ve had illness a long time and I’ve gone through such a lot of things. Had a kidney transplant, had it failed, had different things, but all through the kidney problems it was just another thing along the line. I’ve found that I don’t, I try not to dwell on it as it makes you depressed. You’ve just got to get on with it really. So, it was just another thing that I’d got to have done.”

Sandy (trans met amputation) p. 2

Several of the participants, namely, Clive, Albert, Guy, Frank, Alison, Tom, Steve, John, Charles, and Andrew all expressed that they wished for amputation rather than living with a chronic ulceration, which they perceived was of detriment to their quality of life. They were actively involved within the decision making for the amputation to occur, and so had accepted the necessity of the amputation, perceiving this as a positive event.

“The first one with the toe, I was glad to get rid of it, it wasn’t getting better and it went on and on, and as I say, I would have been happier if they had done it the first day, to be honest as it was stopping me doing the things I wanted to do.”

Guy (3rd toe removed, then tips of 2nd 3rd, bone out of 1st amputation) p. 8

“I pressed for it actually. They kept it, but it was dragging on for months and months and months. And it was non-weight bearing the same. I can’t do anything, and after about over a year of not doing anything, I picked a load of weight up and that was pulling me down, even though I’m quite a positive person. I do have days where I am down, so actually I was glad when they did take it off.”

Steve (1st toe amputated) p. 5

Laughing about the Situation

Laughter, making light of the situation and changes was a positive way of being able to openly discuss the amputation. The use of humour enabled the honest sharing of events and changes to life, enabling the truth of the situation to be explored whilst maintaining a positive perspective.

“When I see the doctor and nurses, the nurses say we love to come here because we can have a good laugh and joke and you are not in tears. I think it’s a bit of a waste of time getting like that.”

Louisa (2nd, 3rd, 4th, 5th toes amputated) p. 6

“I’m the worst for making jokes about it, I must admit, I’m one of the worst. We have a bit of a laugh don’t we? Having a laugh at things is my way of dealing with it.”

Tom (1st toe amputated) p. 5

“Don’t worry about talking quite openly, because Steve and I have got a mutual, well we’ve all got a mutual friend, another fellow customer who’s had that done on both feet due to diabetes, but he’s had it done elsewhere, and he’s just been in hospital to have one of his lungs re inflated, lives up the road, so we compare notes. And whilst I’ve been going through all that, Peter’s a recovering bowel cancer patient. So, this is hospital hotel. We have shares in Smith Kline Beecham and Molnlycke and all sorts of things in here.

Peter

I mean really its ok (with reference to talking openly)

Natasha

Do you think that’s been important to share?

Keith

It's kept the bloody place going. It caused... (pointing to Peter) he will talk openly to me about losing half his guts. I talk openly about, the standing joke in here is what good am I to the wife as I'm no good to, you know. I might have sixteen stone to me but only a foot and a half."

Keith (trans met amputation) p. 17

The Importance of a Social Network

This was expressed by all the participants, how vital immediate family and friends were to provide support through the amputation journey. Those who had effective support from their partner, family or friends valued this highly and thought deeply about the consequences if this were not the case and imagined the sense of loss this would leave in their coping during the rehabilitation process and their current quality of life.

"Yes, I think so, I'm a fairly positive person, I'm a social person, I've got lots of friends, do a lot of networking so I am lucky in that respect. Yes, I could understand it if you were a bit of a person who didn't have many friends or hadn't got a good family it could drag you down a bit, but I haven't allowed it to drag me down. I am positive, as I say."

Bob (2nd, 3rd, 4th toes amputation) p. 7

"I think I've accepted it quite well, Harry would say "goodness sake Louisa, you've done wonders" and that boosts me up."

Louisa (2nd, 3rd, 4th 5th toe amputation) p. 12

“So you know, the big thing is if it wasn’t for my brother or the kids, the cost of that, the business wouldn’t bear it at all, and if I was not self-employed, and I was employed, I probably wouldn’t be working. I’d be probably thrown to the state. I’d be a burden to the state, financially and probably house wise or whatever”

Keith (trans met amputation) p. 14

For some, the healthcare team were an integral part of the social network, recurring elements arose in all transcripts concerning the relationship with the healthcare team. Elements included valuing their knowledge and being able to trust this to guide the rehabilitation process.

“There are some lovely doctors, but Prof, she has to be my favourite. I could ask her anything.

Natasha

Do you think that made a difference?

Louisa

Definitely, I wouldn’t have got, I might not have got through it like I have now. But Prof was with me from day one and I could talk to her in a way that I didn’t have to be rude, or she knew exactly what you were talking about. She was so kind, and she’d say, “anything else I’ll be here the day after tomorrow, so write anything down”.”

Louisa (2nd, 3rd, 4th 5th toe amputation) p. 15

“Best specialist you could ever ask for. I mean, Prof as well, been very nice, been very good, and the other consultant is a different sort of doctor, very quiet, and he seems to disappear, consults, and comes back with what his thoughts are. All 3 of them, they’ve been brilliant”

David (3rd, 4th toes and 5th toe and shaft V section amputations) p. 20

“That day I could have kissed the doctor when she said right, we’ll have you walking, we’ll try walking. So, I thought, flipping heck, I could have thrown my arms around her, manna from heaven definitely manna from heaven yes.”

Angela (5th toe amputated) p. 20

Drive to Gain Physical and Emotional Independence

For some finding fault with medical management was used as motivation to regain independence after the amputation. Frank holds anger at the lack of due care and attention which he felt attributed to the amputation occurring, when he moved from one location to another in the country there was a lack of communication between the Trust services. Frank utilised this anger as a coping strategy to drive his determination for self-reliance and self-care.

“I’d been up here a year and a half, and I hadn’t seen anybody properly, which kind of annoyed me a lot, this could have been prevented, well perhaps not, or could have possibly prevented this, anyway. I hold them partly responsible for this happening and for several years I stopped going to my GP, again, idiot. Complete idiot, imbecile. I stopped going to diabetes nurses, I didn’t stop, I simply went in and out. The whole transition things, a. it could have saved me having the amputation in the first place, b. slightly before that the whole process, it may have been saved if after several years of complaining of this severe pain in the legs and barely being able to walk and loss of nearly half of my body weight,

someone might have 'said shall we send him for a scan there might be something wrong?' not make me have scans after they have cut my foot, odd."

Frank (1st toe amputated) p. 8

For Gerry, the lack of contact and health care post amputation led to him undertaking his own care, becoming his own expert.

"You saw the doctor every 3 weeks or every 2 weeks and that was it. Everything else you had to do yourself. There is no one going to come and knock on your door; I'll wrap your foot up and this and that. They do it once and they've had enough. After that, nothing, no actual major care. You do it yourself. I have 56 bandages, 56 pads a month, every month and then you get used to wrapping it up on your own."

Gerry (1st toe amputated) p. 6

For others, they used practical problem solving skills to adjust to mobility changes after the amputation.

"I think the word firefighting is the best, you can't plan, because everything comes on top of you. You basically just, well it's got to be done, but if you do it, you're doing something; and you think, there must be an easier way of doing that. And you adapt"

Keith (trans metatarsal amputation) p. 15

This drive for independence motivated some through their rehabilitation and adjustment to the amputation

“Now I’ve got them (the shoes), and I can get back in the car my independence is back, that’s great. That’s what’s inspired me and kept me going, got me through; because I think if you were sat there watching daytime telly all day you would go round the twist. Nothing against daytime telly for people that like it, but that’s not for us.”

David (3rd, 4th toes and 5th toe and shaft V section amputations) p. 9

Photographs for Self-motivation

Photographs were used by participants to create their own personal record of the events leading to amputation and progress of wound healing post amputation. These images were used to illustrate the amputation experience during the interview process, enabling participants to recall and narrate the key aspects of the experiences. Quite often partners would contribute to this narrative, either by adding to what had been explored, or the participant would clarify aspects of the amputation with them unprompted. The photographs enhanced the reflection upon the amputation experience, post-operative care and enabled the participants to be able to explore their current quality of life at present in contrast to life before amputation. Photographs were a normal aspect of care within the foot clinic, the researcher observed that photographs were taken on a secure measurement device at every appointment and reviewed by the consultant with the patient to discuss either validity of the current management plan or to explore when changes to plans were necessary. This active engagement and discussion enabled participants to have a locus of control over their own health, enabling them to not just be the passive recipient for health care, but to be actively involved and engaged with the foot team.

Patients at the clinic also gave clinicians their phones so that photographs of the foot could be taken for them. These images were shared with partners, immediate family and a wider social network, the sharing of the photographs was an easy way to engage in conversation about the amputation experience.

“David

Keeping a record like this is pretty useful, and you’ve seen the pictures, you know exactly where we’re coming from. We never thought about it at the beginning. We did it just out of curiosity, we’ve got our own personal record of what happened.

Sue

You just look at that when you get fed up. Look how far you’ve come, look at the picture, because he couldn’t see what it looked like. This is what it was, this is it now, and that’s what you’ve got to keep in your head all the time.”

David (3rd, 4th toes and 5th toe, and shaft V section amputated) & Sue p. 23

“I’ve got them here. I’ve got my phone somewhere. You’ve got a date stamp.”

Keith (trans met amputation) p. 11

“I took one 2 weeks ago, when she debrided it and compared it to how it was up till yesterday. I thought, yes it did get narrower, and then I took another one last night before I went to bed. I’ve been at it every day and said oh that’s got smaller.”

Tom (1st toe amputated) p. 29

“Have you seen any photographs of it or anything like that? One of my friends, she’s a podiatrist, now I take pictures of things. I’ll show you before and then I’ll show you after, God I take a lot of pictures, there you go, that’s the toe beforehand, that was the toe after. That is the bit where it all started, it started as a little hole there and grew down that way, that bit healed up and then the two toes got infected whilst I was away, so they took them off.”

Andrew (2nd 3rd met V section amputation) p. 16

Coping Strategies Identified in Participants Purporting a Worsened Quality of Life

From the 28 interviews, there were a minority of participants who attributed a worsened quality of life to the amputation. There were similarities in the coping strategies adopted by these participants; there was a desire to have better mobility to gain independence and widen the social network, however, within the interviews there was little exploration of how to practically achieve this, instead the participants demonstrated a passivity and little adaptation to the amputation. Themes identified in the analysis were grief for the life changes, the participants focussed upon the losses rather than the gains and blamed others for the amputation. Participants expressed they were not involved in the decision about amputation, a passenger to the events that happened to them or that it was a forced choice between amputation or more serious consequences.

Some individuals, such as Annie, struggled to accept the amputation and the subsequent life changes. The focus was upon what had been lost and that quality of life had been diminished. This was despite recollections of the severity of the pain prior to the amputation and vocalising relief that the amputation had happened. There was a focus upon grief for the loss of the body part and grief for loss of previous life, with little progression towards acceptance or adaptation.

“They just kept saying we’ll leave your toes, we’ll leave your toes, and eventually the pain was absolutely excruciating I couldn’t walk. Because I never slept in bed, I sat on the edge of the bed crying all night and then it came to where I didn’t even go to bed for months. I was just lying on the settee. Because crying, I was waking everyone up. The pain you wouldn’t think it in just three toes the pain that I suffered sitting on the edge of the bed. In fact, I did think to myself I’ll chop them off my bloody self. It’s funny isn’t it and when they told me I was having it done I, it could be my foot, I thought oh my god. The only good out of an amputation is you’ve got no pain because the pain I had in my foot, I know I keep repeating myself, that it’s only three toes, but the pain I got from those three toes I couldn’t bear it I’d rather have 10 children. But that went as soon as I went out of the hospital and everything was getting better, I didn’t have pain anymore. So, it wasn’t very nice, I was a bit upset even, you know, losing toes, you know what you like, you like to wear nice shoes and that will never be again obviously.

It’s only three toes I’ve lost but it’s amazing how it does change you. It’s still an amputation, obviously people worse, God bless them, so, I don’t know how they manage. It’s still a big change especially like I said going to work and then you have to pack up work. And you’ve got all your work friends, 28 years is a long time in one job. I sit there and sometimes, everything, it just hits you.”

Annie (3rd, 4th, 5th toes amputated) pp. 10-11

Andrew reflected upon individuals he had seen when visiting for clinical appointments who had not adapted as well as himself,

“There are people, ‘oh I’ve lost my foot I cannot do anything,’ not like me, I couldn’t do that. If you worry about what you have lost instead of finding out what you have gained. They are still grieving for the part that they have lost.”

Andrew (2nd & 3rd metatarsal V section amputation) p. 21

Aspects Negatively Impacting upon Adaptation

Lack of Information to Prepare

In addition to exploring adaptation and coping strategies, thematic analysis exposed there were recurring themes around the ability to be prepared for the amputation and to have an expectation as to the process of healing. There was an unclear rehabilitation pathway, and many were shocked at the time to heal. There was a lack of information given with regards to realistic rehabilitation time scales and an outline of what stages to expect post amputation. This lack of information may have hindered the adaptation process. Angela (21 months), Sandy (still healing over 1 year), David (18 months so far), Frank (18 months) and Gary (3 years) all expressed surprise at the slow rate of healing, and the associated curtailment of their mobility and social life.

“I didn’t realise that I would be so inactive for such a long period well it’s a long time 21 months. It’s just short of 2 years really and I just wasn’t prepared mentally for that period of time where I would be so inactive really.”

Angela (5th toe amputated) p. 22

“I think it’s been the worst thing ever, you know, it’s the recuperation takes, well it has with me, I don’t know about other people, but it’s taken so long for the feet to heal, and then walking.”

Sandy (trans met amputation) p. 3

“David

It might seem like it’s a never-ending journey, which we thought a time or to, is there ever going to be an end to this?

Sue

We went for a check-up, and you said to him, "I'm fed up, I'm really fed up"

David

It was a down day, you get good days and bad days

Sue

And he said at the time "I'll offer you the alternative"

David

And I said what's that then? "Amputation I'll take the whole lot." Thank you very much but I'll pass on that thank you. That was my obvious answer to that one. We've laughed about it since.

Sue

Glad we said no. I think it probably would have healed quicker if they'd done the full amputation

David

Probably would have done, been carrying on the next 6 months' sort of thing

Sue

I think if people are asked which way do you want to go? I would still say the way we've been.

David

The way we've gone is the best way without a doubt, oh yes, you've just got to be prepared for the long slog.

Sue

Nobody tells you how long that is going to be.

David

They can't can they?

Sue

Nobody tells you you're going to lose about 18 months"

Excerpt from interview with David (3rd, 4th toes and 5th toe and shaft of metatarsals amputated) and his wife Sue p. 19

"I just expected to get back to, you know, some normality, quicker than what it has done. I didn't expect it to take as long, and then through not being so well, I wasn't getting fit quickly, not quickly enough for me. I mean, I don't know how long other people take, but it's not been quickly enough for me. When I had the transplant done, I worked at it, and I was quite fit. But I was quite fit before I went in for the transplant, so when I had this operation, I wasn't fit prior to it and I think obviously that has made a difference. I wasn't really poorly or anything, but obviously I was run down."

Sandy (trans met amputation) p. 5

Ted explored that he could have been better prepared for the amputation. By not offering a depth of information prior to the amputation, this eliminated the opportunity for Ted to integrate this into his coping and adaptation to the amputation.

“When I said about the information, I would have thought you would have been able to give a very broad information sheet. If you’re going to have your toes off, you’re going to have problems walking without a doubt. I would say you would need 2-3 sentences for that. The expected issues might be getting on and off vehicles of any calibre – buses, trains, or up steps. Well, it has been for me major, major, and I would imagine the further you get amputated above the ankle you’re either on a peg-leg or you’re on a prosthetic. Not everyone is on a prosthetic, not everyone would get offered one. And then I suppose it’s the rehabilitation and the physiotherapy. It’s not just a case of you have it off and then you’re back walking next week because it doesn’t work like that. I’m talking to the converted here, the knowledgeable, when you speak to other people. Health wise, things like that, I thought a booklet would have assisted.”

Ted (2nd, 3rd, 4th and 5th toes amputated) p. 19

These thoughts were echoed by Frank,

“But, the pre and post op information, well I didn’t even know it was coming off which was a bad start, but even afterwards, wearing that thing for a year and half, the medishoe, no one prepares you for that, no one says well what is going to happen is... (pauses to think)

Natasha

Do you feel like you are left to find your own way?

Frank

Well not really, I'm almost fortnightly in the foot clinic, so you see prof and the consultant and all that and it's kind of ok, but they're individual specialists thathmmmm..... I know they are specialists that fix the end problems sort of things, but I'm thinking of the build up to it, there should be a little more done in the way of informative clinical sessions. It doesn't have to be one on one, somebody like the Prof maybe not, but the next one down at the clinic or here locally, one of the main NHS trusts smaller hospitals. They might say let's have a look at the overall system, in the overall area we've got potentially 15 people who are going to be due for an amputation in the next 2-3 months let get all of them in, lets book this day 2 hours in the church hall, and sit these folks down and tell them what to expect. That's got to be a lot more beneficial to the NHS and the people themselves than the 2 minute one on one with the rushed surgeon or the very rushed consultant."

Frank (1st toe amputated) p. 11

Inconsistent Post-operative Care

On first meeting Frank and Gerry at the foot clinic, they appeared to be challenging patients, at times being angry or exasperated with the care. During the interview process when exploring their experiences of amputation and the consequences of amputation, this was related to lack of individualised care being in place. This led to a need for self-sufficiency and independence, as there was not the necessary level of post-operative care available.

"They don't do anything for you, they wrap you up in 5 lots of stuff like a club foot. Try and get it in a shoe, you cannot get it in. They don't care. End of the day you either do it yourself. Like she was saying, "do you have a nurse?" No the NHS cannot afford to do it. Unless you train yourself to do it. I've got my mother

to do it perfect, so why can't these? Because they don't care, there's no care in it."

Gerry (1st toe amputated) p. 24

"I was doing my own dressings to save time, I got peed off going down to the surgery and waiting for 2 hours, what is the point? Hospital appointments are kept because you are seeing Prof or the other consultant, but the in-between I said, look I can do this better myself, so I ended up doing it myself."

Frank (1st toe amputated) p. 26

For others who accessed community wound care post-operatively there were recurrent themes focused upon lack of consistency of care and the quality of care provided. This demonstrated a systematic need for training within diabetic foot, and potentially improved integration of the acute foot care team with the community provision of wound care. Participants and their families were more familiar with the wound dressings, however, the relationship between health care worker and the patient was not on an equal footing, meaning that at times, although the participants were aware that wound care was not appropriate, they conceded for it to happen. This was associated with unfortunate consequences such as wound deterioration. Clive reflected upon this issue,

"You are vulnerable as a patient, you are putting your trust in somebody else, and you have to be happy to do that and accept their advice"

Clive (5th toe amputated) p. 5

"Gary

So, I mean I never really, well I didn't complain about it, but they got the district nurses to come and put one of the vacuum pumps on, and they could never get it to stick right.

Julie

There was only 1 out of the 5 that they trained to do it, that could do it, and there were 2 older ones one day doing it saying, "we can't get it to do it, we can't get it to do it" and I said, "well it's got to do it otherwise it will beep all day the machine" "it will be alright when the bandages are put on" and I said you can't do it and they did. We went to the hospital the day after, and he was in pain and the consultant said why are you in pain? I think the nurses put it on too tight to stop the machine beeping, and because of the bandaging in his leg he ended up losing the next toe because that was black, because they had basically crushed the supply to his foot, so he lost his toe.

Gary

I could have claimed, they could have turned round and said you were going to lose that toe anyway, so what's the point?"

Julie & Gary (3rd, 4th, 5th toes amputated) p. 5

"Sue

It would be nice to have 3-4 nurses and you would keep to them, they knew what was happening and they dressed it and that. I mean, we had one nurse come from Leicester. She was a nice lady, don't get me wrong, beautiful, nice person, but she just didn't know where to go with it. What to do. We told her how to dress it.

David

In the end we wound up telling 90% how to do it, because the original staff had gone from 10 to next to nothing. I know it's not their fault, but it's no way to go on really."

Sue & David (3rd, 4th and 5th toes and shaft of metatarsals amputated) p. 14

Within this data collection site, there were differing perspectives upon the patient's role within their post amputation wound care. The immediate foot care team empowered patients to be actively involved with their care, undertaking dressing changes between review appointments. This approach and ethos was not reciprocated within other services accessed by participants within the same Trust. The researcher observed health care professionals challenging a participant who undertook their own redressing. Rather than exploring the rationale for self-care, they chose to passively admonish him, potentially causing further disengagement and break down of the relationship with the health care team.

"Gerry

She can't wrap up; did you see what she did yesterday? Four layers, a pad, bandage then a cotton pad, I looked like a footballer.

Nurse

Is it leaking?

Gerry

Yes, it's leaking, why do you want to open it and all?

Nurse

I'm not dressing, are you still with the foot clinic?

Gerry

Yes

Nurse

So, I'm not opening now, I don't want to see. I'm not doing it now, who is doing the dressing?

Gerry

Me, because you lot cannot wrap it.

Nurse

So why are you not trying to get a district nurse? If you are going to the foot clinic, you could ask and get the district nurse. Normally if it's a big dressing the district nurse will do.

Gerry

There isn't a district nurse, there is only me.

Nurse

Did you check with the foot clinic, are they happy about that?

Gerry

Yes.

Nurse

Normally my patients, the dressings are done by the district nurse”

Nurse on Renal Ward & Gerry (1st toe amputation) p. 4

Environmental

Several participants expressed difficulty in gaining support from state systems, for those not at pensionable age Personal Independence Payments (PIP) were difficult to get, and in several cases, appeals were held, and payments backdated 2 years. This lack of monetary support left economic difficulties, forcing some individuals to return to work when not fit, in direct opposition to advice to rest and recuperate from the amputation. The consequences of increased ambulation led to slower healing rates, increased hospital appointments and restrictions to freedom. In addition to lack of access to monetary support, there was little information available as to what could be claimed, this led to partners becoming the unofficial, unpaid carer for their spouse. Lack of support also extended to difficulties in gaining mobility aids, adaptations to housing to assist with maintaining mobility and independence, thereby impacting upon social activities and day-to-day activities.

“You cannot get anything. You are not entitled to anything. If you go and ask, you are entitled to nothing. I’ve had an automatic car for 6 months, all that kind of thing I bought it myself. You cannot get disability aids, cannot get parking help. When you go to the people who do it, “Ahhh, you can walk 10 yards, you do not need to be on disability”. That’s it.”

Gerry (1st toe amputated) p. 23

“I shouldn’t be working, as you know, you can’t live if you don’t work. I’ve put my shoes on and rest at night. I’ve told the Prof this, but she infuriates me, she doesn’t understand she on 100-odd thousand a year and us mere mortals have to earn a living, I’ve got to go to work, and she says it just won’t heal until I rest it.”

Andrew (2nd 3rd met V section amputation) p. 9

“When I went for benefits, they said oh you’ve only lost half a foot (laughs) I paid tax and national insurance for 35 years, ended up going to court to get it. It was terrible, took me over a year just to get sickness benefits. I ended up going to court and the judge didn’t even ask me any questions, just gave me the points I needed, because you have to have so many points, they gave me as many points as I needed just looking at my paperwork. So, that was that. That was terrible that was, struggling, they gave me £43 a week hardship payment. I said you tell me, for 35 years I’ve paid tax and national insurance to get treated like that.”

Sam (trans met amputation) p. 4

“Someone has told me to apply for disability, I just, I’m just in turmoil because I’ve got a mortgage to pay obviously it’s my own house and I don’t want to fall behind and its money worries as well because obviously if I could, I would like to go to work. I’ve worked all my life but there’s no chance because I can do limited walking you know and every job nowadays you’ve got to even on the till you can’t sit down you’ve got to stand. So, it’s definitely changed.”

Annie (3rd, 4th 5th toes amputated) page 3

“She didn’t have hardly no help whatsoever from the social, because I went up to get her money once, and her money had been stopped, and it took 2 years and we ended up at Nottingham at a tribunal and she won her case. Talk about them

being shown up, because they asked us almost immediately to leave the room and we left the room and they went out, come back and the doctor said the case, you've got two years back pay and you know for years and years I wasn't even claiming care, I was just doing it till a nurse told me, but then when I was 65 they stopped my care money."

