

# **A NARRATIVE INQUIRY INTO THE EXPERIENCE OF SURVIVING A CARDIAC ARREST**

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School of Nursing and Midwifery, Faculty of Health and Medicine,  
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# Declaration

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## STATEMENT OF ORIGINALITY

I hereby certify that the work embodied in the thesis is my own work, conducted under normal supervision. The thesis contains no material which has been accepted, or is being examined, for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made. I give consent to the final version of my thesis being made available worldwide when deposited in the University's Digital Repository, subject to the provisions of the Copyright Act 1968 and any approved embargo.

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## **THESIS BY PUBLICATION**

I hereby certify that this thesis is in the form of a series of published papers of which I am a joint author. I have included as part of the thesis a written statement from each co-author, endorsed by the Faculty Assistant Dean (Research Training), attesting to my contribution to the joint publications.

Signed: .....

Gunilla Haydon

# Acknowledgments

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It is a big decision to start a PhD and to complete a thesis without support it is an impossible task. To have a group of people supporting you, pushing you when it is needed, console and encourage you when the doubts of your capacity creeps into your mind is more valuable than words can describe.

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that I want to have said and that is vital in a thesis. Thank you, Kerry your support and involvement in my PhD candidature has made me a better researcher and writer.

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As this is the last part to be done, it is with great excitement I put the final thank you words together. It has indeed been a long and sometimes arduous time, but in the end a time that has been worth while as these findings can support future survivors of a cardiac arrest. This research endeavour has taught me many skills, I have seen places and met many interesting people and for that I am eternally grateful.

## Published articles included in this thesis

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The articles are listed in the order of appearance in the thesis.

**Haydon, G.**, van der Riet, P., & Maguire, J. (2017). Survivors' quality of life after cardiopulmonary resuscitation: An integrative review of the literature. *Scandinavian Journal of Caring Sciences*, 31, 6–26. doi: 10.1111/scs.12323.

**Haydon, G.**, van der Riet, P., & Inder, K. (2017). A systematic review and meta-synthesis of the qualitative literature exploring the experiences and quality of life of survivors of a cardiac arrest. *European Journal of Cardiovascular Nursing*, 16(6), 475– 483. doi:10.1177/1474515117705486.

**Haydon, G.**, Browne, G., & van der Riet, P. (2017). Narrative inquiry as a research methodology, exploring person centred care in nursing. *Collegian*, 25(1), 125–129. doi:10.1016/j.colegn.2017.03.001

**Haydon, G.**, van der Riet, P., & Inder, K. (2020). A narrative inquiry of survivors' experiences of the time just before and after a cardiac arrest. *Collegian*, 28(2), 190-196. doi:10.1016/j.colegn.2020.06.008

**Haydon, G.**, van der Riet, P., & Inder K. (2020). The experience of returning home after surviving cardiac arrest: a narrative inquiry. *Nordic Journal of Nursing Research* 40(4), 188-196. doi:10.1177/2057158520932348

**Haydon, G.**, van der Riet, P., & Inder, K. (2019). Long-term survivors of cardiac arrest: A narrative inquiry. *European Journal of Cardiovascular Nursing*, 18(6), 458-464. doi:10.1177/1474515119844717

## Conference presentations related to this narrative inquiry

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Research from this thesis was presented nine times at eight conferences during my period of candidature. The presentation titles are listed below starting with the most recent abstract. A copy of the abstracts and posters associated with these presentations are detailed in Appendix One.

**Haydon, G.**, van der Riet, P., & Inder, K. (2020). Using narrative inquiry to explore the experience of surviving a cardiac arrest. *Nordic Conference in Nursing Research "Methods and Networks for the future."* June 2020, Copenhagen, Denmark. Oral presentation

**Haydon, G.**, van der Riet, P., & Inder, K. (2019). Nursing Research and Narrative Inquiry a great fit. Qualitative Methods Conference, "Qualitative Methods in a Time of Change" May 2019, Brisbane, Australia. Oral presentation

**Haydon, G.**, van der Riet, P., & Inder, K. (2019). Cardiac arrest survivors experience immediately before and after the event: A narrative Inquiry. Research week School of Nursing and Midwifery, Newcastle, Australia September 2019 Poster presentation

- Haydon, G.**, van der Riet, P., & Inder, K. (2018). Narrative Inquiry in Nursing Research: Tensions, Bumps, and the Research Puzzle. *International Journal of Qualitative Methods*, 17, 1-39. doi:10.1177/1609406918801621 May 2018, Banff, Canada. Oral presentation.
- Haydon, G.**, van der Riet, P., & Inder, K. (2018). Long term survivors of cardiac arrest: Findings from seven individuals using narrative inquiry. Research week School of Nursing and Midwifery, Newcastle, Australia. September 2018. Poster presentation
- Haydon, G.**, van der Riet, P., & Maguire, J. (2016). The Suitability for Narrative Inquiry in Health Research. *International Journal of Qualitative Methods*, 17, 1-39. doi:10.1177/1609406916628953 April 2015 Melbourne Australia. Oral presentation.
- Haydon, G.**, van der Riet, P., & Maguire, J. (2016). Qualitative and Quantitative Research in Quality of Life After Surviving a Cardiac Arrest. *International Journal of Qualitative Methods*, 17, 1-39. doi:10.1177/1609406916628953 April 2015 Melbourne Australia. Oral presentation.
- Haydon, G.**, van der Riet, P., & Maguire, J. (2016). Narrative Inquiry: a suitable method in health research. *Nordic Conference in Nursing Research "Methods and Networks for the future."* June 2016, Stockholm, Sweden. Oral presentation.
- Haydon, G.**, van der Riet, P., & Maguire, J. (2016). Narrative inquiry, a relational research methodology. Asia Pacific International Conference on Qualitative Research in Nursing Midwifery and Health. Newcastle, Australia. October 2014. Poster presentation.

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Gunilla Haydon

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# Abstract

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Cardiac arrest accounts for approximately 20% of deaths in Western societies, although the survival rate is increasing. This leads to the question, or puzzle, of how does post-cardiac arrest survivors' experience life after cardio-pulmonary resuscitation? A cardiac arrest is a catastrophic and tumultuous event for all involved, but little is known of survivors' individual experiences. This thesis aims to provide an original contribution to knowledge about individuals' experiences of surviving a cardiac arrest and includes six articles published in peer reviewed journals.

A modified approach to Connelly and Clandinin's narrative inquiry framework has been used to address my research aim and unpack my research question/puzzle of participants' experiences of surviving a cardiac arrest. Connelly & Clandinin's (1990) narrative inquiry supports the concept that people live "storied lives and tell stories of those lives" (p. 2), where telling and retelling lived experiences creates order and makes meaning of experiences. Stories are collected, studied and narratively described as research findings. In this thesis I analysed my participants' stories through a three-dimensional space/lens involving temporality, place and sociality.

Eligibility in this inquiry required participants to have survived a cardiac arrest, be living independently in the community and fluent in English. Seventeen participants, including four females and 13 males, participated in a semi-structured interview. The participants had a diverse background in education, employment, age, and living conditions, ensuring a broad spectrum of experiences. Meetings were held from November

2016 to June 2017, at a time and place of shared convenience. While narrative inquiry normally has a small numbers of participants, in this inquiry, a larger number of participants expressed interest. All fulfilled the inclusion criteria and participated in an interview, hence a modified adaptation to Connelly and Clandinin's narrative inquiry approach was used.

Findings are presented in three published articles, each focusing on specific time periods: the immediate time before and after the cardiac arrest; the transition from hospital to home; and following long-term survival. The immediate time before the arrest describes an ordinary time changing to an extraordinary event where survivors had no control, entering a liminal space of chaos and confusion. As they returned home their changed reality became confronting. Extra time and effort were needed to complete everyday tasks. Mental (memory loss and thinking capacity) and physical (slowness and fatigue) limitations were daily reminders of their changed reality and future. However, long-term survivors became comfortable in their embodied reality; life had settled. The event remained a vivid memory. The cardiac arrest had altered their life, but they had adapted to their limits and found acceptance in living as a cardiac arrest survivor.

For the survivor, the cardiac arrest is a defining moment where their life changed in a moment from ordinary to an extraordinary and unknown reality. The survivors entered a liminal space of betwixt and between involving a 'before' and 'after' the event. An awareness of liminality may well help healthcare professionals to understand what support survivors of cardiac arrest seek from their illness experience.

# Glossary

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## **Cardiac arrest**

Cardiac arrest is the abrupt loss of heart function in a person. Cardiac arrest can come on suddenly, or as a flow on effect from other symptoms. A cardiac arrest is often fatal, unless appropriate interventions, such as cardiopulmonary resuscitation, are commenced immediately (American Heart Association, 2020a).

## **Cardiopulmonary resuscitation**

Cardiopulmonary resuscitation (CPR) is an attempt to restore spontaneous circulation by performing chest compressions with or without ventilations (Jacobs et al., 2004) and is an emergency lifesaving procedure performed when the heart stops beating (American Heart Association, 2020b).

## **Embodiment**

Embodiment involves experiences that are incorporated into the body and expressed through the body. In health, nurses encounter embodied expressions of pain, discomfort, fear, anxiety, shame and embarrassment among their patients. While attending to their patients care, nurses note the patient's embodied verbal language as well as their body language in order to provide holistic care (Fernandez, 2020).

## **In hospital cardiac arrest**

An in hospital cardiac arrest (IHCA) is a cardiac arrest while in hospital (American Heart Association, 2020).

## **Health related quality of life**

Health-related quality of life (HRQOL) is a person's, or a group of people's perceived physical and mental health measured over time. HRQOL is a means of calculating the way health is observed to affect quality of life (Karimi & Brazier, 2016).

## **Holistic care**

Holistic nursing care refers to the care of patients based on a mutual understanding of their physical, psychological, emotional and spiritual dimensions. Holistic nursing care considers and assists the persons and the effects of the illness on their body, mind, spirituality and their personal relationships (Jasemi, Valizadeh, Zamanzadeh & Keogh, 2017).

## **Implantable cardioverter defibrillator**

An Implantable cardioverter defibrillator (ICD) is a battery-powered device placed under the skin that keeps track of the heart rate. Thin wires connect the ICD to the heart. If an abnormal heart rhythm is detected, the device will deliver an electric shock to restore a normal heartbeat (American Heart Association, 2020).

## **Out of hospital cardiac arrest**

An out of hospital cardiac arrest (OHCA) is a cardiac arrest while out in the community (American Heart Association, 2020).

## **Pacemaker**

A pacemaker is a small device that is placed in the chest or abdomen to help control abnormal heart rhythms. This device uses electrical pulses to prompt the heart to beat at a normal rate (American Heart Association, 2020).

## **Person-centred care**

Person-centred care is the underpinning of safe, high-quality healthcare. Person-centred care is care that is respectful and responsive to the preferences, needs and values of the person (Australian Commission on Safety and Quality in Health Care, 2019).

## **Post-traumatic stress disorder**

Post-traumatic stress disorder (PTSD) is a condition generated by an experience of a traumatic event that is severe enough to create strong feelings of fear, helplessness, and horror. PTSD can be caused by fragmentary memories from their time spent in intensive care where nightmares and hallucinations, recalled afterwards making it difficult for patients to make sense of what has happened to them. The fragmented memories are often described as vivid, realistic and terrifying (Torres, 2020).

## **Quality of life**

Quality of life (QOL) is a broad multidimensional idea that includes subjective calculations of both positive and negative aspects of life (Jenkinson, 2020).

## **Return of spontaneous circulation**

Signs of the return of spontaneous circulation (ROSC) is defined as the restoration of a spontaneous perfusing rhythm that results in more than an occasional gasp, fleeting palpated pulse, or arterial waveform (Jacobs et al., 2004)

## **Snowball sampling**

Snowball sampling may be described as the technique for finding research participants through 'word of mouth' via conversations with other participants (Blackstone, 2012).

# Abbreviations

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AED	Automated external defibrillator
CA	cardiac arrest
CPR	cardiopulmonary resuscitation
IHCA	in hospital cardiac arrest
OHCA	out of hospital cardiac arrest
RN	registered nurse
ROSC	return of spontaneous circulation

# Background and Autobiography

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*This chapter includes an overview of the six chapters in this thesis. This is followed by the background and my autobiography that led to my narrative inquiry into the experience of surviving a cardiac arrest.*

*Ever since closed chest cardiac massage was described by Kouwenhoven, Jude and Knickerbocker (1960), both health professionals and the general public have had an interest in the survival outcome after a cardiac arrest. This chapter contains the background of cardiopulmonary resuscitation, and the progress to present time, as well as my own background and interest in the survivors' experience of surviving a cardiac arrest.*

*This thesis explores the experience of seventeen participants' stories of surviving a cardiac arrest. I used a modified Clandinin and Connelly's approach to Narrative inquiry involving the three-dimensional space the interpretation of findings of temporality, place and sociality to analyse my participant stories. In this first chapter I provide my autobiographical narrative and my personal justification as well as the practical and social justifications for this inquiry. Part of the personal grounding in narrative inquiry preparation is the personal justification and interest in the research. As Clandinin (2013, p. 44) points out,*

*"... studies involving participants other than the researcher, autobiographical narrative inquiry is an inquiry starting point. As participants' and researchers' lives meet in the midst of each of our unfolding complex and multiple experiences, we begin to shape time, places, and spaces where we come together..."*

*My autobiographical beginning, and thoughts, were written in preparation for my PhD in April 2016 and outline the background to my interest in the question “How do post-cardiac arrest survivors experience life after cardio-pulmonary resuscitation? The choice of narrative inquiry as the methodology framework in my study will also be presented.*

*This autobiography was reviewed in October 2020 and supporting literature has been updated or added.*

~ ~ ~

## **OVERVIEW OF CHAPTERS**

This thesis explores the experience of surviving a cardiac arrest, where 17 participants told their story of survival. As I collected their stories, I was guided by a modified version of Connelly and Clandinin's narrative inquiry to interpret and present the findings. Below is a summary of the chapters included in this thesis.

### **CHAPTER ONE: BACKGROUND AND AUTOBIOGRAPHY**

The first chapter presents the background to cardiopulmonary resuscitation (CPR), the further development of CPR to present time and the need to know more about cardiac arrest survivors' experiences. The following is my autobiography, introducing me as a researcher and my experiences that lead the inquiry to my selected study topic of surviving a cardiac arrest. The narrative inquiry framework (Connelly & Clandinin, 1990; Clandinin & Connelly, 2000) supports the use of an autobiography to begin the inquiry where the researcher situates themselves in the midst of the research puzzle.

### **CHAPTER TWO: LITERATURE REVIEW**

I searched for literature exploring and synthesising research about cardiac arrest survivors' experiences and the literature is presented in two published articles. The first article titled 'Survivors' quality of life after cardiopulmonary resuscitation: An integrative review of the literature' published in Scandinavian Journal of Caring Sciences 2017, explores a broad range of literature on the quality of life for survivors

of a cardiac arrest, with the specific aim of examining literature that explores the quality of life for survivors after CPR and the influence cognitive impairment, anxiety, depression and post-traumatic stress disorder has had on their quality of life. The findings from the integrative review created a sense of wonder and a search for more knowledge about the survivors' embodied experience. I did a second systematic search in databases with a focus on qualitative literature and found seven articles that met the inclusion criteria. My aim was to critically appraise and synthesise the qualitative literature on survivors' experiences of a cardiac arrest and cardiopulmonary resuscitation and identify common themes that could inform clinical pathways and improve survivor quality of life. This was the second published literature review titled 'A systematic review and meta-synthesis of the qualitative literature exploring the experiences and quality of life of survivors of a cardiac arrest.' published in European Journal of Cardiovascular Nursing 2017.

### CHAPTER THREE: METHODOLOGY AND METHOD

This chapter contains the rationale behind the selection and background of narrative inquiry as the chosen methodology. Major contributing authors to narrative research are introduced as narrative research is a broad field and can take many forms. Connelly and Clandinin's (2000) theoretical framework of narrative inquiry and Clandinin's (2013) further development of the methodology is introduced as a way of making meaning of the stories of 'lived lives'. These stories become the basis for this

study, using a modified version of narrative inquiry exploring the research puzzle of the experience of surviving a cardiac arrest.

The second part of the chapter describes the recruitment of cardiac arrest survivors and the setting for this research puzzle. The meeting with participants, collection of, and analysing of the field text are outlined, followed by ethical considerations and rigor of my study. The final part of the chapter presents an article titled 'Narrative inquiry as a research methodology exploring person centred care in nursing'. This article is published in Collegian 2018 and augments the usefulness of narrative inquiry in health research.

#### CHAPTER FOUR: PRESENTATION OF FINDINGS

Chapter Four presents the findings from this narrative inquiry as three published articles. The three articles follow the timeline (temporality) of recovery from the cardiac arrest to the long-term survivors. The first two articles include the 17 participants and in the final article, seven participants were eligible for inclusion.

The first article, titled 'A narrative inquiry of survivors' experiences of the time just before and after a cardiac arrest', attends to participants experience immediately before and after the cardiac arrest as little is known of the experiences of survivors within this time period. The narratives describe the unpreparedness and confusion surrounding the cardiac arrest, indicating that a cardiac arrest changes the ordinary to the extraordinary. Surviving a cardiac arrest is confusing and the survivor has to adapt to a new reality. This article is published in Collegian 2020.

The second article, titled 'The experience of returning home after surviving cardiac arrest: A narrative inquiry', explored the participants' experience in the time of returning home from hospital and is published in Nordic Journal of Nursing Research 2020. Arriving home, the survivor is confronted with the reality that life has changed, where common everyday tasks that were previously done with ease now take time and effort to complete. The participants describe a catastrophic event where they now have to accept and adjust mentally, physically and socially, since the cardiac arrest encompasses all aspects of life.

The final article, titled 'Long-term survivors of cardiac arrest: A narrative inquiry' published in 2019 in European Journal of Cardiovascular Nursing, explores the long-term survivors' experiences after cardiac arrest and describes how these survivors have adjusted to their new reality. Seven individuals who survived a cardiac arrest between five and 36 years ago contributed their stories as long-term survivors. They all expressed a positive attitude to life and although there were hurdles to overcome, they report a heightened appreciation for living. After adaptation to the reality of being a cardiac arrest survivor, their life returned to a new normality.

## CHAPTER FIVE: DISCUSSION

This chapter begins with a discussion of the importance of story and a recapitulation of Clandinin and Connelly (2000) and Clandinin's (2013) ontological and epistemological stance of the learning from experiences, and the dimensions of time, place and sociality. This is followed by a discussion of the inquiry and the findings using the modified narrative inquiry as a methodology. The literature review in

Chapter Two was limited to the literature published before 2015, therefore, inclusion of recent published literature is included while discussing the threads found in this inquiry. Eleven plotlines were derived from the multiple threads of the cardiac arrest survivors' experience, involving their liminal embodied transition in their recovery. Finally, the synthesis and conceptualisation of my study will be presented.

## CHAPTER SIX: CONCLUSION

This final thesis chapter contains the strengths and limitations of this inquiry, relevance to clinical practice, and recommendations for further research. I include a reflection of my research experience and final conclusion where the findings and new knowledge of the cardiac arrest survivors experience will, if acted upon, support an improved person centred care for this group of survivors.

## **BACKGROUND OF THE STUDY**

Cardiac illnesses are one of the largest causes of death in our modern society and cardiac arrest accounts for approximately 20% of deaths in western countries (Paratz et al., 2020). A recent meta-analysis of 141 eligible studies exploring survival rates after a cardiac arrest found the pooled rate of survival to hospital discharge was 8.8% (Yan et al., 2020). In western countries, the bystander knowledge of cardiopulmonary resuscitation (CPR) and the use and availability of automated external defibrillators (AED) has greatly improved survival among cardiac arrest sufferers (Yan et al., 2020). In Australia every year more than 22,000 people are estimated to suffer an out of hospital cardiac arrest (Beck et al., 2018). An Australian survey of 1076 individuals found that only 16% could correctly identify the difference between a myocardial infarction and a cardiac arrest (Cartledge, Saxon, Finn & Bray, 2020). According to the Australian Resuscitation Council (2016) the criteria for cardiac arrest is un-responsiveness and not breathing normally.

A cardiac arrest is usually caused by an electrical malfunction in the heart's electrical system when the electrical impulses cease or does not generate strong enough contractions to produce an effective pulse to circulate blood throughout the body (Davidson, 2017). This can occur as a result from hypovolaemia, hypothermia, hypoxia, myocardial infarction, a primary arrhythmia and overdose of medication or drugs (Davidson, 2017). A deficient heartbeat or non-beating heart is a medical emergency leading to an imminent death unless prompt action is taken, such as CPR and defibrillation (National Heart Foundation of Australia, 2020). Myocardial infarction, or heart attack, is when a coronary artery becomes blocked, stopping the blood flow and reducing the oxygen supply to the

heart muscle; this can lead to a cardiac arrest (National Heart Foundation of Australia, 2020).

After Kouwenhoven et al., (1960) published the successful recovery of 17 cardiac arrest sufferers using closed chest heart massage, the modern concept of chest compressions to keep up blood pressure and blood flow when the heart stops working was adapted. Since then, there has been an interest in the improvement of survival after a cardiac arrest. The lowering of body temperature to protect cerebral function has, for a long time, been accepted practice (Alne, 2020; Paauwe-Weust, 2018). Automated chest compression devices were introduced in the early 2000s (Colombo et al., 2019; Perkins et al., 2010; Schmidbauer, Friberg, Herlitz, Axelsson & Karlsson, 2017) and extracorporeal cardiopulmonary resuscitation is becoming more common (Daou et al., 2020; Chen, Liu, Huang, Zeng, Lin, Zhu, Liu, 2019).

With continued interest and research in the variables influencing survival rate, increased bystander knowledge of CPR and positive trends in the survival rate after a cardiac arrest, it is important to explore the measurable variables influencing survival of a cardiac arrest. Exploring the experience from the survivors' point of view is important in order to provide care that is tailored to the survivors' needs.

