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ANGELA HILLEMANN
Dip BSc (Hons) MSc

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Section A:
Long-term quality of life in adult cardiac arrest survivors:
A literature review

Word Count: 8,922

Section B:
Happiness in adults who had a Near-Death-Experience:
An Interpretative Phenomenological Analysis

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

APRIL 2018

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

DECLARATION FOR MAJOR RESEARCH PROJECT

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I would like to thank all the people who supported this project and made it possible, thank you. My thoughts go out to the participants who trusted me with such personal and intimate stories. It has been a moving and humbling experience throughout. I am very grateful to my supervisors, Dr Joe Hinds and Professor Paul Camic, for their support and advice, particularly when unforeseen challenges threatened the timely submission of this piece of work. To Martin for sparking my interest in this research area, to Conan and Anita for your continuing belief in me and finally, to Nicola for being such a stable source of thoughts and feedback.

MRP Summary

Section A describes a literature review addressing the long-term quality of life in adult cardiac arrest survivors beyond four years. Drawing on three online databases, thirteen quantitative studies were identified and reviewed. Although there was a trend for studies to include longer follow-up groups, research designs remain weak overall, involving few comparisons between groups or between time points. All of the studies had taken place outside of the UK so findings would need to be considered with caution in terms of generalisability. A consensus on how to define and measure quality of life has not been reached yet. Current measures focus on physical ability, and pay little attention to other aspects such as happiness or spiritual well-being. Clinical and research implications were discussed.

Section B presents a qualitative study on the experience of happiness in relation to Near-Death-Experiences. Six semi-structured interviews were conducted, and data was analysed through Interpretative Phenomenological Analysis. Five master-themes emerged: Sense of self, Attitude toward life and death, Effects of Near-Death-Experience, Relationship with others, and Experience of happiness. Overall, participants had experienced the NDE as a positive influence on their happiness, although this was not the case immediately for all of them. Findings were discussed in relation to the previous research literature and psychological theory on Post-Traumatic-Growth. Implications for clinical practice and future research examined.

Table of Contents

Section A: Literature Review

Abstract	7
Introduction	8
Cardiac Arrest (CA)	8
Quality of Life (QoL)	9
QoL in CA Survivors	11
Review Aims and Scope	12
Method	13
Literature Search	13
Review Structure	14
Results	22
Follow-up: 4-5 years	22
Follow-up: 5-6 years	24
Follow-up: ≥ 6 years	26
Summary	28
General Critique	30
Sample characteristics	30
Outcome measures	34
Design and analysis	37
Discussion	39
Research Implications	39
Clinical Implications	41
Conclusion	43
References	45

Section B: Empirical Study

Abstract	57
Introduction	58
What is a Near-Death-Experience (NDE)?	58
NDE Evidence and Critique	59
Negative Aftereffects of NDEs	60
NDEs and Post-Traumatic Growth (PTG)	61
Happiness	62
This Study	63
Method	64
Design	64
Participants	64
Procedure	66
Recruitment	66
Interviews	66
Measures	67
Near-Death-Experience Scale (NDES)	67
PTSD Checklist for Civilians (PCL-C)	67
General Health Questionnaire-12 (GHQ-12)	67
Analysis	68
Quality Assurance	68
Ethical Considerations	69
Results	69
Sense of Self	70
Renegotiating identity	70
Reflecting on one's life purpose	71

Attitude Toward Life and Death	72
Leaving behind the fear of death	72
Embracing a greater appreciation of life	73
Re-assessing spirituality and religion	74
Effects of NDEs	75
Attaching value to NDE	75
Considering temporal effects of NDEs	76
Questioning causation	77
Relationship with Others	78
Facing hurdles in receiving support	78
Noticing and respecting NDE differences	79
Connecting and offering help	80
Experience of Happiness	81
Contrasting an inside vs outside source	81
Choosing one's perspective	82
Enjoying greater happiness and better mental health	83
Discussion	84
Limitations	86
Clinical Implications	87
Research Implications	88
Conclusion	89
References	91
Section C: Appendixes of Supporting Materials	105

List of Tables

Section A

Table 1. Summary of included papers

Table 2. Study scores based on the 'Standard Quality Assessment Criteria for Primary Research' (Kmet et al., 2004)

Section B

Table 1. Participant characteristics

Table 2. Master-themes and sub-themes

List of Figures

Section A

Figure 1. Flow-chart illustrating the systematic search process

List of Appendices

Appendix A: Standard Quality Assessment Criteria for Primary Research

Appendix B: Recruitment Poster

Appendix C: Information Sheet

Appendix D: Online Questionnaire

Appendix E: Questions of the Semi-Structured Interview

Appendix F: Consent Form

Appendix G: Demographic Questionnaire

Appendix H: Debrief Sheet

Appendix I: Research Summary for Participants

Appendix J: Research Summary for Ethics Panel and R&D Committee

Appendix K: Example Summary of Participant's Account: Amy

Appendix L: Example of Coded Transcript: Amy

Appendix M: Example of Initial Emerging Themes from a Transcript: Amy

Appendix N: Bracketing Interview Reflections

Appendix O: Excerpts from Reflective Research Journal

Appendix P: Letter of Ethical Approval

Appendix Q: Additional Illustrative Quotes

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Abstract

Objectives: With the introduction of defibrillators, the survival rate of post-cardiac arrest patients has greatly increased since the 1960s. However, research studies have paid little attention to quality of life, or focus on the six to 12-month period following a CA, despite the fact that survivors live on average another 16 years after a CA.

Method: Three electronic databases (PsychINFO, Medline, Web of Science) were searched for three main search terms (surviv*/patient/client* and cardiac-arrest/CPR/resuscitate* and quality-of-life/QOL/life-satisfaction/well-being/wellbeing/happiness). Thirteen quantitative studies were identified that investigated quality of life in adult survivors beyond four years after a cardiac arrest. Google Scholar and reference sections of reviewed papers were also searched.

Results: Quality of life was overall reported to be “good”, “favourable”, or “comparable” to the general population. Yet results are likely to be positively biased due to sample recruitment methods and the choice of measures and analyses. Most investigations were lacking in statistical comparisons between and within participant groups. Comparisons between studies were further hindered by a wide range of different methodological designs and measures applied. Quality of life tended to be a poorly defined construct and still appeared to be only a secondary outcome in this field of research. Studies predominantly focused on physical functioning, and excluded other areas of quality of life.

Conclusion: It is recommended that existing literature is interpreted with caution. Future research would benefit from including neurologically impaired survivors, comparing changes in quality of life over time, and using measures that explore the individuals’ satisfaction with areas of life that are important to them.

Keywords: Quality of Life, Wellbeing, Well-being, Cardiac Arrest, Resuscitation

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Long-term Quality of Life in Adult Cardiac Arrest Survivors: A Literature Review

Cardiac Arrest (CA)

CA represents a life-threatening condition. CA is a leading cause of death (OHCA Steering Group, 2017) and occurs suddenly, usually without warning. Due to electrical malfunction, the heart stops pumping blood and vital organs are starved of oxygen. The person loses consciousness and death occurs within minutes. In contrast, during a myocardial infarction (commonly known as heart attack) the blood flow to the heart is partly blocked and the person is usually conscious and breathing (British Heart foundation, 2014a).

Over 350,000 people experience an out-of-hospital CA in the USA (The American Heart Association, 2018) and about 30,000 in the UK annually (OHCA Steering Group, 2017). The number of survivors has significantly increased and is expected to grow with medical advancements and positive trends in life expectancy in the general population (Leon, 2011). In the 1960s, cardiopulmonary resuscitation (CPR) was introduced (Safar, 1989) positively affecting survival outcomes. Since then, further efforts have been undertaken to increase the availability of defibrillators in the community and educating the public in their use (Resuscitation Council UK and British Heart Foundation, 2013). A person's survival chance to hospital discharge is currently at about 10% in Europe (Gräsner et al., 2016) and 8% in the UK (OHCA Steering Group, 2017).

Survivor outcomes range from no lasting effects to a persistent vegetative state. The prognosis is more favourable if the arrest occurs within a hospital, yet 80% take place outside of hospitals (Andersson, Rosen, & Sunnerhagen, 2015). Overall, between 30-50% of CA survivors suffer hypoxic brain injury leading to cognitive impairments (Green, Botha, & Tiruvoipati, 2015). Psychological effects such as post-traumatic stress, anxiety, and mood

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

issues are also common and affect up to 60% of CA survivors (Schaaf et al., 2013).

Consequently, people are often limited in their daily functioning and participation in society, and require regular support (Lilja et al., 2018).

Given the increase in CA survivors, focus has gradually shifted from mortality to morbidity rates, and research has shown a greater interest not only in survival rates but in survivors' wellbeing following a CA. Researchers have started advocating that an individual's quality of life should be taken as a main outcome measure when evaluating the success of CPR (Neumar et al., 2008).

Quality of Life (QoL)

QoL is a broad and personal construct which is understood differently by many professions. Within cardiac research QoL is increasingly assessed (O'Reilly, Grubb, & O'Carroll, 2004) and is often defined based on a statement made by the World Health Organization (WHO). The WHO defined QoL as an individual's evaluation of their position in life in relation to their culture and value systems as well as their goals, standards, expectations and concerns (WHO, 2014). Additionally, the WHO highlighted three broad domains of QoL: biological, psychological, and social functioning.

Psychological perspectives of QoL have frequently surrounded concepts of happiness and affect. In public health research, for instance, data has been captured by the 'Happy Planet Index' (New Economics Foundation, 2013) and 'the WHO Quality of Life Assessment Instrument' (The WHOQOL Group, 1994). Yet the psychological dimension of QoL has usually received less attention than physical life aspects in health-care research, in which bodily functioning and symptomatology have been commonly the focus (Patrick & Erikson, 1993; Testa & Simonson, 1996).

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

A greater psychological perspective on QoL might be supported by drawing on psychology research into happiness. Happiness has received revived interest through the study of Subjective Well-Being (SWB) through Diener's Tripartite Model (1984). The model suggests SWB has three distinct but related components: cognitive evaluations (such as life satisfaction) as well as positive and negative affect. Research into top-down factors have highlighted global features of personality and genetics as stable long-term factors that determine a person's SWB baseline. It followed the development of the Set-Point Theory (Diener, Suh, Lucas, & Smith, 1999) and the Hedonic Treadmill theory (Brickman & Campbell, 1971). Both suggest the SWB is only temporarily affected by major life events, but that people adapt to them over time and return to their baseline SWB. Yet, more perspectives on SWB point out differences in adaptation levels. For instance, people can rapidly adapt to events such as imprisonment, but slowly to the death of a loved one, and adapt not at all to sexual intercourse (Diener, 2000).

Another influential theory on psychological well-being was contributed by Seligman, a founder of positive psychology; the scientific study of "what makes life most worth living" (Seligman, Steen, Park, & Peterson, 2005, p.874). Seligman (2002) proposed his initial theory of three paths to happiness; according to this theory, 'the pleasant life' involves the experience of positive feelings. "The good life" describes the deep immersion into an activity; a concept resembling the notion of "flow" or "true engagement" coined by Csikszentmihalyi (1990). "The meaningful life" involved being a part of and contributing to something larger than oneself such as social groups or belief systems. Seligman's theory offered the foundation for several happiness measures such as the Steen Happiness Index (SHI; Seligman et al., 2005) and the Authentic Happiness Inventory (AHI; Peterson & Park, 2008). Such questionnaires with their origins in positive psychology might support or inspire

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

further investigations into the psychological domain of QoL in cases where physical perspectives have usually prevailed (Patrick & Erikson, 1993; Testa & Simonson, 1996).

Ultimately, the WHO (2014) had advocated for a QoL definition that incorporates physical, social, and psychological views equally.

QoL in CA Survivors

Several studies have explored the long-term QoL of CA survivors and have found varied results. Elliott et al. (2011) conducted the first systematic review, and concluded that the QoL of survivors was at a generally acceptable level. Of 70 reviewed studies most indicated QoL was “good”, and seven indicated negative effects. Findings highlighted that many studies compared people’s QoL to the time before the CA, which might lead to more negative responses than if compared to the alternative of death. Results were broadly presented rather than separated into health-related domains, such as, for instance, the WHO-defined psychological, physical, and social outcomes. Most studies had a follow-up time within the first six months following CA. Other follow-up times varied greatly (i.e., between 28 days & 15 years), and the review would have benefited from reporting differences in QoL over time, and considering longer-term recovery and adjustment trajectories (Tedeschi, Park, & Calhoun, 1998).

A more recent review drew on 36 papers published between 2000-2015 (Haydon, van der Riet, & Maguire, 2017a). The authors concluded that QoL in CA survivors was generally acceptable, yet pointed out that drawing meaningful comparisons had been challenging between papers. Over 50 different assessment tools were used, and QoL was not clearly defined in most papers. Timeframes of collecting data varied, and it was unclear if QoL was measured as survivors’ current experience, or in comparison to a state before the CA. The review cautioned that papers did not offer information on comorbidity, and usually

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

only included neurologically intact survivors. Two subthemes were identified from the findings of five qualitative studies, namely “existential insecurity” and “distress and vulnerability”. Similar to Elliott et al., follow-up times tended to be within the first six months, and longer-term effects were not separately explored.

These two reviews offer evidence of good QoL after CA but do not focus or compare the results for different time intervals. The reviews also did not include some longer-term studies with follow-up times beyond four years (e.g., Karhunen, Jokinen, Raivio, & Salminen, 2011; Khan, Bunch, White & Packer, 2004; Mahapatra, Bunch, White, Hodge, & Packer, 2005). It was unclear if studies were excluded intentionally, and if so, on what grounds. Yet researchers have pointed out a need for longitudinal studies to advance the research field of resuscitation (Aiyagari, & Dringer, 2015). The importance of long-term investigations is further highlighted by people living on average another 16 years after a CA (Graf et al., 2008). Clinically, information on longer-term QoL might also be of specific interest to patients who anticipate poor QoL after a CA and are deciding whether to apply for a “Do Not Resuscitate Order” (DNR). Exploring long-term CA effects on QoL also appears of importance in informing clinical care pathways. Professional support decreases rapidly after hospital discharge, and survivor reports reveal patients frequently feel “abandoned” by their health care team at points when they might require longer-term input (Forslund, Zingmark, Jansson, Lundbald, & Soderberg, 2014).

Review Aims and Scope

The aim of this literature review was to investigate the long-term QoL in CA survivors of four years and beyond. Haydon and colleagues (2017b) highlighted that to date, no international guidelines have been published for the psychological care of CA survivors. This review might also offer insights informing future clinical pathways of care and health

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

professionals who support CA survivors and patients considering a DNR. QoL is a subjective concept, and research has identified significant differences in the perception of QoL between patients and other observers (Pusswald, Ferti, Faltl, & Auff, 2000). These might be due to personal differences in expectations and values, but also a lack of self-awareness - particularly in people who acquire cognitive impairments following a CA (Pusswald et al., 2000). This review focused on the experience of the people who had had a CA, and studies exploring views of healthcare professionals or significant others were not considered.

Method

Literature Search

An electronic search of PsychINFO, Medline, Web of Science databases was conducted. The following search terms were combined:

1. ("surviv*" OR "patient*" OR "client*")
AND
2. ("cardiac-arrest" OR "CPR" OR "resuscitat*")
AND
3. ("quality-of-life" OR "QoL" OR "life-satisfaction" OR "well-being" OR "wellbeing" OR "happiness")

To maximise scope, additional articles were checked for their eligibility using Google Scholar, and reference sections of papers referred to in this critical review examined. Titles were screened and, when required, abstracts and the full-text. Only articles published in academic journals were considered. Articles were excluded if they did not represent original primary research (e.g., reviews, theory-based contributions, commentaries), used participants under the age of 18, did not involve CA survivors, or did not explicitly measure concepts related to QoL, or if the mean or median time of data collection was under four years following the CA or discharge from hospital. Similar to previous reviews (Haydon et al.,

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

2017b), studies exclusively investigating CA survivors with Implantable Cardioverter-Defibrillators (ICD) were also excluded as they focused on the experience of living with an ICD rather than the CA survivor QoL. Lastly, papers were only included if they specifically referred to a search term in cluster three in their title or abstract.

A flow-chart showing the screening process for eligible articles can be found in Figure 1. This resulted in the inclusion of 13 papers in this critical review. All studies were quantitative, and included prospective and retrospective studies published between 1999 and 2015. Six studies included control groups, all of which had a general population group, and three studies had an additional non-CA disease matched control. A summary table of the reviewed studies can be seen in Table 1.

Review Structure

The result section is divided into three parts. These relate to the different long-term follow-up times: (1) 4-5 years, (2) 5-6 years and (3) 6 years and beyond. This allowed for comparisons by follow-up years. The last follow-up period was kept open-ended due to a paucity of studies beyond six years. Within each follow-up group, studies were presented in chronological order with brief descriptions of the research. An overall summary of all study results is provided at the end.

In the general critique section, major methodical issues are discussed across all the reviewed studies. The quality of the studies was evaluated against the “Standard Quality Assessment Criteria for Primary Research” (Kmet, Lee, & Cook, 2004). A breakdown of individual study scores can be found in Table 2 and the manual for scoring the tool’s 11 criteria in Appendix A. The overall score ranges between zero and one with higher scores indicating more rigorous study methodologies. This tool was chosen as it allows the quality appraisal across research designs including controlled and uncontrolled studies. The tool is

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

frequently used for systematic health reviews (Shaw et al., 2009) and has been validated (Kmet, Lee, & Cook, 2004). Finally, clinical and research implications of the literature review are addressed in the discussion section.

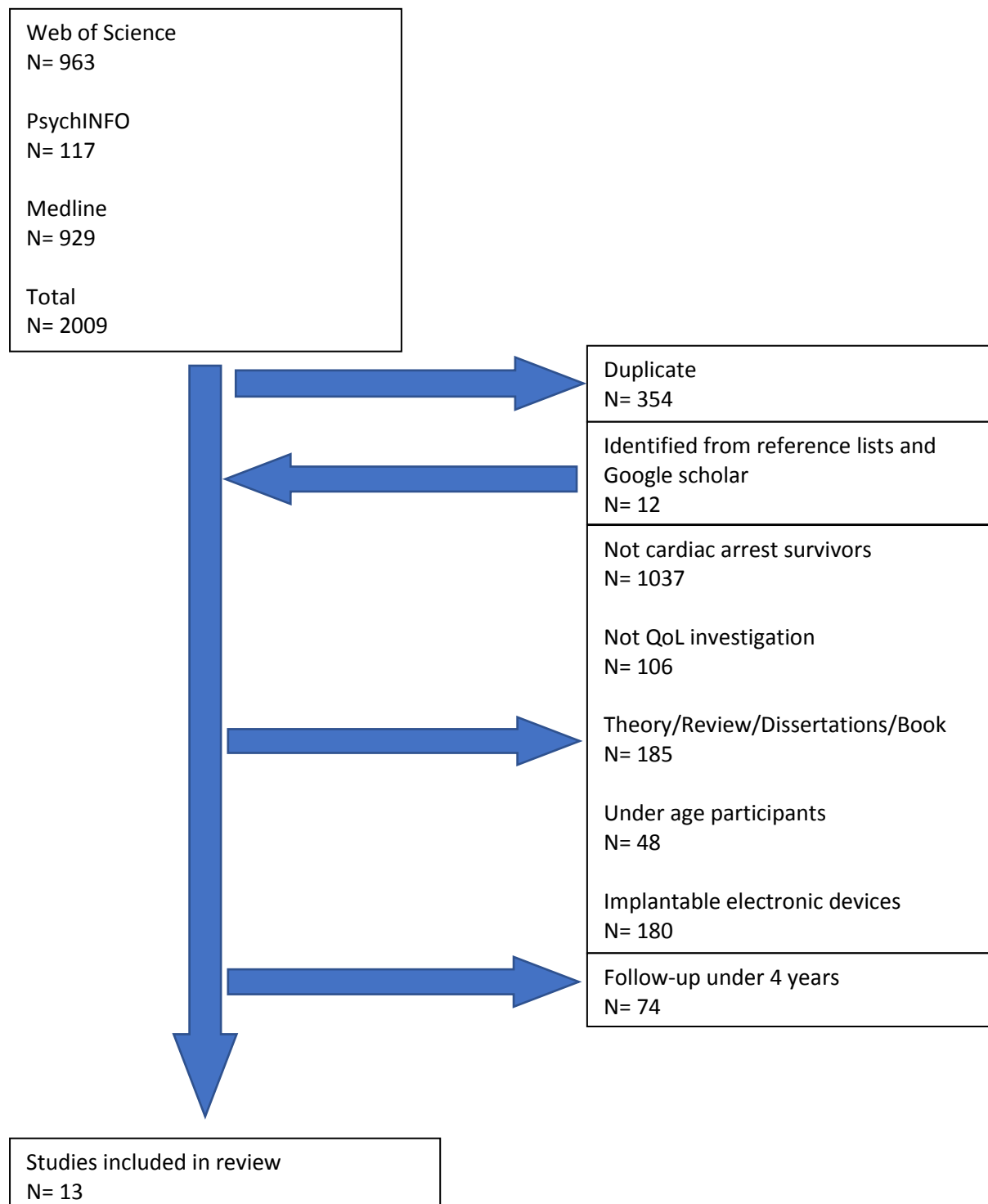


Figure 1. Flow chart illustrating the systematic search process.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Table 1