Albert, Alison's husband (Trans Met amputation) p. 10

"People were saying apply for this, apply for that, apply for the other. We got no help at all. My son is classed as disabled now; he can walk about but he's got learning difficulties. But it was a struggle with him as well as he couldn't understand it. I've never got carers allowance for him; we've done it ourselves. Well, we had the respite care, but no help at all. And what I think is wrong is they even take my lads money into account, which is wrong. People tell you it's separate, but not to them it isn't. And when I retired, they said you can't get carers allowance now because you have retired, and I was sort of caring for two of them because I had him to look after and I'd got my lad. He had to go for a medical in-between sorting his money out, he had to go to a medical. There was a nurse there, she was only a bit of stuff. "Do you want to look at my foot?," no we don't need to look, and because he could walk a bit that was fine, they failed him, just because you can walk. People can't understand what you go through. You've still got to live; you've still got your rent to pay. Now he is on a pension they have stopped my rent and council benefit. Now I'm having to pay full rent which is nearly £100 a week and the council tax which is over £100 pound and that's £200 out of the money already. Good job we've got our bus passes otherwise it's going to cost us a fortune on buses, especially to the hospital it's terrible on the bus."

Marge, married to Charles (2nd toe amputated) p. 9

For Gary, as there was no previous experience with having to access support services, there was no signposting as where to gain assistance, or how to appeal to gain support needed. In Louisa's case, it was by chance that she even knew about support available.

“And you know because he has worked, it was so difficult to know where to go, what to do, what to claim, trying to get hold of a wheelchair, we ended up at the red cross for that it was 22 weeks before a hospital wheelchair. My father-in-law saw one in a charity shop and went and bought it for him so that he could get out of the door.

We put in a claim for disability living allowance and he was totally refused as they said he would be well in 9 months. We went, I went to the social services and this gentleman wrote me this piece out and sent it back and he got the mobility side, but he was given no care. Which we left, I left it at that because I thought that's twice, I've done it now, we've got the mobility and the blue badge. We moved here and in end of 2014 they sent an assessor to him, this is 2 years after the operation, and he's given care and was given care for another 4 years. And I think to myself when he needed the care at the beginning and not to get any crutches, not to get any help for a wheelchair or where we could get them from that was the hard part.

I didn't think there was a lot of support once you'd had it done and out of the hospital you are left to your own devices really. When they refused to say he should have a disability allowance, the consultant came and said I'm fed up of this not being able to get support and she gave you a letter which did help.”

Julie – married to Gary (3rd, 4th, 5th toes amputated) p. 36

Louisa

“With the matron I've got so much to thank her for. We were here, this is going back a few months, talking about things and she said, “what about buses” I told her and said the only other way I can do it; I can only use an ambulance for

hospital, but I said the only other thing is taxi and I'm not being funny, we've not got money to throw to taxis. She said, don't you claim? I thought, claim what? PIP – disability changed to PIP. I've never heard of it, she said, "oh Louisa that's stupid"

Harry

She got straight on the phone and made a few enquiries and started the ball rolling and we got a form sent through. She arranged to come and help fill the form out.

Louisa

I was so lucky because they gave me £400 so that will pay all my taxis and anything else. It's sort of who you know, no one was saying this at the hospital to me, not even other patients.

Harry

You would think they would have a social working in the hospital, wouldn't you?"

Louisa (2nd, 3rd, 4th, 5th toes amputated) & Harry p. 11

Lack of support also led to limitation of mobility, Dianne in social housing was not granted ramps to enable her to safely leave the house due to not fitting assessment criteria. The failure of a criteria limited Dianne's mobility and choice.

"They said they would send somebody to measure up and if it was granted, I passed the criteria, I said, could I have a ramp outside the back door? Because if I go out I have to take my Zimmer frame, and I can just get the Zimmer frame

on the step outside. No, I didn't meet the criteria, I had to be in a wheelchair permanently then they'd give me a ramp. I said, so I can go out of that back door then, stumble and fall and you still won't give me a ramp. No, you don't meet the criteria, we haven't got any money, there's no spare money, and that's all it boils down to is money."

Dianne (4th toe then subsequent 1st toe) p. 16

There was also a shortfall between what the expectations of help would be, and what was available,

"They said they would send somebody, social services. And when they came they said, we've not come to do it, we've come to watch you do it. I said what's the point of coming then? I just need somebody to shove something in the microwave for me. But no, that's not the idea, they come to see if they can give you a few ideas and tips to make life easier. I said well, you might as well not bother then. I said, there's no point in you coming, and I had to stay in hospital until they put that in place. I could have been out a week sooner. They don't help you; they don't help you."

Dianne (4th toe then subsequent 1st toe) p. 15

Ted reflected upon the level of support needed to adapt to the amputation and what was offered,

"Out in the big bad world they are not prepared to give you that support because of the money and the cost situation"

Ted (2nd, 3rd, 4th, 5th toes amputated) page 15

The cases highlight those in need of financial and social support to be able to adapt to changes due to the below ankle amputation found the support systems lacking. The impact of the below ankle amputation did not fit to the pre-determined criteria for gaining support. This lack of access to services was experienced by interview participants regardless of their level of multiple social deprivation. This infers a systemic issue with the benefits system. The lack of support impacted detrimentally upon the ability to adjust to life post amputation and ultimately upon whole quality of life. Figure 9 provides a visual summary of the data analysis and themes which were related to adaptation.

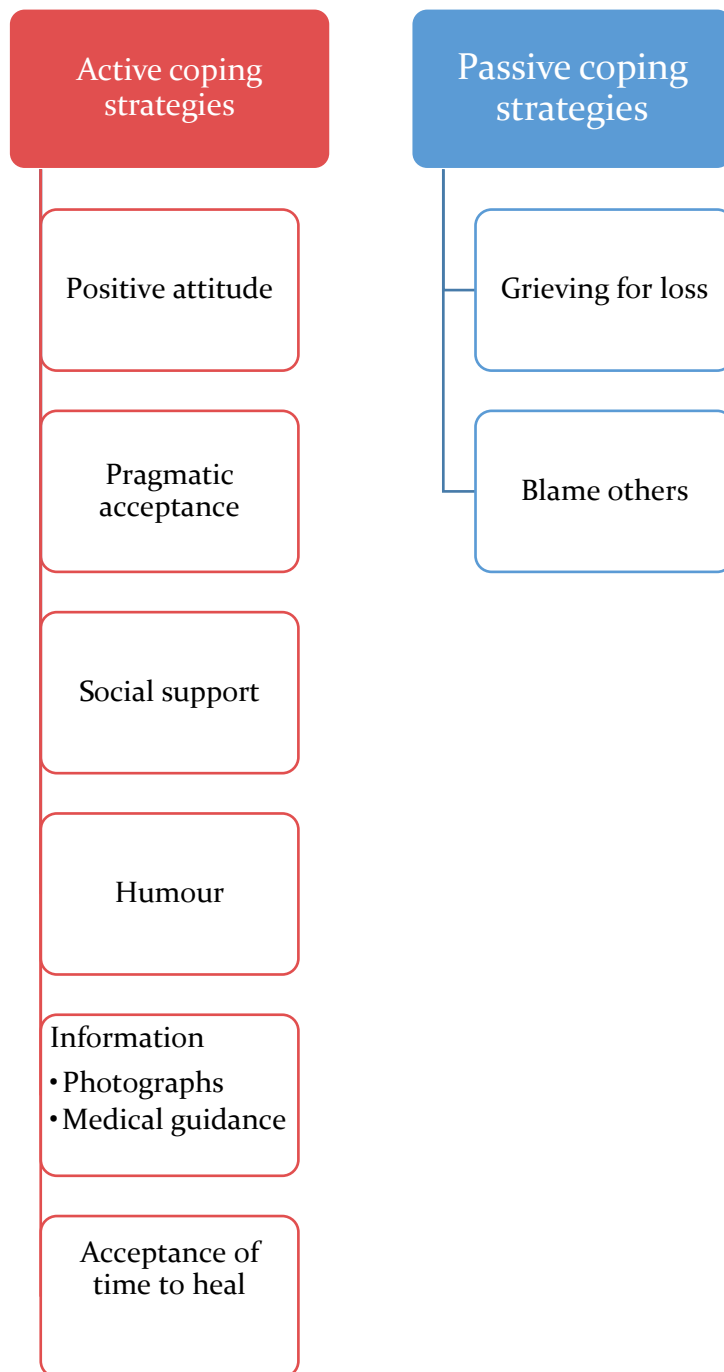


FIGURE 9 ACTIVE AND PASSIVE COPING STRATEGIES UTILISED BY PARTICIPANTS

Discussion of New Knowledge Elicited from Exploring Adaptation and Coping Strategies

“The physical aspects of a disability are much less central to the adaptation process than the psychological, developmental, and social environment and resources of the individual who acquires the disability.” (Rybarczyk et al., 2004 p944)

This findings chapter has explored the experiences of the research participants, focussing upon their acceptance of the need for amputation, and subsequently exploring the coping strategies used to adapt. The concept of pragmatic acceptance in the eventuality of amputation was also found in a study exploring the concerns of 15 patients at risk of below or above ankle amputation with a diabetes associated chronic wound. The physician led questionnaire determined that there was range of responses to the thought of amputation from anxiety and fear to acceptance that it was necessary (Cornell & Meyr, 2018). The Cornell and Meyr pre-amputation study participants expressed most concern over issues relating to changes to mobility – being unable to balance, walk, perform activities and self-sufficiency. However, the causes of concern explored were predetermined by the researcher, giving little opportunity for the participants to express their own personal concerns for life post-amputation and the open-ended questions were focussed upon the immediate effect of amputation, rather than considering adaptation or consequences to quality of life.

The process of acceptance and adaptation via coping is clearly documented within psychology and rehabilitation literature focussed upon chronic illness and disability. Amputation being defined within this sphere as an acquired chronic illness or disability (Livneh & Antonak, 2005). Literature exploring reaction to amputation identified immediate responses of stress, crisis and grief for the loss of the body part. The longer term responses were denial, wishing for immediate

recovery, depression when the reality of the situation was realised, anger couched as self-blame for the amputation or anger directed at poor medical care and lack of support services. Adjustment was identified as a reconciliation to the amputation and its consequences and adapting by utilising a range of coping strategies (Livneh & Antonak, 2005; Livneh et al., 2000; Martz & Livneh, 2016). The research explored within this thesis was focussed upon participants who had undergone amputation and their current quality of life, so the experiential data derived from the interviews was focussed not on the immediate reaction to the thought of amputation, but rather upon post amputation experiences and the successful or unsuccessful adjustment to life after. As such, the findings presented within the thesis are explored within the context of literature pertaining to coping strategies and adaptation to amputation.

A range of coping strategies were utilised throughout the adaptation process. These strategies have been named and conceptually defined in a manner of ways by researchers, Lazarus and Folkman (1984b) provided a catalyst for researchers exploring coping strategies and adopted the terms of emotion and problem focused coping strategies. Emotional coping strategies were employed to reduce the distress of a situation, whilst problem focussed strategies actively dealt with the changes because of amputation. The development of this work led to the design and publication of the Ways of Coping Questionnaire, focussed around 8 factors conceptualising coping strategies, which were titled positive reappraisal, problem solving, seeking social support, self-controlling, accepting responsibility, confrontative coping, distancing and escape avoidance (Folkman et al., 1986).

Within the current research, some participants chose to heighten the emotion of the situation, they attributed the amputation to their previous lack of self-care, accepting personal responsibility as a driver to adapt and regain independence. Other emotional strategies used by participants lowered the emotional distress of the situation. They reached out for social support, shared the amputation experience, and gained emotional and practical support during the adaptation process. Practical measures utilised by participants in this research included

awareness of changes amputation had made to their to life and undertaking practical problem solving to resolve the situation, or if the circumstances could not be altered, to cope by reappraising from a differing perspective. These techniques can be seen to reflect the coping strategies suggested by Lazarus and Folkman (1984a). However, since publication of this questionnaire other authors have built upon this work, below is a brief synopsis and then exploration as to how the findings of this research would map against 3 published coping strategy conceptualisations.

Carver (1997) developed the COPE measure and Brief COPE measure (coping orientation to problems experienced) which benchmarked coping strategies the individual held per se. The measure was developed to assist in determining adaptive or maladaptive strategies used by an individual. The factors measured were active coping, planning, suppression of competing activities, positive reinterpretation, acceptance, religion, social support to gain emotional support, social support to gain instrumental support, self-distraction, denial, venting, substance use, mental disengagement, and self-blame. The measure has been used widely within health research.

Work by Skinner and Edge (2003) recognised that coping strategies were multifaceted and could be simultaneously emotionally and physically driven. Following critical review of 100 published assessments of coping a new set of 13 distinctly defined core coping themes were developed. The coping themes were problem solving, support seeking, escape, distraction, cognitive restructuring, rumination, helplessness, social withdrawal, emotional regulation, information seeking negotiation, opposition, delegation, and self-pity.

The choice of words may differ between these 3 coping conceptualisations, however, there are similarities between them. Whether the coping style is described as emotional or physical, positive or negative, adaptive or maladaptive strategies, active or passive, research focussed upon below knee amputation has identified that coping strategies which enable acceptance and

adaptation result in higher levels of social integration and life satisfaction (Desmond & MacLachlan, 2006; Dunne et al., 2014; Oaksford et al., 2005; Perreira et al., 2018; Phelps et al., 2008; Wilson et al., 2021). The range of strategies adopted by participants from this research are resonant with the theories of coping outlined above. For clarity, the coping strategies identified within this research are mapped against the coping strategies outlined by Folkman and Lazarus, Carver, and Skinner and Edge within Table 11. In Table 12 consideration is given to the factors identified in the research as being a potential block to coping and adaptation, the coping strategies which have been blocked because of deficits in social care and benefit provision are documented, and additionally the potential consequences of this are suggested.

TABLE II MAPPING COPING STRATEGIES IDENTIFIED IN THIS RESEARCH TO PUBLISHED FRAMEWORKS FOR COPING AND ADAPTION

Coping strategies identified in this research	Emotional and Physical Coping Strategies (Adapted from Folkman & Lazarus 1986)	Brief COPE scale factors (Adapted from Carver 1997)	Coping Families (Adapted from Skinner & Edge 2003)
Determination to have a positive mental attitude	Positive reappraisal	Positive reinterpretation & growth	Cognitive restructuring Positive thinking Self-encouragement
Drive to regain physical and emotional independence	Planful Problem Solving	Active coping & Planning	Problem-solving Decision making Planning Direct action Instrumental action
Pragmatic acceptance	Accepting responsibility	Acceptance	Distraction Acceptance

Coping strategies identified in this research	Emotional and Physical Coping Strategies (Adapted from Folkman & Lazarus 1986)	Brief COPE scale factors (Adapted from Carver 1997)	Coping Families (Adapted from Skinner & Edge 2003)
Social network Aka relationships with friends, family, partner, & medical team	Seeking social support	Emotional Support Instrumental Support	Support-seeking Comfort Help
Photographs	Planful- problem solving	Planning & Suppression of competing activities	Information seeking Observation Monitoring
Compare self as more fortunate than others	Positive reappraisal	Positive Reinterpretation	Accommodation
Laugh about the changes	Distancing	Emotional support Acceptance	Cognitive restructuring Positive thinking Self-encouragement

Coping strategies identified in this research	Emotional and Physical Coping Strategies (Adapted from Folkman & Lazarus 1986)	Brief COPE scale factors (Adapted from Carver 1997)	Coping Families (Adapted from Skinner & Edge 2003)
Anger at lapses in quality of care	Escape- Avoidance	Venting	Opposition Aggression Blame others
Grief for loss of body	Escape avoidance	Behavioural Disengagement	Rumination, Self-pity Helplessness
Not involved in the decision about amputation	Escape-Avoidance	Behavioural Disengagement	Opposition Aggression Blame others
Happened to them – a forced choice	Escape-Avoidance	Focus on emotions	Helplessness Inaction, passivity Giving up

TABLE 12 IMPACT OF ASPECTS IDENTIFIED AS NEGATIVELY IMPACTING UPON ADAPTATION

Elements hampering adaptation	Emotional and Physical Coping Strategies (Adapted from Folkman & Lazarus 1986)	Brief COPE scale factors (Adapted from Carver 1997)	Coping Families (Adapted from Skinner & Edge 2003)
Lack of information to prepare, inconsistent care, difficulty in gaining benefit and social support	<p>Impacting upon problem solving and accepting responsibility and positive reappraisal.</p> <p>Could result in Escape Avoidance and Self-controlling</p>	<p>Impacting upon Instrumental support, active coping, planning & suppression of competing activities</p> <p>Could lead to behavioural disengagement</p>	<p>Impacting upon problem solving and support seeking.</p> <p>Could lead to helplessness and opposition</p>

It is clear, regardless of which of these conceptualisations of coping is accepted and adopted, new knowledge has been presented here exploring the experiences of those with below ankle amputation. This study has determined that there were multiple responses to amputation – anxiety or relief that amputation had occurred, grief for loss of the body part, adjustment, acceptance of changes to self-identity and adaptation to this. Some seemed to be stuck in grief, focussed upon the loss of body part, and the losses they perceived this had brought to their previous quality of life. Other participants expressed they wanted to move forwards and adopted coping strategies to achieve this. The active strategies associated with no detriment to quality of life included determination to have a positive attitude to amputation, comparing self as more fortunate than others both emotionally and physically - using this as a driver to gain physical and emotional independence, pragmatic acceptance of the amputation, using the social network to support them, using photographs to share the experience or to motivate themselves throughout the wound healing process and using humour to be able to express their emotional response to the amputation. These strategies are well documented within chronic illness or disability literature, but never for those with below ankle amputation.

Discussion of New Knowledge Exploring Aspects Negatively Impacting upon Adaptation.

As explored above, this research has identified that there were barriers to successful adaptation, namely lack of information to prepare for amputation, inconsistent post-operative care, and lack of social and benefit system support. Focussing upon information and education provided pre-amputation, only one piece of research has explored preparedness for rehabilitation for those undergoing below ankle amputation, and the results concur with this study, lack of information is of detriment to coping and adaptation. The study by Dillon, Anderson, et al.

(2020) explored the experiences of 10 individuals who had below ankle amputation and subsequent transtibial amputation in Australia. The study concluded that for below ankle amputation there was a lack of information regarding the procedure, potential risks, and the rehabilitation journey. Conversely, structured systems were present for transtibial amputations, participants accessed health professional education and peer support, thereby enabling the individuals to be prepared and utilise a wider range of coping strategies to adapt to amputation. Dillon, Anderson, et al. (2020) concluded that structured systems should be in place for below ankle amputation to aid adaptation.

Until this research, no studies have explored the experiences of below ankle amputation within the British Isles, studies have focused upon diabetes related above ankle amputation. Research by Ostler et al. (2014) and Delea et al. (2015) found education and emotional support was lacking for participants within the respective studies, despite having recruited individuals from prosthesis rehabilitation units, who should arguably have had a more formalised rehabilitation structure than those with a below ankle amputation if guidelines and recommendations were successfully implemented (British Society of Rehabilitation Medicine, 2003, 2018; National Confidential Enquiry into Patient Outcome and Death [NCEPOD], 2014).

Ostler et al. (2014) explored with 8 individuals their expectation of rehabilitation 2 weeks after they had undergone transfemoral or transtibial amputation in England. Through semi-structured interviews and thematic analysis, the study found a similarity with this research that those with a lack of information pre-amputation had little idea of what to expect for rehabilitation post-amputation. Participants within Ostler et al's. study had unclear rehabilitation expectations, and were focussed upon a return to normality, rather than adaptation to the amputation. The study concluded that more discussion pre and post amputation was necessary to enable patients to be engaged with active coping.

A study undertaken In the Republic of Ireland also confirmed a lack of standardised information to guide an individual through the rehabilitation process, potentially impacting upon successful adaptation. Delea et al. (2015) study explored the experiences of 10 individuals who were in receipt of free medical treatment via the medical card, 9 of whom had an above ankle diabetes related amputation, one who had a current foot ulceration. Despite participants stating that education for rehabilitation was vital, the reality demonstrated the level of education varied, from participants who considered themselves 'expert patients' and were confident with self-care to those who had little knowledge or confidence for their care. Delea et al. concluded that rehabilitation services needed to provide support to enable patients to successfully adjust to the amputation both psychologically and physically.

There is a clear theme that those who have undergone amputation require more educational input and psychological support to adapt successfully to life post amputation. As the research above identifies, within the British Isles, there is lack of support for those with above ankle amputation despite clear guidelines and recommendations emphasising the need for psychologist or councillor support pre and post amputation (British Society of Rehabilitation Medicine, 2018). Integration within current rehabilitation systems, as proposed by Dillon, Anderson, et al. (2020) would still be insufficient to give optimal support. The findings of this research and the studies outlined above lead naturally to questioning the implementation of current guidance in place for supporting lower limb amputation and demonstrate the importance of the new knowledge derived from this research project which adds confirmation with regards to the limitations of the support provided. The current research adds new knowledge for those who have experienced below ankle amputation who are likely to fall outside of the structures of the prosthetics rehabilitation units, as the majority of below ankle amputees will not have prosthesis, rather custom made orthoses and footwear (Crowe et al., 2019). The research outlined above, and the results of the current research should act as a driver for

improvement to provide adequate educational and emotional support necessary for successful adaptation and limitation of impact to quality of life.

Inconsistencies with post-operative care, including the provision of benefit and social support all acted as blocks to the adaptation process. As illuminated above, these circumstances were experienced by a wide range of participants, regardless of their societal background. Those unable to work during the healing process experienced difficulties in gaining financial support. Those with families became reluctantly reliant on spouses or immediate family for physical care, due to difficulties in provision of this by the care system. All these aspects impact negatively upon coping strategies, adaptation, self-identity and ultimately quality of life.

Amputation resulting in detrimental change to personal economic situation and lack of effective support has been identified in previous research. A study exploring the experiences of 10 individuals with varying levels of lower limb amputation in Ghana identified participants were unable to continue with physically demanding jobs and were then reliant upon other family members for financial support and self-care. This negatively impacted upon coping and subsequent quality of life. Participants perceived themselves as a burden to the family rather than supporting it (Amoah et al., 2018). A qualitative study in Singapore of 9 individuals who had undergone below ankle amputation in the 12 months prior to the study identified that individuals were unable to fulfil previous employment rolls, were concerned about the financial burden they now had become due to the costs of medical care and were reliant upon immediate family for physical and social care (Zhu et al., 2020). A later USA-based qualitative study of 15 participants with either ulceration or amputation also identified the challenges of slow to heal below ankle amputation. Participants expressed the inability to weight bear for 18 months had social and economic consequences. People were unable to maintain employment and complete their normal duties, the consequences of which were financial difficulties, increased emotional distress and reliance upon family members (Crocker et al., 2021).

This findings chapter has explored the importance of adaptation, and the coping strategies successfully utilised to accept and adjust to life post amputation. The chapter has also highlighted avoidance strategies which have hindered adaptation. The blocks to successful adaptation such as lack of pre-operative information regarding time to heal or the rehabilitation process, inconsistent post-operative care, and difficulties in accessing and gaining social and financial support have been presented. In conclusion, these barriers are harmful to both adaption and quality of life.

Chapter 6 will present new knowledge exploring the impact of diabetes related below ankle amputation upon quality of life. The chapter will explore factors which are perceived by the participants as important to quality of life. The new knowledge presented within Chapters 5 and 6 is integrated within Chapter 7, and a conceptual framework for quality of life for diabetes related below ankle amputation is presented, incorporating the importance of adaptation to quality of life.

Chapter 6: Findings on Understanding the impact of amputation upon Quality of Life

Introduction to Impact of Amputation Findings

The previous findings chapter explored the experience of adaptation to amputation, discussing the impact of using active and passive coping strategies to accept and adapt. Those able to use a range of active coping styles, such as adopting a positive attitude, using a wide social network for support, deriving knowledge to assist with understanding the process of rehabilitation; accepted the amputation had happened and adapted. Successful adaptation resulted in a positive attitude to quality of life post amputation.