From the time when Kouwenhoven et al., (1960) first described closed-chest cardiac massage, there has been much research carried out exploring variables that can improve survival rates. Although the defibrillator was already in use, it was a heavy stationary object. Historically, the first portable defibrillator was developed by Frank Pantridge in 1965 (Cakulev, Efimov, Waldo, 2009) weighing 70 kg and placed in an ambulance. Technology has improved and the portable defibrillator now weighs 3kg or less (Cakulev et al., 2009),

and is commonly available at sports clubs and shopping centres, further improving survival chances for cardiac arrest sufferers (Cakulev et al., 2009; Doan, Schultz, Rashford & Bosley, 2020). With the training of citizens in cardiopulmonary resuscitation and availability of portable defibrillators, a cardiac arrest is not the death sentence it once was. As Kouwenhoven et al., (1960, p.1064) states *“Anyone, anywhere, can now initiate cardiac resuscitative procedures. All that is needed are (sic) two hands.”*

In our western society the use of highly qualified emergency personnel, availability of portable defibrillators and public education in CPR has increased the likelihood of survival (Doan et al., 2020). However, there are regional differences and one of the most important factors to increase survival is bystander interventions and knowledge of CPR (Doan et al., 2020).

The promotion and interest in providing education in CPR among the general public and thereby increasing the likelihood that a bystander will initiate CPR for a person suffering a cardiac arrest has been a longstanding priority (Doan et al., 2020; Liaw et al., 2020). Importantly, the probability of survival can be doubled if bystander-initiated CPR is enacted (Doan et al., 2020; Nielsen, Isbye, Lippert & Rasmussen, 2013). The increased availability of AEDs in public places has also had an impact on the cardiac arrest survival rate (Bækgaard et al., 2017; Kim et al., 2019). As the AED now includes voice instructions and prompts for actions during the emergency, there is an increased likelihood of survival if the cardiac arrest happens in a public place (Bækgaard et al., 2017; Doan et al., 2020). There are improvements to be made as less than half the individuals suffering an out of hospital cardiac arrest globally receive bystander CPR (Viereck, Palsgaard Møller, Kjær Ersbøll, & Lippert, 2017). With ongoing information and CPR training provided to the

general public, recognition of a cardiac arrest and subsequent bystander support is likely to increase (Bækgaard et al., 2017; Viereck et al., 2017),

This inquiry focusses on the experience of surviving a cardiac arrest. This inquiry does not differentiate between an in-hospital cardiac arrest or an out-of-hospital cardiac arrest. Neither does it explore if there is a difference between those survivors who had hypothermia treatment, i.e. cooling of core temperature to 32-36°C by targeted temperature management for at least 24 hours (Hassager, Nagao, Hildick-Smith & Nagao, 2018), pacemaker implantation, a small implantable device that uses electrical pulses to prompt the heart to beat at a normal rate (Moore et al., 2019), or given an implantable cardioverter defibrillator, i.e. a device that can deliver electric shocks to the heart when an abnormal heart rhythm is detected (Karnik, Helm & Monahan, 2019). This inquiry is about the experience of surviving a cardiac arrest, nothing more, nothing less, and what can be learnt from these survivors' experiences.

# **AUTOBIOGRAPHY**

## **THE PERSONAL JUSTIFICATION**

In this section I present my personal justification on how my inquiry came to fruition by listening to stories and through my own experiences. In this section I share, with you the reader, some inward gazes on my own life experiences that are relevant to this study. I will share my own ontological stance as my autobiography sets the scene for my thesis. Autobiographical narrative inquiries are an important part from the onset of this study and are ongoing throughout the inquiry, as even a modified version of narrative inquiry starts and ends in the midst of living for both researcher and participant (Clandinin, 2013; Connelly & Clandinin, 1990; Clandinin & Connelly 2000).

An autobiographical narrative is part of the composing process of narrative inquiry, where the imaginary shape of the research puzzle will take form, justifying the narrative inquiry personally, practically and socially. As Clandinin (2013) explains, in the beginning of a narrative inquiry the researcher needs to engage in a thoughtful autobiographical narrative, to find their own narrative beginning and to find their standpoint in the research puzzle. By writing an autobiography the researcher will engage in the research puzzle by starting to imagine how the researcher and the participants can shape the inquiry and influence the collected narratives.

In this inquiry, it is important to find my 'own place' in the project. To explore my relation to the research question/puzzle and what I hoped to find. My aims and my driving passion behind the project will be exposed. I will also disclose why I have chosen this modified version of narrative inquiry as an appropriate methodology for this research. As a

foundation and framework to the modified version, Connelly and Clandinin's (1990, 2000) narrative inquiry does not only fit well with my research puzzle, but the relational aspects and the way the findings are presented are also suitable for this inquiry.

As the participants' and my narratives merge in the middle of our continuing and multifaceted lives, I imagine the narrated experiences starting to take shape, where time, place, social and cultural dimensions mould into an experience that I can share with the reader and where the reader can learn from our collective experiences. As is highlighted by Connelly and Clandinin (1990) and, Clandinin and Connelly (2000), John Dewey's philosophy is pragmatic in that our experiences influence how we learn, behave and react and how our experiences impact our future decisions and experiences (Dewey, 1938). The experience of surviving a cardiac arrest is not that common and is an event most of us would not like to experience. Therefore, we may learn from cardiac arrest survivors by reading and learning from their experiences. This knowledge is important for nursing. The enormity of the event and realisation of being very close to death and knowing that without prompt intervention death would be imminent can create an overwhelming feeling for the survivor. Therefore, there is a need to understand these survivors' embodied experiences so that we, as nurses, along with health professionals can provide comprehensive support for this group of survivors. This knowledge can support the nurses in providing holistic care and support for this group, and possibly prevent survivors of cardiac arrest from entering a downward spiral of illness. While the survivor is in the liminal transition adapting to life as a cardiac arrest survivor illness such as self-doubt and depression may influence the future health of the survivor. Schwind, Fredericks, Metersky & Porzuczek (2016, p. 473) argue that "embodied knowing has the potential for making connections with those in our care".

As Clandinin (2013, p. 82) writes “The personal, practical, social and theoretical justification allows us to respond to the ‘so what’ and ‘who cares’ questions that all social sciences researchers must answer. Narrative inquirers must begin, then, with inquiring into our own stories of experience.”

Growing up on a farm in Sweden has influenced and shaped my ontological view of life and humanity. Living on the farm was hard work and my participation was needed. Responsibility and stubbornness were needed and taught to me by my father from an early age. I always had animals around me. The runt of the litter of lambs and piglets ended up in the kitchen where it was my role to take care of them. With animals, especially the ‘runt of the litter’, there is always the possibility that they might not survive, and I had a number of small animals having an uneventful death in a box under a blanket in the kitchen. My father told me I should always look after the animals as well as possible, including how these animals end their life; a stress-less death was the best option. Of course, on a farm, there are economic and ethical issues, but one cornerstone ethos was quality of life for the animals. This view about quality of life has been and remains one of my cornerstones (both professionally as a nurse and personally) when I look after any living thing.

However, I will share with you the reader, one episode on the farm where we did not apply this ethical notion of a ‘stress-less death’. I can remember a dairy cow that managed to get into the feed shed overnight and ate too much fodder, hence she was very bloated when we found her in the morning. In our rescue attempts we were quite intrusive and in hindsight perhaps we should not have tried so hard in our futile attempts to rescue her. I still feel an embodied discomfort about this and wish we had done things differently. This

experience has influenced my view of death and dying, and I regret the futile resuscitation attempts we did for this dying animal. What I found disturbing was that we continued our attempt to rescue the cow even after realising it was futile.

How I ended up migrating from Sweden to Australia permanently in 1995 is not of importance to this study, but here I am. My career in nursing started when my two sons started high school. After completing my education as a registered nurse (RN), I worked in the local hospital, first in the oncology unit and then in the intensive care and cardiac care unit. Working with patients in these environments where you often meet and support people when they are at their most vulnerable was a privilege. During my work as a RN in the intensive care and cardiac unit I witnessed cardiac arrests but more often I was involved in the recovery after the event, giving me a lived nursing experience.

I began collecting stories of cardiac arrest survival, beginning the creation of my research puzzle. During my first year studying nursing, the research question developed from my various life stories, or ontological experiences. The first time I heard a story about a cardiac arrest was during an introductory course in aged care. We were talking about patient awareness for unconscious patients. Our tutor, who also worked as a RN in one of the local hospitals, told us about an incident where she had, together with a colleague, performed CPR. As the patient regained spontaneous circulation, the two nurses shook hands across her chest. A couple of days later this RN looked after the same patient in recovery and she was rather surprised when the patient asked her who she shook hands with after the CPR. The RN was amazed that the patient was so aware of her surroundings so close to the incident and even more surprised when the patient said, "Don't ever do that

to me again!”

The following story was told during my last year of my undergraduate nursing degree by one of my fellow students. She did her clinical placement in a renal ward and one of her patients had a cardiac arrest during the haemodialysis. Excitedly my friend told me how she had pressed the red button and been the first one to put the oxygen on before more experienced nurses and doctors moved her to the side. My friend continued to nurse this woman at the hospital who subsequently told her that she was distressed about the attempts to rescue her life. She considered herself to be old and ‘living a crappy life attached to a dialysis machine’ and opted to sign a ‘not for resuscitation’ order shortly after the event.

The next story came from a student of mine who told me how she had decided to study nursing after her mother had survived a cardiac arrest. She also told me how her mother, whilst suffering multiple cardiac arrests, had pleaded with the paramedics to stop trying to resuscitate her as they continued to perform CPR. Although she recovered with only minor ailments, it was still a very traumatic experience for my student’s mother, as well as for my student. My time working in an intensive care unit at my local hospital there were some sad deaths. One especially stands out; this was a middle-aged indigenous woman who I had nursed on a previous occasion for a cardiac related issue. She was a gentle and softly spoken woman. I arrived at work one day to find that she had returned to the ward and was now on a bed with the whole team intensely working on her, trying to resuscitate her. The situation at the bedside was palpable, with the team leader giving orders, a wards-man providing CPR and nurses and doctors doing their part in the resuscitation, while her

husband, adult children and grandchildren were waiting outside alone in the corridor in silence. I found this to be a sad experience, instead of having a peaceful death in the company of her family she was now surrounded by strangers trying to keep her alive. Although I was not actively involved in her resuscitation, it still saddens me to think of her and her family. Like small pieces of a puzzle, these stories all contributed to my decision to explore the survivors' experience of surviving a cardiac arrest.

These short-storied moments of cardiac arrest, survivors' fear of a repeat cardiac arrest and my experience at work, created some tensions within me. I wanted to find out the lived experience of surviving such an intrusive ordeal. What was it like to have the knowledge of being so close to death and knowing without intervention from bystanders that death would be certain? How did that knowledge influence the experience of survival? These questions were the impetuses for me take the step to begin this inquiry. I hoped to have a conversation with people who had survived a cardiac arrest and find out how they experienced the event. I wished to meet survivors who survived with great success as well as survivors who were less fortunate. I wanted to be able to have a conversation with the whole spectrum of survivors from those who had a positive story to tell, to those who did not have a great experience and to then explore the experience of being very close to death and how that experience influenced their future.

## **NARRATIVE INQUIRY AND THE RESEARCH PUZZLE**

The choice of selecting narrative inquiry as a methodology for my PhD holds many merits. The relational aspects between researcher and participants', the holistic three-dimensional space, and the presentation of findings as well as the ontological aspect of learning through experience, appealed to me as a researcher. Narrative inquiry does not have a 'research question' leading to a quest for "a precise definition or expectation of an answer" (Clandinin, 2013, p. 42) rather instead framed as a 'research puzzle' shifts the purpose and meaning of narrative inquiry. The shift to a 'research puzzle' changes the concept of a narrative inquiry — Instead of searching for a definite answer, there is a realisation that as human beings we are always in transition and as our experiences and environment changes, so will answers to the research puzzle (Clandinin, 2016). Hence my research puzzle seeks to explore "How do post-cardiac arrest survivors experience life after cardio-pulmonary resuscitation?"

Finding a suitable methodology for my inquiry I explored many narrative inquiry authors such as Connelly, Clandinin, Daiute, Riessman and Czarniawska. I am confident I have chosen the right methodology, using Connelly and Clandinin's approach of narrative inquiry although it has been modified to accommodate the larger number of participants.

During this early PhD time, I was searching for articles to get a feel for narrative inquiry, I found many journal articles discussing the methodology of narrative inquiry. However, there were few nursing research articles using narrative inquiry to present their findings. These articles all had their own way presenting findings from narrative inquiry.

Hence, narrative inquiry as a framework supporting the research is well documented, however, the narrative way of presenting the findings is evolving and are in part constrained by the limitations of publishing in health journals.

An important aspect of narrative inquiry, for me, is the way the stories are analysed and the relational space that is created between the researcher and the participant. To have the participants involved in a relational methodology, such as narrative inquiry, creates a security and trustworthiness that the research findings are not a misinterpretation of their story.

## **THE SOCIAL JUSTIFICATION**

Much has happened since the defibrillator became portable in the late 1960s (White, 1995). Television shows, such as 'Emergency!' (Webb & Cinade, 1972-1977), where CPR and defibrillators were successfully used in almost every episode have contributed much to public awareness of cardiac arrest. I can remember watching the show every week with great excitement, however, the portrayal of a cardiac arrest in many shows does not reflect reality and this can distort the expectations of a cardiac arrest amongst the public (McFadden et al., 2020). The medical emergency of cardiac arrest has continued to be part of medical and emergency television shows and continues to influence the public view of cardiac arrest and CPR (Harris & Willoughby, 2009; Portanova, Irvine, Yi & Enguidanos, 2015).

As research has continued to improve the success rate of CPR and the survival rate increases, CPR has become normal practice and is used in almost any situation where the

heart has stopped beating. Although the success rate is small, at an estimated 12-14% survive worldwide to hospital discharge (Sasson, Rogers, Dahl & Kellerman, 2010; Schluep, Gravesteijn, Stolker, Endeman, & Hoeks, 2018; Yan et al., 2020). According to Berger (2017), Gräsner et al. (2016), Myat, Song & Rea (2018) and Yan et al. (2020), we routinely perform CPR even in futile situations. The difference between what is reality and the presented success in film and television shows can create distress among bystanders that are involved in CPR which results in a poor outcome. This perceived view of success of CPR among laypersons may also influence the survivor of a cardiac arrest as they recover after the ordeal.

### **THE PRACTICAL JUSTIFICATION**

All interactions we have, may it be a brief encounter among strangers, a family reunion or in a research project, personalities and how we react and respond to each other influences outcomes. The framework of narrative inquiry (Connelly & Clandinin, 1990; Clandinin & Connelly, 2000) acknowledges the influence the researcher may have on the outcome of encounters with participants. To be accepted as a visible participant and not an observer in this inquiry was important to me. Among many different narrative inquiry authors providing different frameworks for how to approach the methodology, I found Clandinin and Connelly's framework the most suitable for my research. Exploring and having conversations about closeness to death and dying, I felt I needed to have a relationship, albeit relatively brief and professional, with the participant. Clandinin and Connelly's narrative inquiry framework allows the researcher to be visible in developing a narrative of the inquiry.

Narrative inquiry is a 'relational' methodology. The relational aspects of narrative inquiry are not only about the relationship between the participant and researcher, but also the relationship between 'time', 'place' and 'social (culture)' — exploring where the story is placed in relation to the three-dimensions (Connelly & Clandinin, 1990; Clandinin & Connelly, 2000; Clandinin, 2013). Sometimes time (past, present and future) will be the most prominent feature of the story. For instance, if the participant's story is exploring the past, not only 'time' is present but also 'place' where the participant describes the location. This description of 'place' can be very detailed and perhaps overshadow the 'time' aspects of the story. The social and cultural interactions between the people involved in the story are another dimension. These relationships between 'time', 'place' and 'social and culture' give depth to narrative inquiry. These dimensions are always present in all stories (Connelly & Clandinin, 1990; Clandinin & Connelly, 2000; Clandinin, 2013). This will be further explored in the methodology chapter.

## **MY AIMS BEHIND THE INQUIRY**

In unpacking my research puzzle, I focused on the following aims:

- ❏ To seek knowledge from people who have experienced a cardiac arrest and from their stories, seek to find pieces to build into my research puzzle, using the dimensions of time, place and sociality to explore threads found in the participants' stories. Using these threads, I aimed to transfer the knowledge I have gained to publish articles and present at conferences thereby influence and improve clinical practice.

❏ To inform nurses, other healthcare professionals and the general public about the reality of a cardiac arrest from the survivors' point of view and what matters to them. My purpose in publishing my findings during this candidature is to present nurses and healthcare professionals with information to encourage a holistic and person-centred approach to the individual who survived a cardiac arrest.

## TO SUMMARISE

My autobiography is my story, my ontological stance, of becoming a narrative inquiry researcher and coming to this research with a puzzle. It provides my personal justification for this inquiry. In this first chapter I have also provided a social and practical justification for this inquiry I have attended to the past and the things that have mattered to me. This narrative inquiry has been a long road conducted together with personal and professional lives that have demanded time and consideration. The following quote from Clandinin (2013, p. 43) resonates with me;

*“Narrative inquirers enter into a relationship in the midst. We mean this in several ways: in the midst of researchers ongoing personal and professional lives; in the midst of the researcher’s life enacted with particular institutional narratives such as funded projects, graduate student research and other research; in the midst of institutional narratives such as university or other organisational narratives; in the midst of social, political, linguistic, and cultural narratives. Our participants are also always in the midst of their lives. When our lives come together in an inquiry relationship, we are in the midst. Their lives and ours are*

*shaped by attending to the past present and future unfolding social cultural, institutional, linguistic and familial narratives.”*

We are all living in the ‘present’ with the experiences we have gained previously. This first chapter and autobiography are the starting point for my PhD and thesis. We are constantly influenced by our surroundings and experiences; therefore, this autobiography will be just that — the beginning. As you the reader read more literature and meet my participants, you will see that my ontology stance has changed. What I thought was set in stone has changed.

My understanding of my participants’ experiences is quite different to the one I perceived at the beginning of this study. My own embodied knowing in this study has been transformed through thinking narratively through a lens of the three-dimensions of time, sociality and place. As seen above in my autobiography, my previous experiences shaped my interest that research cannot be truly objective and separated from the researcher, as Pinnegar and Daynes (2007, p. 29) state,

*“...it fails to take into account the fact that researchers choose to study one thing rather than another, and that just the facts of choice, curiosity, and interest without considering passion, caring, or insight connect the researcher in a non-natural way to what is being studied.”*

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# Literature Review

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*In the first chapter I presented the background to cardiopulmonary resuscitation (CPR), the development of CPR and why we need to know more about the cardiac arrest survivors' experience. This was followed by my autobiography, scope of the thesis and why I am interested in the topic of surviving a cardiac arrest.*

*As the survival rate increase among cardiac arrest sufferers there is a need to explore their experience of the event. Therefore before I commenced my inquiry, I needed to explore what was already known about cardiac arrest survivors' experiences. I started a literature search and found that cardiac arrest is a well-researched area, a large amount of research exploring factors that influence cardiac arrest survival, although less research focused on the survivors' experience.*

*In this second chapter I present two articles encompasses my literature review. The first article titled: 'Survivors' quality of life after cardiopulmonary resuscitation: an integrative review of the literature' explores a broad range of literature on the quality of life for survivors of a cardiac arrest with the aim to examine literature that explores the quality of life for survivors' after CPR and the influence cognitive impairment, anxiety, depression and post-traumatic stress disorder has had on their quality of life.*

*In my search of literature, I found a difference in the qualitative and quantitative literature, awakening curiosity, and a wonder of what the qualitative literature findings. Therefore, I completed a systematic search for qualitative literature exploring the experience of surviving a cardiac arrest. In the second article 'A systematic review and*

*meta-synthesis of the qualitative literature exploring the experiences and quality of life of survivors of a cardiac arrest' I found five themes: multitude of contrasting feelings; disruption in the continuum of time; new reality and psychological challenges; changed body with new limitations; and confrontation with death.*

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## **PUBLICATION: SURVIVORS' QUALITY OF LIFE AFTER CARDIOPULMONARY RESUSCITATION: AN INTEGRATIVE REVIEW OF THE LITERATURE**

### **The impact of the article**

At the time of thesis submission 'Survivors' quality of life after cardiopulmonary resuscitation: an integrative review of the literature' had 21 citations Scopus and 48 in Google Scholar. The article has a Field Weighted Citation Impact\* of 1.30, and a Prominence percentile of: 76.181

\*Field-Weighted Citation Impact shows how well cited this document is when compared to similar documents. A value greater than 1.00 means the document is more cited than expected according to the average.

In ResearchGate this article has 274 reads and 27 citations.

**Author contribution statement see appendix 2.**

### **Publication copyright**

Permission to reproduce this article in this thesis see appendix 3.

# Survivors' quality of life after cardiopulmonary resuscitation: an integrative review of the literature

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Scand J Caring Sci; 2017; 31; 6–26

## Survivors' quality of life after cardiopulmonary resuscitation: an integrative review of the literature

**Background:** The incidence of cardiac arrest and cardiopulmonary resuscitation continues to increase worldwide largely due to greater awareness of the symptoms of cardiac events and increased attention to cardiopulmonary resuscitation training in the community. Globally, predicted survival rates after cardiopulmonary resuscitation have remained at 10% for decades and although patient outcome remains unpredictable, there is a positive trend in life expectancy. For a resuscitation attempt to be classed as successful, not only survival but also quality of life has to be evaluated.

**Aim:** The aim of this review was to examine literature that explores the quality of life (QOL) for survivors after CPR and the influence cognitive impairment, anxiety, depression and post-traumatic stress disorder (PTSD) has had on their QOL.

**Review methods:** This review follows Whittemore and Knafl's framework for an integrative literature review. Electronic databases EBSCO, Ovid, PubMed and EMBASE were searched. After application of the inclusion and exclusion criteria, thirty-six papers published from January 2000 to June 2015 were included in this review.

**Results:** These papers represent a broad spectrum of research evaluating quality of life for survivors of cardiopulmonary resuscitation. The heterogeneous research methods and vast number of different research tools make it challenging to compare the findings. The majority of papers concluded that quality of life for survivors of cardiac arrest and cardiopulmonary resuscitation was generally acceptable. However, studies also described survivors' experience of anxiety, depression, post-traumatic stress and cognitive dysfunction.