Summary of included papers

Study & Location	Aim & CA Location (In/Out of Hospital)	Mean Follow-Up Time	Follow-up: Sample Size, Gender, Mean Age	QoL Control Group	QoL Measures	QoL Main Findings
4-5 Years Follow-Up						
1 Dimopoulou et al. (2001) Greece	Research long-term functional status and QoL in people who experienced a CA after cardiac surgery In	4 years	N = 16 88% male 61 years	None	Questionnaire based on Nottingham Health Profile	<ul style="list-style-type: none"> All lived independently and did not report emotional difficulties Nearly all could look after their home and enjoyed a social life Most had sexual relationships, engaged in hobbies and holidays Overall, the majority had a “good” QoL and two thirds had a preserved QoL up to 4 years after hospital discharge
2 Bunch et al. (2003) USA	Long term survival and QoL in survivors following CA from VF Out	4.8 years	N = 50 At hospital discharge: 84% male 62 years	Scores were adjusted to age and sex matched controls of the general US population	SF-36	<ul style="list-style-type: none"> There were no significant differences except on vitality between CA survivors and control group The majority had “nearly normal” QoL except for lower scores on vitality
3 Bunch et al. (2004) USA	Impact of age on long-term survival and QoL of CA survivors from VF	4.8 years	N = 50 At hospital discharge: 84% male 62 years	Scores were adjusted to age and sex matched controls of the	SF-36	<ul style="list-style-type: none"> In people below the age of 65 QoL is comparable to the general population In people over 65 scores were significantly lower than the

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

	Out			general US population		<p>general population on physical functioning, role-emotional and the role-physical subscales indicating reduced physical and emotional QoL</p> <ul style="list-style-type: none"> 65% of the younger group and 56% old the older returned to work
4 Khan et al. (2004) USA	<p>Explore the early ejection fraction as a predictor of long-term mortality and QoL after CA from VF</p> <p>Out</p>	4.8 years	<p>N = 50 At hospital discharge: 84% male 62 years</p>	<p>Scores were adjusted to age and sex matched controls of the general US population</p>	SF-36	<ul style="list-style-type: none"> At follow up there was no significant difference between a lower (<40%) and higher (>40%) ejection fraction group on any of the 8 subscales on the SF-36 At follow up survivors had a near-normal QoL comparable to that of the general population with the exception of a significant lower vitality subscale
5 Mahapatra et al. (2005) USA	<p>Investigate sex differences in survival and QoL after VF CA</p> <p>Out</p>	4.8 years	<p>N = 139 78% male 64 years</p>	<p>Scores were adjusted to age and sex matched controls of the general US population</p>	SF-36	<ul style="list-style-type: none"> There were no sex differences in 5/8 subscales of the SF-36 at follow-up and the authors conclude that QoL is similar for both sexes QoL in CA survivors for men and women was comparable to age and sex matched controls It was concluded long-term QoL is equally favourable in both sexes

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Study & Location	Aim & CA Location (In/Out of Hospital)	Mean Follow-Up Time	Follow-up: Sample Size, Gender, Mean Age	QoL Control Group	QoL Measures	QoL Main Findings
5-6 Years Follow-Up						
6 Lederer et al. (2004) Austria	Investigate neurological functioning and QoL in CA patients who received a recombinant tissue plasminogen activator during CPR Out	5 years	N = 13 83% male 62 years	None	LSQ	<ul style="list-style-type: none"> • Mean scores were above five for all LSQ subscales indicating “excellent satisfaction” • The majority of long-term survivors reported a “good” subjective quality of life
7 Graf et al. (2008) Germany	Assess costs and health status of patients following resuscitation Both	5 years	N = 81 70% male 61 years	Scores were adjusted to age and gender matched German norms	SF-36	<ul style="list-style-type: none"> • Women rated their QoL significantly higher than men • QoL was not significantly different to other published samples: CA survivors and other ICU patients • If CA survivors did not have a severe neurological impairment than they had a “reasonable” QoL compared to a German norm
8 Deasy et al. (2013) Australia	Assess QoL and functioning of young adult CA survivors Out	5 years (median)	N = 56 (EQ-5D) N = 46 (SF-12) 71% male 35 years	SF-12 results were adjusted to Australian norms for component scores only	SF-12 EQ-5D	<ul style="list-style-type: none"> • Mixed results were obtained by the EQ-5D • The SF-12 indicated a typical physical component summary score and a lower mental component summary score • Overall, most had “good” outcomes

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Study & Location	Aim & CA Location (In/Out of Hospital)	Mean Follow-Up Time	Follow-up: Sample Size, Gender, Mean Age	QoL Control Group	QoL Measures	QoL Main Findings
>6 Years Follow-up						
9 Kuilman et al. (1999) Netherlands	Research long-term survival of CA patients Out	6.7 years	N = 109 72% male (at baseline) 65 years	Patients resuscitated by (1) ambulance staff before hospital arrival, (2) ambulance staff after hospital arrival, (3) physicians or (4) bystanders	EQ-5D	<ul style="list-style-type: none"> • Response rate to the EQ-5D was 83% which was described as “high” • At follow-up there were no significant differences on the total score of EQ-5D between the four groups • Overall, the total EQ-5D score of 85.2 suggested a “good” QoL
10 Harve et al. (2007) Finland	Evaluate long term functional status and QoL in VF CA survivors Out	(1 year) 15 years	N = 10? 73% male 72 years	None	Self-generated QoL questionnaire	<ul style="list-style-type: none"> • All survivors lived in their own home, were independent in their activities of daily living, engaged in regular hobbies and physical exercise • After 15 years 88% were at least satisfied with their overall QoL • Once “good” QoL was achieved then it can be maintained for over 10 years
11 Karhunen et al. (2011) Finland	Study long-term survival and QoL after resuscitation in people who had undergone coronary artery bypass	15 years	N = 19 57% male (at CA) 70 years	1. Age and sex matched CABG participants without postsurgical complications	RAND-36	<ul style="list-style-type: none"> • No statistically significant differences between the 3 groups on any of the 8 domains on the RAND-36 questionnaire • After 15 years patients who needed to be resuscitated after CABG had a

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

	grafting (CABG) surgery In			2. Age and sex matched Finish referencing group		similar QoL as the general population
12 Saarinen (2012) Finland	Evaluate long-term outcome of resuscitated patients with initial pulseless electrical activity (PEA) Out	6.5-7.5 years	N = 5 At hospital admission: 70% male 69 years	None	15D-questionnaire	<ul style="list-style-type: none"> • All patients scored as normal or mildly impaired their seeing, hearing, eating, sleeping, speech, defaecation, urination, energy, depression and distress. • Patients with mild neurological impairment reported moderate difficulties with occupational activities, leisure activities, psychical functions, sexual life and mobility. • Overall, QoL appeared to be generally “good” with mild to moderate difficulties in activities of daily life
13 Andersson et al. (2015) Sweden	Investigate the survival, reasons of death and long-term life situation after a CA Out	17 years (median)	N = 8 100% male 66 years	None	EQ-5D	<ul style="list-style-type: none"> • The majority was content with their QoL and situation • Scores for 38% of participants indicated low QoL • For 71% of survivors the EQ-5D score was below that of the Swedish general population

Note. EQ-5D (also known as EuroQoL-questionnaire): European Quality of Life Measure questionnaire, LSQ: Life Satisfaction Questionnaire, RAND-36: Short Form 36-Item questionnaire (different scoring convention to SF-36), SF-12: Short Form 12-Item questionnaire, SF-36: Short Form-36 questionnaire, 15D-Questionnaire: 15-dimensional questionnaire.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Table 2

Study scores based on the "Standard Quality Assessment Criteria for Primary Research" (Kmet et al., 2004)

Study Criterion → ↓	Dimopoulou et al. (2001)	Bunch et al. (2003)	Bunch et al. (2004)	Khan et al. (2004)	Mahapatra et al. (2005)	Lederer et al. (2004)	Graf et al. (2008)	Deasy et al. (2013)	Kuilman et al. (1999)	Harve et al. (2007)	Karhunen et al. (2011)	Saarinen et al. (2012)	Andersson et al. (2015)
1. Aims	2	2	2	1	2	1	2	2	1	2	2	2	2
2. Design	0	2	2	2	2	0	2	1	1	0	2	0	0
3. Recruitment & Selection	1	1	1	1	1	1	2	2	2	1	1	2	2
4. Sample Description	2	1	1	1	1	1	2	2	1	1	1	1	1
5. Randomisation	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
6. Blinding of Researchers	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
7. Blinding of Participants	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
8. Measures	1	2	2	2	2	2	2	2	2	1	2	2	2
9. Number	N/A	2	2	2	2	N/A	2	2	2	0	2	N/A	N/A
10. Analysis	2	2	1	2	2	1	1	1	1	0	2	2	2
11. Variance	0	1	2	2	1	2	1	1	2	0	1	2	2
12. Confounders	1	1	1	1	1	1	2	0	2	1	2	2	2
13. Results	1	2	1	1	1	2	2	2	1	0	1	1	1
14. Conclusion	1	2	2	2	1	1	2	1	1	1	2	1	1
Total Score	11/20= .55	18/22= .82	17/22= .77	17/22= .77	16/22= .73	12/20= .60	20/22= .91	16/22= .73	16/22= .73	7/22= .32	18/22= .82	15/20= .75	17/22= .77

Note. 2: yes, 1: partial, 0: no, N/A: not applicable.

Results

Follow-up: 4-5 years

Five studies are reviewed in this section. In 2001 Dimopoulou and her colleagues were first to research QoL in survivors four years after CA. They focused on long-term functional status and QoL in people who experienced CA in the immediate postoperative period of a cardiac surgery. QoL data was collected from 16 survivors four years after discharge. Their QoL questionnaire was based on the Nottingham Health Profile (NHP; Hunt, McEwan, & McKenna, 1985) and covered several aspects of health and activities of daily living (ADL). All 16 CA survivors were living independently. None reported emotional difficulties, social isolation or physical disabilities. Thirty-eight percent had mild sleep disturbances, 20% returned to work, 94% could look after their home, 96% enjoyed a social life, 63% had sexual relationships, 81% engaged in hobbies and 75% had taken holidays during the four-year post-CA period. The authors concluded that the majority had good QoL with two thirds enjoying a preserved QoL at four years after hospital discharge.

Bunch and his team (2003) published the first of three papers, all of which involve the same sample tested at a follow-up time of 4.8 years post-hospital discharge. The paper explored long-term survival and QoL in survivors of a CA following Ventricular Fibrillation (VF). When recovering from a CA, VF is an initial heart rhythm whereby the lower heart chambers quiver and prevent blood circulation (Meaney et al., 2010). Fifty out of 60 patients alive at follow-up completed a SF-36 to measure QoL (Ware, Snow, Kosinski, & Gandek, 1993). The SF-36 provides a physical and mental component score by measuring eight QoL domains: general functioning, physical functioning, role limitations due to physical problems (role-physical), bodily pain, energy/vitality, social functioning, mental-health and role limitations due to emotional problems (role-mental). Compared to a US general

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

population control group (age/sex-matched), there were no statistical QoL differences on the SF-36, except for vitality scores. Vitality was lower in CA survivors, who alluded to feeling more tired and worn-out. Sixty-five percent of survivors under the age of 65 returned to work. The authors concluded that, with the exception of vitality, the majority of these survivors had “nearly normal” QoL compared to the general population. It was suggested that the positive results were partly due to a relatively low interval between the emergency call and administration of the first shock (i.e., between 5.7-6.6 min).

Bunch and colleagues (2004) published a second paper on the previous sample. This investigated the impact of age on long-term survival and QoL of VF CA survivors. They found that, based on the SF-36 results, people below the age of 65 have a QoL comparable to that of the general population (age/sex-matched). In contrast, people over 65 scored significantly lower than people below 65 or the general population, on three of eight subscales: physical functioning, role-emotional, and role-physical subscales. Additionally, 65% of the younger group and 56% of the older returned to work.

In the same year a further paper was published (Khan, Bunch, White, & Packer, 2004) again based on the same CA survivor sample of the previous two studies. It explored the early ejection fraction (EF: the amount of oxygenated blood pumped out of the heart) as a predictor of long-term mortality and QoL after CA with VF. The mean EF of survivors was 42. The authors noted that a score less than 40 indicates a left ventricular dysfunction. At the 4.8 years follow-up, there was no significant difference between a lower (<40%) and higher (>40%) EF group on any of the eight subscales on the SF-36. The authors concluded that survivors with and without ventricular dysfunction have a similar long-term QoL. This suggests long-term QoL appears to be independent of EF survivors of VF CA. Additionally,

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

survivors had a near-normal QoL comparable to that of the general population with, as previously notes, the exception of a significant lower vitality subscale.

In contrast to previous studies, Mahapatra et al. (2005) conducted a study to investigate sex differences in survival and QoL after VF CA. The mean call-to-shock time was six minutes. After a mean time of 4.8 years, QoL was assessed through the SF-36 survey. Scores were adjusted to a control group; a age/sex-matched US general population. There were no sex differences on five subscales (i.e., general health perception, pain index, mental-health index, vitality, social function) but women had lower scores on the other three (i.e., physical function, role-emotional, role-physical). Nevertheless, the authors concluded that “QoL was equally favourable in both sexes” (p.197).

Follow-up: 5-6 years

Three studies are reviewed in this section. Lederer and his team (2004) published a study involving a five-year follow-up. They researched long-term neurological functioning and survival in CA patients who had received a “recombinant tissue Plasminogen activator” (rtPa). RtPa is a protein that is involved in breaking down blood clots used in thrombolytic therapy. QoL was assessed by the Life Satisfaction Questionnaire (LSQ; Fahrenberg, Myrtek, Wilk, & Kreutel, 1986), by which 13 patients were scored on a seven-point scale, five health domains: general health, social life, financial situation, married life/partnership, and personal performance. The mean scores were above five for all LSQ subscales which indicated “excellent satisfaction”. “Excellent satisfaction” was reported by 62% on general health, 77% on social and financial situation, and 85% on personal performance. The researchers concluded that survivors’ appraisal of life was “generally euphoric” with the exception of one participant who struggled with the loss of his wife.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Graf et al. (2008) were the only team to use the common SF-36 survey for a QoL follow-up at five years. Their research interest was to identify the long-term costs and health status of patients following resuscitation. Five years after hospital discharge, participants completed the validated German version of the SF-36. Results indicated that QoL was slightly lower to age and gender-matched controls on five of eight subscales (physical function, physical role, general health, vitality, social function). However, they did not comment on the mental or physical component summary scores which appeared to be very similar, and below the comparison norm. Additionally, women generally rated their QoL significantly better than men. The differences were on three of eight subscales: pain, physical role function, and emotional role function. Sex differences could not be explained by differences on admission diagnosis, severity of illness, hospital length of stay, or age. There were also no significant differences of the total QoL to that of another CA survivor group and other ICU patients published elsewhere.

Among the studies in this review, Deasy and colleagues (2013) appeared to offer the only investigation employing two QoL questionnaires, the ED-5D and SF-12. Their focus lay on the long-term QoL and functioning of young adults after out-of-hospital CA. They assessed 56 young adults between the ages of 18-39, of which over two thirds were male, at follow-up times of five years after CA. Covering five health domains, scores on the ED-5D suggested that just under two thirds experienced anxiety or depression symptoms, a quarter had mobility issues requiring personal care, and about a third experienced physical pain and had physical problems affecting their engagement with usual activities. Responses on the SF-12 were presented as percentages for all eight subscales such as a half of survivors reported that their engagement with social activities had been affected. SF-12 component scores adjusted to an Australian norm were provided that indicated typical

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

physical wellbeing, but lower mental wellbeing. The researchers reasoned that the majority had good QoL outcomes.

Follow-up: ≥ 6 years

Five studies are considered in this section. The first is Kuilman and his colleagues (1999), who were the first researchers to evaluate long-term QoL in CA survivors beyond five years. Their main aim was to research long-term survival of out-of-hospital CA patients, and 109 patients also received an EQ-5D questionnaire at a seven-year follow-up.

Participants were divided into four groups which did not differ in mean age, duration of hospital stay, and diagnosis at baseline: patients resuscitated by (1) ambulance staff before hospital arrival, (2) ambulance staff after hospital arrival, (3) physicians or (4) bystanders. Response rate to the EQ-5D questionnaire was 83%. There were no significant differences between the four groups on the total scores at follow-up. The authors commented that the overall score of 85.2 indicated a “good” QoL.

In 2007 Harve and colleagues conducted the first study that included a 15-year follow-up. The study evaluated functional status and QoL in VF CA survivors. Of 11 survivors, 10 took part, of which four had mild cognitive problems. It was unclear what QoL measures were employed and it appears that a self-devised questionnaire was used scoring on a six-point Likert-scale, seven domains of life: overall QoL, hobbies, ADL, marital, family, social and sexual life. However, the result section did not refer to the last four domains. The remaining domains were rated by 10 of 11 survivors. All survivors lived in their own home, were independent in their ADL, and engaged in regular hobbies and physical exercise. Forty percent had returned to work. Seven were at least “satisfied” with their QoL of which three had also been at least “satisfied” after one year. The researchers concluded that once “good” QoL is achieved then it can be maintained for over a decade.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Karhunen and co-workers (2011) represented the only long-term study over 15 years that included control groups. The study explored the long-term survival and QoL of people who had a cardiac resuscitation in the early postoperative phase after a coronary artery bypass grafting (CABG) surgery. The median time between resuscitation and CABG was three hours. However, 73% of patients needed to undergo additional emergency surgery immediately afterwards. With a drop-out rate of 20%, 19 resuscitated CABG survivors completed the RAND-36, and their scores were compared to two further groups: an age/sex-matched CABG control group who had an uneventful postoperative recovery, and an age/sex-matched Finish control group. At follow-up there were no statistically significant differences between the groups in any of the eight domains on the RAND-36 questionnaire (physical functioning, role-physical, role-emotional, bodily pain, general health, vitality, social functioning and mental-health). The researchers concluded that long-term QoL was “excellent” in this population.

A year later, Saarinen and colleagues (2012) published the only study exclusively exploring a CA followed by a Pulseless Electrical Activity (PEA). During PEA a heart rhythm can be identified, but it does not produce a traceable pulse (Meaney et al., 2010). The researchers evaluated long-term outcomes of resuscitated patients with initial PEA after seven years. The researchers pointed out that the incidence of PEA has increased in recent years and it has a worse survival rate than VF. The 15D-questionnaire (Sintonen, 1994) was completed by five CA survivors which represented the smallest sample size of the reviewed papers. This measure assesses the performance in ADL using 15 questions. Results indicated that 87% of the properties were estimated as normal or mildly affected. All patients scored as normal or mildly impaired in regard to their seeing, hearing, eating, sleeping, speech, defecation, urination, energy, depression, and distress. Patients with mild to moderate

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

neurological impairment on the CPC before CA reported moderate difficulties with occupational activities, leisure activities, psychical functions, sexual life and mobility. The authors concluded the self-assessed QoL appeared to be generally “good” with mild to moderate difficulties in ADL.

In 2015, Andersson and colleagues published a study that had the longest follow-up time to date. The paper reported on the survival rate, reasons of death and long-term life situation of CA survivors. At 17 years after resuscitation, eight males of 14 survivors (57%) completed the EQ-5D. There was a large range of results, from 55 to 100 points. The median EQ-5D score of 0.78 was below the Swedish general population score of 0.84, with 71 percent of survivors having a reduced QoL. At follow-up, two of the eight working age participants were in full-time employment. Seven lived with another person and one survivor lived in residential care. About half were below normal cognitive function on the Mini Mental State Examination (MMSE). The authors concluded that QoL tended to be lower in the survivors who were cognitively affected by the CA.

Summary

Five studies had follow-up times between four to five years. The first study reported that the majority of survivors had a “good” QoL (Dimopoulou et al., 2001). Bunch et al. (2003) concluded their sample’s QoL was “nearly normal” with the exception of vitality on the SF-36 which was worse. A year later in 2004, Bunch et al. found that the QoL of CA survivors under the age of 65 was “equal” to that of the general population. Khan et al. (2004) reported that long-term QoL was “favourable” and independent of ejection fraction. Mahapatra et al. (2005) concluded that QoL in the women and men in their sample had a comparable QoL to each other and to sex and age-matched controls. Overall, for this

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

follow-up period of time the researchers concluded that their CA survivors had a positive QoL, and that it was comparable to that of the general population.

Three studies incorporated a five-year follow-up point. Lederer et al. (2004) found that the majority of their CA survivors had a “good” QoL on the LSQ measure. Graf et al. (2008) reported QoL was better in their participating women than men, but overall similar to another ICU patient group. They also described QoL was “reasonable” in their sample in comparison to a norm control. Finally, Deasy et al. (2013) found that their CA survivors had a typical QoL when compared to a norm group on the SF-12, and reasoned the majority had a good QoL. Overall, the researchers termed the QoL of the samples as “generally euphoric” or “reasonable” five years after their CA.

Five studies drew on a follow-up time of six years or beyond. Kuilman et al. (1999) reported that their total EQ-5D score indicated a “good” QoL and that the QoL was independent of the type of professional who provided the CPR and whether it was an in or out-of-hospital resuscitation. Harve et al. (2007) concluded that, once “good” QoL was achieved it could be maintained for over ten years. Karhunen et al. (2011) presented results suggesting that the QoL of their sample was comparable to that of a norm control group and patients with a CABG without an immediate CA. A year later, Saarinen described that QoL appeared generally “good” for CA survivors with PEA as they had only mild to moderate difficulties in ADL. Finally, the most recent study by Andersson et al. (2015) suggested the majority of out-of-hospital CA survivors were “content” with their QoL after 17 years. Overall, QoL was usually presented as “good” and similar to the other two follow-up time groups.