Those who adopted strategies such as denial, being passive within the amputation experience, disengaged within the decision making for the amputation, were focussed upon the losses caused by the amputation and the subsequent healing and rehabilitation process. They did not adjust well, even after healing was achieved, and elucidated a poorer quality of life because of the below ankle amputation.

This findings chapter is focussed upon exploring the new knowledge derived from the analysis of the rich interview data indicating the impact of amputation upon quality of life. The presentation of this data will illuminate what factors are perceived to be important to quality of life for individuals who have undergone a below ankle amputation. Chapter 7 draws the two findings chapters together and a summary of the new knowledge is presented as a conceptual framework of quality of life for individuals with below ankle amputation.

Self-identity

Analysis of the data revealed many themes identified as being important to quality life related to self-identity, these were:

- ♦ Physicality
- ♦ Emotional identity
- ♦ Economic identity
- ♦ Body image
- ♦ Dignity, Pride, Persona

Figure 10 below presents what themes were identified as being important to self-identity and the boxes below each theme heading explore the potential impact of these issues expressed by participants within the individual interviews. These aspects are explored overleaf.

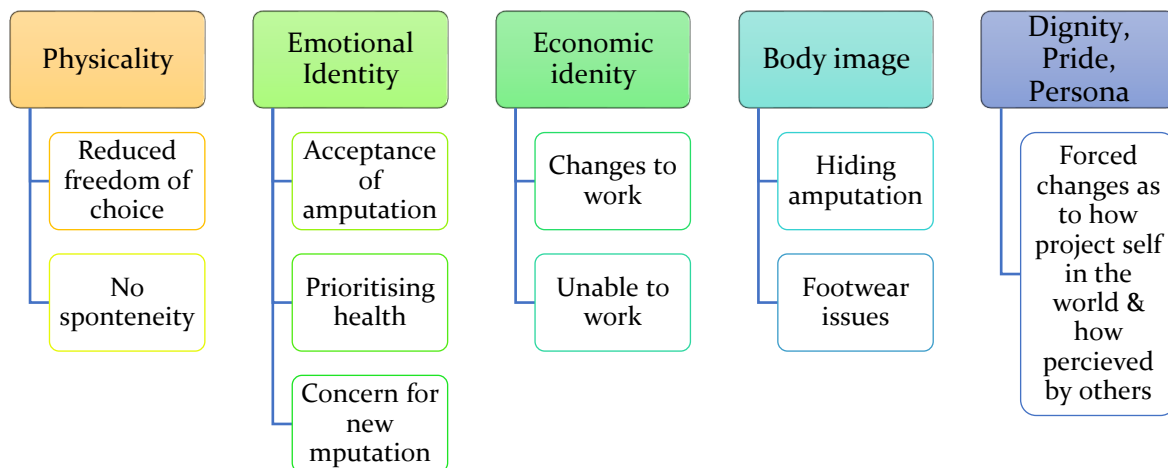


FIGURE 10 COMPONENTS OF SELF-IDENTITY AND HOW THIS COULD IMPACT ON QOL

Physicality

Mobility was explored by participants, not just for the physical act of exercise, but also for the alterations this made to work and social life choices, understandably this had emotional impact for some. Reflections on changes to mobility were clearly delineated into limitation during the rehabilitation process, or the long-term consequences to mobility when amputation had healed. Recurrent elements centred upon the reliance of walking aids, mobility scooter, motorbike, or car to resolve issues attributed to the amputation such as poor balance, limited walking, unable to stand for prolonged periods or alterations to walking style.

“It’s been difficult, because when I was coming down here for the best part of 6 or 7 weeks or however long it was with that. I had a Zimmer frame, all that was bandaged, I couldn’t put it to the floor. It didn’t have a shoe on it or anything, I was hopping on a Zimmer frame. I couldn’t have crutches and do that because I was attached to the vac, and I’d got to carry it with me. I couldn’t disconnect it to you know, go anywhere and I was connected.

Going back to 6 years ago when I had the amputation, when I came out, I was, when I first had the prosthetic shoes, it was no problem at all. But I think progressively my walking structure, stance, call it what you like, altered. I now walk slightly like that (twisted).”

Keith (Trans metatarsal amputation) p. 13

“I’ve got a stick permanently now. I go upstairs with the stick. I run a little nursery which is on the level, but I have got a bit of a ramp. Even with a ramp you’ve got to remember which is your good foot, as you’re not on the level your feet are a bit twisted.”

Ted (2nd, 3rd, 4th, 5th Toes amputated) p. 9

“I don’t walk very steadily. I do have a walking stick, I have more than one, but I only use it if I’m on my own and I am needing just the reassurance or the support, or I might need an umbrella, as I’ve got a stick with an umbrella on, because normally I find relying on the stick does not help me to try to walk properly, and that is what I do try to do, but I have to do like the Queen does and walk with my legs apart a bit. She walks as if she has just got off a horse doesn’t she, but very steadily. She wears nice little Cuban heels, which I cannot do, I’m wearing flat shoes all the time.”

Judy (2nd toe amputated) p. 6

“Loads of difference, its ruined my life really. I can’t work no more because I’m a scaffolder, I lose my balance. The balance on my right side now is terrible, do you know what I mean, I keep falling downstairs actually. When you trip up, something like that, you go for your toes to steady you, but I haven’t got them on my right side now, so my right side goes, do you know what I mean?”

Sam (Trans metatarsal amputation) p. 2

“Having no big toe effects your balance. You tend to lean forwards somehow. You don’t but you feel like you are leaning forward all the time, so that was a bit strange”

Tom (1st toe amputated) p. 4

“When you lose your toes, you lose your balance. When you lose your toes, your balance goes. Went out of the window.”

Derek (3rd, 4th, 5th trans metatarsal amputation) p. 12

“The only way I can get about really is by using my motorcycle. To come up here I had to come on my motorcycle and get one of these buggies to bring me up to the clinic. Yes, like last week, we went on the ride to the wall, where the bike was parked to the actual monument you had to walk to get to it and I couldn’t do it. I got halfway up the road and that was it I went back to my bike and came home. I go up to my friend’s house once a week to have a chat and that and whatever. I can ride up to his house on my bike, park the bike outside and it’s only a short walk to his front door. I’m alright-ish on short distances. If I’ve got to walk so far, and I’ve got to carry stuff as well, it’s impossible at the minute.”

Albert (2nd toe amputated) pp. 1 & 3

Mobility impacting freedom of choice

In addition to the physical aspect of ambulating, standing, or driving, this reduced mobility also had consequences for some to freedom of choice, ability to socialise or participate within activities which were part of normal life prior to the below ankle amputation. Sandy, a trans metatarsal amputee was unable to visit her favourite restaurant due to the access, others lamented the loss of ability to drive and the curtailment of their independence, and the necessity of relying upon others.

“I can get about at home, but I then have to sit down because I’ve not got enough strength at the moment. So, at the moment, my husband is taking me out, maybe in the park and I walk hanging on to the wheelchair trying to get more strength, things like that. But, yes it has been difficult, that type of thing you know when you are used to being quite active, and then you are stuck in a wheelchair and everybody’s doing everything for you. You are not doing your housework yourself, and you’re not doing, basically what you want to do yourself and you are relying on everybody else.

Yes, when you've been quite an independent person, you know, I've gone out, had my own car and I've gone out meeting friends for lunch and what have you, oh my husband will take me, but I want to do that myself. That's taken his time up as well. So, I have gone and met friends and what have you, or they come and see me, but it's taken that independence, I'm not driving."

Sandy (trans met amputation) pp. 3 & 4

"Do I think the amputation's have changed, me? Oh, there's loads you can't do, loads, but then I just say as I was coming down into town, they were on about going into town the girls were and Sally was on about Primark and I said oh I used to go in Primark every Friday, I did when I was in town, and I did every Friday, I can't go in now, it's too much bother, it's such a performance to get yourself into town it really is."

Alison (trans met amputation) p. 8

"I don't rely on a stick as such, but I always take it with me. When we're in, say, crowded places like town for instance, big shopping areas, I've always got the stick. It's always folded up in the bag but it's there if I need it... yes, yes, it, yes it has changed me I won't say it's not, it has."

Angela (5th Toe amputated) p. 12

"It's changed a lot, it hampered me in doing pretty much everything. You don't go out, I used to love dancing, believe it or not, I don't go out. I can't get on with the garden. I got rid of my big camper van because it was too heavy for me to throw about. I have dropped down again to 7 stone something. I couldn't do the gear change, so I've got a little automatic car, I'm hampered with that. The gardening, I've not been able to do a deal of anything out there. This year I will though."

Frank (1st toe amputated) p. 19

“I miss a car, I know it sounds daft, but I really do miss a car. Because now, you know, you are registered disabled and whatever, and Harry is my carer. The only time I go out from here is to go to the hospital by ambulance, and I’ve been in this room 4 years, just sitting looking out of the window. Harry got me a computer so I could play my games on it, but when I think I was going to do such a lot when I got home.”

Louisa (2nd, 3rd, 4th, 5th toes amputated) p. 7

“I was happy always out going, things stop now I can’t do nothing till my partner comes home, because obviously he drives so he puts the chair in the back. My friends come to see me, and we’ll get a taxi and go and get something to eat but I used to always go to their house or have them come to me and like you say that’s all changed. People have to push me in a wheelchair, or my partner would rather take me my wheelchair when we go shopping. You can’t even enjoy shopping really because he’s pushing me around and you can’t have a good look around shopping, clothes shopping like women like to do, and I’m being pushed around and I think I would love to walk so I could browse and have a look.”

Annie (3rd, 4th, 5th toes amputated) p. 6

Loss of spontaneity

The changes to mobility also led to changes to lifestyle. Keith, Louisa, Tom, Sandy, David, Alison, and Ted all expressed that there were no impromptu social events, social activities that were automatically done prior to the amputation required planning.

“You are double, treble thinking when you go to walk. It is more planning in your head as it’s happening, its instantaneous. When I’m walking, I can do a, b, c. It’s common sense really.”

Ted (2nd, 3rd, 4th, 5th Toes amputated) p. 11

“Hell of a difference, you could do things, we could just say “oh we’ll go to this, we’ll go to that.” Now you’ve got to think, hang on, can we get a wheelchair, are we going in our car or whatever, is there a wheelchair there? You’re thinking doubly of what’s available at the other end before you even set out.”

David (3rd, 4th toes and 5th toe and shaft V section amputations) p. 8

“You are doing different things to what you would have done before without thinking. You’ve got to think about it, and plan it out rather than, you know, ring up and book a table and go. Yes, you’ve got to think about places and the access. I would have never thought about that prior to my having to be in the wheelchair, I would have thought everywhere wheelchair accessible now, but it’s not always as easy. I feel quite sorry for some people in wheelchairs who haven’t got the support that I’ve had as they must find it difficult. You just compromise round it don’t you? Well, you’ve got no choice, you either compromise round it or don’t do it, and that’s not me. I think you’ve to be like that, you’ve got to compromise round it otherwise you, again, you would just sit at home and get depressed, and I wouldn’t want to do that.”

Sandy (trans metatarsal amputation) p. 19

Mobility caused no negative change to Quality of Life

For individuals who had accepted and adapted to the amputation, change to mobility did not necessarily result in a negative impact on quality of life, this was irrespective of the level of amputation undertaken. For Andrew, Rowan, Guy, Clive, and Dianne (for her first amputation), once the amputation had resolved there was little impact.

“No, no, I mean I’ve walked in excess of 30 miles, that was what I did, I went to the point I wouldn’t consider going out unless I was doing 20 plus.”

Guy (3rd toe removed, then tips of 2nd 3rd, bone out of 1st amputated) p. 4

“Quite honestly, it’s a foot, you can get a false foot and carry on living just normal. It’s just one of them things it doesn’t bother me.”

Andrew (2nd 3rd met V section amputation) p. 12

“And then, as I say, all of this happened. Once I’d had that big toe, I was still driving, I was still going out and about. My balance was terrible. I had to have a walking stick; if there was somebody with me, I could put my arm in theirs and walk along that way, but if I was on my own it was like I was drunk. I just could not walk in a straight line. I was just so unsteady it makes such a difference. But, again, I was positive, I still drove, I still continued, did all my ironing washing, cooking, cleaning, lived a normal life.”

Dianne (4th toe then subsequent 1st toe amputated) p. 8

“Now it’s healed, what are things like now? A lot better, a lot, lot better. I can do most things, obviously I mean I can’t run for a bus because I’ve got this. But in the ordinary way we’ll get up on the canal on a Sunday morning have a good long

walk and I can walk for, usually I can walk for miles. It's good but we can sort of get back to what normal is for me and for Ken."

Angela (5th toe amputated) p. 17

"I couldn't walk a long way before the amputation, no. Sit down, find a seat, you know the routine. But it was still nice to go out, go where you want, see what you want to see, get your bum down then carry on. I can't walk far now obviously, because you think about it when you're sitting there for 18 months or whatever it is your leg muscles gone to pieces. It's a long walk from the front room to the door and back again. Without a wheelchair we'd be lost. Got to take that, but if that's there, I've got my freedom to a degree. Happy with that."

David (3rd, 4th toes and 5th toe and shaft V section amputations) p. 12

"Life never alters, it stays the same. I go shooting at weekends, when I can get out, I go shooting, make platforms in trees, shooting rabbits all day. That kind of stuff."

Gerry (1st toe amputated) p. 2

Emotional Identity

The emotional impact of amputation could be considered in both a positive and negative light. Gary and Ted summarised that there was widespread impact to self-identity that went beyond the mere physicality of the amputation itself.

“The hardest judgement is not being able to do owt. It affects you physically and mentally, it’s not just having your toes off, is it? It’s what it does to you as a person.”

Gary (3rd, 4th, 5th toes amputated) p. 47

“Ted

You’re not prepared for anything like that and its only minor. I’m not complaining, I see, I deal with army lads – arms, legs, two legs blown off, blinded, I only had 4 toes off, and luckily, my spoilt quality of life, to me, its major, but in the bloody atmosphere it’s like having a tooth out.

Natasha

Personal is always personal. You can look at someone else but that’s not you or your life, is it?

Ted

Without a doubt. It’s not my mind set at present and its 2 ½ years ago, it’s not just like it’s the last month, I’ve had time to think about it. At the present, you push it to the back of the mind, but you do think about it. At certain times, I don’t know, like I say there are people who are a hell of a lot worse. So, I don’t know if the people who are worse if their thoughts are worse than what I’ve got. Are their thoughts multiplied up with the severity?”

Ted (2nd, 3rd, 4th, 5th Toes amputated) p. 15

For some the amputation experience led to reflection and reprioritisation of what was important to their quality of life. For Clive, a partner in a private medical care business, there was pressure to focus upon returning to work from the practice partners. He reflected that his priorities prior to the amputation were on providing financial support to his children. During the process of the amputation there was a shift of focus for Clive, towards looking after himself.

“I look to myself and think I haven’t looked after my diabetes well enough to prevent me having those complications. I’m the sort of person who when something goes wrong the first thing I think is what could you have done differently? So, I beat myself up a bit about that, but I’m now reconciled to the fact that we’re in this position, that this has happened, and we’ve got to move forward from it. So, I’m in a better frame of mind now I think than I was before, it’s just a shame that it’s taken something so extreme, perhaps, to give me the wakeup call. I realise now I need to take more care of myself, but I think I’ve ended up in this position for the right reasons, does that make any sort of sense? In terms that I’ve felt that I’ve responsibilities that I’ve allowed to outweigh my diabetic control, and this has happened.

Although my life is still my life, I still have the same parameters, it definitely gives you a different perspective. How do I feel differently? It’s motivated me more to take more care of myself, that’s the simple answer to that question.”

Clive (5th toe amputated) pp. 2 & 9

Focussing upon health became a priority for others following amputation. The amputation led to Bob prioritising weight loss to prevent future complications.

“I’m going to slimming world and weight is dropping off every week. I’ve got a target initially of 16 stone and to be able to get a wedding suit on I wore at a wedding 12 years ago. If you’d seen me in June when I was 20 stone, and I’m 17 stone 6 now, so, it does make a difference when you think how many bags of sugar that it. I’ve always been big, my nickname is Chunky, and to be honest with you I’ve had diabetes since I was 40, it’s the same old story, I went to a well persons’ clinic, found sugar in my urine, started off just on diet, didn’t really go on a diet, didn’t really treat it seriously enough, then went on to tablets, metformin, not sure what else I was on another tablet. It’s only since I’ve gone on this diet, and you’re talking 20 odd years, it’s took me 20 years to realise that I really ought to lose some weight and I ought to take my diabetes a lot more seriously.

Obviously, I’ve lost 3 toes, but people have lost far more parts of their body than that so I’m quite philosophical about it, I just hope nothing else, because you do hear. I’ve bumped into a couple of people in hospital and get talking and they say, “that’s how I started and now I’ve lost mine to the knee”. That’s the last thing you want to hear when you have had 3 toes off, but touch wood, I’ve had nothing else, no issues going wrong apart from these ulcers.”

Bob (2nd, 3rd, 4th toes amputated) pp. 10 & 12

For Angela, for her quality of life there was importance given to controlling other aspects of her diabetes in addition to her weight.

“Maintaining weight for diabetes. I’m not on insulin I don’t depend on insulin I’m doing it through medication and diet, and I think the last time I went to my doctor, he’s the diabetic doctor down at the surgery, Dr came in and said, ‘how do you feel, like, on the tablet’s you’re taking?’ Well, I said I think I’m coping very well. He said right we’ll have a look at your bloods last time, he said, I’ll tell you now they were six one he said below that you’re borderline diabetic. If it drops to 5.9 it’s super, you’re really doing well. And I thought that’s good to

know, and he said your kidneys are alright there are no ketones and all this that and the other.”

Angela (5th toe amputated) p. 8

For others, the amputation experience led to concern for a future amputation occurring. For some, as illustrated above, there was a priority given to improving health and optimising control of medical conditions. For others, fear of recurrence of ulceration and subsequent amputation led to choosing to reduce social and physical activity, an intentional change to previous lifestyle to preserve life as it currently stood, so there was no deterioration. David placed personally set limits on his activity levels due to concern for relapsing progress made.

“I’ve got there now virtually, there’s no point mucking this up, I’ve just got to be that little bit patient again. And now it’s at that stage, I don’t want to muck things up as you can imagine. Well, I’m not going to do that just yet, 10 minutes with these and so on. When I get to about 1 ½ or a couple of hours in them then I will go to the next bit, jump in the car, and see what happens. But I do try the doctor’s advice, try driving with that foot.”

David (3rd, 4th toes and 5th toe, and shaft V section amputated) p. 8

“I can’t even kick a ball round I daren’t. If I can get a blister on the end of this toe when I don’t know how I’ve done it..... And then it makes you frightened, if I go out walking am I going to get another one?”

Gary (3rd, 4th, 5th toes amputated) p. 39

“Before I used to go to sporting venues, now I’m very apprehensive about it. If you go to a football ground or a cricket ground you’ve got to walk down steps.

Now some places it's a normal step it doesn't create any problems, you go to somewhere that's got a 6-inch step, major problems. A lot of it might be in the head. Difficult on steps. I wasn't one to get buses, but I got a hell of a lot of trains. Major, major problems in the head. You always feel as though everyone is in that much of a rush these days, even if you've got a blind stick people push past you. Just apprehensive that's what it is. Getting into cars, when I used to drive, which foot do you put into the driving place first? The left? It's just in the head, a lot of it is in the head but it does create problems with you. You just block it out, you don't think a great lot about how, why, you just get from day to day to day. That's about the worst, potential harm."

Ted (2nd, 3rd, 4th, 5th Toes amputated) p. 12

Economic Identity

Some participants explored the impact of amputation upon their own identity, the consequence of the physical alteration led some participants to have to leave their previous occupation. This led some to question their own self-identity and self-worth. Sam explored why he wished to return to work, in addition to being financially independent, there was also reflection upon his sense of identity, and how amputation forced a change to his internal scale of self-worth, he felt diminished in the eyes of society.

"Sam

Just start working really, you get your independence back. You're somebody. I think when something like this happens to you, they strip your dignity off you. I know it sounds, it might sound funny to you, but it just strips you deep into your identity. Makes you feel like you're a nobody, do you know what I mean? It makes you feel like that. There is judgement with gaining support, I think the benefits system and stuff like that, the way they are working, the way they make

you feel. It's like those young kids, you can see what they're put off work and stuff like that. You go into job centre and they treat them like shit.

Natasha

You just want to be treated as you.

Sam

Normal, with a bit or respect, that's all I ask for if nobody can speak to me with respect then I don't bother."

Sam (trans met amputation) p. 19

Work linking to self-identity, worth and satisfaction with quality of life was expressed by other participants of working age. Those able to continue working did so, but with adaptations.

"Bill

This, whether I would ever be able to work again, because I've been in the trade years and I can do a bone split, I can do retail, I can do the whole lot, whereas a lot of people they are very limited in what they can do. So, with my cv the phone is always going. So, I'm looking at this, and I'm thinking, well, you know.

Natasha

Do you think you could adapt?

Bill

Yes, yes, because, to be fair, retail is a lot, lot easier. I'm thinking about diversifying because especially in a factory environment we work really fast, so especially getting older and that, maybe it's time to slow down a bit."

Bill (1st toe amputated) p. 10

“When I had it done the surgeon told me to set myself 3 goals. So, my 3 goals were to take the dogs for a walk again, go back to work and drive. The surgeon meant, have a walk round the bed, little things, and I was.... But they were my goals, to go back to work. I’ve worked all my life, I wanted to drive, I enjoy driving and I wanted to go to work, so they were my two main aims. Work were very good, they had a van adapted for me, they’ve been good.

I grew up in a village, a little village and we all worked on the market garden when we were at school and that sort of thing, so we were always working in the summer holidays, we never had 8 weeks off. My dad always worked, both my grandads did.”

Tom (1st toe amputated) p. 4

“In the end, my mum said, we own the factory, well she does, the rat, so all my sick pay goes through the factory as we are all shareholders in the factory.”

Gerry (1st toe amputated) p. 17

Clive expressed his difficulties in trying to balance the needs of the business against his own health needs, this alteration of priority potentially impacting upon his professional relationships.

“And I try to explain that to everybody because with the best will in the world the docs say rest it, sit there with it up in the air, the guys are work are saying Clive we need you back as we’ve got these targets to do. So, I’ve got to try to plot that fine line between the two things whilst not making it worse.”

Clive (5th toe amputated) p. 3

Annie, Gary, and Charles had to stop work due to the amputation, they were unable to return to their physically demanding roles, this altered their self-identity, and they associated the amputation with a worsened quality life.

“I worked here 28 years and you have to pack up a job then you’ve got nothing, you know? I’m not crying depressed, but when you’ve worked all your life and then all of a sudden you can’t do anything it’s like, god knows how people keep having their leg amputated and that because as I say mine luckily was my toes. But it’s still changed everything.”

Annie (3rd, 4th 5th toes amputated) pp. 2-3

“Before I had the amputation, I was a grave digger, I used to cut grass at the cemetery, football 3 times at the weekend. I was really energetic, and then it all stopped straightaway.”

Gary (3rd, 4th, 5th toes amputated) p. 1

“They finished me off.”

Charles (2nd toe amputated) p. 7

Body Image

Interestingly, only male participants explored the physical appearance of the foot post amputation in a negative light, exploring hiding the amputation so that their persona remained unchanged.

“No, I wasn’t expecting that; I tell you what I was expecting. You see all these operations and they seem to fold the skin over and the rest of it. That’s what I expected rather than a piece of meat sitting on a butcher’s platter. It was a shock, believe you and me.”

David (3rd, 4th toes and 5th toe and shaft V section amputation) p. 2

“The other side, not that I was ever a keen swimmer, or anything like that, but I would never ever put shorts on again. I cannot say that I will, I cannot say I would be sitting on a beach with 4 toes off. It looks like a pig’s trotter the foot. And I think psychologically it’s in the head.”