**Conclusion:** A majority of papers reported an acceptable quality of life if the patient survived to hospital discharge. The heterogeneity in quantitative papers was noticeable and indicates a marked variance in patient outcomes. This review highlights the absence of specialized tools used to investigate survivors' experience of the event. Further exploration of the impact cardiopulmonary resuscitation has on the individual may improve ongoing rehabilitation and quality of life levels for survivors.

**Keywords:** integrative literature review, cardiac arrest, sudden cardiac death, cardiopulmonary resuscitation, quality of life, survivor, experience.

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## Introduction

Cardiac arrest (CA) is undoubtedly a life-threatening condition, and worldwide CA is a leading cause of death. Annually, there are approximately 375 000–700 000 CA cases in Europe (1), while in the USA, there are around 383 000 cases over a similar period (2). Internationally, the survival rate for CA is low at <14% and this has not

improved since the introduction of cardiopulmonary resuscitation (CPR) in the early 1960s (1–4). Not surprisingly, a higher survival rate is recorded in communities where intensive promotion and training of CPR are held, from 25% up to 56% (5–8). Hence, survival rates after out of hospital cardiac arrest (OHCA) are increasing and survivors of CPR can expect to live longer (9–11). Having this in mind, not only survival, but also QOL becomes an indicator of a successful resuscitation.

While the goal of CPR is to return the patient to a good functional level of life, data suggest that the evaluation of consequences after CA focuses mostly on survival

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with less emphasis given to other outcome measures. Elements of a person's QOL should be a main outcome measure in assessing the success of CPR (12), as cognitive impairment, predominantly memory dysfunction, plus fatigue, anxiety, depression and post-traumatic stress disorder have been reported as common complaints after surviving CPR (13–15). It is pertinent to note that the World Health Organization defines QOL as 'an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment' (16).

Reporting survival rates after CA does not provide any comprehensive information about the personal experience and effect of CPR on QOL. The data that are available from several studies of QOL post-CA conclude the long-term QOL of cardiac arrest survivors as being 'mostly acceptable' (17–20) and what this actually translates to for the patient is unclear. Indeed, there is a large group of CA survivors who experience ongoing problems and a reduced QOL (21).

In order to support survivors, it is important to explore this experience and to find out what factors influence QOL, as this will provide knowledge to improve our understanding and options for rehabilitation after CA. This review investigated the outcomes of a successful CPR and survivors perceived QOL in thirty-six papers, published between 2000 and 2015. The aim of this review was to examine the literature that explores the QOL for survivors after CPR and the subsequent outcomes such as cognitive impairment, anxiety, depression and PTSD and their influence on QOL.

### Background

Closed chest cardiac massage was first introduced in the literature by Kouwenhoven, Jude and Knickerbocker in 1960 (22) and with that changed the prospects of CA from certain death to a chance of survival. Although research around CPR, chain of survival and patient outcomes are numerous, the survival rate remains low and the outcome for the patient is unpredictable, spanning from almost no physical or psychological effects to a vegetative state and death. There are no known medical variables that can predict the outcome, or QOL, after CPR (23, 24).

There is a positive trend towards improved survival rates and longer lifespan (9, 11, 24). A Canadian study found the 30-day survival increased from 9.4% in 2002 to 13.6% in 2011 and the 1-year survival rate increased to 11.8% from 7.7% (11). However, CPR can

only be classed as successful if the patients survive and their QOL is satisfactory (25, 26). Life after CA survival can be affected and can severely influence survivors QOL. Cognitive impairment, anxiety, depression and PTSD following CPR can lead to increased dependency in activities of daily living (ADL), thereby decreasing QOL (18, 21, 26).

Different aspects of QOL in relation to survival after CPR have been investigated, but not in relation to each other. Thus, it is important to have an overall insight into the survivors' QOL after CPR and how this experience shapes their reality. There have been numerous efforts to develop and provide structure to the evolving field of research surrounding CA and CPR. In 1990, an informal gathering of international experts of resuscitation met at Utstein Abbey in Norway (27). The following year, the Utstein template for uniform data reporting of CPR event was officially launched (27). In 1997 and 2002, the Utstein template was reviewed and updated (28, 29) and although it is difficult to implement these international guidelines, as most of the retrieved papers did not follow the template, it is the most commonly used template for reporting outcomes of CPR. The Cerebral Performance Category (CPC) scale stems from the Utstein template and is regularly used in the reviewed papers to include or exclude participants. A CPC score of 1–2 is seen as a good outcome with independent living and high cognitive function, whereas a CPC score of 3–4 indicates cognitive impairments and limited independence, and finally, a CPC score of 5 equals brain dead.

### Aims

The aim of this review was to examine the literature that explores the QOL for survivors after CPR, and the influence of outcomes such as cognitive impairment, anxiety, depression and PTSD has had on their QOL.

### Methods

An integrative literature review method is used when the evidence base is highly heterogeneous, this review follows the integrative literature review framework of Whittemore and Knafl's (30) method, allowing the inclusion of diverse methodologies, thereby exploring a broad interpretation of theories or healthcare problems significant to nursing. Whittemore and Knafl's method includes the following five steps: problem identification, literature search, data evaluation, data analysis and presentation. This is the broadest type of review method, allowing for inclusion of a wide spectrum of research in order to evaluate the accumulated knowledge in an area of interest (30, 31). This review does not include grey literature such as web pages or policies.

### Literature search method

A sequential search of published literature from January 2000 to June 2015 was conducted and explored the reported QOL for survivors of CPR in the electronic databases EBSCO, Ovid, PubMed and EMBASE. Joanna Briggs Institute and Cochrane Library were searched with the same search strategies; however, no papers were identified.

### Search terms

The search terms used follow the PEO search strategy (Population, Exposure, Outcome) as described by Betany-Saltikov (32) to extract papers of interest. The search words were selected after a primary search in CINAHL for papers and validated by university librarian. As seen in Table 1; Surviv\*, Patient\*, Client\*, CPR, Cardiac arrest, Heart attack, 'Quality of life', QOL, 'Lived Experience', were used in all searches with some minor modifications to accommodate for different search engines.

### Inclusion criteria

To warrant an inclusion, the papers had to be peer reviewed, explore the experience from adult (+19 years)

**Table 1** Search terms and limiters

	String 1 – population	String 2 – experience	String 3 – outcome	Limiters
Boolean operators	And	And	And	Publication 2000-2015
Or	Surviv*	CPR	'Quality of life'	Peer reviewed journal
Or	Patient*	Cardiac arrest	QOL	English language
Or	Client*	Heart attack	'Lived Experience'	Adults +19
Or		Heart stop		Major heading
Or		Resuscitation		Quality of life
				Not myocardial infarction

EBSCO include: CINAHL Complete, CINAHL Plus, Health business elite, Health source: Nursing academic edition, Humanities & Social sciences.

MEDLINE: Psychology and behavioural sciences Collection, Social sciences index retrospective, SocINDEX.

OVID include: University of Newcastle Journals, Embase classic, Embase, The Joanna Briggs Institute EBP database.

Ovid MEDLINE 1946 with daily updates, Ovid MEDLINE in-process and other nonindex citation.

survivors of CPR, their QOL and be published in English language between January 2000 and June 2015.

### Exclusion criteria

Papers that explored premature, new born or children surviving CPR were excluded, as were relatives or health-care professionals' experiences of CPR, since they would not represent the adult CPR survivors' personal experience. Papers exclusively exploring survivors with implantable cardioverter-defibrillators (IDC) were not included in this literature review as they explored the implications of living with an IDC and not the experience of surviving CA or QOL in relation to the event.

The search produced two hundred and forty-seven results from the four databases searched, and illustrated in Fig. 1 is the exclusion process. The Critical Appraisal Skills Program was used to evaluate the selected papers (33). All co-authors were involved in the selection and appraisal of the twenty-eight quantitative, three systematic reviews and five qualitative reviewed papers.

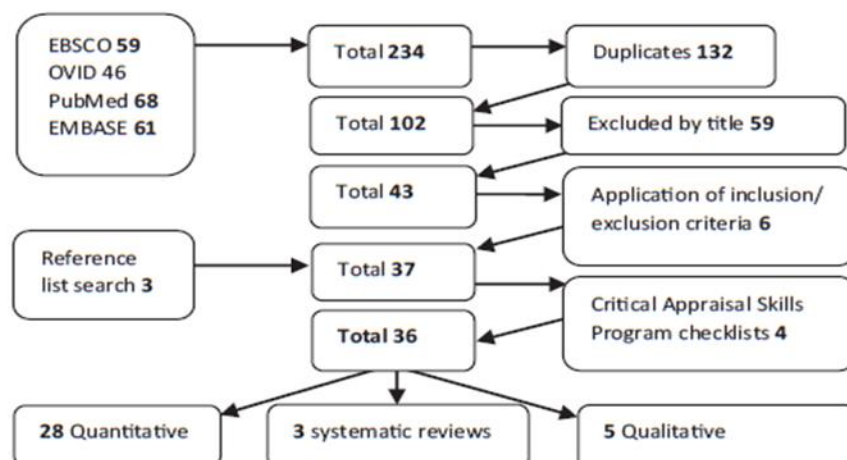
### Thematic analyse in quantitative papers

Thematic analysis is a method to identify, analyse and report themes within data (34, 35). The identification of themes was carried out in a systematic approach involving three stages: Stage one – coding text, Stage two – developing themes and Stage three – generating analytical themes.

Stages one: coding text – The original aim of this research was to explore the QOL for survivors of CPR; however, it became obvious that few studies addressed the aim directly and it seemed that a broader understanding of CPR survivors QOL was needed. Therefore, the review questions were broadened and coding started from the study findings themselves to find the overarching themes for stage two. Stage two: developing themes – involved exploring similarities and differences between the codes and grouping them into themes. In translating themes between studies, generating of analytical themes as in stage three begun. Stage three: generating analytical themes – using the themes emerging from stage two to answer the literature review questions, to examine the literature exploring the QOL for survivors after CPR and to influence the cognitive impairment, anxiety, depression and PTSD has had on their QOL.

### Findings/results

The majority of papers included in this review recorded a low-to-moderate risk of bias in study participation and study attrition. Generally, information was missing with regard to comorbidity or other factors that could influence the outcome of CPR and QOL. However, QOL, cognitive status, anxiety and depression and PTSDs of



**Figure 1** Flow chart of literature search and exclusion criteria.

survivors were measured with validated tools. The evaluation of survivors' situation after CA and subsequent CPR is convoluted, and the studies often interweave different experiences.

It is worth noting that the perception of QOL is individual and what an observer might consider is a low standard of QOL, and for the survivor, this could be viewed as an acceptable QOL.

#### *Findings in quantitative papers*

The main theme in the sourced papers relates to QOL for survivors of CPR. The overarching themes in the quantitative papers were QOL with three subthemes identified: cognitive functioning/impairment, anxiety and depression, and post-traumatic stress disorder. Papers investigating more than one theme were accordingly included under several themes. These themes are listed and evaluated under the following headings: QOL, cognitive impairment, anxiety and depression, and post-traumatic stress disorder.

#### *Quality of life*

As previously stated, QOL is a subjective term where the individuals' values, experience and environment influence the perceived QOL (16). Some papers focussed solely on the overarching concept of QOL. Although there are a vast number of different questionnaires and periods of times between CA and investigation to gather data, the findings from these papers concluded the QOL for CPR survivors are good and do not differ markedly from the general populations view of QOL (17, 34–41). When comparison groups were used, varying from normal populations (36, 40, 42–44) to intensive care unit (ICU) patients (38) or survivors of cardiac diseases (42, 45), none of the results differed markedly between survivors of CA and the various groups. Two papers

investigated the long-time survival for CPR survivors (38, 46). Both studies concluded that the long-term survivors' (>15 years) QOL were acceptable, although no paper defined what 'acceptable' or 'good' entails. A systematic review (20) including seventy papers found there is no significant evidence to propose that survivors of CPR have an intolerably QOL.

The large number of validated questionnaires, time-frame of data collection and study sample made assessment of these papers challenging. Most paper did not have a clear definition of QOL; it was not clear whether QOL was measured as a comparison as before and after CA or whether it was how the participants perceived QOL at their current situation. The overall results from these papers indicate a positive outcome for survivors in regard to QOL. However, with no clear definition of QOL, a multitude of questionnaires, varied timeframes and study samples, makes it difficult to evaluate what a positive outcome actually entails. It is obvious that clearer research guidelines are needed in this area.

#### *Cognitive impairment*

Cognitive impairment is defined as cognitive decline greater than expected for an individual's age, but that does not affect markedly with ADL (47). Numerous papers suggest that cognitive impairment is common for survivors of CPR (13, 18, 24, 37, 40, 42, 46, 48, 49) and impacts on QOL. Although all cognitive areas can be affected, memory was reported to be the most commonly and severely affected area (5, 13, 37, 42, 45, 49) followed by attention and decision-making function (42, 50). Insomnia and severe fatigue (21, 43, 49) were also frequently experienced by survivors. Research design varied in the papers exploring cognitive impairment after CPR, and there is a considerable difference in the findings exploring the prevalence of cognitive impairment after

CPR spanning from 91% (13) to 11% (25). Improvement of cognitive functioning occurred during and up to the first 3 months (13, 49), and in some studies, a large proportion of survivors exhibited normal cognitive functioning after discharge from hospital (5, 38, 41, 43, 51, 52). Conversely, this finding was not consistent and many studies found long-lasting cognitive impairment (18, 21, 42, 53, 54). These contradictory findings could be the result of methodological differences and tools used. The exclusion of survivors with a CPC score of 3–4 in four papers (13, 43, 54, 55) could enhance the results as these survivors have a severe cerebral disability or are in a vegetative state. This vast difference in results highlights the difficulty to grade cognitive impairment. Most studies have a small sample size making the findings less robust. Importantly, cognitive functioning was measured differently in the studies. This makes comparing the studies near impossible, and no clear conclusion can be drawn. Finally, confounding factors were not consistently taken into account. It is not clear how age, duration of CPR, location, co-morbidities or other factors affect the cognitive outcome. However, it is important to be aware that cognitive impairments frequently occur after CPR and should not be overlooked as it could have a high impact on survivors' QOL.

#### *Anxiety and depression*

Anxiety is defined as a strong disposition to worry about one's own personal welfare and/or welfare of significant others (54). Depression is defined as when an individual feels discouraged, sad, hopeless, unmotivated or disinterested in life in general for a period longer than 2 weeks (56). Both these symptoms were influential on QOL. Anxiety and depression were reported with similar findings, spanning from 10–11% (14, 21) to 51–52% (17, 38, 45). Anxiety and depression seem to be at the highest point, while the patient was still in hospital (14) with an increased risk for long-term distress unless measures are in place to support the survivor (57). Although recorded to be the highest in the hospital and time of discharge, it can improve with time (14). However, one paper reported high levels of anxiety after 3 years of the event (21). The paper reporting on the influence of anoxic brain injury caused by CA (15) identified increased levels of both anxiety and depression, compared to survivors without anoxia. Two papers reported that the majority of survivors of CPR did not differ in anxiety and depression from the normal population (42, 43) and a further study (52) claimed that most participants have no cognitive impairment, no depression or severe impairment in health. Sourced papers most commonly included neurologically intact survivors, with only three papers indicating the inclusion of the whole spectrum of CPC categories from 1 to 4 (14, 15, 49).

The variation in time point from 1 month (14) to 5 years (43) between CPR and survey in the papers can also influence the results as some survivors could have sought treatment for their anxiety and depression. However, all papers highlight the commonality of both anxiety and depression and the influence it has on QOL (14, 15, 21, 41, 43, 45, 51, 55). Similar to studies that measured levels of cognitive dysfunction, there was a marked variety of study methods and methodologies. The severity and influence of anxiety and depression on QOL is difficult to measure and is reflected in the sourced papers.

#### *Post-traumatic stress disorder*

PTSD can develop after a traumatic personal experience including actual or threatened death or injury and can be presented as occurrences of reliving of the event with intrusive memories, nightmares and avoidance of activities and situations reminding of the event (57). There is a possibility that the prevalence of PTSD amongst survivors of CPR could be substantial. In a study of survivors with a CPC score of 1–2, assessed within 6 months of CA, a quarter of the survivors fulfilled the criteria for PTSD (55). The systematic review included eleven papers and determined the prevalence of PTSD amongst survivors of CPR to be approximately a quarter (57). The findings confirm the commonality of psychological distress for survivors of CPR and its influence on QOL. The incidence of PTSD is also more prominent in survivors who suffered from anoxia during the event, with a tripling of PTSD sufferers compared to the nonanoxia group (15). Comparing CPR survivors with those who survived myocardial infarction (MI) also indicated tripling of the incidence of PTSD (45). Although PTSD is not the most frequently found ailment in survivors of CPR, PTSD can severely affect an individual's QOL and should not be overlooked in the assessment of CPR survivors QOL.

#### *Findings in qualitative papers*

The qualitative papers offer a different and more in-depth view of CPR survivors QOL. Five papers used an interpretive paradigm to explore QOL after CPR, with phenomenology the most commonly used qualitative methodology. All studies used appropriate methods, such as recruitment approaches, purposeful sampling, and sample size, collection, extraction, analysing of data and presentations of findings. Thematic analysis, a theoretically flexible approach to analysing qualitative data (34, 58), was used to identify the themes in the qualitative papers. Themes emerged after coding and coding of data showed comparisons with an overarching theme of QOL for survivors of CPR with the two subthemes: 'existential insecurity' followed by 'distress and vulnerability'.

### *Existential insecurity*

The sudden change in reality for these survivors has had a large impact on their QOL (59–63). The close encounter with death impacted on their perception of life and realisation of limited lifetime. This was combined with a deep gratitude to be alive and appreciation of family and friends. Often, a feeling of loneliness and estrangement was noted as well as existential insecurity exposed by feelings of vulnerability and search for meaning. There was a difficulty to adapt to a life as a cardiac patient with the limitations it imposed and survivors looked for reasons both for the CA and for their survival (59–63).

### *Distress and vulnerability*

Survivors of CPR found themselves in a new and for them unknown situation. The sudden and elusive threat of death caused fear that had to settle before life could continue. The reduction in physical and cognitive functioning caused distress and the feeling of weakness hindering full participation in activities. The memory gap around the CA often causes distress to awakening in bewilderment due to loss of coherence during the event and not knowing what had happened (59–63).

These themes highlight the complexity of surviving CPR and indicate the reality of a survivor's personified experience that is not able to be captured in quantitative research. The abrupt change in existence after surviving CPR is exposed, and the complexity in adapting to a new reality is a focal theme in the qualitative findings. This new reality encompasses every aspect of QOL (59–63). All these qualitative papers included individuals with good cognitive function, and there is a need to include individuals with cognitive impairment to broaden the knowledge of all survivors of CPR as their QOL could be markedly different.

## **Discussion**

The sourced thirty-six papers represent a broad spectrum of research evaluating the influence cognitive impairment, anxiety, depression and PTSD has on QOL for survivors of CPR. The diverse research methods and vast number of different research tools make it challenging to compare the findings. Research methods, sample size (between 7 and 644) and time between CA and questioning (while in hospital to 17 years) and more than 50 different assessment tools used to evaluate factors contributing to their QOL adds to the challenge. Often factors influencing survival and QOL, such as age, heart rhythm and different time intervals in the chain of survival, were missing in these papers. The absence of this information also adds to the complexity of finding valid assumptions for survivors of QOL. However, it is clear that cognitive

impairment, anxiety, depression and PTSD are common amongst survivors. An awareness of, and guidelines, is needed to provide optimal care to support survivors of CPR.

The majority of papers concluded that the QOL for survivors of CA and subsequent CPR is generally good (17, 36–42, 45). This finding could be due to sampling methods of participants, excluding the more severe impaired survivors, the tools used and interpretation of data. Many people with cognitive deficits are reluctant to participate in research (45), and there is a possibility that participants have modified their answers in questionnaires to adapt to the research. Papers included in this review (Tables 2 and 3) indicate a broad spectrum of results and highlight the heterogeneity in this field of research. There is no agreement on what specific measurements should be evaluated in QOL, or what assessment tools should be used. The use of evaluated questionnaires to assess survivors' experience of CPR and QOL is common in quantitative research; many of the tools are generic and used to assess QOL for many different types of illnesses. It was a challenge to find the number of survivors excluded due to cognitive impairment. This uncertainty with exclusion of severely disabled survivors makes it difficult to find a true value as it could be expected that their view of QOL would influence the findings.

Qualitative research represents a different and deeper perspective for survivors of CPR where participants are not limited by questionnaires to express their view of QOL. The complexity of emotions and feelings has been expressed, although there is no clear description of QOL and how the participants evaluate their current situation (59–63). Themes found in the qualitative research reveal the intricacy and adaptation to a new reality after CPR. In the qualitative papers, only cognitively intact individuals were interviewed, the exclusion of cognitive impaired individuals highlights the need for further qualitative research. Although a meta-synthesis of qualitative literature in this area would synthesise interpretive knowledge (64), this information could provide knowledge to improve tools used in rehabilitation and thus QOL.