In summary, researchers provided positive and “favourable” findings for long-term QoL in CA survivors. However, when evaluating their outcomes, methodological weaknesses

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

need to be carefully considered. The following section addresses strengths and flaws in the studies' presentations of information and research designs.

General Critique

Sample characteristics. In the reviewed studies the participants' mean age was comparable to that of the wider CA population (i.e., around 60 years; Sudden Cardiac Arrest Foundation, 2018). An exception was the study by Deasy et al. (2013), which focused on CA in young adults with a mean age of 35 years. In the reviewed studies the majority of survivors were males comprising between 57% and 100% of the samples. The high proportion of men has also been reported in other CA studies (Middelkamp et al., 2007). This finding could be due to various factors. For instance, men have a higher incidence rate of CA (Kim, Fahrenbruch, Cobb, & Eisenberg, 2001), and a lower mortality rate after a CA than women (see Kuilman et al., 1999). With regard to sample sizes, they were usually clearly reported at follow-up (apart from Harve et al., 2007) and generally satisfied the number criteria on the quality reassurance tool by Kmet et al. (2004; see Table 2). However, none of the studies reported power analyses to justify sample sizes but the studies with smaller samples (e.g., Saarinen et al., 2012) appropriately only involved descriptive statistics. They reported percentages as results, rather than attempting to make greater inferences based on their data.

Of the six studies that investigated CA rhythms, five researched VF (Bunch et al., 2003; Bunch et al., 2004; Harve et al., 2007; Khan et al., 2004; Mahapatra et al., 2005) and one PEA (Deasy et al., 2013). This focus matches up with VF being the most frequent initial cardiac rhythm after CA, and PEA being the second most common (Davis, Young, Eisenberg, Rea, Copass, & Cobb, 2008). Only two studies reported the length between the emergency call and CPR (Bunch et al., 2003: 6.1 ± 1.6 minutes; Mahapatra et al., 2005: 6 ± 2 minutes), and

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

just one study stated the time from CPR to re-establishing spontaneous circulation (Saarinen et al., 2012: 20±8 minutes). Yet this information can be crucial as a timely intervention has been identified to be an important predictor of a patient's prognosis (Valenzuela, Roe, Cretin, Spaite, & Larsen, 1997). For instance, rapid defibrillation has been suggested to be the most crucial health predictor after a CA with VF (White, Aspin, Bugliosi, & Hankins, 1996).

Eight studies were conducted in Europe, one in Australia (Deasy et al., 2013) and four in the USA (Bunch et al., 2003; Bunch et al., 2004; Khan et al., 2004; Mahapatra et al., 2005). Of the European studies, four were set in Scandinavia (Andersson et al., 2015; Harve et al., 2007; Karhunen et al., 2011; Saarinen, 2012) and none in the UK. All USA studies had four to five-year follow-ups, and all Scandinavia based studies had follow-up times beyond six years. As such comparisons between the results of different follow-up times would need to be done cautiously. Cultural differences exist in the general population's QoL (Diener, Oishi, & Lucas, 2003). Additionally, countries are known to practice different CA care and after-treatment and these might impact long-term QoL (Cronberg et al., 2015). For instance, therapeutic hypothermia, which reduces cognitive impairments in out-of-hospital CA, is part of the European Resuscitation Council Guidelines (Deakin et al., 2010), and is more commonly practised in Europe than the USA (Aufderheide et al., 2011; Binks, Murphy, Prout, & Nolan, 2010). Yet many studies did not offer information whether therapeutic hypothermia was part of their participants' standard treatment.

In addition, "sample description" at follow-up tended to be particularly low. Of the studies 77% only partially satisfied this criteria (see Table 2). Studies usually offered very little information on their follow-up participants in comparison to the details available at baseline. For instance, other health-issues such as diabetes (e.g., Bunch et al., 2003;

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Mahapatra et al., 2005) which has been known to reduce QoL ratings (Rubin & Peyrot, 1999,) were reported at hospital discharge but not for the long-term survivors. Providing demographic details at follow-up might be of particular importance if the sample differs to that of the baseline. Pronounced discrepancies could be created, for instance, by considerable drop-out or mortality rates. This was the case in the study by Deasy et al. (2013) in which only half of the participants could be retained. The low retention rate was considered to introduce a substantial confounding factor, and the study received the lowest score on the confounders criteria (see Table 2). Without a clear understanding of the CA survivors' characteristics, comparisons between studies represent a challenge, and it is likely high mortality rates could introduce positive biases.

Only about a third of the studies fully met the recruitment and selection criteria (Table 2). The rest applied methods that restricted the participants' recruitment and likely introduced further positive biases. Many studies excluded neurologically impaired people from the outset of the investigation. In four studies people were excluded who experienced a cognitive disability as a result of the CA (Bunch et al., 2003; Bunch et al., 2004; Khan et al., 2004; Lederer et al., 2004). Three of these studies excluded people who scored below a "two" - which indicates severe overall disability - on their cerebral performance category (Stiell et al., 2009). These people were classified as "non-survivors". This appears misleading and inappropriate as people were clearly alive. The decision to exclude them lacked a sound explanation and might have generated a misrepresentation of CA survivors and their experience of QoL.

The participant sample is also likely to have been affected by the choice of questionnaires. People with cognitive impairments can experience barriers to participation in research, and trials might require adjustments (O'Reilly, Grubb, & O'Carroll, 2004). In fact,

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Saarinen et al. (2012) reported that CA survivors had great difficulties in engaging with the demands of their QoL measure. Two of their six patients were unable to complete the questionnaire on their own and needed support from a family member. In such cases using briefer questionnaires, especially those that might include visual analogue scales (e.g. the EQ-VAS), might have supported patients in expressing their experience. Difficulties in engaging with the questionnaires, possibly due to acquired health difficulties, might also partly explain participants' drop-out rates. For instance, Graf et al. (2008) found that patients who were lost to the follow-up had stayed significantly longer in intensive-care after their CA than patients who completed the questionnaires. Yet, the vast majority of reviewed studies reported no (e.g., Karhunen et al. (2011) or little information (e.g., Bunch et al., 2003) on the reasons for survivor drop-out rates. Having this data could have shed further light on whether survivors with low QoL might have struggled engaging, thus, positively biasing outcomes.

Similarly, it was unclear to what extent neurological impairments accounted for people not returning to work. Seven studies mentioned survivors who had returned to work by the follow-up time, but no direct connection was made with the individuals' ages (e.g. Deasy et al., 2013; Dimopoulou et al., 2011). As such, it remained unclear how many survivors had reached their prospective retirement age during the follow-up period and would have been expected to retire during this point anyway. For these papers it might have been more meaningful to report how many survivors did not return to work due to consequences of the CA (e.g. cognitive impairments) in order to appreciate if people had retired prematurely.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Outcome measures. In the 13 included studies, eight different QoL measures were used. This supports Haydon and colleagues (2017a) in their statement that no standard approach appears to exist to assess QoL in CA survivors. However, the clear majority of studies satisfied the measures criteria of the quality assessment tool as they applied clearly defined measures. The most common questionnaire was the SF-36 used in five studies (Bunch et al., 2003; Bunch et al., 2004; Graf et al., 2008; Khan et al., 2004; Mahapatra et al., 2005), with two more studies using related versions (Deasy et al., 2013: SF-12; Karhunen et al., 2011: RAND-36). It is of note that three of these studies were based on the same patient sample (Bunch et al., 2003; Bunch et al., 2004; Khan et al., 2004). The second most popular questionnaire was the EQ-5D which was employed by three studies (Andersson et al., 2015; Deasy et al., 2013; Kuilman et al., 1999). Other validated measures were the LSQ and 15D questionnaires, used in Lederer et al. (2004) and Saarinen et al. (2012) respectively.

Two studies did not receive the full score on the measures criteria. Dimopoulou et al. (2001) and Harve et al. (2007) used self-devised questionnaires and provided little or no information on what their reasons might have been to turn away from established and validated measures. Similarly, little information was provided on the self-devised questionnaires themselves, and a visual representation would have aided the reader and the study's replicability. Overall, the great variety in questionnaires highlights a lack of consensus and hinders the comparison of results.

Only about a third of the studies satisfied the result criteria completely. The reported results usually appeared to be incomplete. This suggests poor reporting practices or missing analyses. Studies tended to report only one kind of scores: total scores, component scores or subscale scores. In fact, only four studies provided more than one kind of score (Bunch et al., 2003; Deasy et al., 2013; Graf et al., 2008; Lederer et al., 2004). As such, even when

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

studies used the same QoL measure among the multitude of questionnaires, different kinds of scores might be reported. This hampered the comparison of results. In addition, by presenting, for instance, only total scores, differences in subscale or component scores might have balanced themselves out and therefore, not have been noticed.

Regarding the presentation of measures, it was frequently unclear which questionnaires referred to QoL. This lack of clarity might be due to approaching QoL as a secondary investigation, or concurrently investigating related constructs to QoL, such as functional status (e.g. Dimopoulou et al., 2001; Harve et al., 2007). Authors usually did not provide a rationale for their choice of QoL measures. For instance, only three studies indicated that their questionnaire was normed on a national general population sample (Deasy et al., 2013; Karhunen et al., 2011; Saarinen, 2012) and only one study commented on the measure's suitability for this research population (Deasy et al., 2013). None of the studies provided details on the reliability of their measures. As a result, the small amount of provided information on psychometric properties hindered the reader to readily assess the measures' quality or appropriateness.

Yet looking into this issue, it appears, that the most common questionnaires in the reviewed studies were well chosen. The SF-36 assesses functional health status and has been shown to be a reliable and valid measure that has been previously used with CA patients (Dempster & Donnelly, 2000; Falcoz, Chocron, Mercier Puyraveau, & Etievent, 2002). The EQ-5D has also been shown to have good reliability and validity related to QoL (Oster, Willebrand, Dyster-Aas, Kildal, & Ekselius, 2009; Stark, Reitmeir, Leidl, & Konig, 2010). It also correlates with the SF-36, and has been frequently used in research with survivors of critical illnesses (Malmivaara et al., 2009; Pavoni, Giansello, Paparella, Buoninsegni, & Barboni, 2010).

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

The domains the QoL measures were covering also appear noteworthy. Measures tended to divide subscales broadly into psychological, biological, and social functioning in-line with the QoL definition provided by the WHO (2014). However, when examining the two most frequently used measures in this review (i.e., SF-36 and EQ-5D) it can be noticed that this attention was unequally spread across these three health domains. Most subscales seemed to be devoted to physical health foremost, followed by psychological wellbeing, and lastly, social functioning. Yet as QoL is a personal and subjective concept it is possible that other wellbeing domains that are important to CA survivors might have been missed. For instance, none of the QoL questionnaires included questions related to existential or spiritual wellbeing. Yet qualitative research has indicated that CA has a huge impact on survivors' outlook on life and death (Haydon et al., 2017a) and validated QoL measures exist on existential wellbeing (e.g. Cohen, Mount, Tomas, & Mount, 1996; McGill Quality of Life Questionnaire).

Similarly, many questionnaires inquired as to whether patients have functional difficulties with health-related domains rather than about their satisfaction with their function (but see Karhunen et al., 2011). All the review studies followed a quantitative rather than a qualitative approach. That is, none of the questionnaires asked patients what might be important to them in life and whether any consequences of CA have got in the way of reaching or maintaining this. Yet alternative views in research suggest that QoL involves a person's subjective appraisal of their objective ability (Boewling & Windsor, 2001; Testa & Simonson, 1996). To identify individual health values, greater emphasis on a person-centred approach would be of benefit. Unfortunately, this has been given little attention in this research field to date.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Design and analysis. Overall, the reviewed studies performed poorly on the design criteria of the quality assurance tool by Kmet et al. (2004). Of the 13 studies, only eight included any kind of comparison. Six studies involved adjusting scores to a normed control (Bunch et al., 2003; Bunch et al., 2004; Deasy et al., 2013; Graf et al., 2008; Khan et al., 2004; Mahapatra et al., 2005), and six carried out statistical analyses (Bunch et al., 2003; Bunch et al., 2004; Graf et al., 2008; Karhunen et al., 2011; Khan et al., 2004; Kuilman, et al., 1999). As such, over a third of the studies did not involve any direct comparisons and usually presented percentages as their results (Andersson, et al., 2015; Dimopoulou, et al., 2001; Lederer et al., 2004; Saarinen, 2012). Such surveys can only support descriptive statistics, but authors typically interpreted results as “good” or “reasonable”. Yet, without providing a frame of reference and by involving inferential analyses such interpretations carry little weight and need to be considered very cautiously.

Similarly, no study compared QoL before and after CA. This might be linked to many studies being retrospective (e.g. Khan et al., 2004; Lederer et al., 2004; Mahapatra et al., 2005). Yet a longitudinal study would have allowed CA survivors to function as their own control group. This approach appears of particular benefit as normed controls were usually only matched on sex and age (e.g. Bunch et al., 2003) even though the research literature has also identified other demographic characteristics that affect QoL (e.g., socio-economic status and occupational status (Chandola, Ferrie, Sacker, & Marmot, 2007; Pinguart, & Sörensen, 2000). Yet such information was usually not provided by the studies or considered when matching participants to a normed control group and potentially created noise in the data.

In fact, only one study (Harve et al., 2007) made an attempt to compare QoL between different time points. However, it did not involve a statistical comparison between the QoL of the whole samples at two points in time. Rather, the responses only of the survivors at 15

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

years appeared to be compared to their earlier answers at one year. As such, it compared the outcome of a sub-sample and did not report outcomes for the whole of the one-year survivors. People who subsequently passed away were not included at baseline. These people might have had a deteriorating health gradually lowering their QoL up to their end of life (Karimi & Brazier, 2016). By excluding this group of people at baseline, QoL results might appear more favourable than might have been the case.

Similarly, due to considerable mortality rates, only a fraction of participants was available by the follow-up times. Yet none of the studies included adjustments to account for the number of passed-away participants or their QoL in order prevent potential positive biases. A more representative QoL might have been obtained by entering the lowest possible score on the QoL measures for passed-away participants. Alternatively, a more thorough approach could have been the inclusion of the last QoL scores of participants close to their end of life. The last-observation-carried-forward-method has been used in numerous research fields (Nelson & Devanand, 2011). Such a method would have required more comprehensive study designs that included additional follow-up times. Yet researchers might have had little interest in expanding the study designs for their QoL investigation as their primary focus usually appeared to lay on other dependent variables.

In all the studies, QoL was always investigated alongside other concepts that appeared to take the primary focus in the articles. For instance, variables such as neurological status and survival rate were supported with more thorough study designs. That is, in comparison to QoL, these other outcomes were investigated using more control groups, statistical analyses (e.g. Mahapatra et al., 2005; Saarinen, 2012), and comparisons between follow-up times (e.g. Harve et al., 2007). However, the lack in the rigour in the study designs in relation to QoL, might still represent a slow shift in the research literature which has, in the

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

past almost exclusively focused on survival rates (Neumar et al., 2008). In fact, the analyses of other concepts other than QoL were also frequently more thoroughly described. The reviewed studies tended to score lower on the analyses criteria of the quality assessment investigation if little or insufficient information was provided on their QoL analyses. This was true for nearly half of the studies, and affected the replicability of the studies

The overall scores on the conclusion criteria on the quality assessment tool were low. Of 13 studies only five received the full score, and the remaining eight received partial scores. Low performances were due to interpretation difficulties based on weak study designs for example, a lack of statistical comparisons. Other reasons included particularly high drop-out rates (e.g., Deasy et al., 2013). These low retentions challenged the representativeness of the samples, and consequently the interpretation of results. Finally, studies scored low on the conclusion criteria as low QoL data might have been missed by excluding cognitively challenged people as well as passed-away participants. These confounding variables are likely to have biased the results as well as question the conclusions drawn.

Discussion

Research Implications

Important medical advances have been gained since the introduction of defibrillators. One outcome has been that the CA survival rate had greatly increased since the 1960s. Yet research studies still only position QoL as a secondary outcome and favour survival and mortality rates as primary focal points. This might partly be due to continuing difficulties in defining the concept of QoL. Additionally, funding for longer-term studies can usually only be secured after investigations into immediate QoL have first been explored. Yet of 87 studies that this review could identify the majority involved follow-ups of six months, and only 15%

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

were concerned with longitudinal foci beyond four years. The time might have come to support a shift to long-term QoL in research particularly as CA survivors might live for another 16 years after hospital discharge (Graf et al., 2008).

Overall, the review studies appear to suggest that long-term QoL in CA survivors is good and close to normal beyond four years. However, based on the current studies it cannot be determined whether the QoL of the long-term survivors has always been good, or appears better due to people with lower QoL passing away. A particular challenge is represented by the exclusion of cognitively impaired survivors in most of the reviewed studies. Such patients were either excluded from the outset (e.g., Bunch et al., 2003), or the study questionnaires may have been inappropriate for them, so they were lost to follow-up times. Yet their experience could have been possibly captured by visual analogue scales such as EQ-VAS to prevent biasing the results by excluding these participants. This is of particular concern, as many studies do not give information on drop-out rates, nor do they provide reasons why participants might have dropped out. These drop-out rates could be due to neurological challenges that CA survivors frequently face. Additionally, studies are already being done on sub-groups within the CA survivor population (e.g., VF or PEA as initial CA rhythms), although the long-term QoL has not been even fully explored (e.g., statistical comparisons to healthy or other disease controls). Little information is provided on survivors' hospital treatment and after-care, including rehabilitation. This information might be of particular value due to larger differences between countries, and might need further attention when generalising results. Before these study recommendations get implemented it remains a challenge to evaluate the results, and findings are difficult to interpret or to compare to other CA survivor groups. Clearer research guidelines and more rigorous study designs are needed in this area.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Future research would benefit from exploring which QoL measures might be the most appropriate to use for this sample group, and consensus on tools would support the comparison of results between studies. Similarly, to support the transparency and potential replicability of studies, it appears of particular importance for future studies to clearly report the measures they employed as well as their results, such as the overall score along with subscale or domain scores. This is of particular interest when similar concepts are investigated in the same study.

Clinical Implications

For recovery from a CA to be deemed successful, not only do the survival rates need to be considered, but the investigation of long-term QoL deserves particular attention. The reviewed studies seemed to suggest that long-term QoL is at least stable after four years following a CA. However, influential factors have likely biased the findings and the focus of the QoL measures has been questionable. As such, although guidance on clinical implications is needed, recommendations are not possible at this point. Yet drawing on the previously discussed happiness theories (please see the introduction section) several observations can be made.

Papers usually did not provide a definition of QoL explicitly, but did so indirectly through their choice of questionnaires. They predominantly focused on physical wellbeing. If they touched on the psychological wellbeing of their participants, they included questions on their positive and negative emotions. Emotions have usually been identified as a component of happiness in psychological theories. For instance, they resemble the “positive/negative affect” aspect of Diener’s SWB within his Tripartite Model (1984) and “the pleasant life” element in Seligman’s Authentic Happiness theory (2002).

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Yet the papers' QoL questionnaires appeared to neglect other aspects of happiness as suggested by established psychological theories. For instance, according to Seligman happiness is also made up of "the meaningful life" which involves being a part of and contributing to something larger than oneself, such as social groups or belief systems. Very few questionnaires touched on participants' sense of contributing to something larger by exploring people's social involvement and none appeared to address their spiritual wellbeing. However, qualitative research has indicated that CA has a huge impact on survivors' outlook on life and death (Haydon et al., 2017a). Validated QoL measures exist on existential wellbeing (e.g. Cohen, Mount, Tomas, & Mount, 1996; McGill Quality of Life Questionnaire) but were not applied in the reviewed studies. A rich source of such perspectives might have been provided by participants who were unfortunately excluded due to their poor health. Research has suggested this population frequently revisits their spirituality when they approach their end of life, and this process might also carry beneficial effects for their mental-health (Lawler-Row & Elliott, 2009).

Similarly, many questionnaires focused more on whether patients had functional difficulties with health-related domains rather than about their satisfaction with their function (but see Karhunen et al., 2011). That is, none of the questionnaires asked patients what might be important to them in life and whether any consequences of CA have got in the way of reaching or maintaining this. That is, predetermined QoL aspects might have missed the variety of people's actual values that might differ from physical ability. Indeed, alternative views in research suggest that QoL involves a person's subjective appraisal of their objective ability rather than the objective ability per-se (Boewling & Windsor, 2001; Testa & Simonson, 1996). This is in line with Diener (1984) who captured this aspect of

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

happiness in his “Cognitive Evaluations” component of SWB (i.e., how people judge their life instead of what they can do).

Lastly, “the good life” perspective of Seligman also seems not to be an element captured by the current QoL questionnaires. “The good life” advocates the experience of deep immersion into an activity. Some participants were asked about their ability to engage with ADL (e.g., Dimopoulou et al., 2001). Yet Seligman rather promoted the discovery of an individual’s unique strengths and virtues, and then applying them through activities. This subjective nature would require a more person-centred approach and might express itself through the choice of other past-times than ADLs such as hobbies. These and other overlooked happiness aspects could have been explored by already available measures that evolved from the psychological theories discussed here. Examples include the Steen Happiness Index (SHI; Seligman et al., 2005) and the Authentic Happiness Inventory (AHI; Peterson & Park, 2008).