Ted (2nd, 3rd, 4th, 5th Toes amputated) p. 18

“But in terms of, so I’m talking more about the head rather the physical, because I’ve reconciled the physical, I was never going to model sandals anyway.”

Clive (5th toe amputated) p. 11

“I would think if I’d got no pains in my legs or getting pains in my legs I would be alright, it wouldn’t bother me as no one can see what you have had done.”

Gary (3rd, 4th, 5th toes amputated) p. 32

Frustration with Footwear

Following amputation healing, all participants were measured for orthopaedic footwear to provide accommodation and protection to the altered foot dynamics. Recurrently for both male and female participants there was concern with the appearance of orthopaedic footwear, the lack of consideration of individual lifestyle and preferences and how this resulted in unwanted changes to persona.

“I do find that the shoes that I have chosen myself and provided are better than the one’s they make at the foot clinic. They are clumsy things. You can have a look in the corner and there are the trainers. I have my sitting down shoes which are shoes I will wear if I want to look reasonably presentable, and even my little Mary Jane’s someone said to me, “oh well they’re in fashion aren’t they?” but I look enviously at the girls wearing beautiful sandals and thinking it would be lovely if I could wear those, but I can’t.”

Judy (2nd toe amputated) p. 10

“Oh, the shoe thing. I mean, it’s been since October, it’s what is it now, July, so it’s what, nine months and I’ve only just had one appointment with the lady that measures the shoes and I’ve got to have some horrible type shoes to start off with, and its things like that. You want more, erm, I don’t know, shoes that you like, you know, not just something, a pair of boots that, well aren’t my cup of tea sort of thing.”

Sandy (trans met amputation) p. 6

“Actually, in frustration I tried to adapt a pair of walking boots that could accommodate it, because that is what I wanted to do and this was stopping me. I was going to try every trick in the book to try and get me doing the things I wanted to, probably might have been detrimental in some ways, I don’t know, but then again, nothing they were doing was working and they kept saying yes it’s going to be ok.”

Guy (3rd toe removed then tips of 2nd 3rd, bone out of 1st amputated) p. 15

“I’ve just walked out and said I’ll buy my own bloody trainers with what they put you through. You’re supposed to get two pairs a year and every time it’s like you’re a problem. I’ll just go and buy my own. They were supposed to make some special shoes but they’re not very good at all really. In future, I’ll just buy my own. I’d rather just buy my own than mess about. I’ve waited now, and now I’ve got to go back, wait for another appointment, take my old shoe in, because this is the older one before the one I’ve just had, and I’ve got to take my old shoe in to see if it can be repaired and all this, that and the other and it will probably be another 6 months before I get a pair. I’m risking my foot whilst I keep waiting for this shoe.”

Sam (trans met amputation) p. 20

“It’s as if you’re like a production line, you go in and it’s as if there’s no individual needs for a person. It’s one size fits all sort of attitude. I’m stubborn enough to tell them.”

Tom (1st toe amputated) p. 9

Frank summed up the situation with footwear, only having 2 pairs at a time as a rule did not meet the needs of the individual, there was little consideration about individual lifestyle,

“I’ve had a little dog all my life, and I live on the edge of a wood and the only place I’ve got to take this dog for a walk is there and it gets muddy when it’s raining. What do I do, do I go off in the orthotics, or do I put a welly on? And that option should be, I don’t know how to explain it. I should be able to go ah yes, stick a sock on with a padded bit and Velcro stuck to it and into the welly and there I go, come back, sock thing in the wash and put the orthotic shoe back on. I’m only being practical. I’m talking about thinking of the needs and lifestyle of the patients before the practicalities and financial attribution.”

Frank (1st toe amputated) p. 23

Keith’s commentary upon the footwear concisely stated the issues,

“I might even go back in proper shoes”

Keith (trans met amputation) p. 27

Dignity, Pride, Persona

The idea of being unable to accept the altered physical restrictions, and the changes to persona that this might bring were unacceptable to some, like Gary. For him, his persona and quality of life were focused upon his physicality, this remained post amputation, and led to restriction of freedom as he was unable to accept and adjust to this new limitation and did not wish to be judged negatively by others.

“Getting about, I mean I kept saying to the doctors the only thing I want to do is take the dog to the field. I can’t even walk to the field. I mean, basically I’m just stuck in here all the time. I’ve got an electric scooter, but I don’t like folks to see me on them. Now I’ve got to the stage it wouldn’t bother me if I didn’t see nobody. Like I say, they have put me on depression tablets, like I say I sit here all day really and watch telly”

Gary (3rd, 4th, 5th toes amputated) p. 10

Others, like Guy, who accepted and adapted well to the consequences of amputation refused to be defined by it and refused to have others external judgement placed upon him.

“I’ve never had a disability so I’m not being labelled, I’m me. And very often, I would never tell people because I was a competitor, and if I was going to do something and win I wanted to do it on equal terms, not because of special treatment. This is like with the walking. Hospital looks horrified when you walk this distance, that distance the other distance.

I mean I started off easy, you don’t do it the first day, you build up you find out what type of socks suit you, what type of boots and you get on, it’s a challenge and apart from probably a couple of close friends who needed to know, I was doing it on equal terms. That’s been my whole lifestyle. I’ve had some prejudice in the past in the workplace. It’s not always been easy going.”

Guy (3rd toe amputated then tips of 2nd 3rd and bone out of 1st) p. 6

Social Support

There were many aspects of quality of life associated with having effective social support. It was perceived as important not only for the socialisation, but for emotional support and supporting individuals to maintain their previous lifestyle and working life. Figure 11 provides a summary of the elements which are discussed below which pertain to social support.

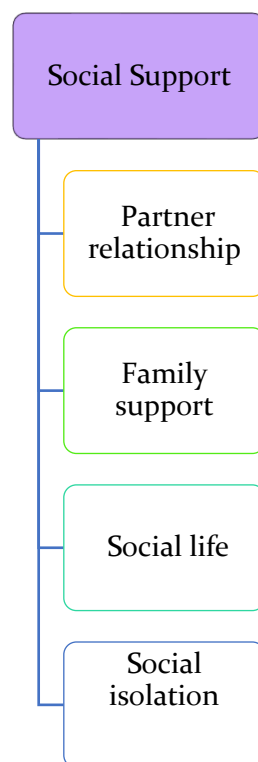


FIGURE 11 ASPECTS RELATING TO SOCIAL SUPPORT

Keith, a publican reflected upon the importance of the social support of his wife and immediate family in maintaining the pub and their lifestyle.

“I don’t know how I’d have coped if I hadn’t had been in here. If I had a proper job and worked out of home, worked at a factory, went to an office or something like that, well basically I would have been on the sick cos I couldn’t possibly get

to work even like this. The amputation in the late August, right on through to say the February I was still in a black shoe, a medishoe.”

Keith (trans met amputation) p. 21

Partner relationship

Reliance on Partner as Carer

Life post amputation caused an alteration to many relationships, for some this was only during the rehabilitation process.

“For me, the most, not distressing, but the awkward time was having to be at home. I was released straightaway home the same day. But all I could do was sit up with it in an up position. At the time my wife had to do everything for me. I’m her carer now, so that it makes it more different. At the time she had to do everything. So basically, I sat in the chair and watched daytime TV and anything else and that was it. It took about 2 months to 3 months for it to heal. When it had healed there was no problem. I went back to work, resumed back at work. I worked for the Department of Pensions and so I went back to work, I was on the phones so it didn’t mean I had to do any walking or anything so I could go back early as I was resting my foot anyway. So, I went back and carried on working. I didn’t need a stick, didn’t need anything.”

Rowan (3rd toe amputated) p. 1

Those with continued altered mobility explored the reluctant need to rely on their partner for personal care.

“David

I was putting on you left, right and centre because I couldn't do anything else. And you felt, you can answer if you like...

Sue

No, it wasn't that bad, but I used to say, used to go to friends at work and have a coffee, but I wouldn't leave you, because it was not safe, that sort of thing, but no, I don't feel. You think, yeah right, what do you want this time? We've been married 44 years”

Sue & David (3rd, 4th toes and 5th toe and shaft V section amputations) p. 9

“Yes, I do feel in a way where Harry's concerned that, it wasn't my fault I got this, but I do feel that I've let him down now that he has to look after me.”

Louisa (2nd, 3rd, 4th, 5th toes amputated) p. 12

“Tom

I don't know what I would have done without her the last 4 years, I really don't, know where I'd have been.

Ffion

You have things to do, and you go do it. If you need someone to help you, say I need someone to help me with this. Its admitting that he needs a hand. He doesn't like asking me to do things for him, he doesn't, I go, what do you want, it doesn't matter, well what do you want? It's just getting that understanding. You can't do it yourself, what do you want?”

Ffion and Tom (1st toe amputated) p. 16

“I’ve dressed it myself, when it started healing up, not as bad as it is now, not as bad as it was when it first was done. I watched the nurse at the doctors do it, so I did it after that.”

Marge, wife of Charles (2nd toe amputated) p. 6

Alterations to relationship with partner

Some participants explored the nature of their relationships, revealing doubt about their sexual attractiveness to their partner following the amputation.

“Alison

You don’t know what the other person’s thinking, your partner’s thinking do you? Well, your husband, not your partner. When you’re thinking, I wonder if he still fancies me? Things like that, all sorts of things.

Albert

She did ask me some time; did I still fancy her? She did, she did.

Alison

Yes it’s there isn’t it? It’s there.”

Albert and Alison (trans met amputation) p. 13

Annie’s reflection when asked if there was a difference post amputation in her relationship with her partner focussed upon her questioning her worth to him.

“Oh yes definitely, definitely. Not that he minds, we’ve been away a couple of times and he will book a nice hotel and we’ll go away you know what it’s like. I think it doesn’t, but deep down I think does he really want to be pushing me around? Does he really want to be with me because I’m not like I used to be? It’s like sometimes also, and he’ll say oh for goodness sake, you know what I mean. He’s never mentioned it because as I say I don’t think he does mind. I used to say to my friend I hope he doesn’t mind pushing me down the road because we’ve only been together 5 years so it’s like new, isn’t it? But he’s been fine, but I think that’s sometimes why I say no I don’t want to go out because I’m thinking does he want to be pushing me round? But that’s probably just silly thoughts because he’s the kind of person who if he was bothered, he would say. It just changes everything, your love life, as you say, quality of life. It does change it. But like I keep saying I’m here just make the most of it if you can.”

Annie (3rd, 4th, 5th toes amputated) p. 9

The stress of the amputation and rehabilitation situation caused fractures within some relationships due to the enforced change of reliance.

“I would say we’ve been better since we’ve moved, I think it’s changed me more that its changed him in the relationship. I really couldn’t do anything for me because it was all, 2013, was basically a year of hospital for Gary, I had so much to do I couldn’t look after me so we moved and I’ve done it here. Yes, it has been hard, we did argue, especially in hospital, you hurt those who are closest to.”

Julie, wife of Gary (3rd, 4th, 5th toes amputated) p. 15

For others, the strength of their relationship meant the amputation made little impact, but there was a desire to return to previous times.

“That’s what I’ve said to him, I would be glad when I can walk next to you and hold your hand because we’ve always held hands when we’re walking down the road even though we’re getting on, we’ve always done it. We’ve always said that to one another about walking down the road. Yes, that changes because he’s above and as you’re getting older sometimes you’re hearing isn’t the same and you miss what one another is saying. Yes, but it’s not been a problem as such.”

Sandy (trans metatarsal amputation) p. 11

Family Support

Some were aware that they needed assistance, particularly whilst the amputation was healing, but were reluctant to become a burden to their family. All conveyed how necessary their family support was to their quality of life.

“See, I’ve got a daughter who would do anything for me, but I don’t like asking her. I’m going to have to ask her more in the future to save me walking about.”

Sam (trans metatarsal amputation) p. 3

“I’ve got family around me; I’ve got 2 daughters and a son. It’s funny because I’ve been married 3 times actually and my first and second wives are still friends, good friends, and the second one lives just round the corner from where I am. When I had to come back to the UK, I’m living in a rented house, and I rented it because it’s in amongst all my family. One daughter lives 2 minutes one way and the other lives 2 minutes the other. My ex-wife who’s a really good friend lives just round the corner. So, there’s people about if I need anything. But I’m a bit reluctant, I don’t like to ask for too much as they’ve got their lives to lead.”

Steve (1st toe amputated) p. 3

“It’s not being reliant on my daughter, 24-7 taxi driver job”

David (3rd, 4th toes and 5th toe and shaft V section amputations) p. 10

“Mine’s pretty good, but it’s not really, if you know what I mean. If I hadn’t got my family, I might as well go.”

Derek (3rd, 4th, 5th trans metatarsal amputation) p. 1

“Luckily, I’m married, lucky that I have kids and grandkids and it all helped that little bit.”

Ted (2nd, 3rd, 4th, 5th toes amputated) p. 15

“Family has been very good, Ffion has a big family, 3 sisters, a brother, I’ve got my sister. Everyone has been understanding, supportive.”

Tom (1st toe amputated) p. 5

“You are pretty open; you talk about lots of things. And our children are as well. They are very supportive; they have all helped where they can. My granddaughter she’s a comfort to you isn’t she. She makes you happy and smile.”

Penny, wife of John (1st autoamputated then other 1st amputated) p. 18

“Even my mum and dad, me dad’s 88 in October, my mum was 85, 86 in June, she does the ironing, Peter supplies the apples, me mother makes the pies, you know it’s even them at their age still come and my mum fetches a basket of ironing every day, so its help because it allows Lynne to come down and do that little bit more in the pub.”

Keith (trans metatarsal amputation) p. 20

No Partner or Family Support

Some participants had no current partner, were estranged or lived far away from family. They reflected upon the effect this had and expressed the difficulties this had caused during the rehabilitation process.

“I dunno really.... Little things, getting about, getting to the shops and stuff like that.”

Albert (2nd toe amputated) p. 5

“I don’t get to see many people at all, the only people I’ve seen recently are the nurses. I just get a bit stir crazy, but I get the nurses coming in twice a week, change the dressing.”

Richard (Right 1st Left 3rd, 4th, 5th toes amputated) p. 5

“A supportive partner, that would be good, I think that would be helpful, but you know, such is life. Just to bounce things off, or somebody to say, ‘For god’s sake Clive, come on, get a grip, get a grip.’ I think after a little while on your own you do become a little more hardened and don’t rely on that, but it’s nice and it’s comforting. I mean especially when you go out of hospital, going back to an empty house you almost miss hearing people’s voices on the ward.”

Clive (5th toe amputated) p. 19

Social life

For some the amputation made no difference to their social life or network, and so these relationships continued unimpeded even if there were mobility changes.

“One set of friends that live in Yorkshire, they’ve been particularly good with us, because they have a caravan in Yorkshire and they say to us, come with us to the caravan, and every time they go to the caravan for the weekend they say, are you doing anything else? Come down. So, we go down Friday and stop till Sunday and come home Sunday afternoon. And they have been brilliant. It’s not bothered them that we’ve had to adjust in the caravan. But it’s all flat so they know it’s all right and everything’s accessible to me., But my friend Katherine is a podiatrist, so she knows a lot of the things that people have to go through, so they have been fantastic. And another set of friends that live by the sea, we’re

going over there this weekend. Other friends of ours come up every week and do any jobs with John. Really good friends, we've been friends a really long time and I think that's important; they treat you the same, not differently. That's been important and the friends that we have treat me normally."

Sandy (trans metatarsal amputation) p. 16

"Plus, I've got a very good support network, my friends, my army friends came straight round after the operation, how are you, only it's just a couple of toes you can't count to 20 now. I joined it for what it was when I was young and it's not the same place anymore. I was in 28 years. I enjoyed myself, total different thing from what it is now, all my friends, when we came out, we've all kept in touch. We're all over the county, but as I say, they all came here to see me."

Andrew (2nd 3rd met V section amputation) p. 11

"I do try to keep up with everything I can. I have good friends they will pick me up. I could drive but I lost my licence, I literally lost my licence when I was in Tenerife, but I was past 70 anyway, 75 when we came back here, so I am now dependant on good friends. As I say I can get a lot of taxi rides for the cost of keeping a car and they are good."

Judy (2nd toe amputated) page 11

"I've got a lot of friends that still work where we did. It annoys me sometimes; they're still doing it and I'm stuck here. So, what I do, that's how we keep in touch and I've got a lot of good friends. If I do have a down day, I quite often let my feelings be known to the groups of people that I associate with and they rally round straight away. So, it's good, good to keep in touch."

Steve (1st toe amputated) p. 11

“I’m a freemason, I still manage to get to the two festivals every year with her indoors. We go to the lunch in autumn so that she can posh frock, collar and tie and go to that function. Then we have a ladies evening, where its ball gown and tie and we’ve managed that each year so things like that haven’t changed for her indoors. She still gets a posh frock and all that.”

Keith (trans metatarsal amputation) p. 26

Social Isolation

For Clive and Annie, both in their 50’s, they were outside of the social normalities for their age. This led to social isolation for Annie as her social network were still of working age, and therefore working, leaving her with little social input during the day and, feeling reliant upon her partner.

He’s a bin man and works from 5 in the morning till 4 so he’s not always wanting to go out. He wants to sit and have a rest, have his tea because he goes to bed for 9 o’clock. So, it’s, I feel like, I feel like I’m letting him down. Sometimes he will say do you want to go out, and sometimes you’re not always in the mood, so I say yes but I don’t really want to go. I know it sounds daft because I’m saying I want to go out and I’m offered to go out, but sometimes, sometimes I can’t, I’m not in the mood. And I feel like I’m putting on him all the time. It’s hard.

Annie (3rd, 4th, 5th toes amputated) p. 6

Others, such as Derek experienced a reduction in their social support associated with the reduction in mobility post amputation.

“I’ve lost my friends, lost quite a few, when you can’t go out, fade away more or less. My best friends at the moment are my carers. I do get on well with my carers. You need to as you need them. My neighbours all decent, but they’re not mixers, more or less keep to yourself. Might say good morning, but it’s about all you’d get.”

Derek (3rd, 4th, 5th trans met amputation) p. 9

“Yes, you lose a lot of your friends, well people who you used to think were friends, yes. I’ve got 3 now I’d consider friends. I mean I was a big man in my time, you know what I mean, I used to help a lot of people out, when you need it, help yourself, you don’t get it. Do you know what I mean? Gut wrenching, yes, it is when people turn their backs on you, especially your friends. Don’t answer the phone to you. All things like that. People who I’d always done a lot for. Some members of my family, people who I’ve done a lot for, when you need them, they’re not there and ignore the phone from you and all sorts. And now they need me, they’ve started coming out of the woodwork again. I just help people who help me. It’s tough to go through that, yes.”

Sam (trans metatarsal amputation) p. 15

Environmental

Some reported very little impact to quality of life, the amputation causing minimal disruption to life. For others, amputation forced a change to lifestyle. As explored within Chapter 5, issues concerning lack of benefit support or post-operative care impacted upon the ability to adapt and resulted in a marked detriment to quality of life. For Gary, whose house was tied into the job role as a groundsman, amputation resulted in loss of the family home.

“It was with the job; it was because he worked for the council. It was in the grounds of the cemetery, so the job was also locking, unlocking the gates and the security and obviously the council workers get paid full pay for 6 months, half for 6 months and they have to go to occupational health to see if he was fit for work, as soon as they told him he wasn’t they wanted him out. Me and him were in a 3 bedroom detached house, and we had to move as well.”

Julie, Gary’s Wife, p. 14

Derek was forced to rehome.

“I thought I was going back to my house, then I realised the chair wouldn’t go through the doors, I wouldn’t be able to get upstairs so I had to go to that horrible place. I got shoved into there whilst they were finding me somewhere to live. I was there a couple of months. The trouble with that was it was over Christmas, I had Christmas in there. No, it was not good, all they do is walk them up the corridors and dump them in a chair. Everything to nothing.”

Derek (3rd, 4th, 5th trans metatarsal amputation) page 7

Other Health Conditions Impacting Quality of Life

For some amputation was not the factor resulting in changes to quality of life. Reduced mobility, inability to return to working life and limitations upon social life were a consequence of additional medical conditions, such as ischaemia and associated pain, arthritis, stroke, and further diabetes related complications such as nephropathy requiring dialysis.

“John

I’ve had enough, I feel as if I’ve had enough.

Penny

I think a lot of the other things have contributed more to how you feel than the amputation really.

John

It’s not really bothered me the amputation.”

Penny and John (1st autoamputated then other 1st amputated) p. 3

“Once one thing started, it’s right what the doctors have said years and years ago that more or less, once, when you get older if the things are going to start, they’ll start when you’re older and its right, I have, mine have. Everything, it’s been everything hasn’t it, one thing after another really. But you’ve just got to get on with it and that’s it”

Alison (trans met amputation) p. 8

“You’ve got vascular problems, you’ve got amputations, you’ve had a vein graft, you’ve got diabetes you’ve got diabetic retinopathy in the eyes, I said ‘who’s going to employ a 58-year-old man if they’ve got an 18-year-old whose fit and healthy?’ It’s common sense isn’t it?”

Julie, Gary’s wife (3rd, 4th, 5th toes amputated) p. 21

“It was the septic arthritis that finished me off I worked so hard to get this knee going again because I was determined...but, I can’t drive now, my life has changed. I’ve gone from doing all my cooking, cleaning, washing, ironing. I have to have somebody to do my ironing because I cannot sit at my ironing board, I can’t iron and sit down. I can’t stand long enough because it’s painful to stand. I

can't get down and clean my skirting boards, I have a cleaner come and goes round and does my bathroom and right through. So, I'm paying for everything to be done for me. I've gone from doing everything myself to be reliant. I cannot get out. The social services dame, I asked for a rail to be put up that slope, I can't even get out of my own bungalow because I can't get up that slope. I can get up with a Zimmer frame, but you can't get a Zimmer frame in a car. I have to, I suppose I could have, but can't go to town with a Zimmer frame. And I asked them if I could have a rail put up so at least I could get out and go to my neighbours.

So, my life has totally changed. The amputations, I was living with them, you know with a walking stick, hanging onto someone's arm. I could still drive, I've got an automatic car, it didn't stop me from driving. I've gone from being independent, driving, you know, from having my amputations I still managed to keep positive and keep doing things for myself. I used to still go to the group. They used to have monthly parties, I still did use to go to them and I could get up and dance if I was hanging onto somebody, and then sit down, and I would have another dance, but I was there socialising, having a, well, we used to only have diet coke cos it's too expensive to drink when you go out to these places, but I could listen to the music and socialise with people. But I can't do that now, I couldn't dance."

Dianne (4th toe then subsequent 1st toe amputation) pp. 9 & 11

"In the meantime, with the loss of the toes, obviously my walking's become different to how you walk. I kept complaining that I had this pain in here (points to hip), so I was referred to a hip specialist, and he's done his bit, x-ray, showed me, "full of arthritis, Keith, you're probably compensating for the wotsit you've got. You're going to, we're going to have to have a new hip at some point."

Keith (trans met amputation) p. 13

“I would think if I’d got no pains in my legs or getting pains in my legs I would be alright, it wouldn’t bother me as no one can see what you have had done.”

Gary (3rd, 4th, 5th toes amputated) p. 12

“You could wake up in a morning and think I want to go there tomorrow or today, and we were allowed to do it and now I’m stuck in a routine coming here 3 days a week and that’s what I fight against. I like to wake up in a morning and decide to do something, not plan it weeks in advance. If I want to go on holiday, which would mostly be this country I’ve got to plan and get in touch with other hospitals at its got to be ok’ed and take all this stuff. It does my head in, I like to wake up and do it.”

Steve (1st toe amputated) currently on dialysis p. 9

Summary of Themes Identified

Thematic analysis of the 28 interviews has identified self-identity, social support, and environmental themes as contributing to quality of life, Figure 12 provides a visual representation of these themes and codes. These aspects are explored within the discussion section below.