To better understand the survivors' situation, a structured approach is needed and specialised tools generated for this specific population developed. Few studies permit the survivors to narrate their personal experience of CPR; their experience of survival needs to be known. This knowledge is important to support healthcare personnel to provide the optimal care in the recovery process. This could be done after in-depth qualitative research has collected data from this group of survivors to find the pertinent issues facing them. In order to improve rehabilitation time and outcomes, there is a need for clear guidelines and specific assessment tools to evaluate survivors' QOL. The Utstein template for reporting of CPR was followed in eleven (14, 23, 25, 26, 36–38, 49, 51,

**Table 2** Literature summary of Quantitative papers. Authors, Aims, Study Sample, Time after CPR, Method, Quantitative results, Conclusion

Authors	Aim	Study Sample	Time after CPR	Method	Quantitative Result Good QOL Mental Anxiety & Depression Cognitive dysfunction PTSD	Conclusion
<i>Quantitative research</i>						
<i>Retrospective cohort study</i>						
Beesems, et al. (26) Netherlands	Study QOL, neurocognitive function independence in ADL of survivors of OHCA.	N = 220 163 males	6–12 months	CPC 1-4, OPC SF-12, MRS, TICS, CSI	Good Physical QOL Good Mental QOL Anxiety & Depression Cognitive dysfunction PTSD	The majority of survivors have normal functioning and cognition after 6– 12 months after OHCA.
Deasy et al. (51) Australia	Evaluating the quality of life of young adult (18– 39) survivors of OHCA.	N = 56 40 males	Not stated	CPC1-4 SF12, EQ-5D GOS-E	Good Physical QOL Good Mental QOL Anxiety & Depression Cognitive dysfunction PTSD	The majority of survivors have good functional and QOL outcomes.
Harve et al. (39) Finland	Assessed functional status and QOL in patients 15 years after resuscitation	N = 10 8 males	15 years	WMS, WAIS, NYHA,	Good Physical QOL Good Mental QOL Anxiety & Depression Cognitive dysfunction PTSD	Once good outcome after cardiac arrest is achieved, and it can be maintained for more than 10 years.
Hofgren et al. (13) Sweden	Describe cognitive function, ADL, housing and return to work after CA.	N = 22 19 males	>2 years	BNIS FIMTM NIHSS MMSE FIMTM	Good Physical QOL Good Mental QOL Anxiety & Depression Cognitive dysfunction PTSD	The majority had persistent cognitive dysfunctions. Persons in sheltered accommodation were dependent for ADL.
Middelkamp et al. (53) Netherlands	To determine the level of ADL and QOL of patients with hypoxic brain injury after a CA	N = 16 9 males	2–7 years	ICF CFQ, FAI, PAQ IPAQ and QOLIBRI.	Good Physical QOL Median Good Mental QOL Median Anxiety & Depression Cognitive dysfunction PTSD	Long-term outcome of patients with hypoxic brain injury after a CA shows that this group is limited in cognitive and ADL, participation and QOL.

Table 2 (Continued)

Authors	Aim	Study Sample	Time after CPR	Method	Quantitative Result Good QOL Mental Anxiety & Depression Cognitive dysfunction PTSD	Conclusion
Wachelder et al. 2009 Netherlands	To study factors related to quality of life after a hypoxic period due to cardiac arrest.	N = 63 54 males	Mean 36 months	SF-36, CQ, BI, FAI, CFQ, HADS, IES FSS	Good Physical QOL Median Good Mental QOL Median Anxiety & Depression Anxiety Depression Cognitive dysfunction Median PTSD Median	QOL is related to cognitive complaints, fatigue, anxiety/depression, post-traumatic stress and difficulties in daily activities in survivors of out-of-hospital cardiac arrest. Rehabilitation programmes for this group should specifically address these topics.
Torgersen et al. (54) Norway	Estimated the incidence of cognitive dysfunctions in CA survivors with a high functional outcome treated with TH. Assess the CA group's level of cognitive performance and HRQOL	N = 26 23 males	13-28 months	CPC-1-2 SF-36 MMSE, CANTAB	Good Physical QOL Good Mental QOL Anxiety & Depression Cognitive dysfunction PTSD	Half of the patients had a cognitive dysfunction with reduced performance on executive function and episodic memory, indicating frontal and temporal lobe affection, respectively. Reduced performance did not affect QOL

Table 2 (Continued)

Authors	Aim	Study Sample	Time after CPR	Method	Quantitative Result Good QOL Mental Anxiety & Depression Cognitive dysfunction PTSD	Conclusion
Wachelder et al. (21) Netherlands	To determine the functioning of OHCA survivors 1–6 years later, to evaluate the predictive value of medical variables on long-term functioning.	N = 63 54 males	Mean 36 months	NYHA, FSS, CFQ, HADS, IES, ADL, FAI, CIQ, SF-36.	Good Physical QOL Good Mental QOL Anxiety & Depression Anxiety Depression Cognitive dysfunction PTSD	After surviving an OHCA, many patients and partners encounter extensive impairments in their level of functioning and QOL. Gender, age, PCI and therapeutic hypothermia are associated with differences in long term functioning of patients.
Retrospective case control Graf et al. (41) Germany	Investigate the costs and health status outcomes of ICU admission in patients who present after sudden CA with CPR.	N = 81 61 males	> 5 year	SF-36	Good Physical QOL Median Good Mental QOL Median Anxiety & Depression Median Cognitive dysfunction PTSD	Patients who leave the hospital following CA without severe neurological disabilities may expect a reasonable QOL compared with age- and gender-matched controls.
Granja et al. (38) Portugal	To evaluate HR-QOL of CA survivors with EQ-5D a generic instrument developed by the EuroQOL group.	N = 19 12 males Control N = 38 17 males	6 months	CPC1-4 OPC GCS, EQ-5D	Good Physical QOL QOL compared to other ICU Good Mental QOL survivors 80% vs. 60% Anxiety & Depression 33% vs. 51% Cognitive dysfunction PTSD	Survivors of CA exhibit a QOL similar to other ICU survivors. A small percentage of these survivors present extreme problems in the five dimensions corresponding to those presenting with several degrees of anoxic encephalopathy.

Table 2 (Continued)

Authors	Aim	Study Sample	Time after CPR	Method	Quantitative Result		Conclusion
					Good QOL Mental	Anxiety & Depression Cognitive dysfunction PTSD	
O'Reilly et al. (45) UK	Patients who suffered an IHCA were compared with patients who had an MI uncomplicated by CA following their event.	CA N = 27 23 males MI N = 27 25 males	10 months	IES, PTSD, HADS, SCID	Good Physical QOL Good Mental QOL Anxiety & Depression Anxiety Depression Cognitive dysfunction PTSD	– – 41 % 30 % – 19 %	The significant minority of CA patients warranting diagnoses of PTSD has implications for their management and rehabilitation. Identification of these patients is an important step towards improving their overall health outcomes.
Prospective Cohort study							
Andersson et al. (46) Sweden	To describe survival and causes of death after CA and the life situation of very long term survivors.	N = 8 8 males	17 years	MMSE, MoCA, EQ-5D, HADS, PCLC, SCQ, BI	QOL MMSE >26 MMSE <25 Anxiety & Depression Cognitive dysfunction PTSD	96 (70–100) 47 (40–100) – 50 % 0 %	Primary finding 17 years after CA, the incidence had a permanent effect on cognitive abilities. Secondly, the majority of study population was content with their situation and QOL even though there were clear cognitive disabilities. Patients with cognitive problems due to OHCA experience lower levels of participation/autonomy and decreased quality of life.
Boyce-van der Wal et al. (47) the Netherlands	To estimate prevalence of cognitive problems due to hypoxic brain injury in OHCA survivors	N = 77 63 Males	4 weeks	MMSE, HADS, CFQ, SF-36,	Good Physical QOL Good Mental QOL Anxiety & Depression Cognitive dysfunction PTSD	58 % 54 % 15 % 23 % –	

Table 2 (Continued)

<i>Authors</i>	<i>Aim</i>	<i>Study Sample</i>	<i>Time after CPR</i>	<i>Method</i>	<i>Quantitative Result</i> Good QOL Mental Anxiety & Depression Cognitive dysfunction PTSD	<i>Conclusion</i>
Bro-Jeppesen et al. (36) Denmark	Assess the impact of TH on cognitive function and QOL in comatose survivors of OHCA.	N = 21 TH N = 24 no TH	6 months	CPC1-4 MMSE SF-36	Good Physical QOL Good Mental QOL Anxiety & Depression Cognitive dysfunction PTSD	CPC at discharge from hospital was improved following implementation of TH in comatose patients after CPR. Improvement in survival, cognitive status or QOL was not detected at long-term follow up. Cognitive impairment four years after cardiac arrest affected more than one-quarter of the patients. Short-term memory was predominantly affected Mild cognitive impairment is common following hypothermia-treated cardiac arrest but has little effect on activities of daily living or quality of life. The prevalence of PTSD in cardiac arrest survivors is high.
Buanes et al. (37) Norway	To investigate cognitive impairment and QOL in CA survivors with good neurologic outcome four years after CA.	N = 30 24 males	4 years	CPC1-2 HADS, EQ-5D-5L, CANTAB DMS, SOC, IED,	Good Physical QOL Good Mental QOL Anxiety & Depression Cognitive dysfunction PTSD	71% 71% 17% 29% –
Cronberg et al. (49) Sweden	To analyse the neurological status of survivors after CA treated with hypothermia.	N = 43 34 males	6 months	CPC1-4 GDS, FAB, RBMT, NCSE, AMPS, FLAB, EQ-VAS, HADS, SRMADRS, GDS, RBMT	Good Physical QOL Good Mental QOL Anxiety & Depression Cognitive dysfunction PTSD	– – 14% 37% –
Gamper et al. (55) Austria	The prevalence of PTSD in long-term survivors of CA; Role of specific stress factors related to CA for the development of PTSD	N = 143 96 males	Mean 45 months	CPC1-2, DTS, EQ-5D	Good Physical QOL Good Mental QOL Anxiety & Depression Cognitive dysfunction PTSD	– – 30% – 27%
Lim et al. (42) USA Canada	Investigate survivors of OHCA, in coma between 12 h and 7 days, their longer-term recovery and QOL	N = 25 21 males Control	3 and 12 months	SIP68, FAI,	Good Physical QOL Good Mental QOL Anxiety & Depression Cognitive dysfunction PTSD	50% 38% 15% 65% – These survivors of OHCA had persistent long term cognitive deficits. QOL one year after OHCA was reduced compared to cardiac controls.

Table 2 (Continued)

Authors	Aim	Study Sample	Time after CPR	Method	Quantitative Result Good QOL Mental Anxiety & Depression Cognitive dysfunction PTSD	Conclusion
Nichol et al. (52) Canada USA	To evaluate survivors of OHCA cognition, functional status, health-related QOL and depression	N = 644 563 males	<6 months	MRS, ALF-IMMSE HUI3, T-GDS	Good Physical QOL Good Mental QOL Anxiety & Depression Cognitive dysfunction PTSD	The majority of survivors of CA had a satisfactory neurologic function, no cognitive impairment, no or mild impairment in health and no depression.
Smith et al. (44) Australia	To describe the quality of life of OHCA survivors at 1-year postarrest	N = 687 537 Males	12 months	GOS-E, SF-12, EQ-5D	Good Physical QOL Good Mental QOL Anxiety & Depression Cognitive dysfunction PTSD	Most patients retain their independence after CA. The majority of patients were discharged from the hospital to their home. Female gender and older age were associated with impaired physical functioning. This study demonstrated that the final outcome of OHCA in terms of QOL and cognitive functioning is acceptable in general.
van Alem et al. (25) Netherlands	Evaluate the impact of the time-related elements of the 'chain of survival' on the QOL of patients.	N = 174 142 males	6 months	CPC1-2 OPC SIP MMSE	Good Physical QOL Good Mental QOL Anxiety & Depression Cognitive dysfunction PTSD	CA survivors are satisfied with life as a whole despite their severe illness that has impaired their physical and cognitive function. Cognitive function seemed to improve over time.
Wallin et al. (23) Sweden	To describe outcome, physical and cognitive function for survivors of CA treated with TH, examine life satisfaction 6 months after CA.	N = 45 29 males	1 months 6 months	CPC1-4, BI, MMSE	Good Physical QOL Good Mental QOL Anxiety & Depression Cognitive dysfunction PTSD	
Prospective observational study						

Table 2 (Continued)

Authors	Aim	Study Sample	Time after CPR	Method	Quantitative Result Good QOL Mental Anxiety & Depression Cognitive dysfunction PTSD	Conclusion
Larsson et al. (14) Sweden	Any changes in, and correlations between anxiety, depression and QOL over time, between hospital discharge and one and six months after CA, in patients treated with TH.	N = 26 15 males	1 month And 6 months	CPC1-3 HADS EQSD EQ-VAS SF12	Good Physical QOL Median Good Mental QOL Median Anxiety & Depression Cognitive dysfunction PTSD	QOL improves over the first 6 months after a CA. Patients reported lower levels of QOL on the physical as compared to mental component. The results indicate that less anxiety and depression the patients perceive, the better QOL they have.
Prospectively data collection Horsted et al. (40) Denmark	To report survival beyond 6 months, including QOL, for patients after OHCA with a physician-based EMS in an urban area.	N = 33 7male	>6 months	SF-36, MMSE	Good Physical QOL Good Mental QOL Anxiety & Depression Cognitive dysfunction PTSD	Summary scores of quality of life were not significantly different from the national norm. Signs of dementia were uncommon as only 6% had an MMSE score below 24.
Observational study Bunch et al. (5) Minnesota, USA	To determine if long-term memory complaints persist in OHCA survivors resuscitated compared to a healthy control population.	N = 50 43 male	1.9-7.9 years	SF36	Good Physical QOL Median Good Mental QOL Median Anxiety & Depression Cognitive dysfunction PTSD	The physical and emotional QOL scores were decreased compared to the younger group.
Longitudinal cohort study Lundgren-Nilsson et al. (18) Sweden	To assess cognitive function, ADL and living situation longitudinally up to 1 year after CA	N = 26 7male	>12 months	MMSE, FIM and IAM. Hr-QOL, NHP.	Good Physical QOL Good Mental QOL Anxiety & Depression Cognitive dysfunction PTSD	Most of the improvement resulting in the independence of ADL occurred during the first 45 days.
Matched control study						

Table 2 (Continued)

Authors	Aim	Study Sample	Time after CPR	Method	Quantitative Result Good QOL Mental Anxiety & Depression Cognitive dysfunction PTSD	Conclusion
Saner et al. (43) Switzerland	The QOL in long-term survivors of OHCA may be a good outcome measure after CPR, the psychosocial situation and QOL in patients after successful CPR was evaluated.	N = 50 40 males	5-68 months	S-A Test, PGWBI, NHPQ, ELQ	Good Physical QOL Good Mental QOL Anxiety & Depression Anxiety Depression Cognitive dysfunction PTSD	QOL was associated with few changes in psychosocial profile after successful CPR. The subjective negative factors bore little impact on the QOL. Continued efforts to improve OHCA resuscitation are justified since long-term survivors can expect a good QOL after successful resuscitation.
Exploratory study case control Wilson et al. (15) United Kingdom	To investigate psychosocial outcomes for CA survivors and explore if there is a greater impact on psychosocial outcome for individuals experiencing anoxic brain injury compared to no anoxia.	N = 27 with anoxia N = 29 no anoxia	6-48 months	QOLS, SFQ, EMQ-R, HADS-D, HADS-A, DEX-S, DEX-I, IES-R	Good Physical QOL Good Mental QOL Anxiety & Depression Anxiety Depression Cognitive dysfunction PTSD	To compare psychosocial outcomes for CA survivors experiencing anoxic brain injury with those without anoxia, the current results suggest that CA survivors with subsequent acquired brain injury experience more psychosocial difficulties. This could be due to a combination of neuropsychological, social and psychological factors.

Table 2 (Continued)

<i>Authors</i>	<i>Aim</i>	<i>Study Sample</i>	<i>Time after CPR</i>	<i>Method</i>	<i>Quantitative Result</i> <i>Good QOL Mental</i> <i>Anxiety &amp; Depression</i> <i>Cognitive dysfunction</i> <i>PTSD</i>	<i>Conclusion</i>
Systematic review Elliott, Rodgers & Brett 2011 UK – US		N = 70 Study population 10–550	0–15 years	>30 assessment tools	Survivors have an acceptable or good QOL after CA Good Physical QOL Good Mental QOL Anxiety & Depression Cognitive dysfunction PTSD	The majority of studies concluded that QOL after CA is good. This review demonstrated a remarkable heterogeneity of methodology amongst studies assessing QOL in CA survivors. There is a requirement for consensus development with regard to QOL and patient centred outcome There are few good studies on the frequency of cognitive impairments after OHCA. However, cognitive problems, in particular memory problems, seem common in survivors of OHCA.
Moulaert et al. (50) The Netherlands –UK		N = 28 Study population 10–308	7–98 months	Not specified	Good Physical QOL Good Mental QOL ADL Anxiety & Depression Cognitive dysfunction. PTSD— 42–50%	

Table 2 (Continued)

Authors	Aim	Study Sample	Time after CPR	Method	Quantitative Result Good QOL Mental Anxiety & Depression Cognitive dysfunction PTSD	Conclusion
Wilders Schaaf et al. (56) US		N = 11 Study population 21–168	3 weeks – 72 months	HADS, IES, CESDS, DTS, SRMADRS, BDI, PTSDS, PMS.	Good Physical QOL Good Mental QOL Anxiety & Depression anxiety rates ranged from 13% to 61% depression ranged from 14% to 45%; Cognitive dysfunction PTSD	Given the occurrence rate of psychological distress after OHCA, psychological screening and early intervention seems indicated in the CA population. Further studies are needed to better establish occurrence rates in both inpatient and outpatient settings, determine appropriate measures and normative cut off scores, and decide on the most appropriate method of intervention.

ADL, Activities of daily living; ALFIMMSE, Adult Lifestyle and Function Mini Mental Status Exam; AMPS, Assessment of Motor and Process Skills; BI, Barthel index = Basic activities of daily living; BNIS, Barrow Neurological Screen for Higher Cerebral Function; CA, Cardiac arrest; CANTAB, Cambridge Neuropsychological Test Automated Battery; CFQ, Cognitive Failures Questionnaire Cognitive complaints; CIQ Community Integration Question Participation in society; CPC, Cerebral Performance Category; CPR, Cardiopulmonary resuscitation; DEX-I, Dys-executive Questionnaire independent rate; DEX-S, Dys-executive Questionnaire self-rate; DMS, Delayed Matching to Sample; DTS, Davidson Trauma Score; ELQ, Everyday-Life Questionnaire; EMQ-R, Everyday Memory Questionnaire-Revised; EQ-5D, Generic Instrument developed by the EuroQol group; EQ-VAS, EuroQol Visual Analogue Scale; EQ-5D-5L, EuroQol group; FAB, Frontal Assessment Battery; FAI, Frenchay Activities Index Instrumental; FIM, Functional Independence Measure; FSS, Fatigue Severity Scale; GCS, Glasgow Coma Scale; GDS, Global Deterioration Scale; GOS-E, Glasgow Outcome Scale-Extended; HADS, Hospital Anxiety and Depression Scale Emotional problems; HADS-A, Hospital Anxiety and Depression-anxiety; HADS-D, Hospital Anxiety and Depression-depression; HUI3, Health Utilities Index Mark III System; IAM, Instrumental Activity Measure; ICF, International Classification of Functioning, Disability, Health; ICU, Intensive care unit; IED, Intra-ventricular set shift executive function, attention and flexibility; IES, Impact of Event Scale Post-traumatic stress; IES-R, Impact of Event Scale-Revised Post-traumatic stress symptoms; IPAQ, Impact on Participation and Autonomy Questionnaire; MADRS-S, Self-reported Montgomery - Åstrand Depression Rating Scale; MMSE, Mini-Mental Status Exam; MoCA, Montreal Cognitive Assessment; MRS, Modified Rankin Scale; NCSE, Neurobehavioral Cognitive Status Examination; NHP, Nottingham Health Profile; NIHSS, National Institute of Health Stroke Scale; NYHA, New York Heart Association Classification basic functioning; OHCA, Out-of-hospital cardiac arrest; OPC, Organ Performance Categories; PAL, Paired Associates Learning; PCLC, PTSD Checklist-Civilian version; PGWB, Psychological General Well-being Index; PTSDS, Post-traumatic Diagnostic Scale; PTSD, Post-traumatic stress disorder; QOL, Quality of life; QOLBRI, Quality of Life after Brain Injury; QOLS, Quality of Life Scale; RMBT, Rivermead Behavioural Memory Test; S-A Test, Self-Assessment Test psychosocial-before and after OHCA; SCID, structured clinical interview; SCQ, Stockings of Cambridge executive function; SF-12, Medical Outcome Survey Short Form-12 questionnaire; SF-36, Medical Outcome Survey Short Form-36 questionnaire; SFQ, Social Functioning Questionnaire Social functioning; SIP, Sickness Impact Profile; SIP68, Sickness Impact Profile short form; SSI, Skane Sleep Index; T-GDS, Geriatric Depression Scale administered by telephone; TH, Therapeutic hypothermia; TICS, Telephonic interview for cognitive status; WAIS, Wechsler Adult Intelligence Scale; WMS, Wechsler Memory Scale; ?, no gender information.

**Table 3** Literature summary of Qualitative papers. Authors, Aims, Study Sample, Time after CPR, Method, Conclusion

<i>Qualitative research</i>					
Phenomenology					
Bremer, Dahlberg & Sandman. 2009 Sweden	Describe patients' experiences of surviving OHCA.	N = 9 8 males	6 months to 15 years.	Semi structured qualitative interviews.	OHCA is a life-changing event of great importance for survivors' quality of life. The meaning of life was found to a varied extent, from a meaningful life to one largely described without any meaning. There were 2 themes, returning to life and missing the life, and five subthemes, waking up and missing the whole picture, realizing it was not time to die, wondering why and seeking explanations, feeling ambiguous in relations, and wondering whether life will be the same. These survivors had memory loss, they searched for a reason why they experienced a CA and had gone from being 'heart-healthy' to having a lifelong illness. They all had the experience of passing from life to death and back to life again. For the participants, these differences led to a revaluation of what is important in life.
Forslund, Zingmark, Jansson, Lundblad & Soderberg. 2013 Sweden	To elucidate meanings of people's lived experience of surviving OHCA with validated myocardial infarction aetiology one month after the event	N = 11 9 males	1 month	Semi structured Interview	Participants' experience is reflected in 5 themes; feelings of insecurity and the need for support; striving to regain former life; emotional challenges; responding to symptoms; and a new view on life. The findings illustrate complex effects of the CA on the survivor's life. Support after hospital discharge needs to be organized in a more structured fashion. The need for security and support was fundamental and should be addressed with continuity and vigilance in health care.
Ketilsdottir, Albertsdottir, Akadottir, Gunnarsdottir & Jonsdottir. 2013 Iceland	Describe survivors' experiences following CA and CPR in order to gain knowledge of the effect of this experience on the needs and concerns of the survivors.	N = 7 7 males	9 - 24 months	Sample was purposive, data were generated through two semi-structured interviews.	Four essential themes were found: 'facing fear', 'the search for meaning', 'feeling death up close and personal', and 'loneliness and estrangement'. Nurses must integrate the lifestyle changes of patients who survive a CA in order to provide adequate care following hospital discharge. As a result, the creation of interdisciplinary support groups and the implementation of follow-up programmes after hospital discharge are fundamental. Survivors' experiences can inform the development of nursing programs and hospital follow-up services that address the survival of CPR.
Palacios-Ceña, Losa-Iglesias, Salvadores-Fuentes & Fernández-de-las-Peñas. 2011 Spain	To investigate the life experiences of Spanish patients who were successfully resuscitated following SCD in order to improve the management of these patients.	N = 9 5 males	Not stated	Purposive sampling. Unstructured interviews were carried out.	