Conclusion

Searching the databases, over 2,000 papers were identified, of which 13 studies qualified for this review. Overall, there was a lack in clearly defining QoL, which might partly explain why it still remains a secondary outcome measure in this research area where other dependent outcomes usually received greater attention. For long-term QoL few comparisons were made, with even fewer involving statistical investigations. The large number of questionnaires, different follow-up times and study samples also made it difficult to assess these papers. The generalisability of the results to the UK was limited. Most studies had been conducted in the USA or Scandinavia where different treatment regimens exist and different QoL rates in the general population. In the future, more methodologically sound longitudinal studies are needed. It would be of particular benefit to compare different long-

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

term follow-up times and to include more cognitively challenged survivors, for instance, by choosing more accessible questionnaires. More research is needed to explore to what degree results are due to people recovering over time or people with poor health passing away. Questionnaires predominantly measured people's functioning, with a main focus on physical abilities. By revisiting happiness concepts such as by Diener (1984) and Seligman (2002), particularly neglected aspects of psychological perspectives on QoL can be drawn out. Lastly, future measures would be recommended to centre on people's satisfaction and happiness with areas of life that are important to them.

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ANGELA HILLEMANN
Dip BSc (Hons) MSc

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Section B:
Happiness in adults who had a Near-Death-Experience:
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Abstract

Objectives: A Near-Death-Experience (NDE) can be a lifechanging event that can initiate deep posttraumatic growth. Yet people can initially be left struggling with their internal changes and feel alienated from their life and social networks. This study investigated whether NDE also have an impact on people's happiness, and if so, how long it lasts, and what kind of support they receive in making sense of the event.

Method: Semi-structured interviews were conducted with six people who had a NDE, and the transcripts was subjected to Interpretative Phenomenological Analysis.

Results: Five master-themes emerged: Sense of self, Attitude toward life and death, Effects of NDEs, Relationship with others, and Experience of happiness.

Conclusion: Almost all participants reported feeling less apprehensive about death, and simultaneously found a greater ability to embrace and appreciate life. Some gained new and profound internal insights that manifested in a renewed sense of self and stronger as well as more pronounced feelings of life purpose. Participants offered reflections on the NDE as a precious gift. Most participants experienced a greater degree of happiness that gradually grew over time. This was largely located internally, and freed them from "the hedonic treadmill" of pursuing it in the outside world. Stigma and a lack of awareness still represent a hurdle for connecting with others and accessing support. Future research is recommended for support groups, expressive writing as a therapeutic tool, and potentially confounding factors such as selective recall or maturation processes. Clinical psychologists might assist people in developing Post-Traumatic-Growth by creating spaces to disclose/share their NDE.

Keywords: Near-Death-Experience, Happiness, Wellbeing, Support, Interpretative Phenomenological Analysis

Happiness in Adults Who Had a Near-Death-Experience:

An Interpretative Phenomenological Analysis

What is a Near-Death-Experience (NDE)?

The term, NDE, was first coined by Moody (1975). It has since gained popularity in the media (Holden, Oden, Kozlowski, & Hayslip, 2011) and sparked the interest of researchers (van Lommel, van Wees, Meyers, & Elfferich, 2001). During NDEs, people usually experience a sense of detachment from their body and of floating above it (i.e. out-of-body-experience; Blanke & Mohr, 2005). Then they might travel through a tunnel and find themselves in the presence of deceased loved ones or a bright light, while feeling an other-worldly sense of love and serenity (Zingrone & Alvarado, 2009). People might also report reviewing their live experiences in detail (Atwater, 1988).

NDEs usually but not necessarily accompany life-threatening events. People's perception that they are close to death appears essential in triggering a NDE (Gabbard & Twemlow, 1991). As such a NDE describes a specific experience during a traumatic event that is perceived to be life-threatening, while PTSD defines a collection of symptoms that might follow subsequently (American Psychiatric Association, 2013). Yet a NDE might increase the chances for developing PTSD. Mental-health problems such as PTSD are more common in people with NDEs than who had a close brush with death without a NDE (Greyson, 2001).

NDEs occur in 10-20% of cardiac arrest survivors and about four percent of people who have undergone general anaesthesia (Parnia, Spearpoint, & Fenwick, 2007; Schwaninger, Eisenberg, Schechtman, & Weiss, 2002). NDEs have also been reported in connection with deep meditative practices and recreational drug use (Strassman, 2001; Van

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Lommel, 2010). Evidence suggests that recollections of NDEs are relatively stable over time and not embellished as other memories might be (Greyson, 2007). The occurrence of NDEs also appears to be independent of whether somebody is religious (McLaughlin & Malony, 1984), although beliefs might influence the interpretation of the NDE (Shushan, 2009). Yet the core phenomenological features of NDEs appear to be comparable across cultures (Belanti, Perera, & Jagadheesan, 2008; Kellehear, 2009).

NDE Evidence and Critique

Support for the authenticity of NDEs has come from veridical research. In such studies people have described having seen or heard events, while they were medically dead, that could be later verified, such as medical procedures and the appearance and behaviour of staff (Van Lommel et al., 2001). Of particular interest have been reports by blind people who have claimed to be able to see during out-of-body-experiences and who gave descriptions that could be confirmed (Ring & Valarino, 2006). NDE accounts by young children have also been of interest as they have been less exposed by cultural and religious concepts of the afterlife (Moody, 1988). For instance, before the popularisation of NDE through Moody (1975), a child of two years and five months old was resuscitated and gave a NDE description four months later (Gabbard & Twemlow, 1984).

However, in five studies images that could only be seen from an elevated position were placed in high locations in hospital rooms (Cardena, Krippner, & Lynn, 2000). Of 12 patients who saw their body below them, none could describe these hidden visual targets. In line with critical approaches, biomedical perspectives suggest NDEs could be explained by oxygen starvation of the brain or hallucinatory side-effects of the drugs used during medical procedures (Hines, 2002; Morse, Veneca, & Milstein, 1989). Psychological models propose

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

that during a life-threatening situation people might profoundly dissociate from their immediate surroundings, or their expectations of an afterlife might become a convincing reality for them (Cardena et al., 2000; French, 2005).

Negative Aftereffects of NDEs

NDEs can be challenging to assimilate, emotionally taxing, and deeply confusing (Boorstein, 1980; Ring, 1984). The brush with death can already be deeply distressing, but 20% of NDEs might also involve visiting anxiety-provoking realms, or include hostile presences (Lindley, Bryan, & Conley, 1981). Furthermore, people's experience or internal changes might be met with disbelief and resistance by their loved ones (Orne, 1995). Support appears particularly important during a first transition period of disequilibrium, yet might not be readily available. People can feel alienated from their previous life, and leave or change their job, partners and friends (Ring, 1984). Negative effects of NDEs might lead to a range of symptoms assessed within a medical treatment model, such as depression or PTSD (Parnia et al., 2007). However, people's distress and spiritual crisis might not neatly fit into diagnostic criteria used in the NHS, and so affected people might turn to private psychological support instead. Others might not reach out for professional support altogether due to concerns about how they might make sense of it. Indeed, people with NDEs report that their transcendent account has sometimes been met with scepticism and prejudice by mental-health practitioners (Ring, 1984; Walsh, 1983). Some felt their experience was pathologised and viewed as a symptom of schizophrenia rather than considered within a spiritual context (Bloomfield, 1980).

NDEs and Post-Traumatic-Growth (PTG)

NDEs also have been associated with PTG in that adversity may represent opportunities for personal development and positive change (Calhoun & Tedeschi, 2001). PTG was originally coined by Tedeschi and Calhoun (2004). They advocated that PTG was not just a direct result of trauma, but of an individual's grappling with the experience, and integrating it into their worldview. They also distinguished it from resilience in that resilience was suggested to be "a return to baseline", whereas PTG is a positive improvement that surpasses it (2004, p.4). Their model advocated five distinct domains of PTG, and gave rise to a now widely-used measure, the Posttraumatic Growth Inventory (PTGI, Tedeschi & Calhoun, 1996). The components are respectively: "New Possibility", "Personal Strength", "Relating to Others", "Appreciation of Life", and "Spiritual Change".

"New Possibility" summarised how people might make life-changing decisions after a traumatic event and take a new path in life. "Personal Strength" described a greater trust in one's ability to cope with challenges. "Relating to Others" included having more meaningful relationships while others social connections might dissipate ("you find out who your real friends are"), and having more empathy for the suffering of others. "Appreciation of Life" involved "feeling lucky", enjoying "the small things" and a changed sense of what is important. Finally, "Spiritual Change" conveyed how people might find or deepen their spiritual identity and faith. Tedeschi and Calhoun proposed that, for these five domains of PTG to occur, a person would need to engage in rumination which in turn would initiate schema changes and the development of a new narrative. In this process self-disclosure and social support were seen as facilitative components.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Greater PTG has been linked with surviving life-threatening events (Tsail, El-Gabalawy, Sledge, Southwick, & Pietrzak, 2015), and having spiritual experiences (Werdel, Dy-Liacco, Ciarrocchi, Wicks, & Brelsford, 2014). As such NDEs might be expected to carry particularly positive effects. One study suggested that all of their survivors were more self-assured and socially aware after a cardiac arrest, but that only those with NDEs had also a greater empathy, sense of spirituality, and less fear of death (Van Lommel et al., 2001). A comprehensive review on NDEs also pointed towards a greater appreciation and zest for life, purpose, compassion for others, and decreased interest in material gains and status (Noyes, Fenwick, Holden, & Christian, 2009). This observation has been summarised in a shift from extrinsic life values, such as possessions and power, to intrinsic life values such as appreciation of oneself, others, and life (Cozzolino, 2006). Yet researchers have pointed out a need for qualitative studies to delve deeper into the “Nuances of an experient’s transformative processes” (Wilde & Murray, 2011, p.133)

Happiness

Another PTG outcome is linked to happiness, which is a personal and complex concept related to life satisfaction (Gundelach & Kreiner, 2004). Happiness is a crucial ingredient of human wellbeing and health (Duckworth, Steen, & Seligman, 2005), and is commonly rated by people as one of their top priorities in life (Tkach & Lyubomirsky, 2006). The two main theoretical approaches to happiness are hedonia and eudaimonia. Both concepts derive from ancient Greek philosophy (Deci & Ryan, 2008). Epicurus defined the hedonistic perspective as a desire for pleasure while avoiding pain (i.e., “pleasurable life”, “subjective wellbeing”). Hedonia suggests a sense of gratification and offers a rewarding yet fleeting sensation. In contrast, eudaimonia, coined by Aristotle, placed importance on

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

following long-term goals. Eudaimonia involves the pursuit of finding purpose and meaning in life, for instance, by striving for self-actualisation, personal growth, and integrity (i.e. “good life”, “psychological wellbeing”).

Research has also addressed a temporal dimension to happiness, questioning the stability and permanence of happiness over time. For instance, “the hedonic treadmill” captures a phenomenon where happiness is only temporarily affected by life events, and readily readjusts to a pre-incident point (Frederick & Loewenstein, 1999; Suh, Diener, & Fujita, 1996). Other studies suggest that long-term changes to happiness follow major incidents (Lucas, Clark, Georgellis, & Diener, 2003). Yet a third line of inquiry highlights how the degree of readjustment to a set-point may depend on the specific life event. For instance, happiness levels show greater adaptation following the loss of a spouse, than losing a job or becoming a divorcee (Lucas, 2005; Diener, Lucas, & Scollon, 2006).

This Study

The purpose of this study is to expand the understanding of NDE effects, and, more specifically, the potential PTG following a NDE. In doing this, the study will also challenge stigma on NDEs by widening the understanding of people’s experience of this phenomenon and its impact on personal change. Specific research questions are as follows:

1. Do people have a different sense of happiness following a NDE, and how do they make sense of this change?
2. How do people view the temporal development and stability of a change in their happiness?
3. Do people have sufficient support to meet potential psychological needs arising out of a NDE, and what kind of support did they find (un)helpful?

Method

Design

This qualitative study was based on in-depth, semi-structured interviews in order to collect rich accounts of participants' experience and understanding of happiness in relation to NDEs. Interpretative Phenomenological Analysis (IPA; Smith, Flowers, & Larkin, 2009) was chosen to analyse the data, as it focuses on meaning-making, and appeared to be a suitable methodology for the study aims. IPA represents an idiographic and phenomenological approach investigating how people experience life events and attach meaning. IPA also acknowledges the influence of the researcher's world-view on the study data (Smith & Osborn, 2004), and has been used in other studies exploring how people make sense of their NDE (Bianco, Sambin, & Palmieri, 2017) and its effects on their lives (Wilde & Murray, 2010).

Participants

For IPA, small sample sizes are ideal to support in-depth interviews and analysis whereas large numbers might compromise this approach (Smith, 2004). Six adults were recruited from the general population through social media and word-of-mouth (Table 1). Participants were between 28 and 62 years old and experienced a NDE between 10 and 41 years ago. All participants resided in South England at the time of their individual interview. Inclusion criteria represented: Living in the UK, being fluent in English, having a NDE, identifying no significant posttraumatic stress (PTSD) and enjoying a reasonable level of psychological well-being (see Measures section, p.67).

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Table 1

Participant characteristics

Pseudonym	Age	Age at NDE	Number of NDE	Ethnicity	Religion	Occupation	Reason for NDE	NDE Score	PTSD Score	General Wellbeing Score
Nicole	62	21	1	White Irish	None	Administrator	Drowning	8	23	0
Steph	28	10/18	2	White British	Christian	Trainee Clinical Psychologist	Fall from great height	9	21	0
Betty	55	35	1	White British	Inclusive	Farmer	Complication during childbirth	10	28	0
James	36	24	1	White British	Buddhist	Legal Advisor/ Trainee Counsellor	Car Accident	14	18	0
Julia	49	38	1	White British	Christian	Primary School Teacher/ Inclusion Coordinator	Complication during childbirth	20	24	0
Amy	53	12	1	White British	Christian Spiritualist	Foot Care Podiatrist	During Sleep, Cardiac Arrest?	23	17	0

Procedure

Recruitment. A study poster was sent to 101 Facebook groups, of which 74 displayed it on their news-feed (Appendix B). About a third of the latter were specific to NDEs and the majority were general notice boards connected to local communities. The study poster provided a link to the information sheet (Appendix C) and to an online questionnaire (Appendix D). The latter included consent questions along with three measures as outlined below. Of 115 participants who completed the online questionnaire: 37 did not leave their contact details, 15 did not live in the UK, 23 did not meet the cut-off score for a NDE, 17 scored high on PTSD symptoms, and six scored low on general psychological wellbeing. The remaining 16 were contacted via email to identify their location. Recruitment was staggered whereby it would be gradually geographically widened following three stages (see information sheet, Appendix C). Nine replied, of which six lived in the first recruitment zone. These were invited to an interview and chose to attend it in person. As financial incentive a prize-draw for a £25 Amazon voucher was included for people who completed the questionnaire.

Interviews. The questions of the semi-structured interview (Appendix E) were developed in accordance with IPA guidelines (Smith & Osborn, 2004). Interviews took place in a private room in the community (e.g. library, community centre) and lasted between one hour and 15 minutes to two hours. Limits of confidentiality were discussed, participants completed a consent sheet (Appendix F) and demographics were collected (Appendix G). After each interview, a debrief sheet was provided (Appendix H), time was offered to participants to reflect on the interview and feedback was sought on the interview's content and process. Interviews were digitally recorded and verbatim transcribed.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Measures

Near-Death-Experience Scale (NDES). Sixteen items are scored from zero to two on a three-point Likert-scale (Greyson, 1983a). The tool yields a maximum score of 32, with greater numbers indicating more severe experiences. A high reliability and validity have been reported and it has been frequently applied in NDE research (Greyson, 1983a). In the research literature a score above six is set to classify a NDE (Parnia et al., 2014).

PTSD Checklist for Civilians (PCL-C). This self-report measure for civilians is a frequently used screening tool based on the DSM-IV criteria for PTSD (American Psychiatric Association, 2000; Weathers, Huska, & Keane, 1991). Seventeen items are rated on a five-point Likert-scale (1= not at all; 5 = extremely) with higher scores indicating greater difficulties. A good validity and reliability have been found in several studies (Coneybeare, Behar, Solomon, Newman, & Borkovec, 2012; Ruggiero, Del Ben, Scotti, & Rabalais, 2003). In a review of PTSD measures by Brewin (2005) a PCL-C cut-off score of 44 was suggested for caseness.

General Health Questionnaire-12 (GHQ-12). Drawing on a four-point Likert-scale, 12 responses are coded as 0-0-1-1 yielding a maximum score of 12. Higher scores indicate greater concerns, with a cut-off at four implying psychological difficulties (Goldberg et al., 1997). The GHQ-12 is one of the most extensively used screening tools for common mental disorders and psychiatric wellbeing in the general population (Gureje & Obikoya, 1990). Its brevity and sound psychometric properties make it attractive for use in clinical settings and research (Werneke, Goldberg, Yalcin, & Üstün, 2000).

Analysis

Interview transcripts were anonymised and analysed using IPA following the guidelines by Smith et al. (2009). Interview recordings and transcripts were repeatedly listened to and read in order to increase the researcher's familiarity with the data. While immersed in the data, a summary of each participant's experience was written (Appendix K). Initial notes were made in the left margin by focusing on three levels of analysis: descriptive, linguistics, and conceptual comments (Appendix L). Emerging themes were included in the right margin. Then these themes were clustered according to similarities which gave rise to initial emerging themes (Appendix M). When interpreting the meaning, the researcher consistently referred back to the data so that the interpretation was "close" to the participant's experience. After this process had been repeated for each interview, themes were compared between interviews to identify overarching master-themes (see Table 2).

Quality Assurance

Recommended procedures were followed to ensure the studies' quality and minimise the potential impact of biases (Yardley, 2000). The researcher took part in a bracketing interview with a colleague to bring into awareness personal preconceptions that might impact the interview style and analysis (Appendix N). This is of particular importance as IPA emphasises the active stance of the researcher who "is trying to make sense of the participants trying to make sense of their world" (Smith, 2008, p.53). A research journal was kept, providing reflections on emotional responses after each interview (Appendix O). To explore inter-coder agreement, the lead supervisor reviewed the analysis of one interview transcript (Appendix L) including a summary of the participant's account (Appendix K). A high level of agreement was found, and any discrepancy in codes or themes were discussed.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

The lead supervisor had considerable experience with IPA and was satisfied with the interpretations drawn.

Ethical Considerations

The study received ethical approval through the Canterbury Christ Church University Ethics Committee (Appendix P). Interested participants were screened for study eligibility and informed consent was collected. Screening was intended to ensure that participants had experienced NDEs as defined in the study, and were of reasonable well-being to minimise unintended negative effects of an interview. Data was anonymised and stored on encrypted devices (hard drive or USB stick) only. The safety of the researcher was addressed, for instance by carrying a personal alarm and by providing the interviews in rented rooms in public places such as libraries or community centres. Participants' emotional state was attended to throughout the meeting and protocol followed if a participant was to become distressed. All participants were provided with a debrief sheet which included help line phone numbers (e.g. Samaritans) and online resources to access accredited therapists in their local area. Participants were recommended to inform a friend/family member of their upcoming interview and to check-in with them afterwards if appropriate. A final report will be forwarded to interviewed participants, the ethics panel, and the R&D committee (Appendix I, J).

Results

Five master-themes, with a total of 14 sub-themes, emerged from the analysis (Table 2). Quotes are presented with a reference: Participant name followed by the transcript line number (for additional quotes see Appendix Q).

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Table 2

Master-themes and sub-themes

Master-themes	Sub-themes	Number of participants contributing to subtheme (N=6)
Sense of self	Renegotiating identity	5
	Reflecting on one's life purpose	5
Attitude toward life and death	Leaving behind the fear of death	6
	Embracing a greater appreciation of life	5
	Re-assessing spirituality and religion	6
Effects of NDEs	Attaching value to NDEs	6
	Considering temporal effects of NDEs	6
	Questioning causation	6
Relationship with others	Facing hurdles in receiving support	6
	Noticing and respecting NDE differences	4
	Connecting and offering help	6
Experience of happiness	Contrasting an inside vs outside source	6
	Choosing one's perspective	4
	Enjoying greater happiness and better mental-health	5

Sense of Self

This master-theme spoke to the participants' new perspective on their identity and life-purpose.

Renegotiating identity. Most participants described an internal shift following the NDE where they felt more in touch with themselves and affirmed.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

“I don’t really know much about myself despite having lived with myself for over 60 years and I think that NDE was basically saying “I’m okay””(Nicole-630)

“I think before I never used to think I was worthy ... but now I think I am ... and now I know I am”-(Julia-1607)

Participants also reported gaining a greater sense of resilience and assimilated the experience into their personal narrative. By doing so, the participants touched on a notion that suggests PTG itself was a narrative process of constructing a positively transformed identity (Pals & McAdams, 2004).

“Is it’s given me an inner strength that maybe wasn’t there before.... Inner belief in myself”-(Betty-438)

“[Viewing the NDE] as a good thing, or as a really important part of my story that I didn’t want to forget”-(Steph-2244)

Reflecting on one’s life purpose. In line with findings by Noyes and colleagues (2009), participants had, on the whole, a stronger sense of having a life purpose, although they might not be entirely sure what that entails in detail. Yet Amy was given her concrete “blueprint” during the NDE, and has since felt “guided invisibly” (Amy-163). This knowledge helps her to stop ruminating when she questions how she lives her life.