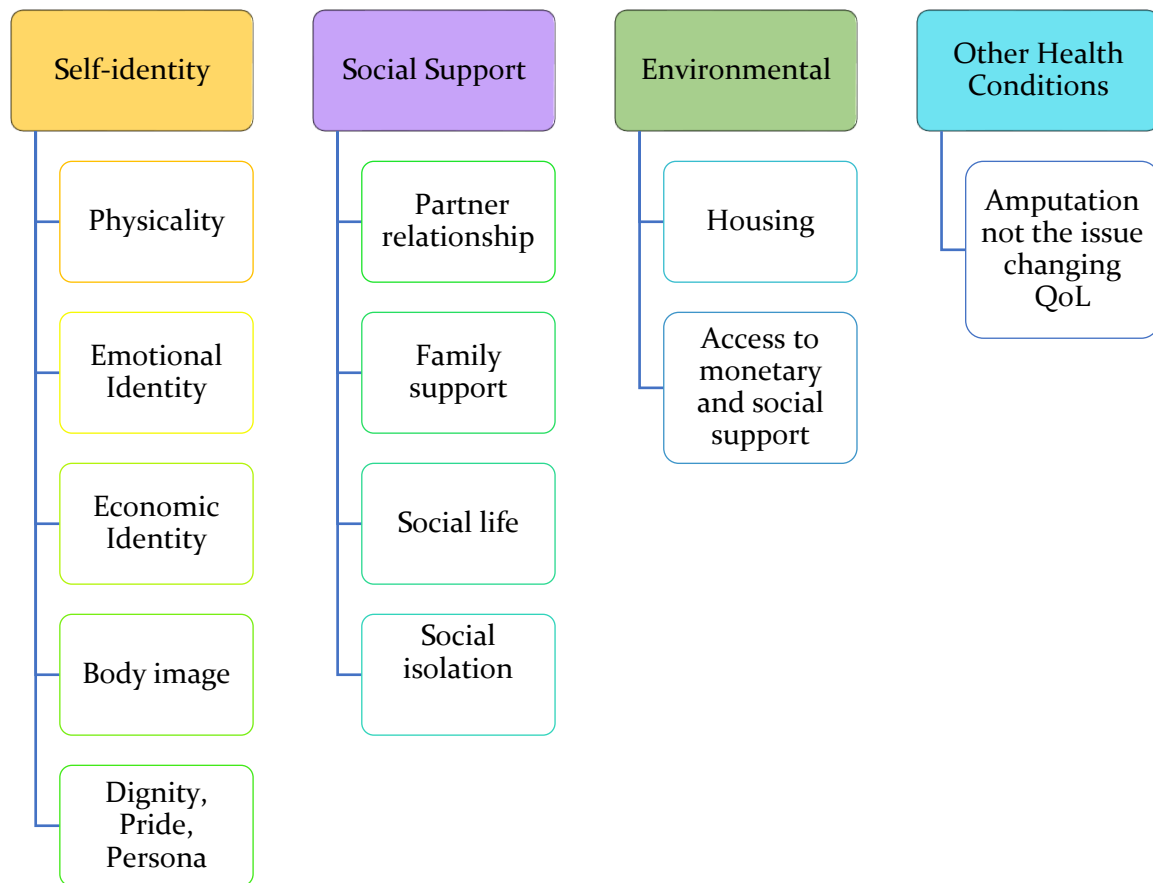


FIGURE 12 FACTORS IMPORTANT TO QUALITY OF LIFE FOR INDIVIDUALS WITH DIABETES RELATED BELOW ANKLE AMPUTATION

Chapter 7: Discussion of Findings relating Impact of Amputation upon Quality of Life

A variety of views were expressed within the interviews concerning the impact amputation had upon quality of life. As discussed within Chapter 5, the ability to accept, cope and adapt to the below ankle amputation related to a participant's perception of their quality of life. Successful adaptation related to those concluding there was no impact to their quality of life, life was just the same, or aspects were improved. Conversely, those grieving for loss of the body part adopted passive coping strategies, which did not result in successful adaptation to the amputation and consequently attributed a worsened quality of life to the amputation.

The results presented within this study demonstrate how interconnected the elements important to quality of life are. Any changes to physicality may impact upon emotional health, social relationships or ability to work, thereby altering defining attributes of self-identity, and potentially overall quality of life. Within published literature aimed at exploring the impact of diabetes associated amputation there is segregation between exploring the effect upon quality of life, changes to body image perception or adaptation to the amputation. Rarely are these elements explored together, and below ankle amputation is seldom the focus for these studies.

Self- identity & Body Image

The physical and emotional aspects of self-identity and the success of adaptation to the amputation appear to be related within this study. Participants expressed that where changes to mobility occurred because of the amputation, this held a deeper resonance than purely the loss of physical function. The attitude to amputation and adaption contributed to quality of life perception regardless of the level of the amputation performed and resultant mobility.

This new knowledge could not have been captured by current quality of life measures. At present time measures do not integrate adaptation and quality of life together. Researchers are left with two options, either undertaking explorative qualitative studies or using multiple assessment tools to explore more widely the impact of amputation. Such was the case for the research undertaken by Dillon, Quigley, et al. (2020) who explored the impact of either a partial foot amputation or trans tibial amputation by using 3 instruments, the demographic aspect of the Trinity Amputation and Experience Questionnaire, the Short Form 36 version 2 to explore health related quality of life aspects and a patient reported outcome measure to determine the impact of amputation to aspects such as anxiety, depression, fatigue and social roles. Although chosen methods of data collection are different, this USA study echoed the findings here that the consequences of amputation are complex and not purely related to the level of amputation undertaken. As no measures exploring adaptation were utilised, there was no comment upon the interplay between acceptance, adaptation and quality of life as has been explored by this current study. This reinforces the need for a wider comprehension of the lived experience of individuals to gain understanding. The consequence of this approach is that this current study has developed new knowledge and understanding about the relationship between quality of life, coping strategies, acceptance and adaptation for diabetes associated below ankle amputation.

Studies exploring amputation, but not quality of life, have commented upon the impact of positive or negative attitude towards amputation. Senra et al. (2012) explored the emotional impact and adjustments made to self-identity for 42 participants following above or below ankle amputation from vascular or traumatic aetiologies. The findings reflect some of the same issues as the below ankle amputation individuals here. Those who looked at the amputation in a positive light were more likely to be positive about their self-identity and report less impact of the amputation to themselves and had better social functioning. Perhaps this similarity of findings was due to similarity of the studies incorporating patients who were either still healing after amputation or had healed but were still accessing care as part of their follow-up. For the

current study, as explored within the method chapter, all participants were still under the care of the multidisciplinary team. Also similarly, unless psychological needs were identified, participants were not automatically provided with psychological support.

The analysis from the current study suggests positive acceptance of the physical change from the below ankle amputation was necessary to maintain quality of life. Accepting the change to body image was an aspect of accepting the changed self-identify and enabled participants to consider adjustment to personal goals and thereby maintain what they personally perceived as a good quality of life. This concept was identified in a study exploring above ankle amputation from vascular and diabetes aetiologies conducted in Austria. Holzer et al. (2014) confirmed the negative impact of distorted body image perception to quality of life, and concluded that assessment of body image perception, quality of life and self-esteem were necessary pre and post amputation to monitor patient progress. A later study by Crocker et al. (2021) also confirmed the detrimental impact of negative body image post amputation, with participants expressing shame and wishing to hide the amputation even from close family. Considered from a phenomenological position, an individual simultaneously has and is one's body, a discord between what one wants and can do necessitates reflection and either acceptance of the changes, or if the discord remains, there are psychological as well as physical consequences (Slatman & Widdershoven, 2009). This perspective was reflected in those participants who express a worsened quality of life within the current study.

The male participants of the current study explored hiding the below ankle amputation in footwear, and expressed alterations to choices, exploring they would not wear sandals or flipflops which would expose the amputation to public scrutiny. Similar results were found by Crocker et al. (2021) who explored the physical, psycho-social and economic impact of diabetes associated ulceration and amputation for 15 individuals residing in Tucson, USA. Crocker et al. identified that a minority of the respondents were embarrassed by the amputation and hid their feet to avoid questions. These findings were also echoed in a Singapore based study by Zhu et

al. (2020) who identified the use of enclosed footwear to disguise the amputation and present a 'normal' appearance. Women interviewed within this current study explored the lack of choice within specialist footwear provided and their resultant forced alteration of clothing worn to hide the footwear rather than commenting upon the physical appearance of the foot. This forced change of apparel led to reflection upon physical appearance, self-identity and the external perception and judgement of others. If the footwear was unacceptable for a social occasion, they compromised and dealt with the consequences of further active foot problems to wear commercial footwear which was personally acceptable to self-identity. These findings of women being more negative about therapeutic footwear was also found in a postal questionnaire study completed in Sweden by Jarl et al. (2019). The replies from 443 individuals who wore therapeutic footwear due to diabetes associated ulceration or below ankle amputation demonstrated women were dissatisfied with the appearance of the footwear and preferred to wear conventional footwear in public, despite recognising the benefits of therapeutic footwear to reducing pain and improving mobility. These findings were also confirmed in a UK study by Churchman (2008), who identified that 30% of all female questionnaire respondents found therapeutic footwear to be unacceptable, leading to 20% of them not wearing it. These findings indicate decisions regarding footwear are complex and is not a simple choice of benefit to physical health. Forced choice of footwear which is discordant to the construct of self-image can negatively impact upon self-identity and quality of life. Barg et al. (2017) supported this perspective and determined that the consequences of amputation go beyond the physicality of reduced function. The participants of Barg et al's. study were reluctantly reliant upon mobility aids post-amputation and drew unwanted external judgements from others. In consequence this resulted in changes to perception of self-image as a healthy person and diminished psychosocial functioning.

Analysis from the current study demonstrates the complexity of factors which may contribute to reduced socialisation. Participants who experienced social isolation post amputation

explored that a combination of factors, namely, body image change, alteration and practicality of footwear, reduced mobility and fear of further trauma led to participants ceasing hobbies such as dancing or reduced participation within social events where there was risk of trauma to the amputation site. These findings have been identified in previous work, Coffey et al. (2009) determined that body image disturbance predicted social restriction in a study which explored psychosocial adjustment to transtibial or transfemoral amputation. A study by McDonald et al. (2014) identified above and below ankle amputation caused body image disturbance, but this in isolation did not account for changes to psychosocial outcomes – rather the complexity of diabetes associated co-morbidities were responsible for reduced psychosocial outcomes as measured by HADS and the WHOQOL psychological and physical subscales. McDonald et al. suggested that clinicians should not just assume people would have poorer outcomes because of an amputation and should consider an individual more holistically. The findings of this current study would meet the recommendations suggested by McDonald to explore more widely, and when published will give clinicians more insight into the impact of below ankle amputation upon quality of life.

The current research is the first study to explore the consequences of below ankle amputation upon quality of life and integrate concepts such as acceptance, body image, and self-perception. The findings of this current study demonstrate that a wider approach to patient care is necessary, and by considering adaptation, body image and self-identity the potential detrimental impact to quality of life could be highlighted and resources targeted to support those for whom amputation may reduce quality of life.

Emotional: Seeking the Positive

Some within this study used the experience of amputation to reflect upon self-care, exploring that they had ignored their own needs prior to the amputation and were now actively focussed upon themselves and their own health. The idea of amputation leading to a positive refocus upon health was also confirmed by Badoux and Fatoohi (2015) who explored the experiences of 12 individuals who had undergone a diabetes associated toe amputation. The study identified that change was driven by participants being awoken to the seriousness of the diabetes diagnosis, and a refocus upon improving health. As seen from the current study, some participants began to prioritise their health, becoming actively involved in optimising aspects of health over which they could exert control, for example changing their diet to improve glycaemic control, or increasing self-care activities. These findings were also confirmed in studies by Crocker et al. (2021) and Gallagher and MacLachlan (2000b), who found participants strove to see the positive in the amputation, using the experience to make positive changes to their health and overall quality of life. Gallagher and MacLachlan also identified that this positive mental attitude related to better health and better physical functioning. The positive reinforcement enabled an individual to engage with social activities, thereby increasing socialisation and emotional support, and enhancing quality of life. Similar findings were identified in a study exploring coping strategies and life satisfaction for 63 amputees. The study identified engaging in social activities and ability to mobilise were indicators of positive adjustment to amputation (Perreira et al., 2018).

Within this current study thematic analysis identified participants with a positive attitude towards amputation adopted active coping strategies to adapt and accept the amputation and reported a self-perceived good quality of life. This was found to be irrespective of the level of amputation. Participants who had more extensive areas of the foot removed, and arguably more limitations to physical mobility, also expressed this perspective and dismissed the idea that the

amputation had reduced social life or overall quality of life. If these participants had been assessed using health outcome measures such as the SF-36 or EQ-5D they would have been reported as having reduced health status, or reduced health-related quality of life; the limitations of these measures to gaining insight into the impact of amputation can be seen. Participants who maintained an active social life expressed a positive life perspective and vocalised the importance of maintaining a positive attitude to the amputation and consequences of the amputation.

A positive attitude was seen as vital to adapt successfully and several participants reflected upon observing other patients who did not have a positive attitude and the negative impact this had. This led to self-reflection as to how vital it was to maintain a positive pro-active approach to the amputation, acknowledgement that there could be low mood days, but it was important to rely upon themselves to regain a positive attitude. As explored within Chapter 5, the idea of positive retelling, making sense of an event and using this in a positive manner could be considered to be a positive coping strategy, necessary to acceptance and adaptation to the amputation as proposed by Carver (1997); Folkman et al. (1986); Skinner and Edge (2003).

This positive attitude, or resilience has been identified as important to adaptation in previous studies. A grounded theory study of 5 individuals lower limb amputation and their carers in Australia identified the importance of endurance (Livingstone et al., 2011). The endurance theme incorporated the concepts of positive attitude, acceptance and adaption identified within this current study. Livingstone et al. chose to code this positive attitude as developing hope, but essentially the description of this name echoes the findings here, of participants deciding to adopt a positive attitude and not enabling the amputation to limit life. A Liverpool based study of 99 transtibial or transfemoral amputees also demonstrated the importance of hope and social support to successful adjustment (Unwin et al., 2009). The study utilised the Hope Scale, which defined hope as a positive state arising from being able to successfully use planning to meet individual goals (Synder et al., 1991). If considered from this definition, the participants of the

current study who expressed a positive attitude, could be determined to have hope, using this accept and adapt to the amputation. Unwin et al. identified that hope at the start of rehabilitation related to positive mood, and that hope and social support positively contributed to adaptation and acceptance. This indicates that conversations with patients prior to amputation may assist in developing meaningful individualised support to maintain quality of life.

Social Support

The importance of Partner, Family and Friends

Within this thesis and thematic analysis, the theme social support incorporated codes exploring the ideas of social life, social isolation and perceived social support from partner, family or friends. Social life being focussed upon the behavioural and cognitive actions of the individual, essentially, how much someone participated in activities and relationships and could relate to their role within these situations. Perceived social support being defined as the extent to which an individual believed that support would be available if necessary (Williams et al., 2004). Both of these aspects are considered below.

Social life was discussed by all the study participants, the importance of being able to share the amputation experience, to have relationships remain despite the amputation and the changed self-identity was identified within this current study. Participants whose social support remained unchanged were able to maintain pre-amputation activities or expressed that those networks were able to accommodate the altered physical function and reduced mobility. Those with a limited social life found this to be of detriment to their quality of life, issues such as isolation and exclusion from physical social activities were explored. Although no previous

studies have explored the effect of below ankle amputation, findings from a study exploring the impact of social integration for 90 individuals who had below knee amputation adaptation determined that those with a better social network had better physical function and quality of life, confirming the importance of a social network for quality of life (Hawkins et al., 2015).

Within the current research, data analysis revealed that social support was necessary for the long term, with some participants nearly 2 years post-amputation still having reduced mobility issues and a healing amputation site. The importance of a social network for support during adaption and life post amputation was identified in research undertaken by Williams et al. (2004) who confirmed the suggestion that social support should be ongoing. The prospective longitudinal study explored levels of social support in the first two years post lower limb amputation (midfoot, below knee, through knee above knee and hip disarticulation patients were included) caused by trauma, diabetes or infection. The study determined from their sample of 89 individuals that perceived support was a predictor of improved mobility and life satisfaction following amputation. The study found, perhaps unsurprisingly, that those with a partner or were married perceived that they had better support than those alone. Delea et al. (2015) explored experiences of health care in Ireland with 10 male participants, one with active foot ulcer, and nine who had undergone above ankle amputation. Thematic analysis identified the importance of partners, family, friends and healthcare professionals for emotional and practical support. A longitudinal study following 206 individuals for 10 months post amputation surgery also identified that social support was a key component for successful adaptation, and support was necessary from healthcare professionals, family and friends (Pedras et al., 2018).

The current research has identified that social support is a key component of successful rehabilitation and quality of life. Previous studies have indicated the links between good social support, coping and wellbeing or improved quality of life (Delamater et al., 2001; Foster & Lauver, 2014; Pedras et al., 2018; Ramkisson et al., 2017; Unwin et al., 2009; Zhu et al., 2020). Conversely, studies where participants have been socially isolated indicate the difficulties faced

for successful adaptation post amputation and the detrimental impact this may have upon quality of life. The reliance upon others can carry a psychological burden, the alteration of an individual's activity levels, ability to work, and inability to participate within previous activities may cause distress (Amoah et al., 2018; Crocker et al., 2021). Within the current study, personal care was mainly delivered by partners or close family members. These changes in reliance were explored both within a positive and negative light. Thematic analysis indicated that this may have brought renewed appreciation for family members, closer bonds to the family and strengthened relationships. Conversely there was frustration about the necessity of reliance upon family members as a result of the reduced physicality of the amputees, and concerns about the negative impact of this for those family members. Both of these perspectives have been identified in amputation studies such as Livingstone et al. (2011) who interviewed 5 individuals in Australia and identified amputees reported reduced socialisation and increased reliance upon a spouse. The importance of social support to positive coping and ongoing resilience to the amputation and subsequent changes was also highlighted. These findings were also identified in qualitative studies by Amoah et al. (2018); Foster and Lauver (2014) Zhu et al. (2020) and Crocker et al. (2021).

The importance of medical team support

Within the current research participants explored the importance of emotional support from healthcare professionals, using them as a sounding board, seeking and gaining confirmation of their own coping strategies and tactics to regain independence during the healing process. The majority of participants expressed the relationships with the immediate foot care team in a positive light, seeking and gaining guidance about the rehabilitation journey. For some the guidance was unclear, and these participants explored that education was necessary for not only

themselves but for future amputees to be able to plan and prepare effectively. Previous amputation research has indicated the importance of patient-healthcare professional relationships. The qualitative study completed by Foster and Lauver (2014) also identified the importance of healthcare professional, family and community support for successful adaption to the amputation. These results have been confirmed by later studies. A study in Ireland identified that transtibial or transfemoral amputee participants wanted additional emotional support in addition to the physical health care management of an amputation (Delea et al., 2015). Rodríguez et al. (2018) demonstrated the importance of a wide social network for quality of life, sixteen people were interviewed and expressed that family support and the relationships with medical health professionals were important to health. Pedras et al. (2018) exploration of psychological adjustment to above ankle amputation 10 months post-surgery identified the importance of the healthcare professional role in attempting to extend and promote social support for amputees. Pedras et al. concluded that little work had been done to establish if the rehabilitation and adaption journey for below ankle amputation had been little researched and recommended this was necessary. The findings of the current research will contribute new knowledge to this area.

Despite the recognition of the importance of education and emotional support within the research literature, there are national issues with formalising this care. The 2014 review of patients who had undergone diabetes or vascular above ankle amputation within the United Kingdom (NCEPOD, 2014) highlighted only 48.3% of hospitals provided written advice or a care pathway for those who had undergone amputation during the 2009-2010 period. Recommendations were that individuals with diabetes should have pre and post amputation review by the diabetes team and planned rehabilitation was needed. A thematic review of clinical negligence claims associated with diabetes lower limb complications by NHS resolution (Mottolini, 2022) indicated that there were still disparities within this care. In the 92 cases explored, social and emotional factors remained unaddressed, and education was woefully

lacking, only 19 of the 92 individuals had education and none addressed expectations of the amputation pre and post operatively. Considered in the perspective of impact to quality of life, ultimately this would impact upon an individual's ability to receive the right education and emotional support to be able to utilise active coping strategies, adapt to the amputation and maintain quality of life.

Other Health Conditions Impacting Quality of Life

As explored within Chapters 1 and 4, the pathway to diabetes related amputation is clear, a combination of co-morbidities such as neuropathy, ischaemia, trauma and infection result in unsalvageable ulcerations or gangrene and subsequent amputation (Ugwu et al., 2019; van Battum et al., 2011). Studies exploring the long-term consequences of diabetes have identified a range of long term micro and macrovascular changes (AADE, 2002; UK Prospective Diabetes Study (UKPDS) Group, 1998b), essentially amputation may be another complication to add to existing health conditions which have impaired quality of life. This perception has been identified within the current study. Participants have expressed that amputation has not impaired quality of life, rather the consequences of peripheral arterial disease, extensive arthritis, nephropathy or dialysis have changed this. These findings were also identified by Dillon, Quigley, et al. (2020) who determined factors such as fatigue, anxiety pain and physical function altered health outcomes and Vogel et al. (2014) who explored that nursing home residents determined that those with end-stage renal disease or stroke as a co-morbidity had worsened physical function that did not return to pre-amputation states.

Adaptation and Quality of Life: A Symbiotic Relationship

The current research has identified that reduced physicality associated with amputation did not necessarily result in participants expressing a perceived lowering of quality of life, that attitude to the amputation, essentially acceptance and adaptation was key. The finding from this qualitative research may possibly account for the lack of consensus surrounding the impact of amputation to quality of life for amputation from studies which have utilised health outcome measures which did not explore adaptation to amputation. As explored within the Chapter 1, studies determining the impact of diabetes associated amputation by utilising outcomes measures such as EQ-5D or SF-36 have reported either there was no impact to quality of life or that physical function was diminished (Boutoille et al., 2008; Patel et al., 2014; Peters et al., 2001; Pickwell et al., 2016; Willrich et al., 2005; Winkley et al., 2009). When adaptation and coping were considered alongside diabetic foot complications, such as the study undertaken by Carrington et al. (1996), there was seldom exploration into subsequent quality of life. A Poland based study by Juzwyszyn et al. (2022) explored the relationship between acceptance, quality of life and nutritional status for 99 individuals, 42 of whom had below ankle amputation. Juzwyszyn et al. identified that those with overall better quality of life, as determined by the WHOQOL-BREF, had improved acceptance of illness. Despite amputation reducing physical function and mobility was for participants those who had a good social network and expressed positive coping strategies to assist with adaptation to amputation expressed no deterioration to quality of life.

This Chapter has focussed upon exploring the impact below ankle amputation had upon quality of life. Exploration of the lived experiences of interview participants enabled the researcher to gain insight into what was essential for good quality of life. These could be considered within 3 main themes, self-identity, social support and environmental aspects. Self-identity incorporated how participants perceived their physicality, emotional identity, economic identity, body image,

and their dignity, pride and persona. In essence, how they saw themselves as a person, and how they contributed to their society. Social support explored the importance of partner, family, friends and social inclusion to quality-of-life following amputation. The necessity of these relationships for those with amputation to feel integrated into their lived world. The importance of medical team support was highlighted, the educational input and guidance important during the rehabilitation process, seen as a positive coping strategy to enable adaptation to the amputation. Environmental themes were related to the situation and world within which the person lived their life. For the majority of participants, they were able to remain within their home. For some, with little social support from a partner, family or friends this resulted in having to move from their home and relocate, impacting upon social inclusion.

The conceptual idea developed within the data analysis process that adaptation and quality of life have a symbiotic relationship and cannot be viewed in isolation has been summarised within Figure B. Although not a perfect representation of the complexities of adaptation and quality of life, the researcher has aimed to provide a visual representation of the consequences of adaptation upon quality of life. Positive adaptation, the use of active coping strategies to accept the amputation resulting in a positive attitude to quality of life. Those still grieving for the amputation stuck purporting a worsened quality of life. The vital importance of social support is seen for both quality of life and adaptation, the medical team contributing to enabling active coping strategies to be chosen by providing expert guidance and educational input as the expectations of the rehabilitation journey.