Table 3 (Continued)

Qualitative research					
Qualitative description	Lau, Kirkpatrick, Merchant, Perman, Abella, Galeski, Becker, Chalmers & Reitsma. 2010 USA	Semi-structured telephone interviews between (20 and 60 min). Participants were recruited from a nonprofit national organization for CA.	N = 9 7 males	Not stated	Questions Immediate postarrest phase
					In the immediate postarrest phase, subjects believed that medical professionals made errors in giving poor prognosis early in the course of resuscitation. While some subjects felt they had experienced 'death', some subjects felt the term 'death' was an inappropriate term to describe their experience. The study elucidated the attitudes and experiences of CA survivors. Variability in prognostication timing and inconsistency in describing CA can complicate discussions between the medical team and families.

54, 55) of the twenty-eight papers. Although it is an internationally recognised template to simplify the collection and sharing of data, the majority of papers did not follow it. This is an indication of the difficulty linking research in CPR and survivors QOL amongst researcher.

There is a need to standardise patient-centred outcome measures after resuscitation. Although validated assessment tools are used to assess QOL, symptoms associated with anxiety, depression, and PTSD, the variety of tools used and time span need to be standardised. Psychological screening to assess possible symptoms and provide early intervention for these individuals could enhance their situation as a well-functioning body after surviving CPR is not the only contributor to QOL.

The population of survivors with cognitive impairment are often overlooked and offer a specific challenge. Screening instruments that are sensitive to the individuals' cognitive impairment needs to be developed to include them in development of standardised tools. Future research for this group is needed as well as for all survivors of CPR.

### Limitations

There are several limitations to these findings. While validated questionnaires were used in the sourced papers, the authors noted the limitation that participants could potentially enhance their perception of reality to reflect what they thought the investigators would prefer to hear (39). Participants who are less healthy might also indicate a 'healthier' value or choose not to participate. As QOL can be defined and expressed in many ways, there is a possibility that papers exploring the survivors experience and QOL have used different key words and these have not been identified in the databases. Almost exclusively the sourced material reports on the QOL of survivors with a CPC score of 1 or 2. The exclusion of the population who had a less favourable outcome of CPR might well influence the results to a more positive outcome of survivors' QOL. The elimination of papers written in other languages than English might limit the range of observations, and finally, the heterogeneity in found literature and their findings makes comparability between the findings difficult.

### Conclusion

Globally predicted survival rates after CPR have not increased above 14%, and patient outcome remains unpredictable. Although survival rate from CA and subsequent CPR remains low, there is an increase in survival rates and those who are discharged from hospital have a longer life expectancy. With this positive trend, QOL for survivors becomes a vital indicator of successful CPR.

Often papers in this review did not include a definition of QOL or what 'good' or 'acceptable' meant in relation to reported findings. The variables in quantitative research such as time after CA, sample population, questionnaires used, cognitive functioning, age and co-morbidities also add to the difficulty to come to solid conclusion for this populations QOL after surviving CPR. The small number of qualitative papers in this area indicates there are a number of concerns that need further exploration. A meta-synthesis of qualitative literature could explore what is known in the interpretive paradigm of survivors QOL and experience after CPR and thus indicate where further research is needed. CA and CPR is a life-changing event, and to be resuscitated is a return from imminent death. The mental implications of CPR warrant research tools that are specifically created for survivors of CPR.

The sourced papers in this review almost exclusively consider patients with limited or no ill effects of CPR, and it could be expected that the exclusion of survivors with moderate-to-severe disabilities would have an impact on reported findings. The majority of papers included in this integrated literature review reported an acceptable QOL if the patient survived to hospital discharge, even though there is no clear evidence as to how quality of life has been defined in these papers. This review highlights the complexity of research into people's experience of QOL. International guidelines need to be developed to guide future

quantitative research, and qualitative research is needed to develop specific research tools for this group of survivors.

It has to be remembered that without CPR death would be the outcome; however, with a low rate of success and a very limited or nonexistent research on individuals with a CPC score of 3-4, there is still much research to be done.

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## Author contribution

GH performed data collection and analysis and drafting of manuscript. PvdR performed data collection and analysis, supervision and critical revisions. JM performed data collection and analysis, supervision and critical revisions.

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## QUALITATIVE LITERATURE

*The findings from the integrative review created a sense of wonder and a search for more knowledge about the survivor's embodied experience. I did a second systematic search in databases with a focus on qualitative literature and found seven articles that fit the inclusion criteria. My aim was to critically appraise and synthesise the qualitative literature on survivors' experiences of a cardiac arrest and cardiopulmonary resuscitation and identify common themes that could inform clinical pathways and improve survivor quality of life.*

~ ~ ~

**PUBLICATION: A SYSTEMATIC REVIEW AND META-SYNTHESIS OF THE QUALITATIVE LITERATURE EXPLORING THE EXPERIENCES AND QUALITY OF LIFE OF SURVIVORS OF**

**The impact of the article**

At the time of thesis submission 'A systematic review and meta-synthesis of the qualitative literature exploring the experiences and quality of life of survivors of a cardiac arrest' had 15 citations Scopus and 39 in Google Scholar. The article has a Field Weighted Citation Impact of 1.53, and a Prominence percentile: 81

In ResearchGate this article has 1171 reads and 21 citations

**Author contribution see appendix 4.**

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# A systematic review and meta-synthesis of the qualitative literature exploring the experiences and quality of life of survivors of a cardiac arrest

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## Abstract

**Background:** Survival following cardiac arrest and subsequent cardiopulmonary resuscitation (CPR) is increasing worldwide, mainly due to greater awareness of the symptoms of cardiac events and an increased attention to CPR training. Although patient outcomes remain unpredictable and quantitative studies suggest that the overall quality of life (QOL) is acceptable, it is valuable to synthesise qualitative studies exploring these phenomena in depth, providing a deeper knowledge of survivors' experiences and QOL.

**Aims:** To critically appraise and synthesise the qualitative literature on survivors' experiences of a cardiac arrest and CPR with the aim of identifying common themes that can inform clinical pathways and thereby improve survivor outcomes and QOL.

**Methods:** A systematic review and meta-synthesis of the qualitative literature, using Thomas and Harden's framework, and confined to peer-reviewed papers published from 2000 to 2015, which were identified through database searches of EBSCO, OVID and ProQuest.

**Results:** The search produced 204 papers, and of these, seven relevant papers were identified for review. Data extraction included setting, participants, research design, data collection, analysis and themes. Five qualitative themes were identified and were the subject of this meta-synthesis: multitude of contrasting feelings; disruption in the continuum of time; new reality and psychological challenges; changed body with new limitations; and confrontation with death.

**Conclusion:** This review provides insights into the experiences of survivors' QOL after CPR. Increased knowledge can improve person-centred care in the immediate and forthcoming care after the event, both in terms of planning for discharge and in the future care of people who survive a cardiac arrest.

## Keywords

Cardiac arrest, cardiopulmonary resuscitation, systematic review, meta-synthesis, quality of life, patient experience

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## Introduction

Cardiac arrest (CA) is a leading cause of death worldwide and the survival rate remains low, even 55 years after the introduction of cardiopulmonary resuscitation (CPR), and currently there are no medical interventions or prognostic indicators that can predict outcomes.<sup>1,2</sup> Although the survival rate after a CA is low, research indicates an increase in numbers and longer lifespans for survivors.<sup>3-5</sup> These positive trends signal a need to explore CA survivors' experiences; not only in terms of survival, but also in terms of quality of life (QOL) as a measure of successful resuscitation. The clinical pathways that are used to guide

evidenced-based healthcare following CA focus primarily on control of biological factors in order to minimise injury, thereby improving the likelihood of a satisfactory neurological outcome.<sup>6-8</sup> Although these are important factors

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**Table 1.** Search terms and limiters.

	String 1 – population	String 2 – experience	String 3 – outcome or themes	String 4	Limiters
Boolean operator	And	And	And	And	Publication 2000–2015
Or	patient*	cardiac arrest	'quality of life'	'qualitative research'	peer-reviewed journal
Or	client*	heart stop	QOL	phenomenology	English language
Or	surviv*	CPR	experience	ethnography	adults +19
Or		cardiopulmonary resuscitation		'grounded theory'	major heading Quality of life
Or		'sudden cardiac death'		narrative*	not 'myocardial infarction'
Or				'thematic analyz*	

for recovery after CA, there is a paucity of guidance supporting the survivor's psychological recovery.

The concept of QOL is challenging to define; Kuyken<sup>9</sup> defined it as 'individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.' The opinion on QOL is personal, and what an observer might consider a dismal level of QOL might be considered to be acceptable by the individual.

A substantial amount of quantitative research has been published investigating the QOL of survivors, frequently using standardised questionnaires.<sup>10–14</sup> These questionnaires, although validated, provide a limited opportunity for survivors to express their views.

This systematic review and meta-synthesis aims to critically appraise and synthesise the qualitative literature on survivors' experiences of a CA in order to identify common themes that can inform clinical pathways and thereby improve survivors' QOL.

## Methods

### Study design

A synthesis of the qualitative literature can produce new insights that would not be visible with individual studies alone,<sup>15,16</sup> thus supporting decision-making, as it can enable a more comprehensive understanding and clarification of phenomena.<sup>15</sup> This review will evaluate and interpret findings in published qualitative studies focusing on the experiences and QOL of survivors of CA. The thematic synthesis as described by Bondas and Hall<sup>17</sup> and Thomas and Harden<sup>16</sup> has been used in the identification of relevant literature for inclusion, critical appraisal, data extraction, analysis and synthesis of findings.

### Data collection

A systematic search for relevant qualitative literature published between 2000 and 2015 was undertaken between March and December 2015 in the electronic databases EBSCO, OVID and ProQuest. Table 1 displays the keywords, MeSH terms and limiters used.

### Criteria for inclusion and exclusion

In order to be included, papers had to, as a quality assurance, be peer reviewed, published in the English language between January 2000 and June 2015, use a qualitative research design and explore QOL and experiences reported from adult survivors of CA.

Exclusion criteria included: papers not written in English; quantitative methodology papers; or qualitative papers that explored healthcare professionals', significant others', children's or teenagers' experiences of the event. Papers exclusively exploring survivors of CA with an implantable cardioverter-defibrillator (ICD) were excluded, as these papers focused on the experience of living with an ICD and not how surviving a CA influences QOL.

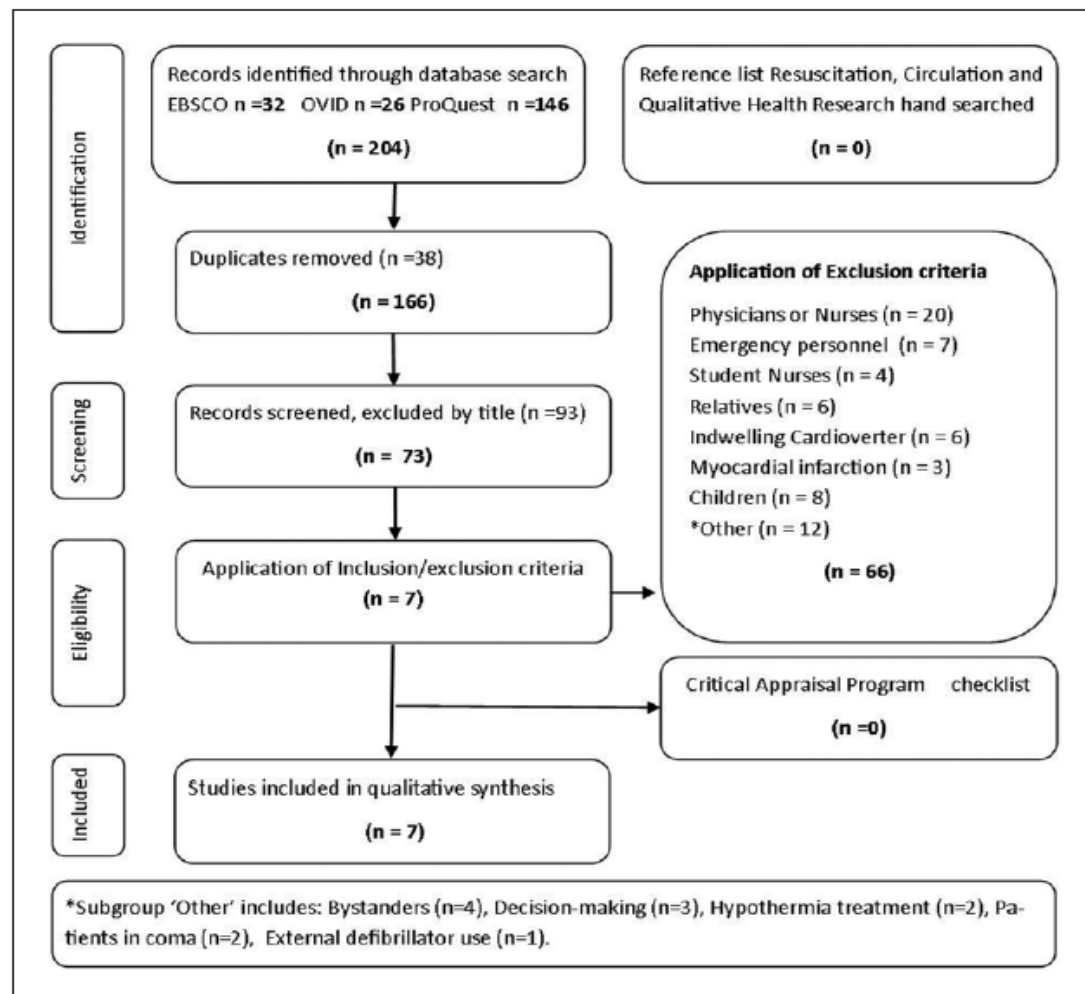
The search found 204 papers from the three databases searched; illustrated in Figure 1 is the exclusion process.

### Quality appraisal

The Critical Appraisal Skills Programme (CASP, <http://www.casp-uk.net/>) was used in order to appraise the seven papers that were included in the analysis, consisting of 10 questions relating to rigour and relevance. Based on methodology and rigour, none of the selected papers were excluded. The papers used appropriate methods for sampling, recruitment, sample size, data collection, extraction, analysis and presentation of findings. The included papers used purposeful sampling, but none included any information about comorbidities or other factors that could potentially influence the survivors' views of their QOL. Only survivors with good cognitive and physiological outcomes were included. The studies were conducted in countries with access to high-quality medical care and predominately western culture.

### Meta-synthesis

A thematic synthesis was used to explore relationships, connections and dissimilarities between the studies, developing an enriched understanding.<sup>15,16</sup> Thomas and



**Figure 1.** Flowchart describing the search and exclusion process following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) model.<sup>36</sup>

Harden's<sup>16</sup> approach was used in a three-stage process: firstly, free line coding in the texts, highlighting the survivors' quotes and naming them; secondly, identifying the descriptive themes by grouping the quotes and adding themes until all quotes were included, using a tree structure; and thirdly, the emergence and identification of descriptive analytical headings from tree structures – these were named and the findings were synthesised under these headings. Consensus was achieved through ongoing discussions among the authors in order to ensure that the themes were supported by the original data.

### Rigour

Rigour was achieved firstly through quality appraisal of the selected papers using the standardised Critical Appraisal Skills Programme (CASP) checklist. Secondly, Sandelowski's (1986) criteria for the credibility and

applicability of the content were checked for representativeness, triangulation across data sources and congruence of findings, adherence to the research question<sup>18</sup> and independent review by the researchers. These findings were individually and then collectively discussed. The results were documented in an audit trail and final decisions were made through discussions and reconciliation of any differences and divergences among the authors.

### Results

Seven papers met the criteria for inclusion. An outline of the aims, populations, times between CA and interview, methods, limitations and conclusions/themes is presented in Table 2.

Derived from the final stage of Thomas and Harden's<sup>16</sup> approach were five themes: multitude of contrasting feelings; disruption in the continuum of time; new reality and

**Table 2.** Summary of included qualitative papers with themes and conclusions as stated on the experiences and quality of life of adult survivors of cardiopulmonary resuscitation.

Study, year, location	Aim	Participants	Time between CA and interview	Method	Limitations	Themes and conclusion
<b>Phenomenology</b> Forslund et al., 2013, Sweden	To elucidate meanings of people's lived experience of surviving an out-of-hospital CA	n = 11 9 male Age 49–73 years	1 month	Purposive sampling Semi-structured interview	Small number of mostly male survivors Excluded survivors younger than 25 and older than 75 years of age	Two themes: • Returning to life • Revaluing life Five sub-themes: • Waking up and missing the whole picture • Realising it was not time to die • Wondering why and seeking explanations • Feeling ambiguous in relations • Wondering whether life will be the same These survivors reported memory loss and searching for a reason why they experienced a CA and had gone from being 'heart-healthy' to having a lifelong illness. They all reported the experience of passing from life to death and back to life again, which led to a revaluation of what is important in life
Kerttinen et al., 2013, Iceland	Describe survivors' experiences following CA to gain knowledge on the effect of this experience on the needs and concerns of survivors	n = 7 7 male Age 50–54 years	9–24 months	Purposive sampling Two semi-structured interviews	Small number of male survivors, similar in terms of age	Five themes: • Feelings of insecurity and the need for support • Striving to regain former life • Emotional challenges • Responding to symptoms • A new view on life The findings illustrate complex effects of the CA on the survivors' lives. Support after hospital discharge was reported as needing to be better organised in a more structured fashion. The need for security and support was reported as fundamental and needed to be addressed with continuity and vigilance in health care.
Palacios-Ceña et al., 2011, Spain	To investigate experiences of Spanish survivors who were successfully resuscitated following CA	n = 9 5 male Age range not stated	Not stated	Purposive sampling Unstructured interviews	Small number of survivors	Four themes: • Facing fear • The search for meaning • Feeling death up close and personal • Loneliness and estrangement The creation of interdisciplinary support groups and the implementation of follow-up programmes are suggested as fundamental and that nurses should incorporate lifestyle changes for survivors of a CA in order to provide suitable care following hospital discharge. Survivors' experiences can inform the development of these nursing programmes and follow-up services
Bremer et al., 2009, Sweden	To describe survivors' experiences of surviving an out-of-hospital CA	n = 9 8 male Age 44–70 years	6 months to 15 years	Purposive sampling Semi-structured interview	Small number of mostly men, long time between CA and interview	Seven themes: • Sudden and elusive threat • Awakening in perplexity • The memory gap: a loss of coherence and searching for coherence • Distressing and joyful understanding • Existential insecurity exposed by feelings of vulnerability • Well-being through coherence and meaning in life CA was reported as a life-changing event of great importance for survivors' QOL. The meaning of life varied from being reported as a meaningful life to one largely described without any meaning

(Continued)

Table 2. (Continued)

Study, year, location	Aim	Participants	Time between CA and interview	Method	Limitations	Themes and conclusion
<b>Interpretive description</b>						
Uren and Galdas, 2015, Canada	Explore how masculinities shape the experiences of survival of a CA	n = 7 7 male Age 29–81 years	<24 months	Purposive sampling Semi-structured interview	Small number of survivors	<p>Three themes:</p> <ul style="list-style-type: none"> <li>• Support and self-reliance</li> <li>• Dealing with emotional (in) vulnerability</li> <li>• No longer a 'He-man'</li> </ul> <p>Masculinity was reported to play a role in men's experiences of recovery and adaptation following CA. Hegemonic masculinity partly explained men's experiences, notably their reluctance to seek professional support and reactions to changes in lifestyle. The findings suggest that nurses would benefit from taking into consideration the potential influence of male gender identities on men's recovery after CA.</p>
Forslund et al., 2013, Sweden	To describe risk factors, lifestyle choices and survivors of an out-of-hospital CA	n = 13 10 male Age 43–75 years	CA between 1989 and 2007	Purposive sampling Semi-structured interview	Small number of mostly male survivors, excluded survivors over the age of 75 years	<p>Three themes:</p> <ul style="list-style-type: none"> <li>• Significance of lifestyle</li> <li>• Modifying the lifestyle to the new life situation</li> <li>• A changed view on life</li> </ul> <p>Seven sub themes:</p> <ul style="list-style-type: none"> <li>• Finding joy and strength in meaningful relationships</li> <li>• Feeling well and doing things of their choice</li> <li>• Finding a reason as to why it happened and making lifestyle changes</li> <li>• Making your own assessment of a risk behaviour</li> <li>• Feeling grateful for a second chance at life</li> <li>• Finding motivation for lifestyle changes and wishing to influence family members to adopt lifestyle changes</li> <li>• Challenging one's fears and adopting a positive outlook on life</li> </ul> <p>A supporting family, feeling happy and having fun were emphasised by survivors. Although survivors were well informed about cardiovascular risk factors, some decided to ignore this knowledge and choose a 'good life', in which risk factor treatment played a minor part. To incorporate a healthy lifestyle linked to meaningful and joyful things in life would improve participation in risk factor treatment.</p>
Lau et al., 2010, USA	To understand CA survivors' issues arising immediately post-CA and the survivors' definitions of death	n = 9 7 male Age range not stated	Not stated	Purposive sampling Semi-structured phone interview	Small number of subjects, similar in terms of race, age and education	<p>No themes reported</p> <p>Immediately post-CA, survivors reported believing that medical professionals made errors in giving a poor prognosis early in the course of recovery. While some survivors reported feeling they had experienced 'death', others felt the term 'death' was an inappropriate term to describe their experience. This study elucidated the attitudes and experiences of CA survivors.</p>

CA: cardiac arrest; QOL: quality of life.

psychological challenges; changed body with new limitations; and confrontation with death.