““have I achieved everything I wanted? Did I take the right pathway in life? Should I have gone in a different direction?”, ... [but] you were told that you had to have and bring up three children and do good works, and, you know, maybe you have fulfilled that and maybe you’re not meant to do much else”-(Amy-93)

In light of their NDE, some participants felt reminded of their life purpose when they witnessed other people prematurely passing away. Emotional responses ranged from

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

“special” feelings to ones of “guilt”, because others were not so “lucky”. People’s sense of purpose also appeared tightly connected to how they understood the reasons for them still being alive. James was conflicted and, on the one hand, speculated if past actions in his current or previous life came to his rescue. On the other hand, he was one of the participants who also wondered if he was somehow indebted, and still needed to pay back his second chance at life through doing “good” now and in the future to come. This brought up further questions around having free will.

“Just feeling that there’s a need to justify still being around ... a sense of, um, yeah, that that happened for a reason and I owe the universe my life, so what can I do”-

(James-339)

Attitude toward Life and Death

Three distinct sub-themes emerged within participants’ attitude towards existential questions: Leaving behind the fear of death, Embracing a greater appreciation of life, and Moving within spirituality and religion.

Leaving behind the fear of death. Similar to Van Lommel et al. (2001) all participants described they had gained a greater acceptance of death through the NDE. For instance, participants explained that having experienced the NDE neither as frightening nor painful made them feel more comfortable about their actual death, whereas they might have felt previously “cheated out of opportunities” (James-1128). Amy and Julia, who scored the highest on the their NDE depth, also acquired the view that death “is not the end” (Amy-485) which gave them happiness.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

“for me it’s as if they’ve emigrated!” “They’re still there, almost as if if you had had a relative that went to Australia [...] or New Zealand [...] well, for me, wherever they’ve gone is slightly further”-(Amy-69)

Some participants also highlighted that their new acceptance of death was not a “giving-up” or feeling tired of their life.

“when I thought I could be dying, I wasn’t, I wasn’t afraid and it wasn’t in that sort of abandoned way, it was just [...], what I am delighted to remember [is] my curiosity about it”-(Nicole-317)

Betty provided a differentiation between an attitude towards death and an immediate fear for one’s life; a view that resonates with Freud’s concept of “eros”, whereby a survival threat might trigger a person’s life instinct (Migone & Liotti, 1998).

“there’s a perception of death and there’s a fear of death [...] The fear of death is a very human instinctive like primitive like brain bit that says “oh my God, I might die now””-(Betty-1876)

Embracing a greater appreciation of life. Every interviewee commented on an increased sense of the value of their own life since the NDE. The brush with death meant for them that they could engage with life more fully which mirrors previous research findings (Noyes et al., 2009).

“happiness is that fully living, like having joy, like really experiencing life in all its fullness. Appreciating and noticing everything that life offers”-(Steph-1598)

For Nicole this also meant just enjoying being alive independent of recreational substances or the company of the opposite sex. Many participants subsequently reconsidered their priorities to use their time more intentionally.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

“really thought about life more, thought about what it meant to be alive, and how to make the most of life, not wasting time, not getting it wrong or messing up”-(Steph-1797)

Steph and Julia in particular emphasised a motivation to protect their life and being more alert to danger since the NDE.

“I would have in the past maybe gone off in situations which could have caused a risk, or or hitchhiked, or taking too many drugs, or, um, other risky situations, being around risky people, dodgy people. But no, I wouldn't do that now. Too important to be alive”-(Julia-905)

Re-assessing spirituality and religion. This aspect represented differently across participants. Steph was initially shaken after the NDE, and worried that she would reunite with God if she were to reconnect with him through prayer.

“so it would be normal for me to pray to God, but I couldn't after the accident, because I felt as though I'd come so close to meeting him.”-(Steph-204)

Nicole also experienced a temporary distance from God in that she no longer needed to pray to feel self-acceptance, as the NDE had provided her with this reassuring sense.

“When I prayed, which was every day, [...] five minutes, everything's okay I don't have to worry about anything.'...' for eight months, it was, I didn't need that little 'click' every day”-(Nicole-1050)

Betty came to a realisation that religion had been a substantial source of conflict in her family and “dropped [it]”-(Betty-1780).

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

“religion has caused so much trouble [...] over the generations, not just in my life but in the generations of our family, and this is all b****, [...] and it just really hit me big time”-(Betty-1804)

In contrast, James, Amy, and Julia felt an increase in their religious beliefs. Julia subsequently felt very akin to people who held a strong faith and passed on her passion through her work teaching Religious Education (RE) at school.

“we really discuss spirituality. And that’s made me a really good RE teacher [...] I’m not teaching them, because they have it inside them naturally, I believe [...] helping them to to question and to be spiritual”-(Julia-2262)

Effects of NDE

Three subthemes were present across all participants’ interviews. The subthemes highlighted the participants’ appreciation, temporal perception and doubts about NDE effects: Attaching value to NDEs, Considering temporal effects of NDEs, Questioning causation.

Attaching value to NDEs. All participants readily linked their relationship with happiness to their NDE. For instance, during the experience, Amy came across a new intensity of happiness and compares it to having received a precious “gift” from elsewhere. “Being gifted” recalls ancient Greek philosophy where happiness is viewed as something that is handed down by the gods and otherwise lies outside of human control (Oishi, Graham, Kesebir, & Galinha, 2013).

“think of the happiest you’ve ever been, you know, multiply that by a million times and you won’t even come close. It was almost as if my whole being or my whole soul was happiness”-(Amy-402)

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

For Nicole the “significance” of the NDE was not apparent at the time but she felt now that she had found “gold”, implying that she rather views herself as an active agent in the process.

“it’s an anchor point to my happiness which if I’m going to continue the metaphor, I’ve let the chain to it be quite tight at times, and at other times very loose, but it’s an anchor to my happiness”-(Nicole-1543)

James took the image away from the sea and into the sky as he compared the NDE to climbing a mountain where on its top he felt closer to the universe. Yet for the two participants who were the youngest at the time of the NDE, they felt neither grounded nor elevated but initially very confused and shaken. A few years passed before Steph concluded she had a choice in how she wanted to engage with this experience, and at last viewed it as an opportunity that has brought her contentment.

“a NDE could be something that could really make someone like sad, or depressed, or be a difficult thing to deal with. But I actually think about what you can take from it [...], like decide what way you want that experience to shape you.”-(Steph-2173)

Considering temporal effects of NDEs. Participant accounts of deep happiness during their NDE compares to “peak experiences”, first described by Maslow (1964), as moments of highest fulfilment and self-acceptance. Yet after the experience, the majority of participants agreed that the NDE effects were not instantaneous but grew slowly over time.

“the influence is trickling through again and again”-(Amy-2097)

However, Julia and Betty wondered if the effects were possibly more consistent over time than they might have originally thought, as their busy lives and adverse events might have been distracting them from noticing.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

“I wouldn’t have been aware of that because, [...] it wasn’t long after that [Ex-boyfriend] left, and I was having, [Son] has had all these operations”-(Julia-1709)

In contrast, Nicole experienced a period of heightened happiness following the NDE which, to her disappointment, ended abruptly after eight months. She felt regret for not making more of it at the time but believed that it would last.

“The NDE gave me a glimpse that I’m sorry that I didn’t pay more attention to, now I’m thinking about it.”-(Nicole-599)

Her attempts to reconnect to the NDE happiness through praying, alcohol, and personal development workshops had limited success until she turned to meditation. Betty also discovered meditation for herself and rated it as a seven for generating the same kind of happiness, whereas during the NDE she had experienced a 10.

“[mediation] has enabled me to connect back to that serenity feeling, that same, from the NDE, the same, exactly the same feeling, and it makes me feel a lot better.”-(Betty-1049)

Questioning causation. All participants considered other factors to be contributory when making sense of their experience of happiness following the NDE and voiced difficulties in separating the effects. These other factors included: supportive or difficult relationships, receiving therapy, completing counselling training, and being shocked by the USA 9/11 terrorist attacks. Steph also wondered if memory distortions might bias her recall of her happiness when making comparisons before and after the NDE.

“I would have said that I was happy for the first 10 years of life. I don’t remember really many times feeling anything other than happy, and maybe that’s a rose-tinted version of childhood”-(Steph-1668)

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

James pointed out that “correlation does not imply causation” (James-1674) and together with Amy wondered to what extent ageing and passing through developmental stages might play a part in their sense-making process.

“there’s a a mixed yes, because I think something changes over time in there, natural cause of maturity and ageing and experience”-(James-1367)

James also suggested that the factors might be cumulative rather than exclusive and that the NDE might have “thrown him forward” in his personal development.

“I’d say a catalyst from being nudged along, being knocked forward, having the growth shortened”-(James-1958)

Considering the NDE as a catalyst, James, who had his NDE at the age of 24, afterward developed a novel focus on “public service”. In support of James’ view, having a wider sense of contributing to society resembles the life task of generativity in Erikson’s psychosocial development theory (1980). The theory suggests this task is more typically faced later in life by people between 40-64 years old.

Relationship with Others

This master-theme concerns changes in how participants relate to people, including those who had NDEs themselves. Three sub-themes emerged: Facing hurdles in receiving support, Noticing and respecting NDE differences, Connecting and offering help.

Facing hurdles in receiving support. All interviewees encountered difficulties in sharing their NDE with others. Amy, for instance, kept hers secret for 10 years before “revealing” it. Their hesitation involved worrying about judgment or ridicule, being labelled as “mad”, or their experience being dismissed as hallucinations. Yet Amy acknowledged that society has become more “open minded” since she had her NDE and is hopeful for the

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

future. Promoting NDEs as “different” rather than stigmatising them as “abnormal” has also seen support by Turner and colleagues (1995) who warned of misinterpreting this spiritual experience as a mental-health disorder.

For James, his prior relationship with help-seeking behaviour stifled his sharing, “a man won’t either ask anybody for help, and I don’t deserve the help anyway” (James-1823). His response might suggest that traditional male stereotypes influenced his decision-making process and rendered him more isolated than he might have wished (O’Neil, Good, & Holmes, 1995). In Steph’s case, her family was so “traumatised” by the accident that her father would leave the room if the topic came up.

Yet support would have been important for validation and not feeling alone or different, particularly if the NDE imparted confusion such as initially happened for Steph. She expressed that without help at the time she could have become easily isolated and depressed. Most participants communicated that hearing of others with similar experiences would have helped. Amy also suggested that including NDE into the RE school curriculum would increase awareness in the next generation and provide support for the youth. Betty recommended patients could be approached during their hospital stay to open-up conversations about possible NDE. Yet Steph emphasised she would have found professional support unhelpful at the time:

“[it would have] victimised me or I may have become some kind of patient, and taking the power away from your family that can do on your, on their own”-(Steph-2034)

Noticing and respecting NDE differences. Participants showed awareness of how their responses might differ from others who have had NDEs.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

“I think it might have hit them in different ways”. She continued, “somebody might come and think “oh my God I never going to do that again that’s the most terrifying thing that’s ever happened to me, I’m never getting in a boat again, or I’m never going to swim again.”-(Nicole-1352)

Four participants expressed concerns of imposing their views of their NDE onto others. They rather perceived themselves as facilitators of other’s sense-making processes. As such they drew largely on a person-centred approach as advocated by Rogers (1995) in his humanistic inspired perspective on talking therapy.

“I read a poem about grief the other day that someone had put on Facebook actually [...] it said don’t sing your own song, um, when you are present around people in deep grief”-(Julia-2948)

Similarly, James felt prompted to avoid taking up an “expert position” and also alluded to difficulties arising out of people making comparisons between each other. In line with social comparison theory (Festinger, 1954) he was concerned that by sharing his affirmative story, others with less fortunate experiences might feel upset and “that’s not fair”-(James-1786).

“social embarrassment [...] [like] someone who otherwise you’re kind of on track with, maybe finding out that your salary is very different from theirs”-(James-1790)

Connecting and offering help. Participants identified how the NDE positively shifted their relationship with others in various ways. James found himself reaching out to the wider community by completing counsellor training and working as a legal advisor helping “ordinary people”.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

“Before, relatively high introvert that I ... I intimate myself as being, small kind of group of friends and that was about it really. Since then I’ve I’ve got a wider kinder idea of of public service”-(James-1331)

Amy believed other people would benefit from hearing of her NDE and is keen to spread her story.

“I do believe that we are given these experiences to share, because I think well we must be because otherwise, you know, why are so many other people, um, not having these experiences?”-(Amy-488)

Amy and Julia also felt a particular satisfaction when supporting bereaved people. It was as if the NDE had provided them with an insight that equipped them to be more present with peoples’ grief. For Steph the new drive for connection following the NDE has particularly involved her family.

“you don’t recognise what’s really important to you until you lose it or until you almost lose it. So perhaps that was like a new-found appreciation for what was really valued and what was really important, and that was connections with people, and that was family”-(Steph-1118)

Experience of Happiness

A master-theme of a new form of happiness emerged comprising three subthemes: Contrasting an inside vs outside source, Choosing one’s perspective and Enjoying greater happiness and better mental-health.

Contrasting an inside vs outside source. Participants alluded to accessing a new source of happiness following the NDE. They described having experienced or discovered

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

happiness that was an internal and lasting resource, whereas previously they had tried creating or chasing after happiness externally.

“that NDE, is it was a glimpse into “I didn’t need context.” I could feel happy I could feel good without friends, academia, job”-(Nicole-476)

Julia also thought that she takes more responsibility over her own happiness now rather than leaving it to others. Yet through her new composure people around her also benefit, such as her RE students.

“I think I really do have that happiness inside, and I think it oozes out of me and I think that’s why I’m a good teacher”-(Julia-1844)

James described he had previously perceived happiness as a limited external source that people were competing for.

“you’ve got to grab it when you can [...] or someone else is gonna come along and take it [...] take my my my share of it, or something”-(James-911)

Choosing one’s perspective. After the NDE, participants drew greater attention to what they have than pondering over shortcomings. Indeed, the research literature has suggested that optimism and PTG promote each other, in that optimism might be a predictor as well as an outcome of PTG (Linley & Joseph, 2004; Zoellner & Maercker, 2006).

“happiness, um, I think it’s always there, it’s just, it’s just it’s a way, your perception of how you look at things.”-(Julia-2727)

Steph pointed out that this also applies to other people and that “having it all” does not necessarily guarantee happiness.

“We can look at other people and, “why are they not happy?” you know they’ve got that relationship, or they’ve got that job, like why... why don’t they feel happy about

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

that? So it's so I think the happiness is something about recognising like...what you've got"-(Steph-1847)

Similarly, half of the participants highlighted their choice of focusing on the beauty in nature. James suggested that this awareness involved "taking the time to notice".

"[a] way of of stopping and listening to birds singing, or stopping and looking at that, yeah, that's a nice sunset"-(James-1920)

However, Julia acknowledged that selectively paying attention might bias her perception.

"I'll sit on the beach and I'll just I'll just "oh my God, it's such a beautiful world". And and it's like superimposed sometimes, it's like a sort of – it may not be that beautiful [actually], but to me it's beautiful"-(Julia-1632)

Enjoying greater happiness and better mental-health. Overall, participants reported being happier after the NDE, and some see the NDE as a pivotal point in this process. Julia admitted that she had only encountered a sense of real happiness a handful of times before, which the NDE changed.

"I'm the most happiest bubbliest person, whereas maybe if you knew me before, I was quite dark and quite sullen"-(Julia-1673)

James felt that his happiness set-point had lastingly been raised through the NDE; a notion that has been presented as a great challenge to achieve in the research literature due to adaptation effects to change (Suh et al., 1996).

"the even keel experience is itself happier, the the baseline is happier"-(James-1199)

The majority also had depressive periods in their past and agreed that their NDE has improved their mental-health. Either they did not have another episode of low mood or

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

they did not “hit rock-bottom again” to the same degree. James commented that the NDE has protected him against depressive episodes.

“[like a] hard reset of the machine and in its rebooted state it doesn’t have that that bit of the programme in it [coding depression]”-(James-1693)

These reports add to the existing research literature as previous study findings have been limited to reductions in suicidal ideation following NDEs rather than considering low mood more broadly (Greyson & Stevenson, 1980).

Discussion

Happiness is a common pursuit of people and is influenced by innumerable factors. This study researched if happiness could be a PTG outcome of NDEs, and whether participants could link several wellbeing effects to the NDE. Half missed the heightened level of happiness that they had experienced during the NDE, and this left them with mixed feelings. On one hand, it was comforting for them to believe this overwhelming sense of happiness exists, and that they might potentially return to it. On the other hand, it was also upsetting “to have lost” this happiness, and people were keen to re-access the heightened happiness during their life-time again. Betty and Nicole pursued it through their engagement with meditation, and emphasised the effectiveness of spiritual practices over the use of recreational drugs.

Another theme involved connecting to a different quality of happiness that is neither as intense as that experienced during the NDE, nor as temporary or externally dependent as the pre-NDE life happiness. Participants described finding a highly valued self-sufficient and internal source. This left them “being” happier, rather than “chasing after” it externally. This newly found sense resembled ideas by Smail (2005), who viewed happiness as a by-product

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

of life and not an end in itself: That is, it cannot be directly pursued. Indeed, other research has suggested the more people pursue happiness the unhappier they become (Mauss, Tamir, Anderson, & Savino, 2011). A sense of internal happiness and freedom from external sources was a finding that has not been directly reported in the NDE research literature, but aligns with previous studies that describe a decreased need for materialism, professional success, and other peoples' approval (Flynn, 1982; Greyson, 1983b; Sabom, 1982).

Social support represents a fundamental aspect of well-being (Gallagher & Vella-Brodick, 2008), yet all participants reported difficulties in sharing their experience. Their accounts suggested that isolation takes place through at least three routes: they felt unable to speak to others fearing judgement, they were unaware of others who had similar experiences and if they came across others with NDEs they expressed hesitation to share, so not to impose or upset them. Drawing on social comparison theory (Festinger, 1954), people might engage in upward comparisons leaving them feeling bereft of more positive NDE experiences that others had. This appears to support a vicious cycle whereby people would feel validated by hearing from others, but struggle to make the first step or lead by example. Yet Amy mentioned a newly kindled wish to publish her story, and considered that the purpose of her NDE was partly to share it. People taking these steps might contribute to an increasing NDE presence in the media (Alexander, 2012; Neal, 2012) which, despite efforts, still appears underrepresented.

During recruitment for this study, the researcher predominantly experienced that people were unfamiliar with the term NDE, or found it misleading. When considering the term NDE people frequently assumed first that it just entailed having a brush with death without spiritual aspects. When hearing the definition of NDEs, people thought they only

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

occurred during an actual life-threatening situation, which is not always the case (Gabbard & Twemlow, 1991). As such, terminology hurdles might represent a contributing factor in the difficulties people face in finding support or information on NDEs; an issue that does not appear to be explored in the research literature.

Limitations

IPA allowed an in-depth analysis of a small sample to explore rich and widely idiosyncratic accounts. In IPA the generalisability or transferability of findings is not a primary focus (Smith et al., 2009). None of the participants had negative feelings during their NDEs, although studies suggest that about 20% have a distressing experience (Bush, 2009). It is possible that people with such experiences either underreport, might be less forthcoming in engaging with the research, or experienced negative mental-health effects following a negative NDE (Greyson & Bush, 1992) and were therefore screened out through the online wellbeing questionnaires.

Two participants had their NDE during childhood. NDEs early in life might offer the study a different insight, independent of popular representations in culture or the media. Yet some research suggests that prior knowledge of NDE does not influence people's reports (Greyson, 1991). Having had NDEs in childhood would also have left participants with little lifetime prior to the event to make sound happiness comparisons before and after the experience, and this was pointed out by Steph in her interview. In addition, as these participants were still going through more pronounced personality changes (Robins, Fraley, Roberts, & Trzesniewski, 2001), it is difficult to assess who they might have become if it were not for the NDEs, and to assess potential NDE effects on happiness. Participants had a great range of lapsed times since their NDE with an average of 24 years. Studies suggest that

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

NDEs are not prone to embellishment over time (Greyson, 2007). However, memories relating to happiness could be subject to distortion, which could impact the study findings. Finally, IPA involves “the researcher as an inclusive part of the world they are described” (Larkin, Watts, & Clifton, 2006, p.107) and there might be other valid interpretations that could be drawn.

Clinical Implications

Considerable overlap was noticeable between current findings and the PTG model by Tedeschi and Calhoun (2004). That is, the model’s five domains of PTG appeared to resemble one or a combination of the (sub)themes in this sample. For instance, “Appreciation of Life” represented a clearly defined experience in both. However, the diminished fear of death was restricted to the current study. This might be due to the specific experience of a NDE, as its spiritual components can influence afterlife beliefs which can be perceived as reassuring. Other differences present for example, the two subthemes “Contrasting an inside vs outside source” and “Enjoying greater happiness and better mental-health”. Both sit under the master-theme “Experience of happiness”, and as such might be more specific to the focus of happiness than a broader PTG investigation.