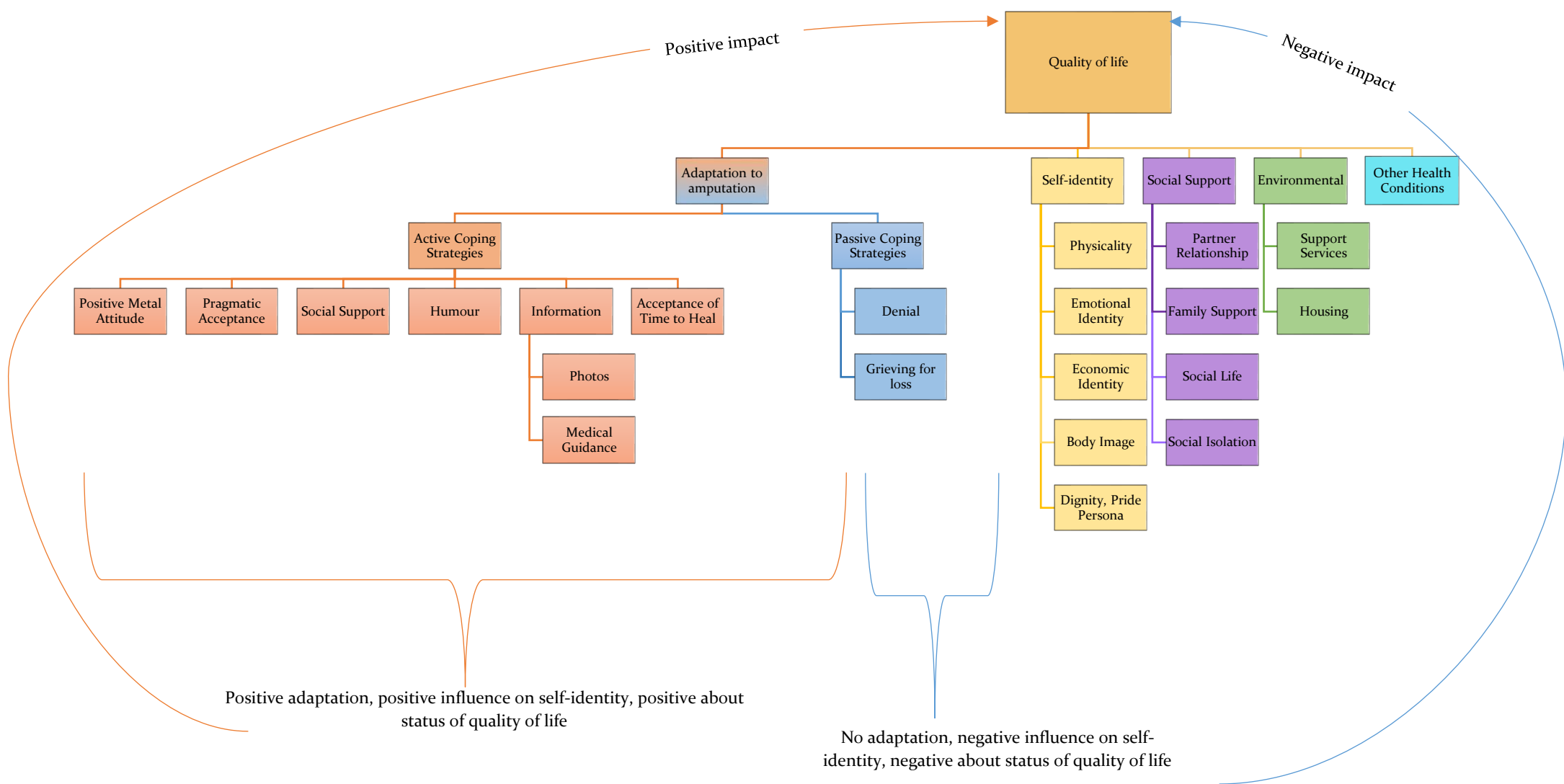


FIGURE 13 CONCEPTUALISATION OF QUALITY OF LIFE FOR INDIVIDUALS WITH DIABETES AFTER BELOW ANKLE AMPUTATION

The logical conclusion if this figure is accepted is clear, quality of life is complex and subjectively understood. By exploring the lived experiences of those who had undergone below ankle amputation the researcher was able to gain insight into what was important to quality-of-life following amputation. Essentially if an individual was able to successfully use positive coping strategies to adapt to the amputation and could adapt to potential changes to self-identity such as reduced physicality, changes to economic identity, body image or persona, then life, although changed, was not subjectively perceived as impaired. This also explains why generic measures such as the EQ-5D provide little insight as adaptation and the complexity of themes and aspects important for quality of life as established by this research are not explored.

Chapter 8 concludes the thesis and provides a synopsis of all findings. This integrates the findings explored within Chapters 5, 6 and 7. Finally the new knowledge presented within this thesis is explored in terms of implications for future research and clinical practice. With plans for dissemination and continuation of this work outlined.

Chapter 8: Synopsis of Findings and Conclusion

Precis of the Research Process

Chapters 5, 6 and 7 have explored the data as derived from the thematic analysis of 28 individual interviews. Template analysis, a form of thematic analysis was utilised to navigate and order this data. The findings identified that the impact of below ankle amputation upon quality of life was multi-faceted, and that this needed to be considered within the context of an individual's ability to adapt to the amputation. As presented in Chapter 1, without exploring adaptation, previous amputation and quality of life research presented unclear findings with regards to the impact below ankle amputation had upon quality of life. Due to the choice of measures used in the previous research, most findings identified that changes to quality of life were focused upon physical function and identified either no, some or large alterations to physical function. Qualitative studies provided exploration of the impact of alterations to physicality, identifying there were psychosocial consequences of amputation.

Within the current research, data collection occurred at one MDT site. This was intentionally chosen by the researcher as the site had responsibility for a county with a mix of urban and rural communities and a wide range of economic situations. The site also provided what was considered to be optimal management of active foot problems within the current national guidelines. The MDT team were research active both in terms of undertaking studies and in implementing findings to enhance care. Twenty-eight individual qualitative interviews of between 30-45 minute duration provided a rich and detailed capture of the world as lived by those who had undergone below ankle amputation. The process of data collection and analysis occurred simultaneously which meant there was reflection upon the insights into the lived world of the individuals. The conceptual ideas and developing themes were discussed with participants to identify if the researcher had accurately captured these experiences. Sharing

findings in this way also enabled participants to reflect upon their own experiences and consider what was important to quality of life.

The researcher sought to be aware of potential bias by publication of a precis of knowledge with regards to quality of life and amputation prior to data analysis occurring (Levy et al., 2017). This acted as a referral point for the researcher, a line in the sand to be able to identify how perceptions altered during the process of analysis, reflection and reflective writing of the thesis. Furthermore, the initial analysis of a subset of data was shared with the supervisory team and presented at a regional conference attended by those working with individuals with diabetes (Levy, 2018). A workshop was held with conference attendees exploring quality of life and this enabled the researcher to explore other world perceptions and interpretations of the data and themes presented (See Appendix 2 for workshop feedback). Consideration of this input was incorporated into the analysis process, the results of which were expressed within Chapters 5,6 and 7.

Synopsis of Findings

The current research identified that physical function, denoted as physicality within the research was not solely important to quality of life. Quality of life was multifaceted and how quality of life was affected by amputation could not be explained if purely expressed in terms of the level of amputation and the resultant reduction to physical function. From this study, it has been identified that an individual's perception of their quality of life was related to how successfully they accepted the amputation. This was regardless of the level of the amputation which occurred or the resulting physical ability to continue to perform activities which were part of their life prior to the amputation. Factors confounding successful adaptation and ergo, quality of life, were social aspects such as having no partner, loss of social activities or

environmental constraints such as lack of availability of benefits and social support services. The lack of support hindered the adaptation process and impaired quality of life.

The author suggests that application of the new knowledge presented here would enable those working with patients pre or post below ankle amputation surgery to identify individuals who may express a worsened quality of life after amputation. Analysis of data from the current study indicated those using maladaptive strategies such as avoidance, blaming others for the amputation, or still grieving for the amputation, reported a reduced quality of life. Despite acknowledging amputation had resolved debilitating pain, life was still worsened for these individuals. Conversely, those who adopted positive adaptation strategies acknowledged their reduced physicality, or compromised social life, but accepted these changes and the revised self-image and as such reflected that quality of life was the same or improved. These results demonstrate why previous research reliant upon outcome measures portrayed contrasting findings as to the impact of amputation upon the individual as adaptation, acceptance and true quality of life exploration was not included.

The findings of this study, that quality of life is impacted upon by factors such as adaptation and that the researcher should look wider was supported by Lounsbury et al. (2014) who explored how social forces impacted upon quality of life. The resultant findings were portrayed within a causal loop diagram and showed the impact of social and environmental factors at play upon quality-of-life perception. In fact, if considered from the adopted definition of quality of life purported by Schalock et al. (2016), this style of research should be the norm, and the complexities of quality-of-life assessment acknowledged in future studies.

The conceptualisation of quality of life within the current research for those who have undergone below ankle amputation has similarities to Schalock et al's (2016) conceptual framework which was adopted as the working definition for quality of life for this current study. Schalock et al. expressed that quality of life was multi-dimensional and should be centred upon

the well-being of the individual. The current study concurred with this idea and identified the importance of physical and emotional well-being, the value of social inclusion, maintaining relationships and social participation for quality of life. These aspects were recognised within the current research as codes relating the themes of self-identity and social support. The current research also recognised the importance of external factors such as living conditions, access and availability of social care support to enable an individual to successfully adapt to the amputation. These were included under the environmental theme, and it was recognised that due to the complexity of diabetes and the likely co-morbidities that quality of life may be impacted upon due to the consequences of these complications rather than the amputation itself.

The current study also identified that adaptation to amputation could positively or negatively impact upon quality of life perception. Those utilising positive, active coping strategies reflected upon no change or an improvement to aspects of quality of life post-amputation. Conversely, those struggling to adapt reported a worsened quality of life. These findings are portrayed within Figure B which provides a visual summary of the conceptualisation of quality of life for those who have undergone below ankle amputation. The figure illustrates the interplay of positive or negative adaptation strategies upon overall perception of quality of life.

Changes to the Author following the Research Process

The process of undertaking this research changed me and my approach to education. As a Senior Lecturer I have leadership responsibilities for modules relating to high-risk patient management, essentially those patients who may experience ulceration or amputation. Module leadership enables me to explore these topics and develop module content, decide upon assessment methods all relating to enabling students to gain insight into this group of

individuals, exploring the current evidence base for assessment and management. I had the opportunity to reflect upon my own educational experiences, and to consider my responsibilities to a new generation of podiatrists and those undertaking masters to deepen their knowledge and understanding, exploring the guidance to use quality of life as an outcome of care.

This led quite naturally to reshaping sessions, exploring the findings of this research with the students. Showing them what outcome measures are recommended for use. Lively discussions were held after students completed the EQ-5D, the recommended measure for England, and led to considering active listening skills, and the importance of holistic care. The undergraduate module is comprised of both theory and clinical sessions, so this enabled students to put theory into practice within the clinical environment at the university. This led to exploration of what outcomes mean and has led to focus also being put upon patient perception rather than purely quantitative measures. For practitioners enrolled upon master's programmes to enhance patient care, this has led to consideration of what measures are used in practice, and also with a wider exploration of what care should look like pre and post amputation.

Conclusion

To conclude, thematic analysis of the 28 interviews has demonstrated the complexity of quality of life, and that tools which only explore health related concepts do not accurately capture life as lived by these individuals. It is the complexity of the interactions between acceptance of the amputation which determines an individual's perception of their quality of life. Adaptation strategies utilised by individuals who experienced below ankle amputation impacted positively or negatively upon perception of quality of life. This new knowledge has been summarised within a conceptual model presented in Figure 13 which includes the causal effect of positive or

negative adaptation strategies and the impact of lack of benefits of social health care support during adaptation.

Implications of the Research

The findings of the research have implications for the clinical teams providing care for those who have experienced below ankle amputation. Data is currently gathered from these individuals to determine service quality and an indicator of quality of life. The current research has identified that measures currently in place and utilised to explore quality of life are insufficient. To gain meaningful feedback a new condition specific measure is necessary. This measure should incorporate factors wider than those currently assessed by the UK recommended EQ-5D and should look to benchmark patient perception about the forthcoming amputation to personalise care around individual needs. To capture individual quality of life this should explore adaptation to amputation and should be flexible, enabling the individual to shape the tool, adding or eliminating elements to capture the essence of what is important to them.

The implication for research is clear, research is required for developmental design and validation of a measure to assist clinicians involved within diabetes care to individualise protocols and guidelines to enable patients to attain their best possible quality of life.

Implications for Future Research

1. Development of adaptation and quality of life measure for diabetes associated amputation.
2. Trialling, validation and publication of measure.
3. Integration of measure into accepted outcome measures for clinical practices.

Implications for Practice

1. Those experiencing below ankle amputation should be considered to have the same needs as those adjusting to above ankle amputation:
2. Physical and emotional needs should be considered throughout the whole experience – pre and post operatively for successful adaptation and quality of life.
3. Care is necessary for years after the event, not just in the short term, and this should be recognised within management plans.
4. A culture shift is required away from terms such as “salvage procedure” or “minor amputation” as this diminishes the lived experience of those undergoing below ankle amputation.

5. Post-amputation care requires joining up. All participants are disadvantaged regardless of level of social deprivation in terms of expert post-operative care within the home.
6. The benefits and social care system have a lack of understanding with regards to the length of rehabilitation time for below ankle amputation:
 - a. Below ankle amputation does not 'fit' within the current assessment criteria, when reviewed by experts at tribunal support is provided. Alteration of the assessment criteria is necessary.
 - b. Time for rehabilitation should be recognised. Support may be required for years rather than months.

When considering the points of implications for practice, the publication of the findings of the thesis within journals and at conferences which target those involved in the management of the diabetic foot is essential. Only by publicising these findings can others working within the field be aware of the lived experiences of those who have undergone below ankle amputation and the impact adaptation can have upon quality-of-life post-amputation.

Within the body of published data and literature, below ankle amputation can be referred to as a 'minor amputation' or a 'salvage procedure' (Nazri et al., 2019; Rajendran et al., 2012). Currently, within the National Foot Audit for England and Wales, below ankle amputation is perceived as a way attain wound healing. The impact to the individual not considered, nor are rates of healing achieved by below ankle amputation documented (National Diabetes Footcare Audit [NDFA], 2019). The continued use of this terminology has trivialised amputation which includes procedures from amputation of a toe to removal of half a foot. The findings of this research indicate that there is an impact of below ankle amputation upon quality of life.

Participants did not just express relief that a limb was saved, that a wound was healed, rather they shared their experiences of events leading to the amputation, their journey to acceptance, coping and adjusting. Even for those who expressed no change to quality of life once wound healing resolved, there were adjustments to self-identity to adapt to changes in persona, physicality, social activities, working life, and family role. Coping strategies were utilised to ensure quality of life remained undiminished. Lesser levels of amputation did not necessarily relate to less impact to quality of life, rather acceptance and adjustment were key. This was clearly individually defined by each participant's own circumstances. Below ankle amputation can no longer be referred to as a 'salvage' procedure. There are physical and psychosocial impacts for the individual.

This work is timely, the Diabetes UK publication "Too Often Missing" (2019) highlighted the psychological impact of diabetes if often not recognised and recommended that psychological and emotional support should be a routine aspect of management, and additional support being recommended to be in place when a complication occurred. These thoughts are also supported by iDEAL's call to action. iDEAL, a multidisciplinary group aiming to ensure best care for all those with diabetes, built upon the Too Often Missing ethos and provided a list of recommendations for health care, to include physical and mental health outcomes with assessment of care, for these to be integrated into NICE guidance so that there is a national adoption of these practices and to provide training and development for health care professionals working within diabetes (Doherty et al, 2020). The author will take this opportunity to approach groups after the publication of the findings have been published to explore the potential.

There is scope for the author to further explore the experiences of those who have undergone below ankle amputation in collaboration with a one of the National Institute for Health and Care Research (NIHR, 2020) key priority area for research is exploring multiple long-term conditions. By collaboration with a MDT diabetic foot team, research could be undertaken to

explore the potential benefits of trailing additional psychological and emotional support as recommended by Diabetes UK and iDEAL.

Only by publishing and connecting to special interest groups, those with an interest in enhancing care will these recommendations for practice come to fruition. The author is keen to be part of this continuing work.

Continuation of Work

“Whatever you’re meant to do, do it now. The conditions are always impossible.”

Doris Lessing

Work Already Completed

The subset data findings were shared at a Diabetes UK Regional conference, providing clinicians with the opportunity to explore quality of life and to consider how to integrate this into patient care. The author has presented the initial findings of the research to the multidisciplinary foot clinic team at the data collection site to influence local patient care. There is the intention to return to the site as a research collaborator.

Work in Planning

The author intends to publish a new review paper from Chapter 1, incorporating research published 2017 onwards. A methods paper is planned as use of template analysis is new within diabetes amputation research and Podiatric research. The findings from Chapters 5,6 and 7 and

conceptual framework presented in Figure 13 will also be published to demonstrate the new knowledge and understanding gained from exploring the lived world of those who have undergone diabetes related below ankle amputation.

The author will integrate key messages surrounding the importance of holistic assessment, and the importance of research within the undergraduate and postgraduate programmes they contribute to.

Concerning the research recommendations, the author is beginning to explore the opportunities for working collaboratively with other researchers interested within quality of life research and enhancing patient care.

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Appendices

Appendix 1 Application of Hawker et al's Critical Appraisal Tool to Studies Included in the Literature Review

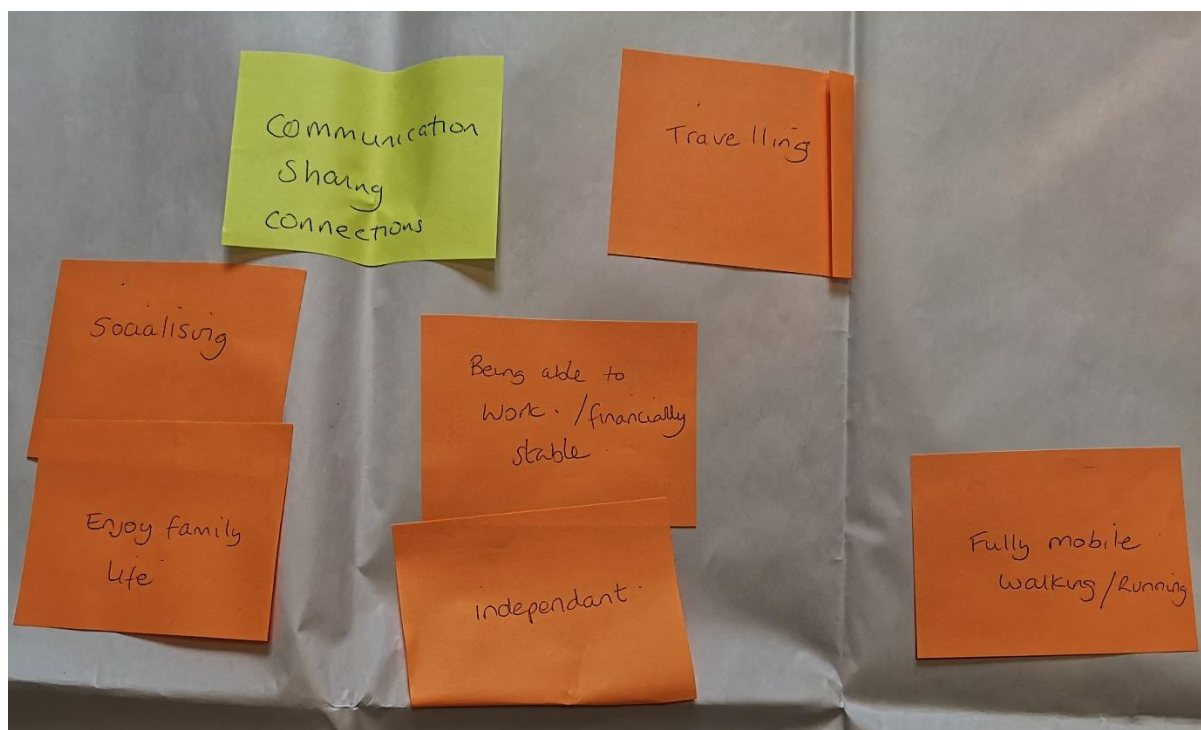
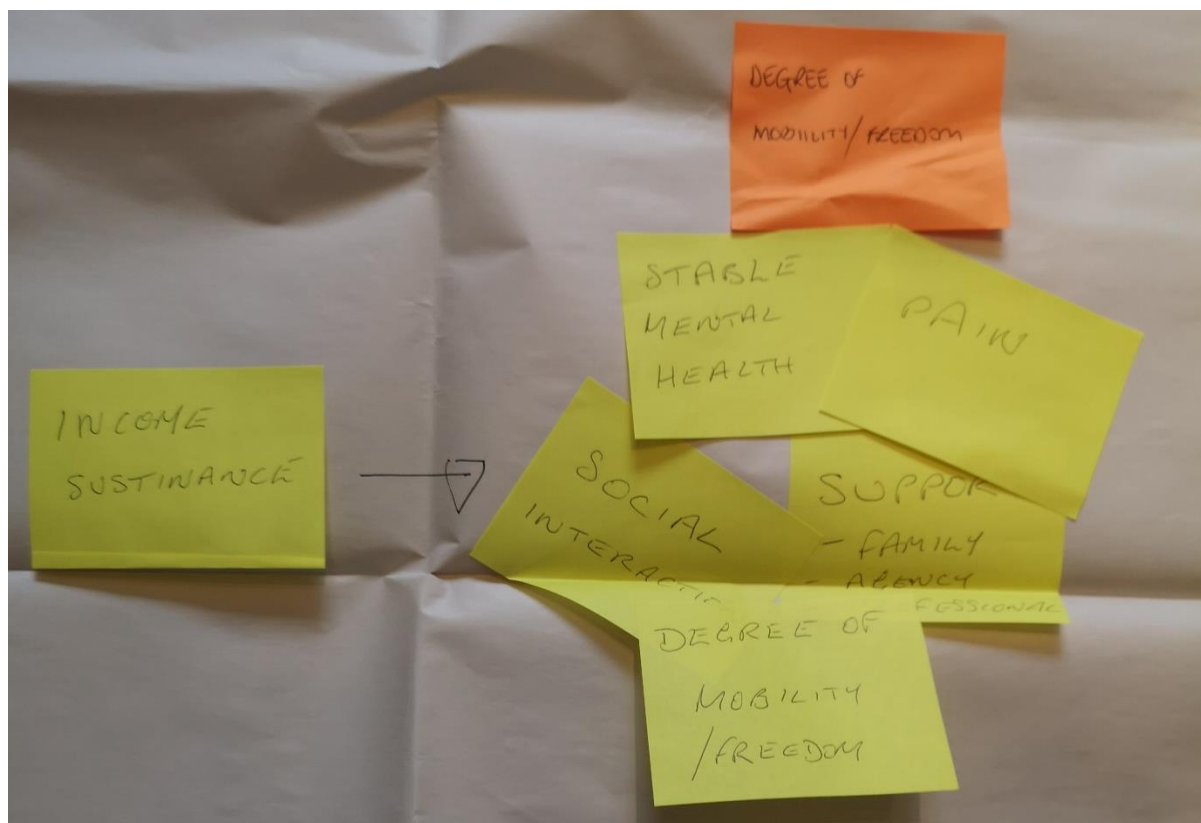
TABLE 13 APPLICATION OF HAWKER ET AL'S (2012) CRITICAL APPRAISAL TOOL TO STUDIES INCLUDED IN THE LITERATURE REVIEW