### Multitude of contrasting feelings

*"If you talk to many CA survivors, you will hear this almost universally. CA survivors go through terrible emotional ups and downs. That is, you are very happy you survived, but at some other period, you might be in deep melancholy."*<sup>19</sup>

Surviving a CA creates a whirlpool of emotions, ranging from fear, vulnerability and loneliness to gratitude and joy.<sup>20,21</sup> Commonly reported were feelings of loss, a search for meaning and a need to find answers as to why it happened to them and why they survived. Impatience and irritability were common in the beginning when survivors had to adjust to their new situation; they wanted life to be as normal, find a reason and determine their possible contribution to the CA, regardless of the real causes.<sup>20,21</sup> Thoughts of being a terrible person who deserved this were occasionally verbalised, creating feelings of separation and loneliness.<sup>20,21</sup>

Survivors expressed fear of an unknown future with the possibility of another CA that could again alter their future, or one they would not survive.<sup>19,21,22</sup> While in hospital, survivors felt safer; after discharge, there were feelings of loneliness and estrangement.<sup>22</sup> Partnerships with the health care professionals who treated them ended, followed by a new team of professionals, creating a feeling of neglect and non-importance from their health institutions.<sup>22</sup>

Survivors described living with anxiety, finding it difficult to adapt to their new situations and to see their lives as opportunities.<sup>19,22</sup> Some male survivors reported insecurity about the impact that the CA could have on their ability to undertake their perceived roles in the future.<sup>22,23</sup> It challenged their sense of independence, and they found it difficult to ask for support during their recovery, as they did not want to be seen as 'weak'.<sup>23</sup>

The vulnerability of surviving a CA is shown in emotional ups and downs, from sheer joy over survival to melancholy over a failing body.<sup>19,20,24</sup> Survivors described not realising the effect the CA would have on their psychological stability, often being close to tears.<sup>19</sup> Laughing and having fun were described as important; cynicism and humour were often used to face emotional challenges, protecting them from being vulnerable or emotional.<sup>21,25</sup>

### Disruption in the continuum of time

*"I am sort of putting my life together again, something I need to live with, I have to face it ... I force myself; otherwise ... I would be all day sitting at home in fear, prisoner to my condition, and I can't allow it. I am making an effort. Maybe, in the future I will have to hunker down, but so long as I am in decent shape, I tell myself: 'Go, move on' ..."*<sup>22</sup>

The realisation that the supposed natural course of life was changed by this event was frightening.<sup>20,21,25</sup> After the event, waking up from unconsciousness and returning to a new reality were frightening. Memory loss created confusion that was difficult to express.<sup>20,24</sup> For some, linking the past with the present was important; there was a need to know what had happened during the time when they had no memory. Stories told by others about the CA and what had happened during the memory gap provided new insights.<sup>20,21,23,25</sup>

Realisation of this threat to life exposed their own mortality,<sup>20</sup> highlighting the finiteness of life, and existential questions emerged.<sup>21,23</sup> There was a desire to be among people; they believed it was important to be active and in a position to re-join daily life.<sup>21,23,24</sup>

### New reality and psychological challenges

*"I can't help but ask: why did this happen to me? Should I have taken better care of myself? What is the meaning of it? It is hard for me to think that there is no cause, nothing to pin this traumatic experience to."*<sup>22</sup>

Survivors described redefining their attitude to life, often involving an evaluation of habits and priorities to reduce stress and live a healthier life.<sup>21,25</sup> Realising that the CPR in fact meant that they were brought back from death, they saw things that they had taken for granted in a new light.<sup>20,25</sup> Many survivors focused on having people around; relationships with their significant others were important and provided happiness and strength.<sup>20,23,25</sup>

Survivors expressed disbelief, guilt and surprise that a CA does not always have obvious warning signs, experiencing self-accusations over missed opportunities to discover the heart failure that changed their life.<sup>19</sup> Fatigue and anxiety decreased with time, and feelings of strength and life returned, resembling normality. They wanted to be able to do the things that they had enjoyed before the CA and to return to 'normal'.<sup>21,24</sup>

### Changed body with new limitations

*"I don't have the strength now either, not a whole day, I have to rest quite a lot. You have to try to get back to normal, get the strength to get everyday life to work out first."*<sup>25</sup>

Survivors found that their body did not function as usual; being unable to do their everyday activities was a new experience.<sup>20,21,25</sup> They had to unite with an unfamiliar body, which was seen as vulnerable and restricted.<sup>25</sup> This changed body created insecurity and anxiety regarding its function and abilities for the future.<sup>20,21</sup> Repeatedly measuring blood pressure in order to ensure that they were within 'safe' limits reveals the insecurity that survivors felt towards their body.<sup>23,25</sup> Survivors described experiencing cognitive problems such as reduced reading ability and memory.<sup>19-21</sup> For many, it was a new experience to go from

being a 'healthy' person to relying on medications; their body was no longer independent, instead requiring medication in order to function.<sup>25</sup>

Following a CA, survivors wanted to 'take care of their body', change lifestyles, exercise, lose weight and eat according to the rules, although some felt that this was a choice, striking a balance between feeling well, enjoying life and following the guidelines for a healthier lifestyle.<sup>21,25</sup>

### Confrontation with death

*"This is death we are talking about here, do you realise what I am talking about? And I get an appointment as if this was something inconsequential like diabetes."*<sup>22</sup>

This confrontation with death was prominent in the survivors' stories; confrontation with the finiteness of life made them realise how fortunate their survival was.<sup>20</sup> Feeling that they had experienced their own mortality,<sup>20,22</sup> this near-death experience made them into a different person; only a person who had experienced the same would understand.<sup>22</sup> Death was experienced as something real, and some survivors actively prepared for their death and funeral.<sup>22</sup>

Survivors commented on coincidences that made their survival possible, sensing that they had been lucky and expressing gratitude towards those who came forwards to help.<sup>20,24</sup> Some saw their survival as a miracle, in that people were around who knew how to perform CPR and that the emergency services were close by, which contributed to their survival.<sup>20,21,24</sup> In their discourse, there was an underlying feeling of gratitude – an obligation to continue to live.<sup>20,21</sup>

For many, the experience of 'death' in itself was not frightening, describing it as peaceful and serene.<sup>20,25</sup> This was somewhat in contrast to the fear and anxiety experienced after the CA. The confrontation with death may be very challenging and confusing for the CA survivor, creating a feeling of insecurity. Continuous engagement with health care personnel is vital in order to support the survivor and enable their acceptance of their situation.<sup>22</sup>

### Discussion

There are few papers exploring interventions focused on improving QOL for survivors of CA; hence, the effectiveness of these programmes is not well known,<sup>26,27</sup> and to date, there are no international guidelines for the psychological care of CA survivors.<sup>26,27</sup> The synthesis of these qualitative papers offers an insight into the complexity of surviving a CA and highlights both the psychological and physical changes influencing survivors' perceptions of their QOL. Surviving a CA is a major event for all involved. What the survivor saw as a predictable future changes to the unknown, and their bodies come to be unfamiliar

entities that can no longer be trusted, or are not what they used to be.

In the continuum of time, a CA is a watershed moment; life before is equated with their current situation and the altered future. The memory gap after the CA impacted on the survivors' experiences, where the survivors lost track of time and wake up to a new and different reality in which they have little input into what is happening. Health professionals have an important role of providing information to survivors in order to help mend the timeline and fill in the memory gap.<sup>20,22</sup> Often, survivors' physical and psychological abilities changed, and adaptation to the new reality was challenging; irritability and disappointment were commonly reported before adjusting to the new reality.<sup>22,23</sup> There is a need for health care providers to support survivors and their loved ones in their quest to adapt to their new reality. Survivors often felt abandoned by the health care team after discharge and before a relationship had formed with the rehabilitation team.<sup>25</sup> A multidisciplinary approach to the transition between hospital wards and home is needed in order to create and implement pathways for these patients in the health care system involving all active partners, improving the survivors' rehabilitation and QOL.<sup>26–28</sup>

For the health care personnel caring for a CA survivor, this multitude of feelings needs to be taken into account. The survivor returning to an altered reality and realising what has happened to them needs both psychological and physical support, as the anxiety and depression some people experience following a CA may be as limiting as any physical ailment.

Existential questions were commonly reported after such an ordeal. Questions as to why this happened to them and how they were able to receive the care needed for survival influenced survivors' QOL. Often, thoughts of the reasons for their CA were highlighted. Lifestyles and habits were scrutinised in order to search for reasons, and many reported changing their lifestyle, although not all found changing their lifestyle to be easy, and some prioritised their enjoyment of life more than the effort it took to live by the recommended health advice after a CA.<sup>24</sup> Support for psychological health was often missing, and research has confirmed that anxiety, depression and post-traumatic stress disorder are common ailments after a CA.<sup>29,30</sup> Currently, there are limited programmes that support survivors' psychological needs during their time in hospital, and further research is needed in order to investigate the psychological needs of survivors so as to provide a tailored care plan.<sup>28,31,32</sup>

The physical changes following a CA can also be debilitating; therefore, medical, practical (such as walking aids or home modifications) and moral support in order to improve physical abilities are implemented and programmes developed so as to coordinate care.<sup>26,27</sup>

To survive a CA is a close encounter with death, and the realisation of the finiteness of life seems to have a strong

impact on survivors' recovery and QOL. Their post-CA experience take them into an existential space, but this is juxtaposed with a desire for practicality in sorting out loose ends in their lives. Cognitive and psychological factors are important components of a CA survivor's QOL.<sup>33,34</sup> The increased possibility of cognitive impairment and early death for CA survivors needs to be taken into account, and multidisciplinary programmes need to be developed in order to support this group of survivors and help them adjust to their new reality.<sup>35</sup> Although research indicates a need for increased psychological support after a CA in order to improve survivors' QOL,<sup>34</sup> there is as yet no clear clinical pathway from hospital care to community care that specifically targets the psychological issues that occur after surviving a CA. The feasibility of an assigned 'mentor' nurse who could give the survivor a personal connection and continuity through the hospital, rehabilitation and home transfer could be considered, providing better communication between care teams.<sup>26</sup>

## Limitations

To find and retrieve qualitative research is challenging,<sup>16</sup> and although a comprehensive systematic search was conducted, there is no certainty that all of the relevant papers have been retrieved. The limit of only using manuscripts in the English language might narrow these findings. This review of the qualitative literature did not find any published research reporting CA survivors' experiences following a less favourable neurological outcome. While this may be due to a reluctance of these survivors to participate in research, their experience would be valuable in order to further develop appropriate and relevant clinical pathways, taking into account all levels of physical and psychological outcomes. The included papers were from countries with access to high-quality technological care. Further research is needed on survivors from different cultural backgrounds and differences in hospital technology in order to provide optimal and equitable post-CA care for all survivors.

## Conclusion

The experience of surviving a CA is undoubtedly a watershed moment for the individual. This meta-synthesis explores survivors' experiences of a CA as a tumultuous and life-changing event. Fear, anxiety, loss of memory and difficulty adjusting to a new reality, both in relationships with other people, as well as in the relationship with their own body, are part of their experiences. This was juxtaposed with gratitude and often a new appreciation of living – a re-evaluation of what is important in life, where family and friends are central to the survivor. In the current clinical pathways, the main focus is on clinical outcomes, and the psychological support that is needed in order to improve QOL is not well incorporated. There is a need to

develop more holistic clinical pathways, focusing on both physiological and psychological function, promoting an improved QOL for survivors of CA.

## Implications for practice

- Healthcare providers play an important part in survivors' recovery and rehabilitation. Often after discharge from hospital the survivors feel an increased anxiety that can be eased with consultation and follow-up.
- In order for healthcare providers to provide person centred care culturally adjusted and applied rehabilitation of patients following cardiac arrest can improve patient centred care and survivors' satisfaction of quality of life.

## Conflict of interest

The authors declare that there is no conflict of interest.

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## Summary of Chapter Two

*In this chapter I have presented two published reviews of the literature. The first article 'Survivors' quality of life after cardiopulmonary resuscitation: an integrative review of the literature' explored a wide variety of articles demonstrating the broad research interest in survival following a cardiac arrest. The second article 'A systematic review and meta-synthesis of the qualitative literature exploring the experiences and quality of life of survivors of a cardiac arrest' explored cardiac arrest survivors' experiences.*

*As I delved into the literature exploring the experience of surviving a cardiac arrest, and although there is ample literature exploring the survival after a cardiac arrest, most quantitative literature focuses on the quality of life for the survivor, not the experience of the cardiac arrest and the impact the experience has on the survivor. The found qualitative literature focused on the overall experience after the cardiac arrest. There was no focus on the transition from the event through to realisation of survival, followed by adjustment to be a cardiac arrest survivor. In the immediate time after the event there may be time specific adjustments where knowledge from survivors can support healthcare professionals to provide support at the right time, indicating that the realisation of survival and adjustment to an altered future need to be further studied.*

*To survive a cardiac arrest is a life-changing event; sometimes the physical ailments are not noticeable, whereas others may have major deficits. The mental impact after the cardiac arrest may have a strong influence on the survivor regardless of the physical ailments and can influence how the person adapts to their new reality. Narrative inquiry has a relational aspect, as well as a long engagement where the person is central in the study.*

*This provides an opportunity to engage with the cardiac arrest survivor and thereby gain a deeper understanding in the different transition stages as the person adapts to be a survivor of a cardiac arrest.*

*Providing the survivor with the opportunity to tell their story and explore / identify what is the most important, or memorable event, in both the long and short term experience of surviving can provide healthcare professionals with embodied knowledge that will promote person centred care and a better understanding of the survivor's experience. In my literature search I found limited literature focusing on the survivor who had a distressing experience of the cardiac arrest. It may be that the survivor sees survival as the optimal outcome by bystanders, and it can be challenging to express a different story where the difficulties of survival are expressed. In narrative inquiry there is an opportunity for the researcher to have multiple meetings, and focus on the relational aspects therefore providing survivors who had a less positive experience following their cardiac arrest more time and space to tell their raw story and add another dimension to the knowledge of cardiac arrest survivors' experiences. Although, as the participants in this inquiry will contact me, there is no guarantee that participants with a less positive experience will come forward and participate.*

*In the following chapter I will present my selected methodology, narrative inquiry, as the framework supporting this study. The beginning of the chapter presents a background of narrative inquiry and an introduction to contributing authors of narrative research followed by an exploration of the theoretical framework used by Connelly and Clandinin's (2000) and Clandinin (2013).*

*Chapter Three will also describe the method involving the recruitment process, how meetings were arranged, the collection and analysis of the field text are outlined. This is followed by a discussion of the ethical considerations and rigor involved in this inquiry.*

*The final part of the chapter presents an article titled: 'Narrative inquiry as a research methodology exploring person centred care in nursing' published in Collegian 2018 augmenting the usefulness of narrative inquiry in health research.*

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# Methodology & Method

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*This chapter contains the rationale behind the selection and background of Connelly and Clandinin's narrative inquiry as the methodology framework I used to model my inquiry from. Contributing authors to narrative research are introduced, as narrative research is a broad field and can take many forms. Connelly and Clandinin's (1990, 2000) theoretical framework of narrative inquiry is introduced and Clandinin's (2013) further development of the methodology as a way of making meaning of the stories of 'lived lives'. In this thesis a modified version of Connelly and Clandinin's (1990, 2000) and Clandinin (2013) narrative inquiry was used due to the larger than usual number of participants. The collected stories become the basis for this study, exploring the research puzzle of the experience of surviving a cardiac arrest.*

*The second part of the chapter describes the recruitment of cardiac arrest survivors and the setting for this research puzzle. The meeting with participants, and collection and analysing of the field text are outlined, followed by ethical considerations and rigor of my study. The final part of the chapter presents an article titled, 'Narrative inquiry as a research methodology exploring person-centred care in nursing', published in Collegian 2017 that augments the usefulness of narrative inquiry in health research.*

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## SELECTION OF METHODOLOGY

In this section I explore different qualitative methods and explain my choice of narrative inquiry for this research project.

Qualitative research is typically interactive and tries to explore the experience, opinions, and meanings from the participants' perspective to answer the research question (Polit & Beck, 2018; Watson & Keady, 2008). The most common form of collecting data is the use of interviews that can be completed in different ways. The interview is often done face to face, as individuals or in focus groups, but also over the phone or in Skype or Zoom meetings. The skills of the researcher will influence the insight, depth and quality of the data collected from the interview (Watson & Keady, 2008). Qualitative research does not claim to provide a universal truth as it is context specific and the participants influence the quality and representativeness of the findings. For qualitative research this can be both strength and a weakness. Although a small number of participants provide the opportunities to provide deeper insight into the research question, findings may, however, not be applicable to a larger population (Polit & Beck, 2018; Watson & Keady, 2008).

To pursue a PhD using a qualitative methodology provides many options of what methodology to choose and in every research endeavour it is vital to find the research methodology that best fits the research question. Thorne (2008) maintains that selection of methodology should be suitable for the aim and research questions. For this study, Connelly and Clandinin's (1990, 2000) narrative inquiry was chosen as the preferred methodology and method where I used a modified version to include the larger number of

participants' in answering the research puzzle "How do post-cardiac arrest survivors experience life after cardio-pulmonary resuscitation?"

I explored phenomenology as a fitting methodology for my study. Of interest was Max van Manen's concept of "punctum, meaning point, sting" (2014, p. 252). I contemplated this methodology, thinking of the cardiac arrest as a 'punctum' in the participant's life. However, the cardiac arrest is commonly a 'black hole' with no memories, hence the cardiac arrest becomes a 'before' and 'after' event and cannot be describes as 'punctum'. Van Manen (2014, 2016) further describe the phenomenological approach emphasising that phenomenology should focus on the "phenomenon itself" (2016, p. 5) and not on the understandings of personal experience. The declaration that phenomenology is about the 'phenomenon itself' (Van Manen, Higgins & van der Riet, 2016) made it clear to me that phenomenology was not a suitable methodology for this study, as I was interested in the understanding of the personal experience and learning through storied lives. As Clandinin (2013, p.13) states "Narrative inquiry understands experience as a narratively composed phenomenon. Narrative inquiry is thus a methodology and a phenomenon, an understanding that is central to what we mean by narrative inquiry." I was also drawn toward the methodology of narrative inquiry because of its relational focus with participants and thus consistent with my ethos and ontology as a nurse of person-centred care.

Other qualitative methodologies such as grounded theory, where the aim is to generate conceptual theories that are abstract from time, place and people (Glaser, 1992) or ethnography, studying culture where the researcher is an 'observer' seen to be observing and analysing the collected data, might also have been suitable. Many of the qualitative methodologies could be appropriate for this research as they focus on the human

experience (Denzin & Lincoln, 2011). The choice of methodology often depends on the researcher's knowledge and experience in the chosen methodology (Pinnegar & Daynes, 2007). Connelly and Clandinin's (1990, 2000) approach to narrative inquiry includes a small number of participants, usually 2 to 5. Therefore, as the number of participants in this inquiry grew, I amended my narrative inquiry approach to accommodate a larger number of participants.

In exploring the personal experience, stories are well suited. However, stories can take many forms with different approaches. Polkinghorne (1988), Riessman (2003), Czarniawska (1997) and Connelly and Clandinin (1990, 2000) are among the more well-known authors promoting narrative inquiry as research methodology. For this research, the modified version of the narrative inquiry framework of Connelly and Clandinin (1990), was found to be suitable for collecting field text (data), analysing and synthesising participants' stories because of the relational aspects through three-dimensional space of time, place and sociality. This three-dimensional space then served as my theoretical framework through which I analysed my participants' storied experiences of surviving a cardiac arrest. Furthermore, the relational aspects between the researcher and participant were also relevant and of interest to me.

## **BACKGROUND TO NARRATIVE INQUIRY**

Narrative inquiry as a methodology is growing in qualitative research, however, narrative inquiry is difficult to define as it takes many shapes (Chase, 2008; Kim, 2016; Riessman, 2003). The interest in narrative research started during the 'narrative turn' in the

1960s when it spread to humanities and social sciences (Polkinghorne, 1988; Czarniawska, 2004), and as Pinnegar and Daynes (2007, p. 29) state

*“What fundamentally distinguishes the narrative turn from ‘scientific’ objectivity is understanding that knowing other people and their interactions is always a relational process that ultimately involves caring for, curiosity, interest, passion and change.”*

Narrative research of the late 1960s focused on how narratives played in the role of people’s lives (Chase, 2008) and researchers within sociology and anthropology studied individual narratives as a form of discourse worth studying (Chase, 2008; Polkinghorne, 1995; Richardson, 1990). Personal narratives were seen to be a valuable and sustainable way to explore in-depth individual experience and to form an understanding of the unique experience and actions of individuals (Chase, 2008, Connelly & Clandinin, 1990, 2000; Polkinghorne, 1995). As the popularity of narratives grew, researchers came to use the term ‘narrative’ to describe multiple manners of collecting data; or as Clandinin and Connelly (2000) call it, collecting ‘field text’. Chase (2008) states, “a narrative may be oral or written and may be elicited or heard during fieldwork, an interview or a naturally occurring conversation” (p. 59).

## **CONTRIBUTING AUTHORS TO NARRATIVE INQUIRY**

Narrative research originated from a broad spectrum of research areas, such as literature, history, anthropology, sociology and education, where these different areas of study have adopted their own approach (Chase, 2008). Since the ‘narrative turn’ in the late

1960s, described by Czarniawska (2004) and Goodson and Gill (2011), different frameworks have evolved in different disciplines where leading authors in their field have made their mark in narrative inquiry. Fisher (1984) highlighted the narratives in politics, Brown (1977) spoke of narratives in sociology, Polkinghorne (1988) in psychology and sociology, McCloskey (1990, a,b) did the same for economics, Czarniawska (1997, 2004) used organisational narratives to explore how organisations present themselves narratively.