Since PTG was first coined it has seen numerous challenges that question whether people experience an actual positive change. For instance, PTG has been viewed as a by-product of cultural scripts, or expectations of experiencing self-enhancement over time (Ross & Wilson, 2001). Other researchers suggested PTG might simply represent memory biases or cognitive reappraisal strategies to threat, whereby people protect their sense of self following a traumatic event (Taylor, 1983). Within research, instead of retrospective assessments, a greater use of longitudinal studies might be required to explore these

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

questions. However, clinically, PTG might represent an adaptive coping strategy following trauma, and the benefit of “perceived change” might carry positive effects in their own right. That is, respecting the meanings that people have developed might rather benefit their well-being in therapy, and take precedence over questions concerning the authenticity of their perceived PTG.

As previously discussed professionals’ responses to a NDE can greatly impact people in either accepting or defending against their experience. Indeed, sharing NDEs has been found to be a predictor for PTG (Prati, 2008). Yet some people might fear disclosing to professionals, and for good reasons. A recent study reported one in five has received a negative, unpleasant, or harmful reaction from a professional (Holden, Kinsey, & Moore, 2014). Similarly, in this study several participants struggled afterwards the NDE but were hesitant in stepping forward to loved ones or professionals. Supporting clients in “revealing” their difference could be eased by asking patients in hospitals or emergency services to complete a NDE questionnaire as part of their existing standard procedure. Due to its brevity and psychometric properties the NDE Scale (Greyson, 1983a) might be a promising candidate. In addition, in this study, a number of participants pointed out the importance of hearing about other people with similar experiences, and clinical psychologists might be well placed in setting up and facilitating support groups that can offer a validating space.

Research Implications

To support people with NDEs, research into support groups might be valuable. Particularly useful might be those that are co-facilitated by an “expert by experience”, as has been successfully established for other client groups (Noorani, 2013). Two participants mentioned that after a long search for ways to reconnect to the NDE-related happiness,

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

they discovered meditation for themselves. As such, research into mindfulness groups or support groups integrating such aspects, might offer beneficial insight into additional support structures for this group of people. Alternatively, investigating expressive writing has been widely used among other client groups (Kacewicz, Slatcher, & Pennebaker, 2007) and might provide a therapeutic tool for people who are not yet in a place to disclose, or who have few opportunities for sharing. Regarding changes in happiness, none of the participants had a negative experience during the NDE. This raises questions as to whether those people also would experience changes in happiness quality, its sources, and to what degree the changes might overlap or differ from that of the current participants. Lastly, NDE research has predominantly been retrospective, raising further questions about factors such as the experiencer's memory reliability (French, 2001), maturation processes (Erikson, 1980), and influential life events. To follow this up, quantitative cross-sectional studies might be more feasible than longitudinal research designs due to the unpredictability of NDE occurrence and its relatively small population (Parnia et al., 2007; Schwaninger et al., 2002).

Conclusion

This study used IPA to explore people's experience of happiness in relation to NDEs. The analysis revealed that participants' happiness was affected by their relationships to their self, their life and mortality, other people with and without NDEs, as well as the NDE itself. Finding opportunities to connect, share their experience and help others were central in their journeys. Following the NDE, participants gained a greater acceptance of death but also developed a stronger appreciation of life. Some felt keen to regain the heightened happiness that they experienced during the NDE while for others happiness was a less

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

pressurised goal as they had found a lasting source inside themselves. Personal relationships were important to participants, but more out of altruistic reasons than deriving personal happiness through them. Overall, happiness was seen as gradually increasing over time, and for those who had previous episodes of depression, none had experienced low moods of the intensity they had suffered before their NDE. Questions arose as to the degree maturation processes or other life events have impacted participants' relationship and experience of happiness since the NDE. Findings greatly overlapped with themes from the PTG literature. There were exceptions however, which might be due to the specific investigation of happiness. Clinical psychologists might assist in identifying people with NDEs and in supporting them in their development of PTG. This could be facilitated by validating their experience and by offering social support through the setting-up of support groups.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

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Appendix A

Standard Quality Assessment Criteria for Primary Research (Kmet, Lee, & Cook, 2004)

Quality Scoring of Quantitative Studies

How to calculate the summary score:

Total sum = (number of “yes” * 2) + (number of “partials” * 1)

Total possible sum = 28 – (number of “N/A” * 2)

Summary score = total sum / total possible sum

1. Question or objective sufficiently described?

Yes: Is easily identified in the introductory section (or first paragraph of methods section). Specifies (where applicable, depending on study design) all of the following: purpose, subjects/target population, and the specific intervention(s) /association(s)/descriptive parameter(s) under investigation. A study purpose that only becomes apparent after studying other parts of the paper is not considered sufficiently described.

Partial: Vaguely/incompletely reported (e.g. “describe the effect of” or “examine the role of” or “assess opinion on many issues” or “explore the general attitudes” ...); or some information has to be gathered from parts of the paper other than the introduction/background/objective section.

No: Question or objective is not reported, or is incomprehensible.

N/A: Should not be checked for this question.

2. Design evident and appropriate to answer study question?

(If the study question is not given, infer from the conclusions).

Yes: Design is easily identified and is appropriate to address the study question / objective.

Partial: Design and /or study question not clearly identified, but gross inappropriateness is not evident; or design is easily identified but only partially addresses the study question.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

No: Design used does not answer study question (e.g., a comparison group is required to answer the study question, but none was used); or design cannot be identified.

N/A: Should not be checked for this question.

3. Method of subject selection (and comparison group selection, if applicable) or source of information/input variables (e.g., for decision analysis) is described and appropriate.

Yes: Described and appropriate. Selection strategy designed (i.e., consider sampling frame and strategy) to obtain an unbiased sample of the relevant target population or the entire target population of interest (e.g., consecutive patients for clinical trials, population-based random sample for case-control studies or surveys). Where applicable, inclusion/exclusion criteria are described and defined (e.g., “cancer” -- ICD code or equivalent should be provided). Studies of volunteers: methods and setting of recruitment reported. Surveys: sampling frame/strategy clearly described and appropriate.

Partial: Selection methods (and inclusion/exclusion criteria, where applicable) are not completely described, but no obvious inappropriateness. Or selection strategy is not ideal (i.e., likely introduced bias) but did not likely seriously distort the results (e.g., telephone survey sampled from listed phone numbers only; hospital based case-control study identified all cases admitted during the study period, but recruited controls admitted during the day/evening only). Any study describing participants only as “volunteers” or “healthy volunteers”. Surveys: target population mentioned but sampling strategy unclear.

No: No information provided. Or obviously inappropriate selection procedures (e.g., inappropriate comparison group if intervention in women is compared to intervention in men). Or presence of selection bias which likely seriously distorted the results (e.g., obvious selection on “exposure” in a case-control study).

N/A: Descriptive case series/reports.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

4. *Subject (and comparison group, if applicable) characteristics or input variables/information (e.g., for decision analyses) sufficiently described?*

Yes: Sufficient relevant baseline/demographic information clearly characterizing the participants is provided (or reference to previously published baseline data is provided). Where applicable, reproducible criteria used to describe/categorize the participants are clearly defined (e.g., ever-smokers, depression scores, systolic blood pressure > 140). If “healthy volunteers” are used, age and sex must be reported (at minimum). Decision analyses: baseline estimates for input variables are clearly specified.

Partial: Poorly defined criteria (e.g. “hypertension”, “healthy volunteers”, “smoking”). Or incomplete relevant baseline / demographic information (e.g., information on likely confounders not reported). Decision analyses: incomplete reporting of baseline estimates for input variables.

No: No baseline / demographic information provided.

Decision analyses: baseline estimates of input variables not given.

N/A: Should not be checked for this question.

5. *If random allocation to treatment group was possible, is it described?*

Yes: True randomization done - requires a description of the method used (e.g., use of random numbers).

Partial: Randomization mentioned, but method is not (i.e. it may have been possible that randomization was not true).

No: Random allocation not mentioned although it would have been feasible and appropriate (and was possibly done).

N/A: Observational analytic studies. Uncontrolled experimental studies. Surveys. Descriptive case series / reports. Decision analyses.

6. *If interventional and blinding of investigators to intervention was possible, is it reported?*

Yes: Blinding reported.

Partial: Blinding reported but it is not clear who was blinded.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

No: Blinding would have been possible (and was possibly done) but is not reported.

N/A: Observational analytic studies. Uncontrolled experimental studies. Surveys.
Descriptive case series / reports. Decision analyses.

7. If interventional and blinding of subjects to intervention was possible, is it reported?

Yes: Blinding reported.

Partial: Blinding reported but it is not clear who was blinded.

No: Blinding would have been possible (and was possibly done) but is not reported.

N/A: Observational studies. Uncontrolled experimental studies. Surveys. Descriptive case series / reports.

8. Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias?

Means of assessment reported?

Yes: Defined (or reference to complete definitions is provided) and measured according to reproducible, “objective” criteria (e.g., death, test completion – yes/no, clinical scores). Little or minimal potential for measurement / misclassification errors. Surveys: clear description (or reference to clear description) of questionnaire/interview content and response options.

Decision analyses: sources of uncertainty are defined for all input variables.

Partial: Definition of measures leaves room for subjectivity, or not sure (i.e., not reported in detail, but probably acceptable). Or precise definition(s) are missing, but no evidence or problems in the paper that would lead one to assume major problems. Or instrument/mode of assessment(s) not reported.

Or misclassification errors may have occurred, but they did not likely seriously distort the results (e.g., slight difficulty with recall of long-ago events; exposure is measured only at baseline in a long cohort study). Surveys: description of questionnaire/interview content incomplete; response options unclear. Decision analyses: sources of uncertainty are defined only for some input variables.

No: Measures not defined, or are inconsistent throughout the paper. Or measures

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

employ only ill-defined, subjective assessments, e.g. “anxiety” or “pain.” Or obvious misclassification errors/measurement bias likely seriously distorted the results (e.g., a prospective cohort relies on self-reported outcomes among the “unexposed” but requires clinical assessment of the “exposed”). Surveys: no description of questionnaire/interview content or response options. Decision analyses: sources of uncertainty are not defined for input variables.

N/A: Descriptive case series / reports.

9. Sample size appropriate?

Yes: Seems reasonable with respect to the outcome under study and the study design. When statistically significant results are achieved for major outcomes, appropriate sample size can usually be assumed, unless large standard errors ($SE > \frac{1}{2}$ effect size) and/or problems with multiple testing are evident. Decision analyses: size of modeled cohort / number of iterations specified and justified.

Partial: Insufficient data to assess sample size (e.g., sample seems “small” and there is no mention of power/sample size/effect size of interest and/or variance estimates aren’t provided). Or some statistically significant results with standard errors $> \frac{1}{2}$ effect size (i.e., imprecise results). Or some statistically significant results in the absence of variance estimates. Decision analyses: incomplete description or justification of size of modeled cohort / number of iterations.

No: Obviously inadequate (e.g., statistically non-significant results and standard errors $> \frac{1}{2}$ effect size; or standard deviations $> _$ of effect size; or statistically non-significant results with no variance estimates and obviously inadequate sample size). Decision analyses: size of modeled cohort / number of iterations not specified.

N/A: Most surveys (except surveys comparing responses between groups or change over time). Descriptive case series / reports.

10. Analysis described and appropriate?

Yes: Analytic methods are described (e.g. “chi square”/ “t-tests”/“Kaplan-Meier with log rank tests”, etc.) and appropriate.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Partial: Analytic methods are not reported and have to be guessed at, but are probably appropriate. Or minor flaws or some tests appropriate, some not (e.g., parametric tests used, but unsure whether appropriate; control group exists but is not used for statistical analysis). Or multiple testing problems not addressed.

No: Analysis methods not described and cannot be determined. Or obviously inappropriate analysis methods (e.g., chi-square tests for continuous data, SE given where normality is highly unlikely, etc.). Or a study with a descriptive goal / objective is over-analyzed.

N/A: Descriptive case series / reports.

11. Some estimate of variance (e.g., confidence intervals, standard errors) is reported for the main results/outcomes (i.e., those directly addressing the study question/objective upon which the conclusions are based)?

Yes: Appropriate variances estimate(s) is/are provided (e.g., range, distribution, confidence intervals, etc.). Decision analyses: sensitivity analysis includes all variables in the model.

Partial: Undefined “+/-” expressions. Or no specific data given, but insufficient power acknowledged as a problem. Or variance estimates not provided for all main results/outcomes. Or inappropriate variance estimates (e.g., a study examining change over time provides a variance around the parameter of interest at “time 1” or “time 2”, but does not provide an estimate of the variance around the difference). Decision analyses: sensitivity analysis is limited, including only some variables in the model.

No: No information regarding uncertainty of the estimates. Decision analyses: No sensitivity analysis.

N/A: Descriptive case series / reports. Descriptive surveys collecting information using open-ended questions.

12. Controlled for confounding?

Yes: Randomized study, with comparability of baseline characteristics reported (or non-comparability controlled for in the analysis). Or appropriate control at

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

the design or analysis stage (e.g., matching, subgroup analysis, multivariate models, etc). Decision analyses: dependencies between variables fully accounted for (e.g., joint variables are considered).

Partial: Incomplete control of confounding. Or control of confounding reportedly done but not completely described. Or randomized study without report of comparability of baseline characteristics. Or confounding not considered, but not likely to have seriously distorted the results. Decision analyses: incomplete consideration of dependencies between variables.

No: Confounding not considered, and may have seriously distorted the results. Decision analyses: dependencies between variables not considered.

N/A: Cross-sectional surveys of a single group (i.e., surveys examining change over time or surveys comparing different groups should address the potential for confounding). Descriptive studies. Studies explicitly stating the analysis is strictly descriptive/exploratory in nature.

13. Results reported in sufficient detail?

Yes: Results include major outcomes and all mentioned secondary outcomes.

Partial: Quantitative results reported only for some outcomes. Or difficult to assess as study question/objective not fully described (and is not made clear in the methods section), but results seem appropriate.

No: Quantitative results are reported for a subsample only, or “n” changes continually across the denominator (e.g., reported proportions do not account for the entire study sample, but are reported only for those with complete data -- i.e., the category of “unknown” is not used where needed). Or results for some major or mentioned secondary outcomes are only qualitatively reported when quantitative reporting would have been possible (e.g., results include vague comments such as “more likely” without quantitative report of actual numbers).

N/A: Should not be checked for this question.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

14. Do the results support the conclusions?

Yes: All the conclusions are supported by the data (even if analysis was inappropriate). Conclusions are based on all results relevant to the study question, negative as well as positive ones (e.g., they aren't based on the sole significant finding while ignoring the negative results). Part of the conclusions may expand beyond the results, if made in addition to rather than instead of those strictly supported by data, and if including indicators of their interpretative nature (e.g., "suggesting," "possibly").

Partial: Some of the major conclusions are supported by the data, some are not. Or speculative interpretations are not indicated as such. Or low (or unreported) response rates call into question the validity of generalizing the results to the target population of interest (i.e., the population defined by the sampling frame/strategy).

No: None or a very small minority of the major conclusions are supported by the data. Or negative findings clearly due to low power are reported as definitive evidence against the alternate hypothesis. Or conclusions are missing. Or extremely low response rates invalidate generalizing the results to the target population of interest (i.e., the population defined by the sampling frame/strategy).

N/A: Should not be checked for this question

**Appendix B
Recruitment Poster**



Have you had a Near-Death Experience?

You will have the chance to win a £25 Amazon voucher

I am conducting a research study exploring the effects of a Near-Death-Experience on people's happiness. Near-Death-Experiences can be very variable, but might include:

- **feeling separated from the body**
- **time seems to pass differently**
- **seeing a bright light**
- **having a sense of peace**
- **seeing old memories**

If you live in the UK please take 10 min to complete and share this questionnaire!

<https://www.surveymonkey.co.uk/r/CYYP6GN>

For more information:

<https://www.dropbox.com/s/ejliahuq.../Information%20Sheet.pdf...>

Appendix C Information Sheet



Salomons Centre for Applied Psychology

Information Sheet-v3 08/03/18

Information Sheet

Study Title: How might a near death experience impact on people's happiness?

Hello, my name is Angela and I am a trainee clinical psychologist at the Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide if you want to take part, it is important that you understand why the research is being done and what it involves for you. Talk to others about the study if you wish. Part 1 tells you about the purpose of the study and what will happen if you take part. Part 2 gives you more detailed information about how the study will be conducted.

What is the purpose of this study?

Happiness is a major life goal for many people and research has explored what might affect it. However, questions remain why after a difficult life experience some people come out stronger while others struggle. Few studies have looked at how happiness might be influenced by a traumatic experience. Such a potentially difficult major life event can be a near-death-experience. A near death experience might occur during an accident, surgery or deep meditation. Sometimes people feel separated from their body and time seems to pass differently. Sometimes, people see a bright light or have a sense of peace or see old memories. On the whole these experiences can be very personal and variable.

In this study we are interested if after a near-death-experience, there is a change in people's sense of happiness and if so, how long it lasts. We are also interested in what support people receive or find helpful after a near-death-experience. The results of this research will help us to better understand what affects happiness and whether a near-death-experience may influence this. Findings will also inform us about what people find helpful to cope with the event and, possibly, how we might better support them.

Who can take part?

A near-death-experience can happen to anybody. In our study we use word of mouth and social media such as Facebook to advertise the research. If you have not had a near-death-experience but know somebody who has, please feel free to pass on this information. To participate you need to be fluent in English, live in the UK, and be over 18 years old.

As we are not sure how many people would like to take part in this study, we will gradually widen the geographical area to invite people to an interview. On the next page you can find a map showing the three stages how we will do this. During stage 1 people who live in Sussex, Surrey, London and Kent might get invited to an interview. During stage 2, the area will be expanded to also include Hampshire, Dorset, Wiltshire, Berkshire, Oxfordshire, Buckinghamshire, Northamptonshire, Bedfordshire, Cambridgeshire, Norfolk, Suffolk, Essex and Hertfordshire. In the last stage we will consider people living anywhere in the UK. If enough people are interviewed during the first stage, then we might not need to widen the area. This is sometimes difficult to predict in advance and so we would encourage you to complete the online questionnaires if you are interested in this study. I will then be in contact with you to let you know if we would like to invite you to an interview.

Do I have to take part?

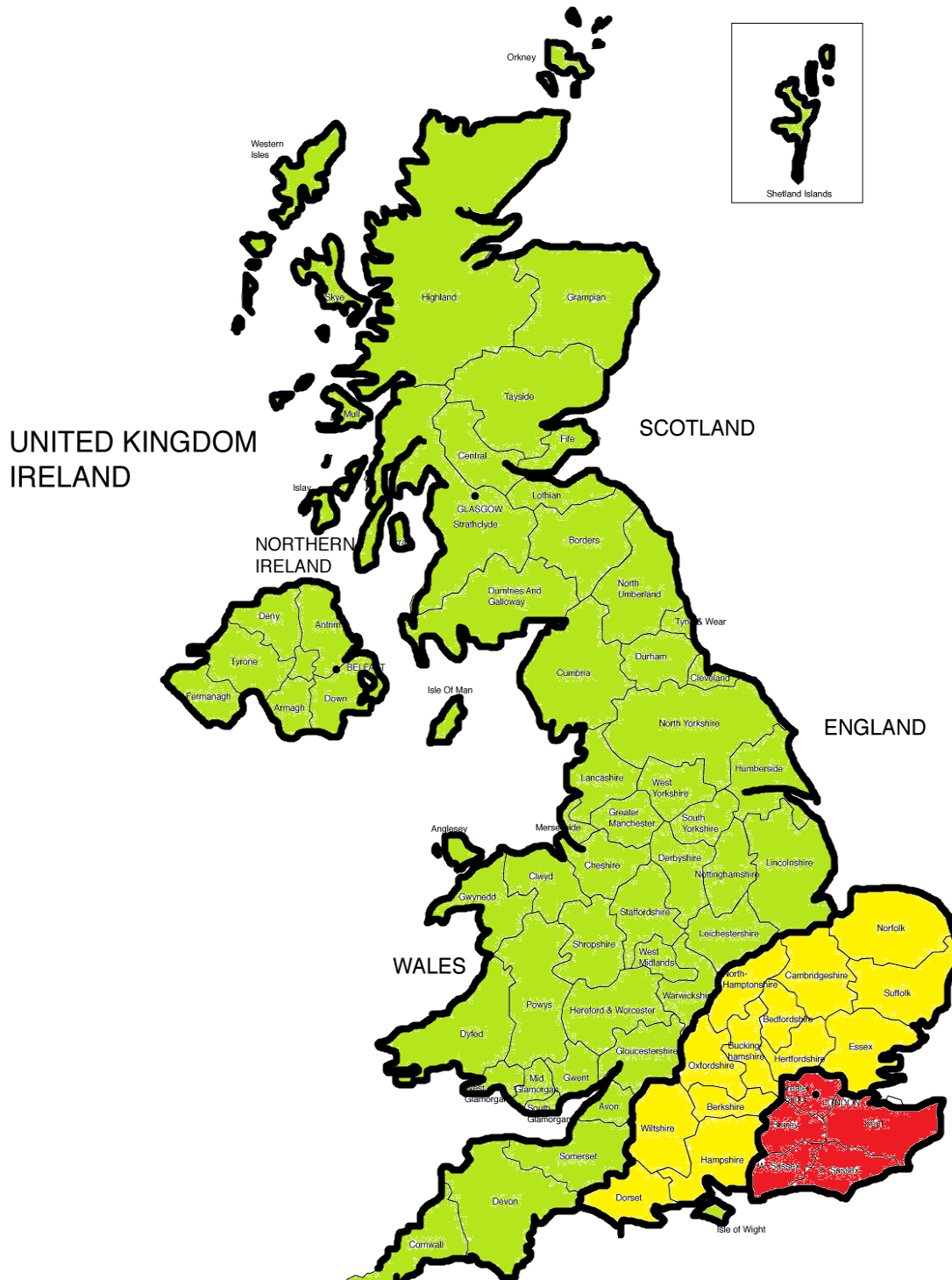
No – It is up to you to decide whether to participate in this study. If you agree to take part, I will ask you to complete a consent sheet. You are free to withdraw at any time, without giving a reason and if you wish, any information you had given me could be removed from the final report.