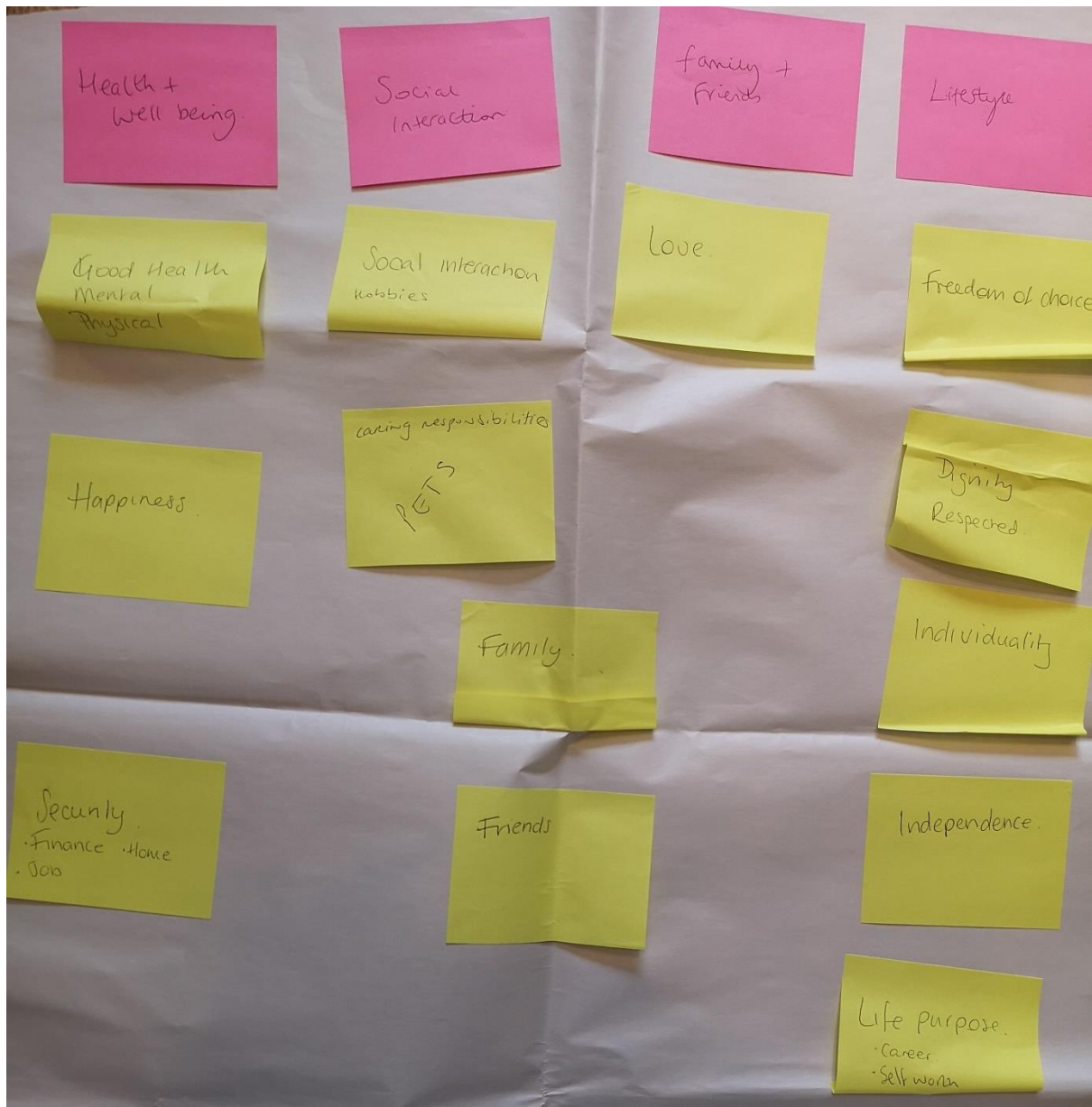
Author	Abstract and Title	Introduction and Aims	Method and Data	Sampling	Data Analysis	Ethics and Bias	Findings/ Results	Transferability/ Generalizability	Implications	Total Score
Alva et al. (2014)	Good	Good	Good	Fair	Good	Very Poor	Good	Poor	Fair (research)	29 High
^Amoah et al. (2018)	Good	Fair	Good	Fair	Poor	Very Poor	Fair	Fair	Fair (research)	26 Fair
Aprile et al. (2018)	Good	Good	Good	Good	Good	Good	Good	Good	Fair (research)	36 High
^Barg et al. (2017)	Fair	Good	Fair	Fair	Fair	Very Poor	Fair	Poor	Fair (research)	25 Fair
Boutoille et al. (2008)	Good	Poor	Fair	Poor	Fair	Very Poor	Good	Poor	Fair (research)	24 Fair
Carrington et al. (1996)	Good	Good	Good	Poor	Fair	Very Poor	Fair	Poor	Good	26 Fair
^Crocker et al. (2021)	Good	Fair	Fair	Good	Fair	Poor	Good	Fair	Fair (research)	23 Fair
^Dillon, Anderson et al. (2020)	Good	Good	Good	Good	Good	Fair	Good	Fair	Fair (research)	33 High
Dillon, Quigley et al. (2020)	Good	Good	Good	Good	Good	Fair	Good	Good	Good	34 High

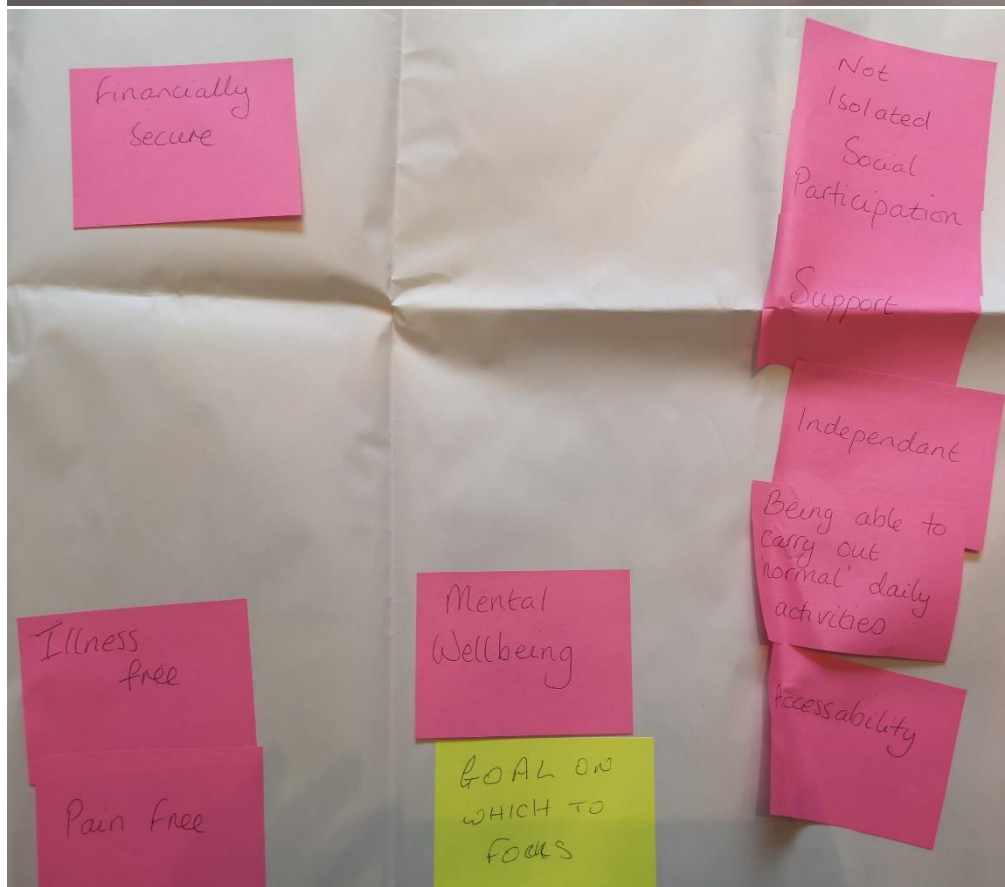
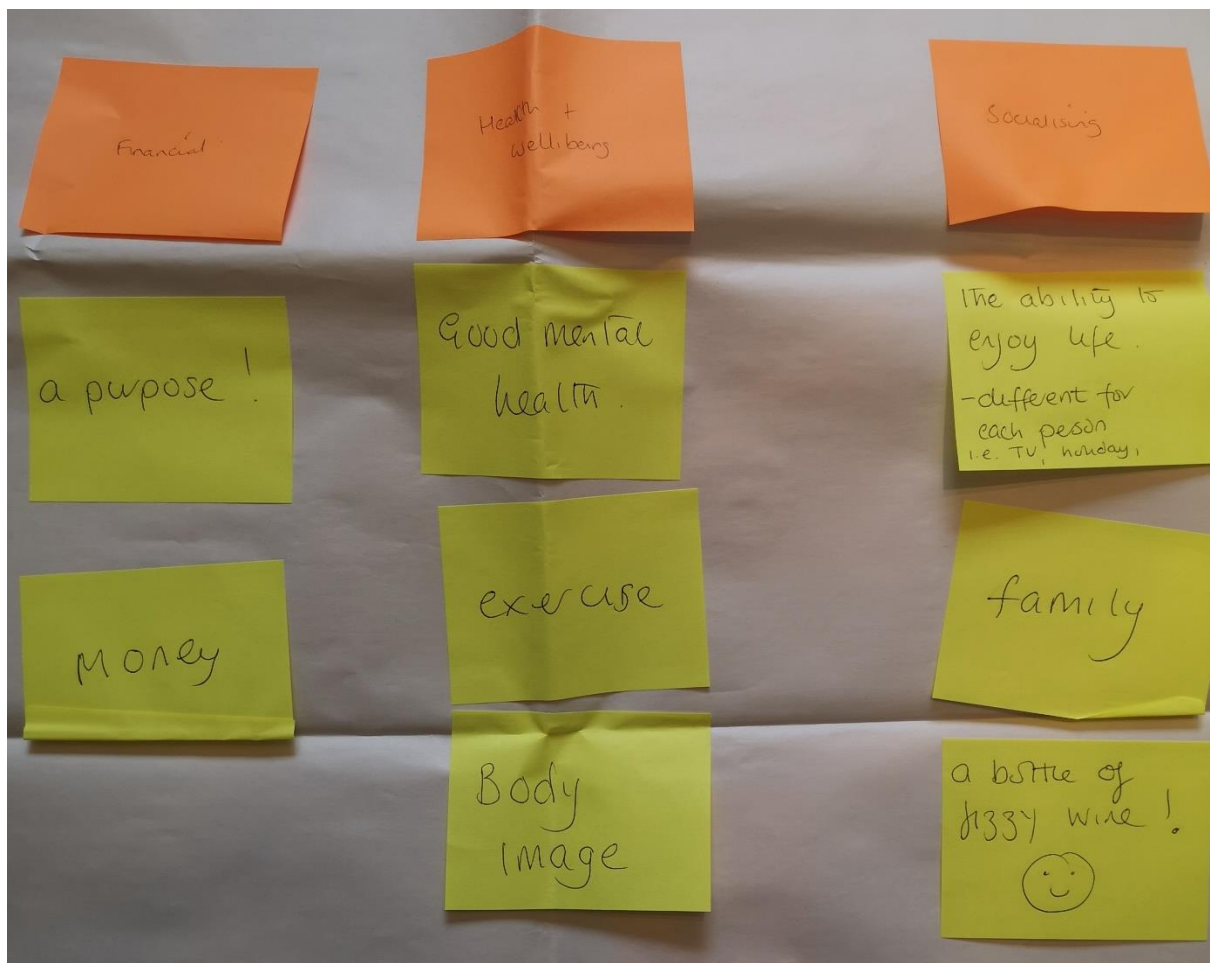
Author	Abstract and Title	Introduction and Aims	Method and Data	Sampling	Data Analysis	Ethics and Bias	Findings/ Results	Transferability/ Generalizability	Implications	Total Score
^Foster and Lauver (2014)	Good	Good	Good	Good	Good	Good	Good	Fair	Fair (research)	34 High
Hayes et al. (2016)	Good	Good	Good	Good	Good	Very Poor	Good	Good	Good	33 High
Juzwisy et al. (2022)	Fair	Good	Good	Very Poor	Good	Fair	Good	Fair	Poor	28 High
McDonald et al. (2014)	Fair	Good	Good	Very Poor	Good	Poor	Good	Poor	Fair (implications for policy)	27 High
Nazri et al. (2019)	Good	Fair	Fair	Fair	Poor	Poor	Fair	Fair	Fair (research)	23 Fair
Pedras et al. (2016)	Good	Good	Good	Good	Good	Fair	Good	Good	Fair (research)	34 Hight
Peters et al. (2001)	Good	Fair	Good	Poor	Good	Very Poor	Good	Very Poor	Fair (research)	26 Fair
Pickwell et al. (2016)	Good	Good	Good	Good	Good	Good	Good	Good	Good	36 High
Quigley et al. (2016)	Good	Good	Good	Good	Good	Good	Good	Fair	Good	35 High
Ragnarson Tennvall & Apelqvist (2000)	Good	Good	Good	Good	Good	Good	Good	Good	Good	36 High
Ribu et al. (2008)	Good	Good	Good	Good	Good	Good	Good	Fair	Fair (research)	34 High
Sothornwit et al. (2018)	Good	Good	Fair	Poor	Good	Very Poor	Fair	Poor	Poor	25 Fair

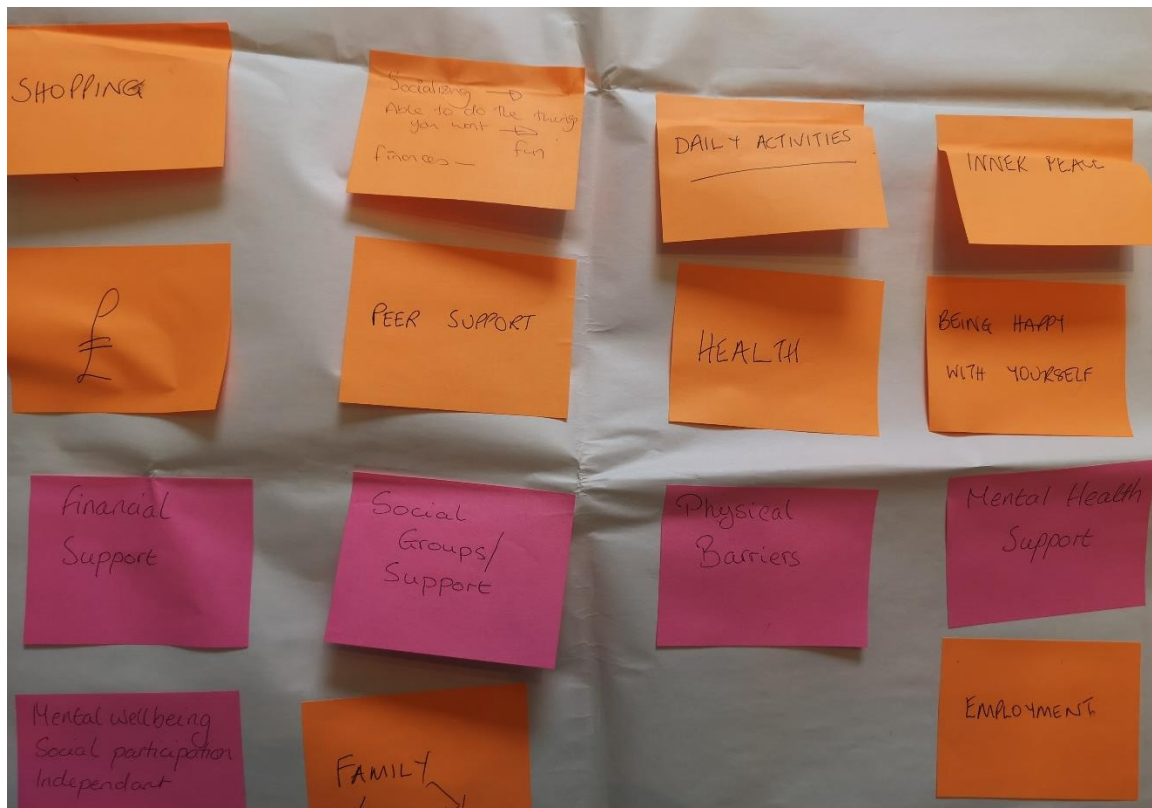
Author	Abstract and Title	Introduction and Aims	Method and Data	Sampling	Data Analysis	Ethics and Bias	Findings/ Results	Transferability/ Generalizability	Implications	Total Score
Spanos et al. (2017)	Good	Good	Good	Poor	Good	Good	Good	Good	Fair (research)	30 High
Willrich et al. (2005)	Good	Fair	Poor	Very Poor	Fair	Poor	Fair	Very Poor	Poor	21 Fair
Winkley et al. (2009)	Good	Good	Good	Good	Good	Poor	Good	Good	Fair (research)	33 High
Zhang et al. (2012)	Good	Poor	Good	Poor – sample size	Good	Very Poor	Good	Fair	Fair (research)	24 Fair

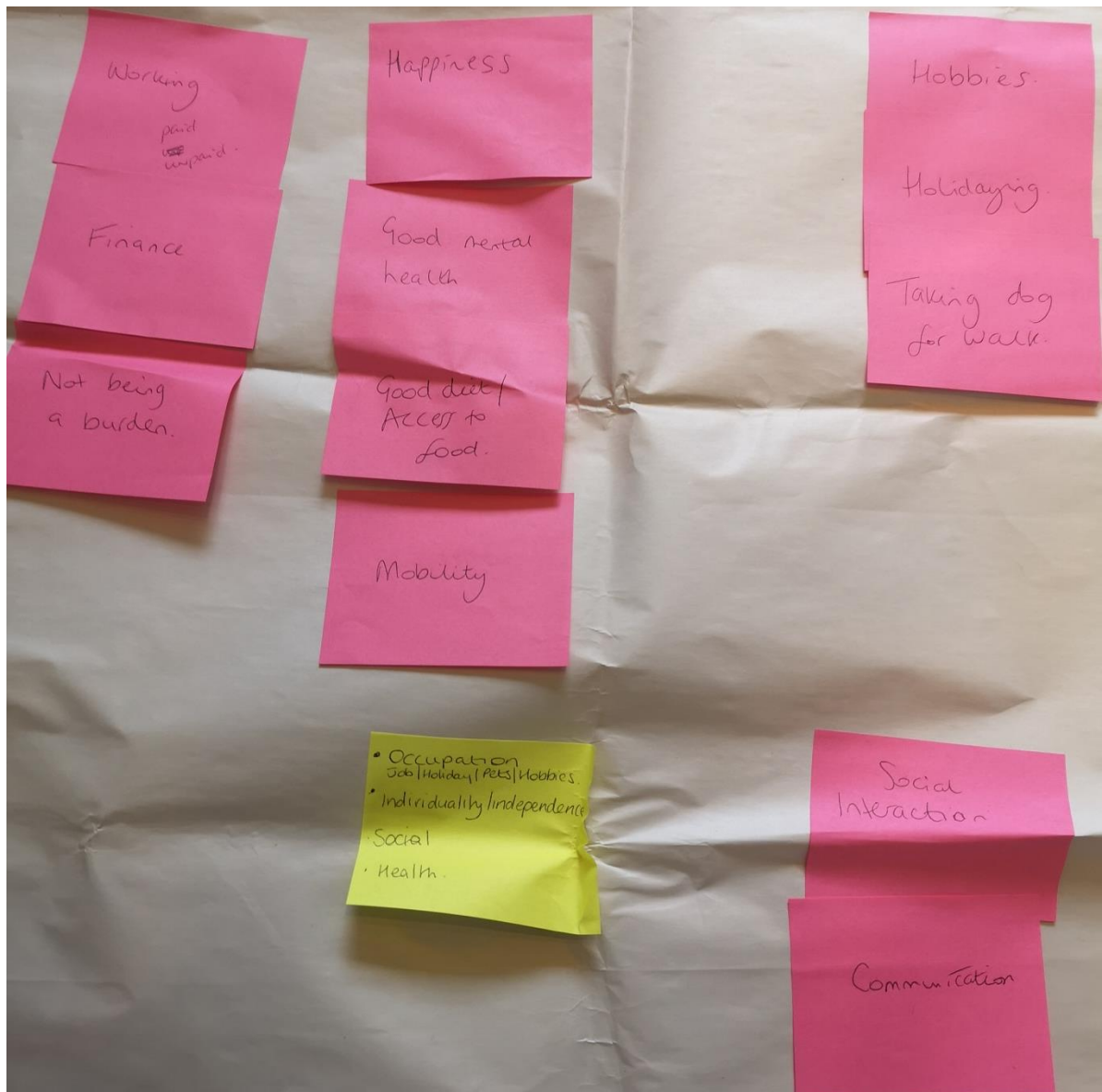
Appendix 2 Feedback from Quality of Life Presentation Workshop











Appendix 3 Documentation Forming Local Research Pack

Research Protocol

Research Protocol for Quality of Life, Diabetes & Amputation Research.

Exploring patient experience of amputation

Main Question:

What is the impact of minor lower extremity amputation on quality of life for individuals with type 2 diabetes mellitus?

Subsidiary questions:

What factors are important to quality of life for individuals with Diabetes mellitus and minor lower extremity amputation?

Aim

The overall aim of the research project is to explore what impact minor lower extremity amputation has had upon quality of life for patients with type 2 diabetes

Objectives

This is a new field of research as such no previous research has explored quality of life for this specific group. In order to achieve the overall aim, the following objectives require completion

- Determining the factors which are included in the conceptualisation of whole quality of life for individuals with type 2 diabetes and minor lower extremity amputation
- Exploring the impact minor amputation has had on conceptualisation of quality of life

Background

The consequences of diabetes associated complications in the lower limb are costly, both to the individual and the economy. Complications which may result in ulceration or amputation are present in 10% of the type 2 diabetes population at diagnosis, and current National Health Service spend on these is £8.1 billion (Hex, Bartlett, Wright, Taylor, & Varley, 2012). Due to this heavy cost, national service frameworks and clinical guidelines recommend regular surveillance, timely investigation and management of complications to minimise morbidity, mortality and economic cost (Department of Health, 2001; McIntosh et al., 2003).

Despite this strategy, the rates of below ankle amputation in type 2 diabetes are increasing within England (Rajendran, Davies, & Coppini, 2012; Vamos, Bottle, Majeed, & Millett, 2010). Authors of these studies have suggested that this is due to minor amputation being used to prevent loss of limb, enabling a patient to maintain physical function, or may be in part

attributed to better survival rates of patients with multiple complex morbidities, resulting in more necessity for amputation.

Regardless of rationale, extensive literature searching indicates that no previous study exists which explores the impact of minor amputation from a patient perspective. Until this proposed project no research has explored how the specific group conceptualise quality of life or the impact minor amputation has had upon quality of life.

As conceptualisation of quality of life has not been established, there is no information as to which factors or domains are important to quality of life, and so the use of a pre-existing quality of life measure could lead to incorrect assumptions and meaningless results. It is therefore important to determine how individuals who have undergone minor lower limb amputation define quality of life. Authors such as (Jenkinson & Ziebland, 1999) support this perspective and believe that work using semi-structured interview techniques is necessary within a new area of study to establish what would be appropriate measures to assess. This is reflected within the intended design of this study, where individual interviews will be undertaken to explore quality of life and minor lower extremity amputation for individuals with type 2 diabetes mellitus.

Design

A qualitative study with a hermeneutic phenomenological approach has been selected. This methodological approach has been selected as it enables the study of the first person experience of a specific situation or event (Todres, 2005). In order to gain a deep understanding of quality of life and minor lower extremity amputation, a maximum of 30 individual interviews are to be undertaken to explore conceptualisation of quality of life with individuals with type 2 diabetes mellitus and minor lower extremity amputation, and the impact amputation has had on quality of life. Interviews will be semi-structured, in that there will be an interview outline, but that additional unplanned questions may be asked to explore new topic areas around quality of life (Kvale & Brinkmann, 2009). This is to ensure the researcher develops a depth of understanding around the topic. Some participants may be asked to review transcripts of interviews to ensure the interview is captured accurately.