Daiute (2013) used narratives to understand the development of individuals in a social frame, Riessman (2008) used a sociological approach to narratives and finally, Connelly and Clandinin (2000), Clandinin (2013) as well as Cortazzi (1993) used narrative in the discipline of education exploring narratives in the educational area. Within health research, Riessman (2008) was prominent. However, lately the framework stemming from Clandinin and Connelly (2000) and Clandinin (2013) has been further developed by Clandinin, Caine, Lessard and Huber (2016) and Clandinin, Caine and Lessard (2018) and are now often used in narrative health research. The adaptation to health research in Clandinin's narrative inquiry originates from the close collaboration over many years with Vera Caine who is an Assistant Professor of Nursing and has co-authored books and articles with a focus on health research.

### **‘NARRATIVE’ IN NARRATIVE INQUIRY**

‘Narrative’ is a term not only used in research but can be used to describe any text or discourse. However, in this inquiry ‘narrative’ relates to the text used within the framework of narrative inquiry (Chase, 2008), and has a specific focus on individuals’ narratives by

collecting their stories, chronologically ordering and reporting their individual experience, and the meaning of those experience (Creswell, 2012). Polkinghorne (1988) describes narratives as

*“the primary way through which humans organise their experience into temporally meaningful episodes”* (p.6). Richardson (1990) states *“Narrative displays the goals and intentions of human actors, it makes individuals, cultures, societies and historical epochs comprehensive as wholes, it humanises time and it allows us to contemplate the effect of our actions and to alter the directions of our lives”* (p.117).

The ontological and epistemological stance of narrative inquiry states it is *“a way to understand and inquire into experience. It is nothing more and nothing less”* (Clandinin, 2013, p. 10). From an epistemological view narrative inquiry delivers knowledge of experiences through the telling and listening of stories (Connelly & Clandinin, 1990; Clandinin & Connelly, 2000; Clandinin, 2013). The ontological view of narrative inquiry research influences each stage, beginning with a personal interest in the experiences (as mentioned in my autobiography in chapter one) and professional inquisitiveness about how participants are managing their experiences under inquiry (Connelly & Clandinin, 1990; Clandinin & Connelly, 2000; Clandinin, 2013). Many authors such as Polkinghorne (1987), Czarniawska (1997, 2004) and Daiute (2013) endorse narrative inquiry as a useful methodology to explore experiences. Narrative inquiry as a qualitative approach that systematically examines human experience, using critical thought and logic, as well as creativity and intuition, throughout the research process.

Connelly and Clandinin commenced their work in the education environment where students and educators spend considerable time together and multiple meetings are held between the researcher and participants. With longer engagement collecting field text, fewer participants are required in the research as the richness of the collected field text provides a deeper understanding of the phenomena with only a few participants. The larger number of participants in this project is not unusual in narrative inquiry, however, not commonly used by Connelly and Clandinin. In health research, unless it is a chronic illness, the participants tend to be engaged in the research project for a shorter time as their health improves. In this research project, a larger number of participants provided richness to my inquiry into the phenomena of surviving a cardiac arrest.

In using a modified version of Clandinin and Connelly's narrative inquiry, the focus is on the participants' perceptions of their changed life situation, where the study focuses on individuals' experiences after a cardiac arrest. Using the participants' stories, I construct narratives from their experiences, exploring through the three-dimensional space and exploring how the three-dimensional space has influenced their lives. This approach supporting my theoretical framework for analysis and will be explained later in the chapter.

## **CLANDININ AND CONNELLY'S NARRATIVE INQUIRY**

Collectively, all narrative research methodologies aim to provide a deeper understanding of an individual's experience (Connelly & Clandinin, 1990; Clandinin & Connelly, 2000; Clandinin & Huber, 2002; Clandinin et al., 2016; Frank, 1995, 2002; Kim, 2014; Riessman, 2008). Narrative research in healthcare environments allows for stories to

be told, providing a wealth of information on patients' experience, their situations and their illnesses. These collected stories are analysed, critically reflected upon and re-created into a framework, or new way of making sense of the presented information (Clandinin, 2013; Creswell, 2012; Riessman, 2008; Tropea, 2011) to become a narrative of the survivor's experience of CA.

Clandinin and Connelly (2000) purports that in narrative inquiry the intent is to “*find a form to represent . . . storied lives in storied ways, not to represent storied lives as exemplars of formal categories*” (p. 141). Representing the participants' lives in storied ways provides an opportunity to focus on how participants make meaning of their individual lives and 'what matters' from their point of view (Chase, 2008; Clandinin, 2013; Clandinin & Connelly, 2000).

Importantly, the findings in narrative inquiry are presented to recount the participants' experience in a way that engages the reader and brings life to their stories. To present the findings in narrative inquiry, the final text requires a deep, detailed description that supports participants' lives and that is multi-dimensional (Saldaña, 2009; Tropea, 2011). To undertake this achievement, it is necessary to collect the stories and retell them in a meaningful way, highlighting the threads found in the original stories. During the recreation process underlying ideas and patterns are found (Creswell, 2012). Cortazzi (1993) states that establishing the chronological sequence in re-writing separates narrative inquiry from other research methodologies. This is achieved by defining a beginning, middle and end, as in a novel, a plot involving an issue, conflict or event, a main character and an ending, or resolution (Grethlein, 2018, Reid & Soundy, 2019; Tropea, 2011). Clandinin and Connelly (2000) describe the plot as the overarching narrative, using the intertwining threads to

create a plot that is situated in a three-dimensional space of time, place and sociality. This three-dimensional space integrates the continuity of past, present and future. The interaction between personal and cultural norms and space refers to the context in which the experience story was experienced.

In relation to experience, the key concept of Clandinin and Connelly's (2000) narrative inquiry is influenced by John Dewey's (1938) pragmatic philosophy where he states that human experiences influence how we learn, behave and react and that our experiences have an impact on our future decisions (Dewey, 1938). Our present experiences are a result of how our previous experiences influence our present situation (Dewey, 1938) and this can be explored in stories. Dewey (1938) identified two criteria of experience; interaction and continuity. Interaction is the realisation that "people are individuals and need to be understood as such, but they cannot be understood only as individuals. They are always in relation, always in a social context" (Clandinin, 2006, p. 46).

In relation to continuity all stories stem from previous experiences, and the present experiences influence how future experiences and stories will be shaped (Clandinin, 2006, 2013). Inspired by Dewey's theory of experience, Clandinin and Connelly (2000) explored the notion that narrative inquiry offers a way for experiences to be understood through the participant-researcher relationship that transpires during the research period. Connelly and Clandinin (1990, 2000, 2006) continued to develop the metaphorical three-dimensional narrative inquiry space of time, place and sociality, creating the conceptual framework of narrative inquiry. Through Connelly and Clandinin's three-dimensional framework and Dewey's theory of experience I've been able to make meaning from my participants embodied experiences of surviving a cardiac arrest.

A modified adaptation of Connelly and Clandinin's narrative inquiry was developed as a suitable research methodology, because of the educational aspects of learning from experiences and the relational aspects between researcher and participant. Clandinin (2013), Clandinin et al., (2016) and Clandinin and Connelly's (2000) narrative inquiry approach begins by attending to the participant in person and listening to their stories. As both participants and researcher enter the inquiry in the midst of their own lives and for a period of time coming together, they are thereby shaping each other's experiences (Connelly & Clandinin, 1990; Clandinin & Connelly, 2000; Clandinin, 2013). After the meetings the researcher listens and transcribes the recorded stories. These transcribed stories are then presented to the participant and once agreed to be accurate by the participant, a time for reading the transcribed conversations commences by the researcher. The researcher will critically reflect upon time, place and social aspects, before reconstructing and retelling the participants' stories as narratives. There is an ongoing opportunity for conversations between the participant and researcher during this time. This facilitates a co-construction of knowledge between the researcher and the participants. Connelly and Clandinin's (1990, 2006), views of narrative inquiry provide a widely used definition of this qualitative research approach:

*“People shape their daily lives by stories of who they and others are and as they interpret their past in terms of these stories. Story, in the current idiom, is a portal through which a person enters the world and by which their experience of the world is interpreted and made personally meaningful. Narrative inquiry, the study of experience as story, then, is first and foremost a way of thinking about experience. Narrative inquiry as a methodology entails a*

*view of the phenomenon. To use narrative inquiry methodology is to adopt a particular view of experience as phenomenon under study.” (p. 375).*

## **TIME**

Time encompasses the notion that we all have an individual past that influences our present situation and will influence our choices for the future (Clandinin, 2013; Connelly & Clandinin, 2006). This means that all events, relationships and people can be, and are most likely, in a temporal transition (Clandinin, 2013; Connelly & Clandinin, 2006). My own past experience working as a registered nurse in intensive care has influenced my quest for knowledge of cardiac arrest and became the impetus for my interest in this area of research.

## **PLACE**

Place is where the experience happened and where the inquiry, or conversations take place (Clandinin, 2013; Connelly & Clandinin, 2006). The impact, and importance of place on the narrative should be recognised and included in the presentation of findings (Clandinin, 2013; Connelly & Clandinin, 2006). Institutions such as schools or hospitals are ‘places’ that can have long lasting influences on our experiences and how we narratively describe our story experiences. I gained institutional knowledge from working in intensive care where I had conversations and listened to patient’s stories after a cardiac arrest. This

knowledge and experience meant that I could relate to the place when I listened to the participants' who had an in hospital cardiac arrest.

## **SOCIALITY**

Sociality refers to personal and social circumstances. Sociality considers our own personal view of our self as well as our own desires and needs in the relationships we have with others, including acknowledging the relationship between the participant and the researcher as significant. The relationship between the researcher and participant influences how the story is told as there is no exclusion of the researcher from the relationship (Clandinin, 2013; Connelly & Clandinin, 2006). The researcher and the participant agree on the final outcomes of the research (Clandinin, 2013; Connelly & Clandinin, 2006). The researcher includes their presence within the relationship and their own relation to the participant (Clandinin, 2013; Connelly & Clandinin, 2006). The social circumstances take into account the conditions of cultural social, institutional, familial and linguistic influences of the participants' stories (Clandinin, 2013)

To explore an experience, narrative inquirers working within the three-dimensional space described above beginning by asking participants to tell them their story. In doing so, the researcher comes alongside the participants to explore their stories (Clandinin 2006, 2013; Connelly & Clandinin, 2006). As the researcher meets the participants, they enter into a relationship with the participant to co-compose the inquiry (Clandinin & Huber, 2010). In this study, participants were invited to participate in a conversation to tell their story in face-to-face meetings.

The stories collected through these meetings have been co-created into narratives of these experiences. These narratives are critically reflected upon, incorporating the three-dimensional space of narrative inquiry, reconstructed and retold with a deeper visible meaning (Clandinin, 2013). As the findings from this inquiry are presented and published in journal articles, participants' stories were shortened as fragments of conversation. This was carefully done without losing the essence of their told experience to adhere to the journals' requirements.

## **THEORETICAL FRAMEWORK**

Within this narrative inquiry study, the theoretical framework of three-dimensional space is used to analyse participants' stories. These stories have been critically reflected upon, throughout the collection of field text and during the field text analysis process (Clandinin & Connelly, 2000; Clandinin, 2013).

**Figure 1. Conceptual framework of Clandinin and Connelly’s narrative inquiry**



## THE PROCESS OF NARRATIVE INQUIRY: LIVING, TELLING, AND RETELLING AND RELIVING

Narrative inquiry commonly begins with participants telling stories, although, it can also be with the researcher 'coming alongside participants' as in 'living with' (Clandinin, 2013). However, to come alongside participants in narrative inquiry is "*a more difficult, time-consuming, intensive, and yet, a more profound method is to begin with participants living, because in the end, narrative inquiry is about life and living*" (Connelly & Clandinin, 2006, p.478). This narrative inquiry starts with the participants telling me the story of their experience of the cardiac arrest. As the participant and I came together, there were already relational aspects influencing the story being told. Multiple relationships are taken into account in narrative inquiry, such as the relationship between the person and their world, their temporal understanding of the relationship between past, present and future, the relation between person and place. There are also the person's internal relations, how an event made them feel and the influence from the person's relationships with their family and other people during the event (Clandinin 2013). Their language, culture and previous experiences from institutions, such as schools or hospitals, will also influence the person's experience of an event (Clandinin, 2013). These external and internal relations influence the experience as it happens and when the story told, thereby becoming part of the narrative inquiry.

A narrative inquiry researcher explores stories in relation to their participants and within themselves and the relation to the three-dimensions of time, place and sociality. The narrative inquiry researcher looks for meaning within the stories and considers the relationship across the three-dimensions of time, place and sociality. In the conversations

the researcher is attentive to the story, since they too, are part of the story. As a listener in this space, the researcher helps to shape the conversation through their presence. The researcher cannot stand ‘metaphorically’ outside the narrative and becomes a part of the studied experience. The stories become co-composed in the conversation between researchers and participants (Clandinin, 2013).

## **RESEARCH PUZZLE**

As qualitative research is grounded in the notion that there can be multiple ways to construct reality and truths, representations narrated by the participants cannot be judged as being the truth, but rather, a truth represented by their experience that can stand alone as a narrative (Clandinin, 2013; Connelly & Clandinin, 2000, Polkinghorne, 1988, 1995; Riessman, 2003). The modified narrative inquiry is focused around a particular experience or phenomenon and instead of creating a research question with a definition or expectation of an answer, narrative inquirers create a research puzzle that includes “*a sense of search, a re-search, a searching again... a sense of continual reformulation and wonder*” (Clandinin & Connelly 2000, p. 124). Clandinin (2013) sees the research as a puzzle with no absolute truth to be found. Contained in the participants’ narratives are expressions of ‘why’ and ‘how’ experiences shape their situation. These open-ended experiences provide the ongoing pursuit of further exploration, rather than giving a concrete answer or absolute truth (Clandinin, 2013; Connelly & Clandinin, 2000; Saldaña, 2009; Polkinghorne, 1995). This shift from research question to research puzzle allows narrative inquirers to make obvious that narrative inquiry is markedly different from other narrative methodologies.

The research puzzle in this modified narrative inquiry study explores how post-cardiac arrest survivors experience life after cardio-pulmonary resuscitation. In the midst of living, a cardiac arrest changes the perceived known future to an unknown reality where mental and physical capabilities may have been seriously altered. The wonder of knowing how a cardiac arrest influences the individual and how they adapt to be a survivor after the event is this research puzzle.

### **RESEARCHERS' AUTOBIOGRAPHICAL NARRATIVE**

To begin a narrative inquiry, there is a need to engage in a thoughtful autobiographical narrative. Writing this will also engage the researcher to start to understand how our imagined participants can shape the inquiry and how the researcher can influence the narrative (Clandinin, 2013). Even before a researcher meets the potential participants, the study is visualised, as the researcher through their autobiography envisages the future event. However, the initial ontological stance of the researcher may change as the researcher and participant co construct a story to create a different narrative of experience. This autobiographical narrative was described in Chapter One in this thesis.

The ongoing relational inquiry space, the meeting place, in narrative inquiry is called the '*field*'. Field is the imaginary space where participants and the narrative inquiry researcher meet and stories and wonders unfold (Connelly & Clandinin, 1990; Clandinin & Connelly, 2000; Clandinin, 2013). This field could be the space where the researcher listens to participants telling their stories or lives alongside participants as they live and tell their stories (Connelly & Clandinin, 2006). Commonly, it begins with listening to stories. Most

often the method of collecting these stories is in conversations, or interviews as conversations (Clandinin, 2013). These conversations are not guided by set questions and do not have the intention to be therapeutic, problem solving or to give answers (Clandinin, 2013).

## **FIELD TEXT**

The information, collected from conversations, is not named 'data' in Connelly and Clandinin's (1990, 2000) narrative inquiry, instead the information collected is referred to as 'field texts'. The composed text in narrative inquiry is an experimental and subjective text rather than an objective text (Clandinin, 2013). These field texts are co-compositions that reflect the experience of both participant and researcher, hence they need to be understood as such; telling and explaining the parts of the experience that the relationship permits.

There is a need to attend to the relational aspects of the co-composed field text within the conceptual framework of the three-dimensional inquiry space. Researchers and participants need to recognise that they are continually interpreting their past from their present vantage points (Connelly & Clandinin, 2000).

## **MOVING FROM FIELD TEXT TO INTERIM RESEARCH TEXT**

These field texts are embedded in research relationships and to transform them to interim research text can be overwhelming. With a large quantity of field text, such as transcripts, field notes and documents, managing and analysing the field text can be

perceived as a daunting task (Clandinin, 2013; Kim, 2016). However, drafting and co-composing interim research text provides the researcher with an opportunity to continue to engage in relational ways with the participants. By creating, analysing and interpreting the interim research text, the researcher continues to think narratively, attending closely to the field text within the three-dimensional space (Clandinin, 2013; Clandinin et al., 2016). Multiple meetings with the participant may be required if more field text is needed to be able to compose research text that the researcher and the participant see as accurate and compelling (Clandinin, 2013; Clandinin et al., 2016).

## **THE FINAL RESEARCH TEXTS**

The final research text is co-composed or negotiated with the participants where the text is read and reread multiple times. Attention is paid simultaneously to time, place and sociality. At the same time, attention is paid to the “institutional, social, cultural, familial and linguistic narratives in which each of our lives *is* lived, and *is* being lived” (Clandinin, 2013, p. 44). The three-dimensions are threaded into place. Events and emotions are not separated from each other and as the final research text is composed, a return to the personal, practical and social justification is needed (Clandinin, 2013; Clandinin et al., 2016). Unlike many other qualitative methods, in Clandinin’s (2013) narrative inquiry, the text is not dissected into codes as it detracts from the complexity of the experience under investigation (Gergen, 2003; Clandinin & Huber, 2010). The threads are found by following particular plotlines that are threaded over time and place in the participant’s story and as more stories are explored alongside each other, common threads are found exploring the

phenomena in the research puzzle (Clandinin, 2013; Clandinin et al., 2016). These collected common threads were presented in the published articles.

The final research text can be presented as traditional academic publications, dissertations and presentations for academic and non-academic audiences (Clandinin, 2013). The large number of participants in this inquiry led to a modified adaptation of Connelly and Clandinin's narrative inquiry in presenting the findings in published articles. Participant stories were presented as conversation fragments instead of long stories. The aim is to create a research text that allows the reader to engage and remember their own experiences and thereby broaden the readers understanding of the investigated experience. The final presented research text will "*not have final answers because narrative inquirers do not come with questions. These texts are intended to engage audiences to re-think and reimagine the ways in which they practice and the ways in which they relate to others*" (Clandinin, 2013, p.51). The role of voice is a key consideration in composing research texts and it is an issue of representation. It is important for the researcher to maintain balance in the weight of voice. I engaged in reflexivity through the use of my autobiography, reflective thinking, as well as writing a journal. This prevented my voice and assumptions from becoming dominant as I immersed myself in field text.

## **PLACING NARRATIVE INQUIRY AMONG OTHER QUALITATIVE METHODS**

Often qualitative methodologies focus on a search of common themes across participants' narratives. However, narrative inquiry does not search for classifications, instead, narrative inquiry attends to individual lives as they unfold over time in relation with

people and situations in a particular place (or places). Narrative Inquiry research aims for a more holistic exploration of the phenomenon under inquiry (Lindsay & Schwind, 2016). The focus is on lives as lived and told in the stories collected for the inquiry. The knowledge developed from the narrative inquiry is visualised in providing opportunities to ponder alternative possibilities and outcomes (Clandinin, 2013).

Narrative inquiry is a qualitative approach that systematically examines human experience, using critical thought and logic, as well as creativity and intuition, throughout the research process (Lindsay & Schwind, 2016). By reflecting on, telling and re-telling personal stories, the path towards the future can become clearer (Clandinin, 2013; Clandinin & Connelly, 2000). As Clandinin and Connelly (1998) stated, “*stories are the closest we can come to experience as we and others tell of our experience*” (p. 155). The key component of narrative inquiry, as previously noted, is experience as articulated through story and then into narratives (Schwind & Lindsay, 2008). Thereby, to understand the puzzle of participants’ experience of surviving a cardiac arrest, narrative inquiry is an appropriate research methodology; it provides an opportunity for participants’ voices to be heard so that healthcare providers can explore the survivors’ perspectives. Exploring the findings from this research puzzle and appreciating how care is perceived from the survivors’ viewpoint, will provide an opportunity for the healthcare providers to adapt future care in a person-centred approach for this unique group.

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## **METHODS**

*The following part of this chapter describes the setting for this inquiry, methods of sampling and defining the criteria for inclusion, recruiting participants and the logistics of arranging meetings with them and collecting information during interviews. This is followed by a description of the analysis of field text, rigour and the ethical considerations of this inquiry.*

### **SETTING FOR THIS INQUIRY**

The following information provides a background and context to this inquiry, demonstrating the living standard, health care conditions, and incidence of cardiac arrest and knowledge of CPR in the population that was part of this inquiry. This inquiry was initiated in March 2014 and completed in April 2021.

Australia is a nation continent with a population of nearly 25.7 million people (Australian Bureau of Statistics [ABS], 2020). New South Wales (NSW) is one of six states and is located on the east coast of the continent. NSW has a population of 8.1 million people with the state capital of Sydney (ABS 2020). The population of metropolitan Sydney is estimated to be just above 5.3 million people (ABS, 2020). NSW have a well-functioning ambulance and emergency care service, and the NSW health care system includes more than 220 public hospitals and an equal number of private hospitals (Australian Institute of Health and Welfare, 2021). These hospitals provide a high standard of care that is accessible for all residents. The knowledge of how to perform cardiopulmonary

resuscitation could improve. In a sample of 1076 Australians, 56% had knowledge of CPR and 22% had participated in CPR training the last year (Cartledge et al., 2020). The availability of automated defibrillators in public places is steadily increasing, although more are needed in rural areas (Kumar, Chow, Jan & Angell, 2017).

Port Macquarie is a coastal town located 5 hours' drive north of Sydney, famous for pristine beaches, the largest urban koala population and comfortable all year around weather. Port Macquarie area has a population of 73,131, where 44,830 live within the town limits. The population aged 65 or older is 28% in Port Macquarie compared with 16% in Australia as a whole (Australian Bureau of Statistics, 2016). Of the seventeen participants, one person lived across the border in the state of Queensland and, sixteen people resided in New South Wales, Australia. Of the 16 New South Wales participants, four lived north of Port Macquarie and two participants resided south of Port Macquarie. The other nine live locally within a 45 minute drive from Port Macquarie.