What will happen if I take part?

After completing the consent form online, you will be provided with a link to a webpage to answer some questions on your current well-being. Completing the questions should not take longer than 20 minutes. Afterwards there might be an opportunity for you to be invited to an interview for which people will be randomly selected. Please be aware that your answers to the previous questionnaires might influence your eligibility for the interview. If you have not heard back by April 2018 then you have not been selected on this occasion. Should you be selected for an interview, then I will aim to get in touch with you within 7 days to arrange a mutually convenient time.

The map on the next page will help you to think about in which geographical area you live and the options you have for the interview. If you live in the geographical areas 1 and 2, then you can choose whether you would like to meet in person or have the interview via skype. If you live in geographical area 3, the interview will be via skype.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH



Colour coding:
 Stage 1 in red
 Stage 2 in yellow
 Stage 3 in green

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

If we meet in person for the interview it will be in the community at a place near you. The interview will be held in a room that I book and will be private and quiet, such as in a library, university or GP practice in your area. You will have the chance to let me know of any mobility issues before we meet.

At the meeting you will also be able to ask any remaining questions you may have. The interview will be a conversation about your near-death experience and happiness since the event. Everybody taking part in this study will be asked similar questions but as everyone's experience is somewhat different, it will slightly differ for each person. The interview will last up to one and a half hours and will be audio recorded by me. You do not have to give any personal information unless you choose to share this, and you do not have to answer a question if you do not feel comfortable to do so. You may take a break if you need to. We would recommend participants to speak with a friend or family member after the interview. This is so that you have an opportunity to speak with a person close to you about the experience of taking part in this research. Talking to them might also help you to notice if you are in a settled state of mind after the interview.

What are the possible disadvantages or risks of taking part?

The interview is unlikely to be overly distressing. However, it is possible that you may feel upset when talking about some of the topics I will ask you about. If this causes you to feel more distressed than usual, you may want to speak to a family member or friend after the interview. I will also provide you with some useful helpline numbers if you would appreciate this. The interview questions are not designed to upset you and you have control at all times over what you feel comfortable to talk about.

What are the possible benefits of taking part?

We cannot promise the study will help you directly but the information we receive will improve our understanding of how near-death-experiences might impact people's experience of happiness. By taking part, you will be adding to an important area of research and possibly contributing to improving future support people receive who might be in a similar situation to you.

What if there is a problem?

In case you have a problem during the study which cannot be easily addressed, there is a procedure for making a complaint if you wish to do so. Detailed information on this is given in Part 2.

If I take part in this study, will it be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. Very occasionally there can be a need to pass information on to others. The details about this are included in Part 2.

THIS COMPLETES PART 1.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2 of the information sheet

Will my taking part in this study be kept confidential?

Yes. All information that you provide will be kept securely and password protected on a computer and online domain. You have the right to check whether the information we have about you is right and to correct any errors.

I will audio record your interview and then transfer it onto a password protected computer. The interview will be transcribed (written up in words) with your name changed so that you cannot be identified. You will be asked to choose a pseudonym (fake name) for yourself during the interview and this will be the name under which your data will be stored. This data will also be encrypted and stored on a memory stick. Encrypting a file means that a password is required to open and decode it. Other people may ask to look at the data in its anonymous form (without your real name). This may include my research supervisors, Dr Joe Hinds and Prof Paul Camic. Your confidentiality will be maintained at all times. Your anonymous data will be held securely at Canterbury Christ Church University for 10 years and destroyed after this point.

When would you need to tell somebody about something I said in my interview?

There are only a few special circumstances when I would need to tell someone else about something you said in the interview. If you told me that you were going to harm yourself or another person in any way, I would need to contact professional services such as police or ambulance. Another example is if you were to tell me you knew somebody else who was to cause serious harm to themselves or another person. Lastly, I would need to breach confidentiality if there was a legal duty for me to do so for instance when it involves terrorism or I am asked by a court. These are the only times that I would need to share information in order to protect your and other people's wellbeing and safety.

What will happen if I do not want to carry on with the study?

If you stop taking part in the study, we would like to use the data collected up until then. However, if you do not want us to use your interview data in the study at all, you have the right to request that this is taken out and destroyed.

What will happen to the results of the research study?

If you would like a copy of a brief summary report, then you can let me know this during the interview or at a later point using my contact details. When the study will come to a close (expected: April 2018), then a summary report will be sent out to the address you provided. A more comprehensive report is also likely to be sent to a journal to be published. If this is accepted, it will then be available for others to read. The report might include some quotations from your interview. This means I would write out a very small section of what you said for other people to read. If I write about something you said I will make sure you cannot be recognised by removing any identifiable information such as your name.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Who has reviewed and is funding the study?

This research project forms part of the assessment for the Doctorate in Clinical Psychology training programme. The research is funded by the Canterbury Christ Church University. It has been reviewed by a research panel and an ethics panel.

What if there is a problem?

If you have any problems during or after our interview, please let me know. If you feel unwell or uncomfortable during or after the interview, feel free to speak to me about it.

Complaints

If you have a concern about any aspect of this study, you should ask to speak to me and I will do my best to address your concerns. If you leave a message using the 24-hour Research Voicemail on 0333 011 7101, please ensure to mention my name so it can be passed on to me.

Angela Hillemann
Trainee Clinical Psychologist
Salomons Centre for Applied Psychology
Canterbury Christ Church University
1 Meadow Road
Tunbridge Wells
TN1 2YG

If you feel as though this still has not been resolved and you want to complain formally, you can do this by contacting the Director of the Salomons Centre for Applied Psychology:

Prof Margie Callanan
Director of Salomons Centre for Applied Psychology
Salomons Centre for Applied Psychology
Canterbury Christ Church University
1 Meadow Road
Tunbridge Wells
TN1 2YG

Further information and contact details

You might like to speak to someone about this information and whether you want to participate. There is a lot of information to take in and you might want to talk it through with a family member or friend. You are also welcome to contact me if there is anything you are unsure of, or have concerns about. If you would like any help with understanding this information sheet or you would like to ask more questions before making a decision, please contact me. You can leave a message on the 24-hour voicemail phone line at 0333 011 7070. If you call, please mention the message is for me [Angela Hillemann] and leave your contact number so that I can get back to you.

If you would like to read more on participating in research studies, the Mental Health Research Network is a useful website: www.mhrn.info

Appendix D Online Questionnaire



How Might a Near-Death-Experience Impact on People's Happiness?

Thank you for your interest in undertaking this research

In this study we are interested if after a near-death-experience, there is a change in people's sense of happiness and if so, how long it lasts. We are also interested in what support people receive or find useful after a near-death-experience. The results of this research will help us to better understand what affects happiness and whether a near-death-experience may influence this. Findings will also inform us about what people find useful to cope with the event and, possibly, how professionals might better support them.

A near-death-experience might occur during an accident, surgery or deep meditation. Sometimes people feel separated from their body and time seems to pass differently. Sometimes, people see a bright light or have a sense of peace or see old memories. On the whole these experiences can be very personal and variable.

Please take a few minutes to answer the following questions:

(Please be aware that individual feedback on the outcome of the questionnaires will not be provided)

OK

* Are you over 18 years old?

- Yes
 No

* Do you live in the UK?

- Yes
 No

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

* Are you fluent in speaking English?

- Yes
 No

If you answered 'Yes' to all of the above, please continue....

* Consent:

(please tick as appropriate)

1. I confirm that I have read the information sheet for this study and I confirm that I understand it. I have had the opportunity to think about the information and to ask questions. I fully understand what I am being asked to do.
2. I understand that my participation is voluntary and that I can stop at any time without giving any reason.
3. I understand that data collected during the study may be looked at by the lead supervisors [Dr. Joe Hinds, Prof. Paul Camic]. I give permission for these people to have access to these data in anonymous form.
4. I agree that anonymous quotes from my interview may be used in published reports of the study findings
5. I agree to take part in the above study

If you agree with the 5 points above, please continue....

To help us determine the depth of your possible Near-Death-Experience please complete the following questions as truthful as you can:

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

* (1) Did time seem to speed up or slow down?

- No
- Time seemed to go faster or slower than usual
- Everything seemed to be happening at once; or time stopped or lost all meaning

* (2) Were your thoughts speeded up?

- No
- Faster than usual
- Incredibly fast

* (3) Did scenes from your past come back to you?

- No
- I remembered many past events
- My past flashed before me, out of my control

* (4) Did you suddenly seem to understand everything?

- No
- Everything about myself or others
- Everything about the universe

* (5) Did you have a feeling of peace or pleasantness?

- No
- Relief or calmness
- Incredible peace or pleasantness

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

* (6) Did you have a feeling of joy?

- No
- Happiness
- Incredible joy

* (7) Did you feel a sense of harmony or unity with the universe?

- No
- I felt no longer in conflict with nature
- I felt united or one with the world

* (8) Did you see, or feel surrounded by, a brilliant light?

- No
- An unusually bright light
- A light clearly of mystical or other-worldly origin

* (9) Were your senses more vivid than usual?

- No
- More vivid than usual
- Incredibly more vivid

* (10) Did you seem to be aware of things going on elsewhere, as if by ESP?

- No

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

- Yes, but the facts have not been checked out
- Yes, and the facts have been checked out

* (11) Did scenes from the future come to you?

- No
- Scenes from my personal future
- Scenes from the world's future

* (12) Did you feel separated from your body?

- No
- I lost awareness of my body
- I clearly left my body and existed outside it

* (13) Did you seem to enter some other, unearthly world?

- No
- Some unfamiliar and strange place
- A clearly mystical or unearthly realm

* (14) Did you seem to encounter a mystical being or presence, or hear an unidentifiable voice?

- No
- I heard a voice I could not identify
- I encountered a definite being, or a voice clearly of mystical or unearthly origin

* (15) Did you see deceased or religious spirits?

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

(15) Did you see deceased or religious spirits:

- No
- I sensed their presence
- I actually saw them

* (16) Did you come to a border or point of no return?

- No
- I came to a definite conscious decision to return to life
- I came to a barrier that I was not permitted to cross; or was sent back against my will

* In connection with your **possible Near-Death-Experience** please indicate below how much you have been bothered by the following problems in the **last month**:

	Not at all	A little bit	Moderately	Quite a bit	Extremely
Repeated, disturbing memories, thoughts, or images of a stressful experience from the past?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Repeated, disturbing dreams of a stressful experience from the past?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Suddenly acting or feeling as if a stressful experience were happening again (as if you were reliving it)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling very upset when something reminded you of a stressful experience from the past?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having physical reactions (e.g., heart pounding, trouble breathing, or sweating) when something reminded you of a stressful experience from the past?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Avoid thinking about or talking about a stressful experience from the past or avoid having feelings related to it?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Avoid activities or situations because they remind you of a stressful experience from the past?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble remembering					

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

important parts of a stressful experience from the past?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Loss of interest in things that you used to enjoy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling distant or cut off from other people?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling emotionally numb or being unable to have loving feelings for those close to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling as if your future will somehow be cut short?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Trouble falling or staying asleep?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling irritable or having angry outbursts?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Having difficulty concentrating?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Being "super alert" or watchful on guard?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Feeling jumpy or easily startled?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

For the next questions: How have you been feeling, *in general*, over the *past few weeks*?

Been able to concentrate on what you're doing?

better than usual	same as usual	less than usual	much less than usual
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Lost much sleep over worry?

not at all	no more than usual	rather more than usual	much more than usual
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Felt that you are playing a useful part in things?

more so than usual	same as usual	less so than usual	much less than usual
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Felt capable of making decisions about things?

More so than usual	same as usual	less than usual	Much less capable
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Felt constantly under strain?

not at all	no more than usual	rather more than usual	much more than usual
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Felt you couldn't overcome your difficulties?

not at all	no more than usual	rather more than usual	much more than usual
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Been able to enjoy your normal day to day activities?

more so than usual	same as usual	less so than usual	much less than usual
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Been able to face up to your problems?

more so than usual	same as usual	less than usual	much less than usual
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Been feeling unhappy and depressed?

not at all

no more than usual

rather more than usual

much more than usual

Been losing confidence in yourself?

not at all

no more than usual

rather more than usual

much more than usual

Been thinking of yourself as a worthless person?

not at all

no more than usual

rather more than usual

much more than usual

Been feeling reasonably happy, all things considered?

more than usual

about the same as usual

less than usual

much less than usual

Thank you for your interest in undertaking this research and completing these questions. Your input is much appreciated.

What happens next?

There might be an opportunity for you to be invited to an interview for which people will be a randomly selected. Interviews might be run in person or online via Skype. If you have not heard back by April 2018 then you have not been selected on this occasion. Should you be selected for an interview, then I will aim to get in touch with you within 7 days to arrange a mutually convenient time.

Please leave your preferred contact details below if you would like to be considered for an interview and be entered into a prize draw for a £25 Amazon voucher.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Name

Phone Number

Email Address

DONE

Appendix E

Questions of the Semi-Structured Interview

Note: As this represented a semi-structured interview the researcher was led by the participants' responses. The questions provided below are neither exhaustive nor asked in a certain set order. This schedule is to provide the reader with an idea of the kind of topics and questions that were used.

Introduction:

- Preamble

In this study I am interested if, after a NDE, there is a change in your sense of happiness and if so, how long it lasts. I am also interested in what support people receive or would find helpful after a NDE. The results of this research will help to better understand what affects happiness and whether a NDE may influence this. Findings will also inform us about what people find useful in coping with the event and, possibly, how professionals might better support them.

- Expectations/Fears/Hopes for the Interview
- Aim: Capture your experience, the more detail the better but only as much as comfortable
- Meaning of semi-structured interview
- Interview length, time-keeping
- Being mindful of the recorder (speak up!)
- Confidentiality and limits
- Possibility of having breaks
- Questions

- Consent sheet
- Collect demographics details
- Briefly get a sense of NDE

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Main Section:**Nature and depth of happiness:**

- What means happiness to you? ... sometimes it helps to think of examples
- How would you describe your relationship with happiness before the NDE?
- How do you understand happiness now in comparison to before the NDE?
- Has how happy you feel changed following the NDE and if so why do you think that is?
- Do you place a different priority or importance on happiness following the NDE?
- Do you derive happiness from different/new things following the NDE?
- If you did not have the NDE would your relationship to happiness be the same or different?

Stability/permanence of happiness and support during readjustment:

- If there was change in your happiness has it lasted or was it transient?
- How long did the change last?
- Did you manage the life changes alone or did you ask and receive help?
- What kind of support at the time was helpful/unhelpful for you?
- What influenced you making sense of the experience?
- If you could go back, would you wish for a different kind of support differently following the NDE?

- What would you say or recommend to somebody who had a NDE recently?

End:

- Have we missed anything important?
- Checking-in/debrief
- Feedback (from client on the interview: content and process)
- Reminder of self-care
- Questions
- Gaging interest to receive a research summary report later

**Appendix F
Consent Form**



Salomons Centre for Applied Psychology

Consent Form-v2 29/11/16

Consent Form

Project Title: How might a Near-Death-Experience impact on people’s happiness?

Name of Researcher: Angela Hillemann

Please tick as appropriate	
1. I confirm that I have read the information sheet for this study and I confirm that I understand it. I have had the opportunity to think about the information and to ask questions. I fully understand what I am being asked to do.	<input type="checkbox"/>
2. I understand that my participation is voluntary and that I can stop at any time without giving any reason.	<input type="checkbox"/>
3. I understand that data collected during the study may be looked at by the lead supervisors [Dr. Joe Hinds, Prof. Paul Camic]. I give permission for these people to have access to these data in anonymous form.	<input type="checkbox"/>
4. I agree that anonymous quotes from my interview may be used in published reports of the study findings	<input type="checkbox"/>
5. I agree to take part in the above study	<input type="checkbox"/>

Signature

Print name

Date

Appendix G
Demographic Questionnaire

Demographic information

1. Your initials:
2. Number of NDEs:
3. Age
- Current:
- At time of NDE(s):
4. Sex:
- Female
- Male
- Other
5. Please tick the box that best describes your current employment status
- Part time employee
- Homemaker
- Not in paid employment due to disability
- Not in paid employment due to long term sickness
- Full time employee
- Unemployed
- Retired
- Student
- Other:

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

6. What is your current occupation (or previous occupation if unemployed)?

.....

7. Ethnicity:

White British

White Irish

White African

White Other:

Indian

Pakistani

Bangladeshi

Black African

Black Other:

Other:

8. Religion

Christian

Buddhist

Hindu

Jewish

Muslim

Sikh

Other:

None Applicable

Appendix H Debrief Sheet



Debrief Sheet

How might a near death experience impact on people's happiness?

Happiness is a major life goal for many people and research has explored what might affect it. However, questions remain why after a difficult life experience some people come out stronger while others struggle. Few studies have looked at how happiness might be influenced by a traumatic experience. Such a potentially difficult major life event can be a near-death-experience. A near death experience might occur during an accident, surgery or deep meditation. Sometimes people feel separated from their body and time seems to pass differently. Sometimes, people see a bright light or have a sense of peace or see old memories. On the whole these experiences can be very personal and variable.

In this study we are interested if after a near-death-experience, there is a change in your sense of happiness and if so, how long it lasts. We are also interested in what support people receive or find helpful after a near-death-experience. The results of this research will help us to better understand what affects happiness and whether a near-death-experience may influence this. Findings will also inform us about what people find helpful coping with the event and, possibly, how professionals might better support them.

If you have any questions or queries you can contact me on a.hillemann732@canterbury.ac.uk or leave a message using the 24-hour Research Voicemail on 0333 011 7101 (please ensure to mention my name so it can be passed on to me). Alternatively, you can contact the University Department: Salomons Centre for Applied Psychology, Canterbury Christ Church University, 1 Meadow Road, Tunbridge Wells, Kent, TN1 2YG.

Further support

Speaking about your near-death-experience in connection with your happiness can be difficult and might be upsetting. We hope that the conversation was open and welcoming and that you leave feeling safe. However, if you are left feeling unsettled we would suggest you check in with a friend or your GP. Other ways you can get support after the interview might be by contacting:

1. The Samaritans – call 116 123 or look at their website if you prefer to text or email: www.samaritans.org
2. International Association For Near Death Studies (IANDS) – look for information on www.iands.org

What happens next?

Once I have interviewed a number of people, I will collate the responses by looking for themes. I am intending to complete the project for the university by April 2018. If you are interested in the results of the study, please send me an email before Sep 2018 and I will forward you a summary of the findings. Finally, I hope to publish the results in an academic journal. For both the write up for the university and the academic journal, your responses will be anonymised.

Thank you again for participating.

Angela Hillemann

Trainee Clinical Psychologist
Canterbury Christ Church University

Appendix I

Research Summary for Participants

Study Title: How might a Near-Death-Experience impact on people's happiness?

Dear Participant,

I am writing you as you recently were interviewed for this study and this letter is to let you know of the findings. I would like to thank you again for taking the time to take part and share your experiences with me. I have felt privileged to carry out this study and have heard your story.

Below you can find a brief summary of the study's background, method, findings and conclusion.

Background

There has been much research that looks at the effects that Near-Death-Experience (NDE) can have on people. Negative outcomes include feeling deeply confused or shaken by the experience, feeling alone or different through the experience, and fearing or experiencing disbelief and judgment by others (e.g., Bloomfield, 1980; Boorstein, 1980; Orne, 1995; Ring, 1984). Yet positive personal change can also arise which is referred to as Post-Traumatic Growth (PTG). Examples for PTG after a NDE can include greater appreciation for life, sense of life purpose, empathy, and compassion for others (Noyes, Fenwick, Holden, & Christian, 2009; Van Lommel et al., 2001).

This study was interested in the potentially positive outcomes after a NDE, specifically concerning happiness, or if people's relationship to happiness evolves or changed afterwards. In doing this, the study also challenges stigma on NDEs by widening the understanding of people's experience of this phenomenon and its impact on their personal development. Specific research questions were as follows:

1. Do people have a different sense of happiness following a NDE, and how do they make sense of this change?
2. How do people view the temporal development and stability of a change in their happiness?
3. Do people have sufficient support to meet potential psychological needs arising out of a NDE and what kind of support did they find (un)helpful?

Method

As this study used interviews, a qualitative design was applied. Interviews were analysed by a method called Interpretative Phenomenological Analysis (IPA) which explores how people make sense of their world, and particularly what meaning their experiences hold for them. Six people took part in the interviews who had had a NDE at some point in their lives.

Findings

Five themes emerged through the analysis each with sub-themes: **Sense of self, Attitude towards life and death, Effects of NDEs, relationship with others, and experience of happiness**. There was a considerable overlap between participants' views. However, not all themes applied to all participants.

Sense of self

Most participants expressed gaining a greater sense of themselves, self-worth, and resilience which they could integrate into their life story. The NDE provided participants with a stronger sense of life purpose, although they might not have been entirely sure what that entails. This offered them a means by which they could stop ruminating over their use of time, and was particularly present when other's passed away. Some felt indebted by the NDE, compelling them to make good use of their second chance, imbuing within them a sense of giving back.