Population

Defining the Population

Within the NHS data is collected on a standardised coding system, the Office of Population, Census and Surveys classification of Interventions and Procedures. Through a combination of this and the use of the international classification of diseases it has been possible to identify individuals with type 2 diabetes mellitus who have undergone minor lower extremity amputation.

Defining Lower Extremity Amputation

Currently there is no global definition for minor lower extremity amputation, and the level of amputation presented as minor varies. To ensure that the results of this study are comparable to previous work the definition of minor lower extremity amputation for this study is to be *any amputation distal to the ankle joint*.

Inclusion Criteria

Type 2 Diabetes Mellitus

Non-traumatic minor lower extremity amputation

Over 18

English speaking

Exclusion Criteria

No diagnosis of Type 2 Diabetes Mellitus

Individuals unable to understand English

Impaired capacity of provide informed consent

Traumatic lower extremity amputation

Under 18 years of age

Sampling Strategy

It is envisaged that there will be interviews with a maximum of 30 participants. This limit is in part due to the intention of the researcher to develop rich data to be thematically explored, and also in part due to time constraints of a doctorate programme.

The study will be advertised within NHS premises. Staff involved within direct care will be informed of the study. Patients can approach a member of the direct care team for a participant information sheet and then decide if they may wish to participate in the study. The direct care team will then complete the Permission for Researcher Contact forms.

The Researcher will then contact these individuals directly to answer any further questions about the research. If the individual wishes to proceed to being part of the study, then a suitable location and time will be arranged. Consent to participate within the research will be signed after this.

Interviews will be held in a location convenient for the individual. This may be within a private consultation room within NHS premises to co-ordinate with a follow-up appointment, or within the home of the interviewee.

Data Collection

All interviews will be audio recorded. Notes will also be taken by the researcher immediately after the interview of key ideas that have emerged during the interview process. Transcripts will be pseudonymised and transcribed. NVivo (computer software package) will be used to aid with organisation of data for analysis.

Data analysis

Template analysis will be used to analyse the transcripts. Template analysis has been chosen as it is based upon a phenomenological philosophy and allows for an awareness of the topic area and *a priori* themes to be utilised within the initial template developed to analyse transcript (King, 2012).

Reflexivity / Researcher Awareness

A research diary will be kept throughout the data collection and analysis phases of the study. For the researcher, an awareness of personal beliefs and biases will assist in keeping an open mind throughout data collection and analysis to prevent interpretation being limited to the researcher's own perceptions. For readers, it will aid with understanding what has influenced the researcher's world view, and the philosophical context in which the research has been undertaken and analysed.

Credibility

Within the data collection, this responsibility lies in accurately capturing the participants experience-as-lived. Credibility can be assured by sharing these transcriptions with the participants to ensure the interview has been transposed accurately. Throughout data analysis, the researcher must recognise the aims and objectives of the research. A researcher journal will be kept so that ideas relating to thoughts regarding analysis are able to be reported within the thesis.

Ethical Issues

Informed Consent

Participants will be fully informed of the nature of the study; this will be ascertained by providing the participant information sheet to all interested in participating within the study and by the Researcher discussing any queries prior to consent form been completed.

Confidentiality

Members of direct care team will be aware of potential research participants for the study. This is because they may be dispensing and discussing the information sheet with patients interested in participating in interviews.

Likewise, if interviews occur on NHS premises rather than the individual's own home, the direct care team may be aware of participation within the study, but the data gathered from this will not be divulged to the team.

Confidentiality for the content of the audio recorded interview will be maintained by participants being allocated a pseudonym during transcription. Audio recordings will be uploaded and stored as MP3 files. Once uploaded, the original recording will be erased from the recorder.

All electronic information will be password protected and stored on a secure server.

Hard copies of documents will be kept in locked drawers within a locked office. Only the researcher and supervisory team will have access to this data.

All data will be destroyed 10 years after completion of the study in line with University of Huddersfield Ethical Guidelines for Teaching and Research (2011)

Anonymity

The identity of research participants will be known only to the researcher. The researcher will anonymise all data, replacing participant names with pseudonyms. Pseudonyms will also be used at the beginning of recording prior to the interview.

Psychological support for participants

There is the potential that participants may find discussing their amputation experience upsetting, although some people find it a positive experience to talk through issues such as this. It is unlikely that there will be on-going distress caused by the interview; however, should any issues remain participants will be offered the details of health psychology support and advised to request referral via their Gp. Should a participant become emotional during the interview, the participant will be asked if they wish to pause or terminate the interview. This will be the decision of the participant.

Right to withdraw

Individuals will have the right to withdraw from the interview at any point. The consent will make clear that data gathered up to this point in the study will be used unless the participant expresses the wish for previously collected data to be withdrawn from the study. The consent will also clearly explain that quotations from the interviews will be used for write-up and publication, these will be pseudonymised.

Benefits of the research

The research will create new knowledge about the effect of minor amputation on quality of life. This is important, as at present there is research which indicates the negative effect of chronic ulceration to quality of life. Chronic ulceration has been found to have a detrimental effect upon aspects such as socialisation, physical and psychological functioning (RagnarsonTennvall & Apelqvist, 2000). Exploring the impact, positive or negative that minor amputation has had may enable alternative treatment strategies to be considered for patients with chronic ulceration.

Currently, amputation is perceived as a failure of care, with foot health profiles (YHPHO, 2014) presenting rates of amputation, but not rationale for amputation. The findings of this research would provide a patient context to amputation.

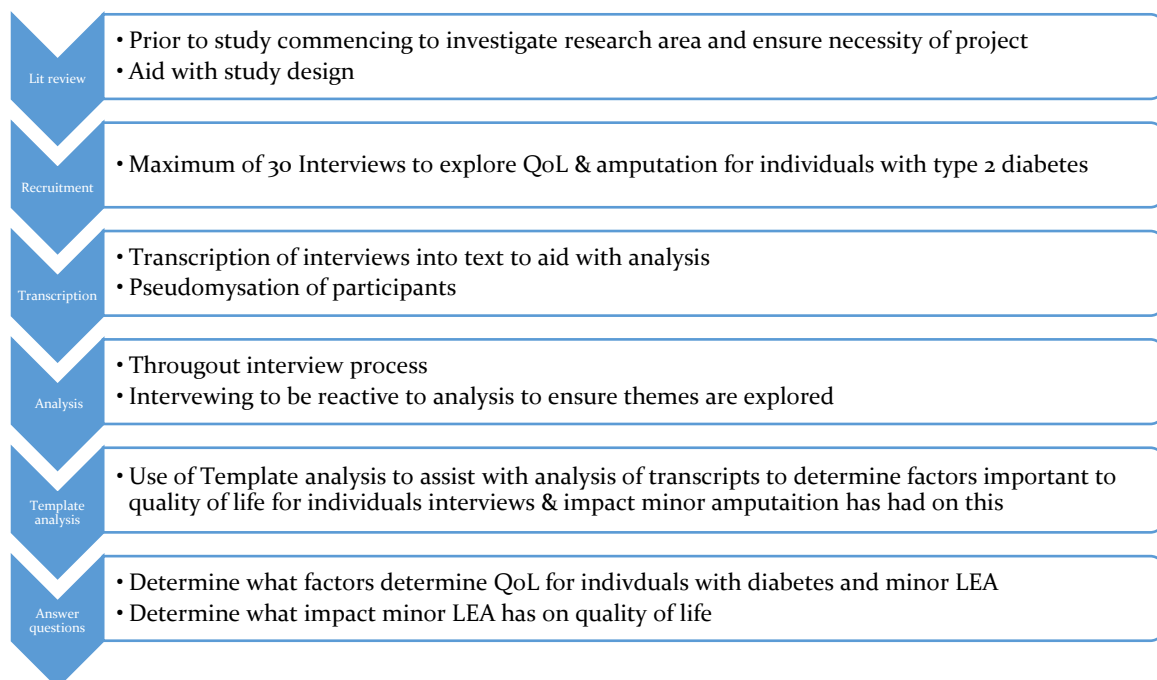
Finally, work conducted by the (Patient-Reported Outcome Measurement Group, 2009) concluded that no single tool exists which encapsulates the entire spectrum of experiences within diabetes. They have recommended that a combination of a health generic measure (EuroQol) and a diabetes specific instrument should be used to benchmark patient reported

outcomes. The findings of this research could contribute to the development of a diabetes specific instrument which would address quality of life and minor amputation to assist with determining patient perceived success of management.

Resources and Costs

This research forms part of doctoral studies, and so is funded by the University of Huddersfield. The researcher is also the chief investigator and is responsible for collection of all data.

Overview of Research





Quality of Life, Diabetes & Amputation RESEARCH

Exploring patient experience of amputation

Information Sheet

What is the purpose of the Study?

The aim of this research is to explore what is important to your quality of life, how this has influenced your decision about having an amputation, and the impact the amputation has had on your quality of life.

At present there is research published about the number of amputations being performed in the UK, and why clinicians think patients choose to have an amputation. This would be the first study to ask patients about the reasons behind having an amputation and to ask about what impact – positive or negative this has had on your quality of life.

The findings from this work will be published and aim to contribute to information available to patients when deciding about having an amputation.

Who is the researcher for the study?

The study is being done by Natasha Levy, a podiatrist and researcher. This study is being done as part of doctoral studies and I am

being supported to undertake the study by the diabetic foot clinic and supervisors at the University of Huddersfield.

Why am I being asked to take part?

You are being invited to take part as because you have diabetes and have had an amputation.

What happens if I agree to take part?

You will be contacted by the researcher and invited to take part in an interview. I will be able to answer any questions that you may have about the study, only then if you agree to take part, I will arrange a suitable date and time for the interview. The interview will take place either at your next clinic appointment or at a venue of your choice.

The interview will focus on what is important to your quality of life, how this has influenced your decision about having an amputation, and the impact the amputation has had on your quality of life.

What happens at the interview?

The study will be explained to you before the interview starts and you will be asked to sign a consent form if you are still happy to take part. You will be interviewed about what is important to your quality of life, how this influenced your decision about having an amputation, and the impact the amputation has had on your quality of life. The interview will last for between 30-45 minutes depending upon how much you may wish to say. There is no payment for participating within the study.

What will happen to the information?

The interview will be audio recorded and notes will be taken. This is to help the researcher record your thoughts and opinions accurately. The audio recordings will be transcribed to assist the researcher with analysing the interview.

Direct quotations are expected to form part of the thesis, publications, and presentations. Your identity will be protected by use of an alias so you that you not be recognisable from these quotes.

All information collected will be stored securely and any identifying material such as names will be removed in order to ensure you remain anonymous.

Both the recordings and transcripts will be kept securely in line with University of Huddersfield guidelines for 10 years and then destroyed.

What are the benefits or risks of taking part in the study?

Taking part gives you the opportunity to share your experiences of amputation and to assist

in developing awareness of the impact this may have on your quality of life. It is hoped that the results of the study will be used to help support future patients who are considering amputation.

There is the chance you may find discussing your amputation experience upsetting, although some people find it a positive experience to talk though issues such as this. It is unlikely that there will be on-going distress caused by the interview; however, should any issues remain you will be offered referral to relevant support from your Diabetes Team.

What happens if I do not want to carry on in the study?

You may withdraw from the interview at any time. You do not have to give a reason for withdrawal, and it will not affect the standard of care you receive. If you choose to withdraw from the study then any data collected up to that point will not be used in the research.

How long will the study last?

I aim to recruit 30 people to the study. I plan to complete interviewing within 12 months, but the thesis will be completed in 2022.

What will happen with the results of the study?

These will form part of the thesis due to be submitted in 2022. Results will be fed back to the department and Trust to hopefully help future patients who are deciding about amputation. These results will be published via conference presentation and research papers to spread the work wider into the diabetes

community. If you would like a copy of the results, please let me know.

Who has reviewed study?

The East of Scotland Research Ethics Service REC 1, which has responsibility for scrutinising all proposals for research on humans, has examined the proposal and has raised no objections from the point of view of research ethics. It is a requirement that your records in this research, together with any relevant research records, be made available for scrutiny by monitors from the University of Huddersfield and Derby Teaching Hospitals NHS Trust, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

Complaints

If you believe that you have been harmed in any way by taking part in this study, you have the right to pursue a complaint and seek any resulting compensation through the University of Huddersfield who are acting as the research sponsor. Details about this are available from the research team. Also, as a patient of the NHS, you have the right to pursue a complaint through the usual NHS process. To do so, you

can phone a Patient Advice and Liaison Officer on 0800 783 7691, or submit a written complaint to [REDACTED]

[REDACTED]. Note that the NHS has no legal liability for non-negligent harm. However, if you are harmed and this is due to someone's negligence, you may have grounds for a legal action against Derby Teaching Hospitals NHS Trust but you may have to pay your legal costs.

Contact Details

Should you have any further questions regarding the study please contact:

Researcher: Natasha Levy

Email: n.levy@hud.ac.uk

Telephone: 01484 473096

If you have any concerns about the study please contact:

Project Supervisor: Dr Warren Gillibrand

Email: w.p.gillibrand@hud.ac.uk

Telephone: 01484 473689

Independent advice re participating in a study:

[REDACTED]
[REDACTED]

CONSENT FORM 1

Agreement for researcher contact

Title of Project: **Quality of Life, Diabetes and Amputation Research. Exploring patient experience of amputation**

Name of Researcher: **Natasha Levy**

Please initial all boxes

1. I confirm that I have been given a patient information sheet dated 2.2.17 for the above study.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

☐

3. I consent to being approached by the researcher to discuss participating.

☐

4. I agree to the researcher contacting me by telephone as indicated below.

☐

Telephone number: _____

Time (please circle): Anytime / Daytime / Evening / Other: _____

Name of Participant

Date

Signature

Name of Person
taking consent

Date

Signature

Level of amputation (please select) hallux / toe / mid foot / below ankle

CONSENT FORM 2

Interview Consent

Title of Project: **Quality of Life, Diabetes & Amputation Research. Exploring patient experience of amputation.**

Name of Researcher: **Natasha Levy**

	Please initial all boxes
I confirm that I have read and understand the patient information sheet dated 2.2.17 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily	<input type="checkbox"/>
I understand that my participation is voluntary and that I am free to withdraw at any time throughout the interview without giving any reason, without my medical care or legal rights being affected.	<input type="checkbox"/>
I understand that if I withdraw I will be asked if data collected up to that point can be included in the study, I can refuse without giving a reason and all information will be deleted	<input type="checkbox"/>
I have been informed that the interview will be recorded and I give my consent for this recording to be made	<input type="checkbox"/>
I give permission for my words to be quoted (by use of pseudonym)	<input type="checkbox"/>
I understand that the information collected will be kept in secure conditions for a period of 10 years	<input type="checkbox"/>
I understand that no person other than the researcher will have access to personal information and all interview responses will be made anonymous	<input type="checkbox"/>
I understand that my identity will be protected by the use of a pseudonym in the report and that no written information that could lead to my being identified will be included in any report	<input type="checkbox"/>
I agree to take part in the above study	<input type="checkbox"/>

Name of Participant

Date

Signature

Name of Person

Date

Signature

taking consent.

Interview Guide

a. Introductions – Researcher & Study

Thank you for agreeing to take part in this interview. My name is Natasha Levy and I am the researcher for this study. This study is being undertaken as part of doctoral studies and I am being supported to undertake the study by the diabetic foot clinic and supervisors at the University of Huddersfield.

The aim of this research is to explore what is important to your quality of life, how this has influenced your decision about having an amputation, and the impact the amputation has had on your quality of life. This is because there is little current research into this area, and the findings of this research will be used to help future patients and clinicians discuss about amputation

b. Intent of the interview - Role of the Participant

Your role today is to talk about your experience of amputation, in particular I would like you to share your experiences of thinking about your decision to have an amputation, and to think about what impact this had on your quality of life. I would like to explore with you what quality of life means to you and how the amputation has affected this.

c. How the interview process will proceed

- a. Be about 30 - 45 minutes depending on how much you want to say
- b. Will be recorded
- c. Transcript produced, may be asked to check for accuracy
- d. May be pseudonymised direct quotations in study publications
- e. Can stop interview at any time
- f. Can withdraw at any point, data collected will be included in the results

d. Ask if any further questions

e. Check consent

f. Key points to be covered

The interview is to be open questions, but there are key areas to consider

Experience of amputation

Can you tell me about your experience leading to the amputation?

(Asking the patient to recount their amputation journey)

Prompt

Why did you decide to have the amputation?

Quality of Life and amputation

Did the amputation change your quality of life at all?

Prompts

What was life like before the amputation?

What impact did you expect for it to have on your lifestyle?

Was it really like that after?

Any other changes?

About quality of life factors

We have talked aboutWhat is important to your quality of life?

- a. Probes as necessary to understand factors more clearly

Final Questions

If you were deciding about amputation again, is there anything that would have helped you make the decision?

Is there anything that you think we have missed that we should talk about?

Is there anything you would like to ask before the interview finishes?



East of Scotland Research Ethics Service (*ToSRES*)

Research Ethics Service

Please note: This is the favourable opinion of the

REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

Tayside medical Science Centre
Residency Block Level 3
George Pirie Way
Ninewells Hospital and Medical School
Dundee DD1 9SY

Mrs Natasha Levy
University of Huddersfield
Ramsden Building,
Queensgate
Huddersfield
HD1 3DH

Date: 8 February 2017
Your Ref:
Our Ref: LR/AG/17/ES/0013
Enquiries to: Arlene Grubb
Direct Line: 01382 383848
Email: cosres.tayside@nhs.net

Dear Mrs Levy

Study title:	What is the impact of below ankle amputation on quality of life for individuals with Type 2 diabetes mellitus?
REC reference:	I7/ES/0013
IRAS project ID:	121517

Thank you for your letter of 7 February 2017, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise). Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion” above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	Version	Date	
Copies of advertisement materials for research participants [Research Poster]	1.0	23 September 2016	
Copies of advertisement materials for research participants [Research Poster]	v1.1	02 February 2017	
Covering letter on headed paper [Cover Letter]	1.0	10 November 2016	
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance]		18 July 2016	
Interview schedules or topic guides for participants [Interview Guide]	1.0	23 September 2016	
IRAS Application Form [IRAS_Form_19012017]		19 January 2017	
IRAS Application Form [IRAS_Form_07022017]		07 February 2017	
IRAS Application Form XML file [IRAS_Form_19012017]		19 January 2017	
IRAS Application Form XML file [IRAS_Form_07022017]		07 February 2017	
IRAS Checklist XML [Checklist_19012017]		19 January 2017	
IRAS Checklist XML [Checklist_07022017]		07 February 2017	
Other [Professional Negligence Insurance]		16 July 2016	
Other [Answers to Provisional Queries from Proportionate Review Sub-Committee]	v1.0	02 February 2017	
Other [Answers to HRA Initial Assessment Letter]	v1.0	02 February 2017	
Other [Statement of Activities IRAS 121517]	v1.0	02 February 2017	
Other [Schedule of Events IRAS ID 121517]	v1.0	02 February 2017	
Participant consent form [Interview Consent Form]	1.1	23 September 2016	
Participant consent form [Permission for Researcher Contact]	1.1	23 September 2016	
Participant consent form [Interview Consent Form]	v1.2	02 February 2017	
Participant consent form [Permission for Researcher Contact]	v1.2	02 February 2017	
Participant information sheet (PIS) [Participant Information Sheet v1.3]	1.3	18 January 2017	

Participant information sheet (PIS) [Participant Information Sheet v1.4]	v1.4	02 February 2017	
Research protocol or project proposal	1.4	23 September 2016	
Summary CV for Chief Investigator (CI)	1.2	04 October 2016	
Summary CV for student [Natasha Levy CV]	1.2	10 November 2016	
Summary CV for supervisor (student research) [Warren Gillibrand CV]			
Summary, synopsis or diagram (flowchart) of protocol in non-technical language [Flowchart]	1.0	23 September 2016	

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance>

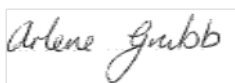
We are pleased to welcome researchers and R & D staff at our RES Committee members’ training days – see details at <http://www.hra.nhs.uk/hra-training/>

17/ES/0013

Please quote this number on all correspondence

With the Committee’s best wishes for the success of this project.

Yours sincerely



Dr Robert Rea
Chair

Email: eosres.tayside@nhs.net

Enclosures: "After ethical review – guidance for researchers" [SL-AR2]

Copy to: Dr Dawn Leeming
[REDACTED] NHS Foundation Trust

Mrs Natasha Levy
University of Huddersfield
Ramsden Building, Queensgate
Huddersfield
HD1 3DH

Email: hra.approval@nhs.net

14 February 2017

Dear Mrs Levy,

Letter of HRA Approval

Study title:	What is the impact of below ankle amputation on quality of life for individuals with Type 2 diabetes mellitus?
IRAS project ID:	121517
REC reference:	17/ES/0013
Sponsor	University of Huddersfield

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* – this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* – this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details

and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *“After Ethical Review – guidance for sponsors and investigators”*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](http://www.hra.nhs.uk), and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](http://www.hra.nhs.uk).

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at hra.approval@nhs.net. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

IRAS project ID	121517
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HRA training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is 121517. Please quote this on all correspondence.

Yours sincerely

Alex Thorpe
Senior Assessor

Email: hra.approval@nhs.net

Copy to: *Dr Dawn Leeming, Sponsor's Representative*
[REDACTED] *NHS Foundation Trust, Lead R&D Contact*

CERTIFICATE of ACHIEVEMENT

This is to certify that

Natasha Levy

has completed the course

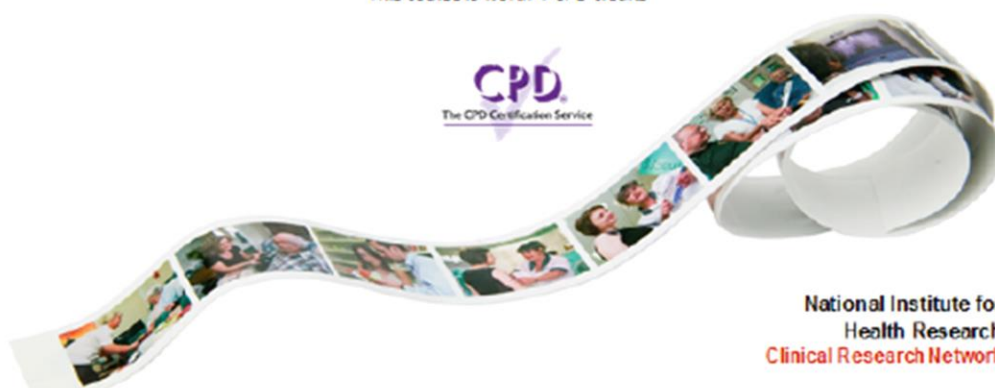
Introduction to Good Clinical Practice eLearning (Secondary
Care)

October 11, 2016

Modules completed:

Introduction to Research in the NHS
Good Clinical Practice and Standards in Research
Study Set Up and Responsibilities
The Process of Informed Consent
Data Collection and Documentation
Safety Reporting

This course is worth 4 CPD credits





Quality of Life, Diabetes and Amputation Research

Exploring patient experience of amputation

**Do you have Type 2 Diabetes and had part of your foot amputated?
If so would you consider being interviewed for our research?**

What is the purpose of the research?

To explore what impact amputation has had on your quality of life, whether this was positive or negative.

Why is the research being undertaken?

At present there is published research about the number of amputations performed in the UK, and why clinicians think patients choose to have an amputation. This would be the first study to ask patients about the reasons behind having an amputation and to understand what impact it has had on your quality of life.

I'm interested, what would I have to do?

Talk to Natasha Levy, a podiatrist and Researcher, about your personal experiences of amputation. Your interview would last between 30-45 minutes depending on how much you may wish to say.

How can I find out more information?

When you attend your appointment, please ask for an information sheet. If you want to take part they will take your details and pass them on to Natasha

Tel: 01484 473960

Email: n.levy@hud.ac.uk

v1.0 23.9.16