Attitude toward life and death

Participants felt comforted that death had not been a physically painful experience, neither was it 'the end'. This knowledge did not bring up questions as to whether to continue living, but instead fostered a greater appreciation of life and an alertness towards danger. Some felt temporarily distant from God after the NDE, either through feelings of happiness and contentment independently of praying, or through fear of returning to him unbidden. Others felt their affiliation with spirituality had grown and noticed an attraction to like-minded people.

Effects of NDEs

During the NDE all participants experienced a heightened sense of happiness and serenity to the point that most of them viewed the event as precious gift. For most, their happiness increased in relation to the NDE over time. Yet some felt disappointment over losing the happiness that they had had during, or for some time after, the NDE and were driven towards seeking a way to reconnect with it through other means. Participants also entertained other life events and maturation processes in making sense of their happiness following their NDE, with one person wondering if the NDE had functioned as a catalyst to their already set trajectory of personal development.

Relationship with others

All participants expressed difficulties in sharing their experience. Those who shared felt it was not given the significance they deemed it deserved, and those who kept it to themselves feared upsetting others, incurring judgement, or not deserving of their help. Participants had an awareness that a NDE might have different effects on others, and were mindful not to impose their views, but to offer to the other person space to explore their experience. This seemed in part due to concerns of instigating negative social comparisons, leaving the other upset. Participants reported a greater appreciation of others, particularly the bereaved, and some reached out more broadly into the community, possibly to give something back.

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Experience of happiness

Most participants alluded to accessing a new or greater happiness through the NDE with a more developed internal source that felt reliable and lasting, rather than 'chasing after it' or 'competing for it' through external gratifications. Their happiness also associated with a greater sense of gratitude and new perspective, whereby one chooses to 'see the good things' or 'being happy with what one has'. Those who experienced spells of depression in the past did not reach the same negative depths again, as if the NDE might have a protective element.

Conclusion

The above findings suggest that people's experience of happiness in relation to a NDE is very idiosyncratic and unique, although there is some degree of overlap. Finding opportunities to connect, share their experience, and helping others, were all central to participants' journeys. Following the NDE participants gained a greater acceptance of death but also developed a stronger appreciation for life. Some felt keen to regain the heightened happiness that they experienced during the NDE, while for others happiness was a less pressurised goal, as they had found a lasting source within themselves. Other people were important to participants, but not necessarily due to a need to derive happiness through relationships. Overall, happiness was seen as gradually increasing over time, and for those who had previous episodes of depression, none had experienced low moods of the intensity they had suffered prior to their NDE. Questions remained as to what degree maturation processes or other life events have impacted participants' relationship and experience of happiness since the NDE. All of these findings have implications for clinical professionals and researchers, but also families, friends, and the wider society.

I hope this summary has been of interest to you. This research study has been insightful and enjoyable to conduct and I am grateful for your participation. Should you have any further questions or concerns with regard to the above summary please do not hesitate to contact me.

Thank you again for your interest and time.

Yours Sincerely,

Angela Hillemann
Trainee Clinical Psychologist

Appendix J
Research Summary for Ethics Panel and R&D Committee

Study Title: How might a Near-Death-Experience impact on people's happiness?

Dear Ethics Panel and R&D Committee,

I am writing to inform you that the above study has now been completed. Please find below a brief summary of the findings of this research. Please do not hesitate to contact me if you require any further information.

Yours Sincerely,

Angela Hillemann
Trainee Clinical Psychologist

Background

There has been much research that looks at the effects that Near-Death-Experience (NDE) can have on people. Negative outcomes include feeling deeply confused or shaken by the experience, feeling alone or different through the experience, and fearing or experiencing disbelief and judgment by others (e.g., Bloomfield, 1980; Boorstein, 1980; Orne, 1995; Ring, 1984). Yet positive personal change can also arise which is referred to as Post-Traumatic Growth (PTG). Examples for PTG after a NDE can include greater appreciation for life, sense of life purpose, empathy, and compassion for others (Noyes, Fenwick, Holden, & Christian, 2009; Van Lommel et al., 2001).

This study was interested in the potentially positive outcomes after a NDE, specifically concerning happiness, or if people's relationship to happiness evolves or changed afterwards. In doing this, the study also challenges stigma on NDEs by widening the understanding of people's experience of this phenomenon and its impact on their personal development. Specific research questions were as follows:

1. Do people have a different sense of happiness following a NDE, and how do they make sense of this change?
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3. Do people have sufficient support to meet potential psychological needs arising out of a NDE and what kind of support did they find (un)helpful?

Method

As this study used interviews, a qualitative design was applied. Interviews were analysed by a method called Interpretative Phenomenological Analysis (IPA) which explores how people make sense of their world, and particularly what meaning their experiences hold for them. Six people took part in the interviews who had had a NDE at some point in their lives.

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Sense of self

Most participants expressed gaining a greater sense of themselves, self-worth, and resilience which they could integrate into their life story. The NDE provided participants with a stronger sense of life purpose, although they might not have been entirely sure what that entails. This offered them a means by which they could stop ruminating over their use of time, and was particularly present when other's passed away. Some felt indebted by the NDE, compelling them to make good use of their second chance, imbuing within them a sense of giving back.

Attitude toward life and death

Participants felt comforted that death had not been a physically painful experience, neither was it 'the end'. This knowledge did not bring up questions as to whether to continue living, but instead fostered a greater appreciation of life and an alertness towards danger. Some felt temporarily distant from God after the NDE, either through feelings of happiness and contentment independently of praying, or through fear of returning to him unbidden. Others felt their affiliation with spirituality had grown and noticed an attraction to like-minded people.

Effects of NDEs

During the NDE all participants experienced a heightened sense of happiness and serenity to the point that most of them viewed the event as precious gift. For most, their happiness increased in relation to the NDE over time. Yet some felt disappointment over losing the happiness that they had had during, or for some time after, the NDE and were driven towards seeking a way to reconnect with it through other means. Participants also entertained other life events and maturation processes in making sense of their happiness following their NDE, with one person wondering if the NDE had functioned as a catalyst to their already set trajectory of personal development.

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All participants expressed difficulties in sharing their experience. Those who shared felt it was not given the significance they deemed it deserved, and those who kept it to themselves feared upsetting others, incurring judgement, or not deserving of their help. Participants had an awareness that a NDE might have different effects on others, and were mindful not to impose their views, but to offer to the other person space to explore their experience. This seemed in part due to concerns of instigating negative social comparisons, leaving the other upset. Participants reported a greater appreciation of others, particularly the bereaved, and some reached out more broadly into the community, possibly to give something back.

Experience of happiness

Most participants alluded to accessing a new or greater happiness through the NDE with a more developed internal source that felt reliable and lasting, rather than 'chasing after it' or 'competing for it' through external gratifications. Their happiness also associated with a greater sense of gratitude and new perspective, whereby one chooses to 'see the good things' or 'being happy with what one has'. Those who experienced spells of depression in the past did not reach the same negative depths again, as if the NDE might have a protective element.

Conclusion

The above findings suggest that people's experience of happiness in relation to a NDE is very idiosyncratic and unique, although there is some degree of overlap. Finding opportunities to connect, share their experience, and helping others, were all central to participants' journeys. Following the NDE participants gained a greater acceptance of death but also developed a stronger appreciation for life. Some felt keen to regain the heightened happiness that they experienced during the NDE, while for others happiness was a less pressurised goal, as they had found a lasting source within themselves. Other people were important to participants, but not necessarily due to a need to derive happiness through relationships. Overall, happiness was seen as gradually increasing over time, and for those who had previous episodes of depression, none had experienced low moods of the intensity they had suffered prior to their NDE. Questions remained as to what degree maturation processes or other life events have impacted participants' relationship and experience of happiness since the NDE. All of these findings have implications for clinical professionals and researchers, but also families, friends, and the wider society.

Appendix K
Example Summary of Participant's Account: Amy
(other spiritual experiences apart of the NDE were excluded)

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Appendix L
Example of Coded Transcript: Amy

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WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Appendix M
Example of Initial Emerging Themes from a Transcript: Amy

Possible Master Themes	Subthemes	Themes
Relationship with life and death	Fear of death	Relationship with death Speaking about death Relationship to death Continuity of life
	Afterlife beliefs	Beliefs of NDE Mortality & appreciation of life
	Appreciation of life	Importance of the living Protecting lives NDE as a tool for good Mortality and life appreciation Relationship with the living
Relationship with NDE	Experiencing a new happiness	The way to true happiness Top happiness during a NDE Intensity of NDE happiness Reexperience NDE happiness Intensity of NDE happiness Power of NDE NDE/death gives happiness Resisting return to life NDE vs materialism Happiness and mental Health NDE, happiness and depression NDE can improve mental health
	Keeping a secret	Needing to keep NDE Protecting the NDE Being left confused Disbelief of others Fear of others' reaction Confidence in yourself to share Needing trust to share Fear of sharing Lacking opportunities to share NDE as a secret Peoples' NDE scepticism Protecting oneself
	Time effects	Continuing NDE effects Growing effect over time Lasting NDE effect Continuing drive through NDE Needing time to recognise impact NDE longer term effects Maturing vs NDE NDE and change

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

		Living by example
Relationship with oneself	Knowing/fulfilling one's purpose	Reassurance Fulfilling one's purpose Life Purpose and mood Purpose and stopping rumination Life purpose Purpose and guidance Support in crisis NDE stops rumination Cannot challenge life purpose Embracing life purpose
	Being different	Why me? Appreciative of being special The gift of a NDE Becoming Special Being Special Being special and faith Being alone Am I alone?
Relationship with others	Giving and helping others	Sharing Having been there Helping others Other peoples' isolation 'Come out' Take your time Tackle isolation Helping the bereaved Making use of NDE knowledge Selfless Giving Relating to others' spiritual experiences Managing crisis Reaching out Reason to have a NDE
	Receiving reassurance and connection	Normalising NDEs through sharing Finding Others Experiencers understand Having missed out Acceptance from others Trust
	NDE awareness in wider society	NDE and RE Novelty of NDE Awareness of NDEs NDE and religion Sharing wider Spread the news Leading by example

Appendix N
Bracketing Interview Reflections

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Appendix O
Excerpts from Reflective Research Journal

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Appendix P
Letter of Ethical Approval

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Appendix Q Additional Illustrative Quotes

Renegotiating identity

- “It made me a person in myself” (Julia-1814)
- “[I learnt] I’m okay yeah yeah yeah I don’t need to worry.” (Nicole-373)
- “It’s something that I hold on to, but not not in a bad way. It’s just something that happened, something that I came out of. And, yeah. It’s marked, and it’s significant, but it hasn’t, it hasn’t left me any worse off, does that make sense? There’s a slight scar on my left eye, but it tells a story and I know it’s there.” (Steph-2194)
- ‘I know what matters to me more than anything is getting connected to myself’ (Nicole-623)
- “I’m not being just a mother. I’m being me, I’m me, I’m [participant’s name]” (Julia-1820)

Reflecting on one’s life purpose

- “I think happiness to me now is knowing that, and feeling that, um, that I’m not here by accident, that I was here to fulfil a purpose” (Amy-430)
- “It’s like the universe is trying to teach me, tell me something, that there is sort of a, something, reason I’m here. And I do think sometimes there is a reason. So I guess I was searching for why have I lived” (Julia-1253)
- “Yeah, I’ve, something, yes, some some merit I have equated, something that I’ve done in this or a previous life has has given has has spared me, and and all I can do, all I can do with that is use that... yeah, and that is the enduring semi-permanent, on and off, I’m not a saint, I’m not a great human being in so many ways, but it’s just

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

in terms of my little contribution to the, to the good life, to the moral life, that really, again, switched me” (James-315)

- “And every time someone dies around me, or or I’m present in their grief, [...] I feel I come away from that, reassured of that of that I am lucky” (Julia-1601)

Leaving behind the fear of death

- “I’ve been far more frightened in other situations but when it feels like you can die there isn't any point in being frightened, and that's not a sort of conscious thing it's simply, “how interesting that thing has come”.” (Nicole-289)
- “[The NDE] might make my relationship now with death slightly more comforting. I don't really think of it as something to be, like, massively feared. Although I don't, though I, both times that I lived it I was quite glad” (Steph-1311)
- “I know that I don't have to be worried about dying. And that's it, and that's the bottom line. I don't need to worry, because it wasn't a painful experience....I believed my brain switched off from my body in order for me to have this other experience, so, and I believed that's what happens in the point of death, that your brain will not allow you to feel the pain, whatever's going on in your body and take you to another realm in order to help you be safe. So if you need to come back, you're in a safe place, if you're not coming back you're in a safe place.... it doesn't make me want to go and take risks though, and that's really clear” (Julia-2869)

Embracing a greater appreciation of life

- “Happiness means the joy of being alive every day, (laugh) I'm really serious, and looking for, looking for the joy in every day.” (Julia-3198)

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

- “I’ll try and do things safely and I won’t take risks that are too big, does that make sense? And, and I’m mindful that things could kill me and that I could die, and that I’d rather not” (Steph-1354)
- “I feel blessed with life, and able to enjoy those things just makes me really grateful” (Steph-1646)
- “there were probably moments of... of near euphoria there that were nothing to do with the drugs or men or anything else, they were simply... “God it’s nice to be alive and feel like this.” (Nicole-825)
- “[being] okay with dying — meant I could be okay with living” (Nicole-850)

Re-assessing spirituality and religion

- “I realized that I had nearly died and I think that, that it scared me more after, does that make sense? And coming so close to meeting God made me really terrified to talk to him because it was like, it was like I’d almost already connected with him and that was so powerful o fearful that even just, I remember wanting to pray to say “Thank you that I survived”, but not being able to.” (Steph-218)
- “when you die in that moment you are going to be by yourself. I proved that wrong though, because I wasn’t by myself... And the other one is once you’re dead, you’re dead. All those things I don’t believe.” (Julia-2542)
- ““who knows at the end of the day, there could be absolutely nothing at all, and it is just brain activity that’s that’s, you know, that’s – you do read about stuff like that and you think, well, maybe it’s just brain activity. Maybe there’s reincarnation, maybe there isn’t. I think there’s there’s infinite amounts and possibilities, and I

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

don't know, nobody can definitively come back and say "oh, this is what happens"

(Betty-1946)

Attaching value to NDEs

- "After the experience I was quite present, and I was, er, and I remember just feeling on top of the world" (Julia-1190)
- "I do feel it's a gift, I really do feel, you know, these experiences and the NDE was a gift, because, um, you know, it's just that feeling of feeling privileged, you know, as if someone's sort of given me a gift in a big box and say, and and, you know, you would think "oh, you know, why me?"" (Amy-217)
- "it was like a sort of gift that I wasn't questioning. You know I was happy and it was another layer of happiness that was... that I felt much more connect... more skin deep.' (Nicole-1523)
- "Having gone in to the universe, now we're back out again, er, climbing a mountain back down the other side of it, er, and back back to, back to the town at the other side." (James-2377)

Considering temporal effects of NDEs

- "this has been slowly influencing me over the years since it happened, I think, actually, and it's only now I'm looking back" (Betty-1817)
- "That serenity is there. Yes, that serenity is is is available, it's available... if I meditate I can connect back to that easy, no problem at all" (Betty-467)
- "that did make me feel better in myself, and more so, um, I think as I have become older. Um, maybe not so much, you know, when I was in my teens or 20's, but I think

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

especially more so as I sort of got in to my later 30's and through my 40's and now in to my early 50's, um, I feel that that feeling has become greater" (Amy-126)

- "And there was just suddenly this feeling of uncertainty, and in a second I knew, it was like something just draining away from me." (Nicole-527)
- "I don't think it's something that happens quite soon after, I think it's more sort-of a hindsight thing". (Steph-1871)

Questioning causation

- "The move it feel to me, in terms of just general healthy adult maturation is, does involve a stepping away from finding satisfaction of happiness outside to generally more being satisfied on the inside" (James-1442)
- "That feels like something that in a healthy and fortunate and and, you know, good life one gets to, and I still have that in my imagination however true or not it is, so I think there is a track, but, yeah, pushed forward along that track" (James-1490)
- "I don't blame them [parents]. But then that could be something to do with another lot of therapy I've done in the past" (Julia-1700)
- 'Yeah. I don't think I really thought about happiness particularly until more recently (laugh), in terms of, I suppose, really in relation to anything. I've never really thought about it, um, until this questionnaire really has come up, in relation to happiness, you know, because it's like what is happiness? I don't know, it's just to kind of get on with day-to-day, don't you, you know, day in, day out, and sometimes you're happy and sometimes you're not, um" (Betty-1470)

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Facing hurdles in receiving support

- “I thought she’s, you know, she’s going to think I’m mad, and, um, but I was quite surprised because she turned round to me and she said, um, she said “I’ve had an experience too” (Amy-192)
- “there wasn't a lot of other people who I ever spoke to at that age who had NDEs or who had had such accidents. So I guess it was, it seemed like quite a standout, standalone sort of experience. Didn't speak to anyone else, didn't know anyone else who something like that had happened to” (Steph-795)
- “it isn’t something that people talk about. And it’s, certainly not then they didn’t, at all. If I’d have told somebody something then, I think they would probably have said, oh, you know, “she’d lost the plot a bit”.” (Betty-2067)
- “Somebody’s got to approach you really, in a way, because then you’re half way there, aren’t you, with the believing thing” (Betty-2236)

Noticing and respecting NDE differences

- “apprehension about [imposing] “this is how it works. This is what you need to do with it”.” (James-2503)
- “I wouldn’t tell them my views, like I said, it’s just helping” (Julia-2314)
- “I feel that what I would want to do is nothing more than facilitate them letting their pieces fall where they need to fall for them in their own, make their own jigsaw of it. I don’t feel any kind of need or interest to press them in to mine’ (James-2443)
- “[wish] to find a way of of sharing that experience without it taking away from theirs” (James-1774)

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

- “If they were worried about it I would ask them to tell me about it, I wouldn’t ever put my view of it on them.” (Nicole-1429)
- “people have to come to their own, arrive at what they experience, you know, what they think about it” (Nicole-1433)

Connecting and offering help

- “actually wanting to know the core of people rather than just on the surface” (Julia-2364)
- “appreciation of people and of experiences and connectedness with people, and I already had an appreciation I think of those things, but it was definitely stronger and more real after.” (Steph-1769)
- “it was simply to be absolutely present with someone, and I would say when, on the occasions in my life when I have really been present with people, that's a very exhilarating feeling not unlike... because what's alive is real” (Nicole-1234)
- “I saw a picture on the internet of of somebody holding their hands out and some like like gold fairy dust stuff being handed to somebody, and it’s like “yes, that’s what I want to do. I want to give that” (Betty-1759)
- “if someone before had died, I’d say all the words which are clichés [...] and I’d be doing what was expected of me [...] and what I think was my duty. Now I won’t do what people think is my duty, I’ll do what I think is right” (Julia-1889)

Contrasting an inside vs outside source

- “it was just wonderful to wake up in the morning and feel good for no reason, rather than because I was going to do something, or meet people, or have an experience, it was simply waking up because I felt in touch with myself” (Nicole-833)

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

- “that I rely on outside myself is, is far less value than anything that I take from within” (Nicole-813)
- “Having all the right things that I wanted, er, having a nice house, but I was more materialistic” (Betty-490)
- “it’s a much more relaxed [...] much more acceptance of of not needing to chase or grasp happiness [...] I don’t feel so pressured [now]” (James-1002)
- “I think the seeds were there for me to have been, er, much more materialistic. Um, but I think that, um, no, um, I think it actually, the experience had the opposite effect” (Amy-1302)
- “now I I see it as happiness is simpler, and and it’s that no-one can drive your happiness except for you” (Julia-2689)

Choosing one’s perspective

- “Rather than being dissatisfied with what you don’t have. Greater satisfaction with, well, just what is and where we are, being happier with what, yeah, be happy with what you’ve got less, feeling, less focussed on unhappy that I don’t have this or that hasn’t happened” (James-1173)
- “whether I’m just at the seaside and I just take in the beauty of the sea and the sand on the beach and sand dunes and the sky, like when I’m especially connected with nature... But again I sort of link back to God and creation, and [...] feeling truly happy. It’s just an appreciation of those things” (Steph-1637)
- “happiness is a way of life” (Julia-2862)

WELLBEING IN ADULTS WHO HAD A BRUSH WITH DEATH

Enjoying greater happiness and better mental health

- “I’ve never been as depressed. I’ve never been, I get depressed and I get down, but I’ve never been as depressed as I was before, actually” (Betty-1000)
- “it almost makes me in a way able to be perhaps more happy about those things, or more joyful.” (Steph-1616)
- “I still have bad days, but I’ve never got anywhere near the that what I experienced as rock bottom, and my hands as low as I can stretch it there, um, never been anywhere close to that no matter how stressed or how grumpy or how objectively things have have maybe not worked out” (James-1661)
- “I can’t remember in the years up to this happening to me, except for the birth of my daughter, being happy [...] that’s so bad to say it, but I don’t think I knew [...] what happiness was.... I’m being honest. I really don’t” (Julia-2472)
- “I’ve never been as depressed since, never, not, not anywhere near. I used to get very bad depression before, and I haven’t been since, regardless of me whether I processed it or not” (Betty-1000)
- “Before that, I think about five times I was happy in my whole life. Honestly. Whereas afterwards I can’t think of a day I’m not happy” (Julia-2610)