## **THE BEGINNING OF THIS INQUIRY**

This inquiry originates from my experiences as a registered nurse working at a local hospital in New South Wales, Australia, where I also work as an academic. I commenced my candidature in March 2014 and ethics approval for the inquiry was obtained June 2015 (Appendix 5).

## **SAMPLING OF PARTICIPANTS**

To be included in this inquiry participants had to be a survivor of a cardiac arrest, be over the age of 18 years, living independently in the community and able to have a

conversation using the English language. People under the age of 18, not able to have a fluent conversation in the English language or be a survivor with cognitive impairment were excluded from the inquiry. Although children and teenagers can suffer from a cardiac arrest, the focus on this inquiry was on adults. The fluency in the English language was needed to have the linguistic nuances necessary for the telling and understanding of their story. The inclusion of a good level of cognition was to ensure the participant had the ability to express their views and experiences. None of the people who expressed interest in participating fell into these exclusion categories, therefore, no interested participants were denied the opportunity to participate.

## **RECRUITMENT OF PARTICIPANTS**

Recruitment of participants was undertaken with the use of information posters (Appendix 7) distributed to local general practitioners' waiting rooms, snowball sampling and newspaper articles. The poster informed prospective participants of the research, including how to contact me, the researcher, for inclusion in the research. There was also the opportunity for recruitment through snowball sampling where interested participants could suggest other individuals who had the experience of a cardiac arrest to contact me for inclusion. Before the posters were put in place, an article about me, the researcher, appeared in the local newspaper. Coinciding with International Women's Day, the theme revolved around me as an inspirational woman and local success story. This article created much interest and was followed up by a radio interview and a further local newspaper article. With the local interest in my research, I was pleasantly surprised when I received

phone calls from interested participants, both from interstate and major cities. Snowball sampling occurred as residents from my hometown contacted their relatives, who did not live locally, suggested to them that they should contact me. This gave me a broad and varied group of participants, from different social settings, education and life experience. As my thesis was completed part time, I had time to meet the participants, either face to face or on Skype. This usually occurred over a four-month period between initial contact and the final version of their story being written. This publicity resulted in 17 participants being recruited and included in the inquiry. Connelly and Clandinin (1990, 2000) commonly have a smaller number of participants, however, there was a larger than expected interest in participation in this study. As I realised how important it was for the first participants to tell their story, I felt obligated to listen to the stories from all interested participants. I felt a commitment to listen to them as they had contacted me indicating that it was important for them to tell their story. The reason for meeting was not for therapeutic purposes but to be able to tell their story and be heard is an important part of human interaction (Avadi & Evans, 2020).

## **METHOD OF APPROACH**

The first contact I had with the participants was either by phone or by email. In either form of initial contact, I explained what was expected of them with their involvement in the study, the risks and benefits of participating and answered any questions they had about the research study. After the first conversation I sent them the participation information statement (Appendix 6) and consent form (Appendix 7). The participation information

statement included information about the research study as well as the option to withdraw from the inquiry without any consequence if they so wished until such point as the transcribed conversation had been de-identified and become part of the field text. Although participants volunteered to participate in the conversations, there was a small chance they could become distressed during the meeting as reminiscing over a major life-changing event can bring them back to the time of the cardiac arrest. Remembering some small detail in conversation can bring back powerful memories. The time of 'past' and 'present' are linked in memories and often expressed in stories. While no participants became distressed during a meeting, I was prepared to stop the conversation and provide emotional support if this did occur. I had a plan of action with information about a local contact for further counselling if needed. Once they received, read and returned the consent form we arranged to meet face to face or on Skype for our conversation/ interview. Skype was used for those participants who resided in metropolitan areas.

**Figure 2. Map of Australia indicating most northerly and southerly participant**



## **MEETING PROCEDURE**

The participants chose the venues for our face-to-face meetings. Most meetings took place in the participants' homes, ranging from inner city locations to rural towns, farms and beach cottages and also in my local library. As I continued my inquiry I travelled to many places, where I met with my participants. To visualise the vastness of the Australian continent I have included a map of Australia and indicated with blue arrows where the most northerly and southerly participants reside. The other participants lived somewhere between the two blue arrows. The red arrow indicates my home town of Port Macquarie (see Figure 2).

As three participants lived more than five hours drive away from Port Macquarie we held our conversations over Skype, a computer software that enables video conversations between individuals. During the field text collection no participants decided to withdraw from the inquiry and each conversation was with the cardiac arrest survivor alone.

## **FIELD TEXT COLLECTION METHODS**

Each conversation was recorded using two voice recorders. The duration of each meeting lasted from 1 ½ hours up to 4 ½ hours. To manage the conversation I had written some questions to support the flow of conversation in case the conversation stifled or ventured off track. I commenced the interview with a broad open question 'Tell me about your experience of the cardiac arrest?' However, I should not have worried as the conversations were fluid and the participants told me their story almost without further

prompting. During the meetings, the participants were often animated and eager to tell their story.

Field notes were completed once I arrived home after the meetings, as I did not want to interrupt the conversation with note taking. The body language I most often noted was that of comfort and willingness to tell their story. Very little discomfort was noted, and there was almost a sense of pride that they could tell their story of survival.

As Connelly and Clandinin (1990, 2000) and Clandinin et al. (2018) emphasise the importance of relationship between researcher and participants, all participants were offered a second meeting. Before a second meeting, I emailed the participants their transcribed conversation from the previous meeting, allowing them time to read it and provide any amendments for me, and prepare questions for the next meeting. I met a second time with four of the participants; the remaining participants were content with the first meeting. They were happy with their involvement in the inquiry, as they felt they had given me all the information they could provide in the first meeting. Although I did not meet these participants again face to face, contact continued via email conversations. The second meetings followed the same pattern as the first although the second meeting had a familiarity, as we were not strangers meeting for the first time. There was no new information gleaned in the second conversation, more of a confirmation that this was their experience as they had expressed the first time. No points of clarification from the first meeting were required in the second meeting with participants. The duration of the second meeting ranged from 44 to 63 minutes excluding greetings and small talk. With the larger number of participants Table 1 provide an overview of meeting time and the characteristics of the participants collected using the personal data form (Appendix 9).

**Table 1. Characteristics of participants and interview length**

No	Gender	Marital status	Age*	Interview		Setting of Cardiac Arrest		Time of Arrest	
				Method	Minutes	In hospital	Out of hospital	Month	Year
1	Male	Widower	92	F2F	58		Yes	June	1982
2	Male	Married	73	F2F	73		Yes	April	2001
3	Female	Married	51	F2F	67	Yes		May	2006
4	Male	Partner	59	F2F	78+44**		Yes	June	2008
5	Female	Single	63	F2F	62	Yes		October	2008
6	Male	Single	75	F2F	108	Yes		August	2010
7	Male	Married	64	Skype	93		Yes	December	2010
8	Male	Married	59	F2F	67		Yes	April	2011
9	Male	Married	58	F2F	63+46**		Yes	October	2014
10	Male	Married	48	F2F	169		Yes	December	2014
11	Female	Single	66	F2F	52	Yes		December	2014
12	Male	Married	57	F2F	229		Yes	April	2015
13	Male	Married	71	F2F	90+63**		Yes	November	2015
14	Female	Married	76	F2F	59+47**	Yes		December	2015
15	Male	Married	62	Skype	71		Yes	February	2017
16	Male	Married	64	F2F	73		Yes	February	2017
17	Male	Married	70	Skype	103		Yes	March	2017

\* Age at time of interview. \*\* Participated in two interviews. F2F: Face to face meeting.

In order to provide insight as to how the event had changed their lives during the interviews, participants told their stories starting with their life before the cardiac arrest. This was important, as it contextualised the three-dimensions of narrative inquiry, how time, place and sociality are intertwined in their continued experience of surviving a cardiac arrest. All of the participants agreed with the content of their narratives that had been created from the conversational interview and have not asked for changes. Hence, the interview and conversation process have been a positive experience for me. Throughout participant recruitment and field text collection, and after each meeting with the

participants', as well as during analysis, I kept a journal noting my thoughts, voice and feelings as I progressed through this study. From this journal I was able to reflect and consider how my own thoughts and voice in the written narrative might influence the interpretation of the collected and analysed field texts. The concept of voice as previously stated is an important consideration in composing research texts. As a narrative inquiry researcher, I needed to have a presence in the text but not an overwhelming presence that diminished the voice of my participants. The mere presence of me as a listener and how the participants relate to me will influence how much information is presented in their stories.

## **FIELD TEXT ANALYSIS METHODS**

In discussing how I analysed the field text used in this narrative inquiry research, it is important to inform how my conversations changed to field texts (Clandinin, 2013; Clandinin & Connelly, 2000). After meeting with each participant, I started to listen to the audio recordings of the conversations and transcribing them word for word. I personally transcribed the audiotaped conversations within a week of the conversation. The transcription of these conversations gave me a deeper understanding of the stories. I noted nuances such as repetitions and pauses in the conversation that were not noted during the face-to-face meetings. I noted changes in tone or emotions displayed, such as laughing, in the recorded conversation.

After the transcription process, I read and re-read the transcription multiple times, familiarising myself with the language the participant used, ensuring that I used the participants' own words to construct their narratives of experience. I kept the original

transcript as a reference, since in narrative inquiry my presence as the researcher is not invisible and it is accepted that my presence and personality, will contribute to the conversation (Clandinin, 2013; Clandinin & Connelly, 2000). I used the participants' words to form a narrative that captured the personality and experience of the individual. I focused on each participant's narrative in its own entity; to make sure I was not influenced by the other participants' stories at the time.

Once the stories had been read by the participants and agreed upon for accuracy, they became the field texts that I worked with during this inquiry. In the seventeen stories of surviving a cardiac arrest there was a large amount of field text. Time as a dimension of narrative inquiry seemed a natural way to separate the field text into meaningful and manageable components. Participants seemed to naturally separate into two groups: those participants who had a cardiac arrest recently (within the last five years) and participants who had survived a cardiac arrest that occurred more than five years ago (seven participants). Therefore, it seemed logical to explore these long term survivors as a separate group from more recent survivors.

As for the three-dimensional narrative inquiry, when analysing participants' words, I considered their stories across time from the event to the present as well as my own past and how the past impacted on the present situation and future choices. For place, I took into consideration where participants' experiences of a cardiac arrest unfolded, among people in the community, in their home or in hospital, their continued living place and where our conversation took place. For sociality, I looked at their external influences, such as hospitals (institutional) and cultural relationships and the relationships participants had with

caregivers and loved ones, their hopes, feelings and desires in the stories they told me, as well as the relationship they had with me as the researcher.

### **JUSTIFICATION: ‘SO WHAT?’ AND ‘WHO CARES?’**

For this research study, the field text was analysed through three levels of analysis in order to address the three kinds of justification required to support the findings: the personal, the practical and the social (Clandinin, 2013; Clandinin, Pushor & Murray Orr, 2007). The first level of analysis, the personal justification, is for me, the researcher, situating myself in the research puzzle (Clandinin, 2013; Clandinin et al., 2007). By reading and re-reading each one of the participants’ stories in the selected group of participants, together with my journal and autobiography (Chapter 1), I engaged in the story, paying attention to my own feelings, wonderings, and to each participant’s language. Within their stories I considered my own reflective thoughts and observations. Hence, my analysis stemmed from my first personal thought and response to the story I was reading.

In the second level, the practical justification of the research, the field text is scanned in this research study to determine how the participants’ experiences might impact on the future care of survivors of a cardiac arrest (Clandinin et al., 2007). Thereby in this justification I revisited each participant’s story, exploring from a wider healthcare professional viewpoint. I returned to my own personal encounters trying to remember how I interpreted these stories and my own experiences as a registered nurse. While contemplating the practical justification I also returned to the literature review in Chapter

Two, to explore the concepts participants had raised in previous research exploring and investigating the experience of a cardiac arrest.

Lastly, the social justification, a step to explore the social perspective and the “So what?” and “Who cares?” questions (Clandinin, 2013; Clandinin et al., 2007). In this process, I was exploring the narratives and how they reflect not only on society but also in the healthcare context. The narrative threads that became visible, not only within individual stories but also seen across multiple narratives were explored in depth, while considering implications on a larger scale. The key findings from these narrative threads are presented in the findings chapter with three published articles through experiences over time. The findings are presented in terms of importance from the participants’ shared stories in providing person centred care after the cardiac arrest event and how surviving a cardiac arrest influences future quality of life.

The justification of “so what’ and “who cares” also influenced my desire to have my findings published in nursing journals. The ‘learning through experience’ that is part of Connelly and Clandinin’s (1990, 2000) narrative inquiry, influenced by Dewey’s (1938) theory of learning, guided me in a modified approach to this study.

## **PERSONAL REFLECTION AND THE RELATIONAL FEATURES OF NARRATIVE INQUIRY**

Throughout this research journey, I have reflected on my own personal and professional experiences of healthcare from the perspective of a registered nurse who delivered care to people who had survived a cardiac arrest, as a lecturer who informs, educates and shapes the future of nurses and as a researcher who expands nursing

knowledge. As a narrative inquiry researcher, I include and am open in my own ontology involving feelings and experiences during the research time, especially with my chosen theoretical framework (Clandinin, 2013; Clandinin & Connelly, 2000). I am also in this inquiry conscious of the epistemological dimension and privilege of co-creating knowledge with my participants. While conducting the study I am mindful not to make assumptions about participants' feelings and experiences, ensuring that while I was analysing each field text, I was present and engaged in their narratives accurately representing their voice and accounts of the event, being careful not to let my voice dominate the narrative, thereby ensuring the trustworthiness of this research.

The relational features of the three-dimensions of narrative inquiry and the relational aspects between participants and researcher are an ongoing exploration throughout this research puzzle. As a researcher, by engaging with each participant a relationship is developed, and the participant and I will learn and change during this research encounter (Pinnegar & Daynes, 2007).

## **RIGOUR AND TRUSTWORTHINESS**

During the research puzzle, I used strategies to uphold academic integrity and held a commitment to trustworthiness and rigour. Defined by Lincoln and Guba (1985), trustworthiness is a set of criteria that refers to the quality of research. Included in trustworthiness are credibility, transferability, dependability and confirmability.

Measures were taken to warrant that the findings met the criteria of trustworthiness, including member checks, peer debriefing and prolonged engagement. Member checking is

very much part of narrative inquiry where the participant is involved in the process of verifying accuracy in transcription, field text and findings (Clandinin, 2013; Clandinin & Connelly, 2000). This is to ensure that the participants and the researcher agree with what is presented in their narratives and is visible to the public, and is without vast differences between the researcher's interpretation and the participants' view of their experience. The transcripts, along with narrated drafts and analyses, were presented to the individual participants to ensure an agreement was established before anything was presented in the public domain.

A different criterion of trustworthiness is the prolonged engagement in the research field. Prolonged stay is characterised as spending time within the chosen field to conduct research. This long engagement contributes to building trust within a relationship and knowing the context within which the participants live and operate (Lincoln & Guba, 1985). This collection of field text lasted a little more than one year, followed by another year of analysing the field text, reconnecting with the participants, peer debriefings with supervisors and writing the findings. During this research study, throughout the collection and creation of field text, I have had continued contact with the participants according to their wishes, mostly through emails.

As Pinnegar and Daynes (2007) suggest, narrative inquiry, in both collection and presentation of the field text, allows a clear arena for addressing questions of trustworthiness of the field text and the interpretations. The narrative inquiry [space](#) described by Clandinin and Connelly (2000) prompts the researcher to both “question explanations and meanings constructed and provides the audience with accounts that uncover and reveal questions of meaning, value and integrity” (p.21). As indicated earlier,

field text was transcribed and analysed by me. In narrative inquiry the text is repeatedly analysed using multiple lenses. The three-dimensions of time, place and sociality to analyse the field text, secondly the search for reoccurring threads and thirdly, the final lens looked deeper into the social dimension searching inward for emotions, reactions and moral responses, including the language and the non-verbal cues used and searching outward exploring the surroundings influence of the event and how it affected the people. This approach helped minimise any uncertainties of mine and helped find inconsistencies in the field notes. To have engaged in this process increased and strengthened the rigor of the research study.

Part of the academic integrity in this research puzzle includes ongoing peer reviews and debriefing sessions with my supervisors. In these peer review and debriefing sessions, the work was reviewed, reflected and input offered while conducting the research (Creswell, 2012). Peers in this research puzzle include qualitative educators and supervisors, co-workers who were familiar with qualitative methods and reviewers of manuscripts for publication. Having external sources, such as journal reviewers review the analytic processes and claims provides additional perspectives (Creswell, 2012; Lincoln & Guba, 1985) and increases trustworthiness and rigor in this research puzzle.

## **ETHICAL CONSIDERATIONS**

### **THE IMPORTANCE OF THE RELATIONAL ASPECTS THROUGHOUT THE INQUIRY**

With the relational aspects of narrative inquiry, where the researcher's intent is to start a relationship with the participants, a reminder for the researcher of the relational ethical responsibilities is warranted. As the researcher and participant come to know each other as individuals a relationship is created, and as all relationships are different, some very positive and some less so, neither researchers nor participants will return from the inquiry unchanged. The researcher needs to have awareness and has the responsibility to create a sound and equal relationship where the participant can enter and leave the inquiry comfortably (Clandinin, 2013).

Throughout the study I, the researcher, was not involved in any coercion of participants. During the collection of field text and when the constructed narratives were shared with each individual for confirmation of their participation, there were no negative consequences stated by the participants. Each participant was informed from the beginning that if they experienced any emotional distress during the conversation discussing their experience of a cardiac arrest and resulting CPR, they had the option of pausing the conversation temporarily, or withdrawing permanently from the research without any questions being asked. If a participant became distressed during the conversation or during analysis, I ensured that I had information to refer them to professional support if needed. The intent was for each participant to feel valued and respected for his or her participation in this research puzzle. During a long collection time of field text, consent was re-evaluated

with the participants, ensuring they were still comfortable with taking part in the research. In any ongoing contact I reiterated that participation in the study was voluntary and I was mindful not to breach the confidentiality of the participants.

I sought ethics approval from the University of Newcastle Human research Ethics Committee (HREC) before commencing the inquiry and ethics was approved on the 10 June 2015 (H-2015-0132, see Appendix 5). HREC guidelines were followed as per ethical approval. The audio-recordings of the conversations and the transcribed field notes have been saved as password protected documents on my university's cloud storage service 'OneDrive'. The signed consent forms and identifiers are stored for five years as per the ethics approval and National Health and Medical Research Council (NHMRC) guidelines.

## **LIMITATIONS AND STRENGTHS OF NARRATIVE INQUIRY**

There are both limitations and strengths in using a modified approach to Clandinin and Connelly's (1990, 2000) and Clandinin's (2013) narrative inquiry to answer the research puzzle. The epistemological assumption of narrative inquiry accepts the notion that people make sense of random experiences, using story structures (Bell, 2002). The key strength of narrative inquiry in this research is that it has allowed an in-depth exploration of a major, traumatic life experience that has not been well understood from the perspective of the survivors or cardiac arrest. This research values the views of the survivors.

In narrative inquiry stories provide an opportunity where complex experiences, both real and created can be explored to make sense and meaning (Clandinin et al., 2018). It is

impossible for the storyteller to tell the whole story as what is told may not even be the complete true story, it reflects what the storyteller finds important (Brushwood, Rose & Granger, 2013; Clandinin, Caine & Lessard, 2018). The remembered story is inevitably incomplete, there may be memory gaps and parts the teller does not want to reveal. What remains untold or silent in a story, can both create and undermine the fullness of the story (Brushwood et al., 2013; Clandinin, 2013). By providing multiple opportunities for the storyteller to repeat the story a more complete story may emerge. Providing the storyteller with a transcript provides a further opportunity for clarification and may also remind the teller about further details missed in the story (Brushwood et al., 2013).

However, the telling of and listening to the stories is important and can be transformative and helpful for both the teller and listener. As listeners we select elements of experiences and attend to the structure of those experiences, and those structures are then replicated as the listener tells the story (Bell, 2002, Clandinin, 2013). While engaging in and interpreting the stories, we, as researchers, need to resist the temptation to interpret them as clear representations of their experience or the event (Brushwood et al., 2013), instead use the three-dimensional framework to see beyond the obvious story (Clandinin & Connelly, 2000).

Clandinin and Connelly's (1990, 2000) narrative inquiry embrace a longer engagement and fewer participants within the inquiry compared to other narrative inquirers such as Daiute (2014) Pinnegar and Daynes (2007) as well as Riessman (2007). This can be seen both as a limitation and strength. A research project with a longer time span has potential to provide insight that is not available if there is limited time for the participant to develop trust and become comfortable in conversations with the researcher (Clandinin,

2013). The large number of interested participants required me to use a modified adaptation of Clandinin and Connelly's narrative inquiry. Instead of presenting the findings as a long story and analysed narrative from each participant, I drew on and presented conversation extracts that encapsulated the found threads from participants. While adhering to the three-dimensional space, the identified threads from the participants' stories were grouped together and presented as narrative plotlines. This modified narrative inquiry maintains Clandinin and Connelly's influence by Dewey's philosophy stating that our experiences influences how we learn, behave and react from previous experiences. The presentation of findings aims to expose the experiences of surviving a cardiac arrest and what we can learn from the participants' experiences. Strength is the presentation of findings in a narrative form which can make the findings more accessible to a broader audience and increase the uptake of the generated findings (Pinnegar & Daynes, 2007).

Pinnegar and Daynes (2007) recognise narrative inquiries variable nature of knowledge, accepting and valuing that "narrative inquiry allows wondering, tentativeness and alternative views to exist as part of the research account" (p. 25) and also recognise that the consumer of narrative inquiry research will determine the value of findings.

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*During my candidature, as I explored the literature and immersed myself in the value of narrative inquiry as a methodology in, I found it to be well suited to nursing research. The opportunity to use narrative inquiry to explore patients' illness experiences by listening to their stories and understanding what is important from their point of view, highlighted the practicality of this methodology. Having said this though, I had to modify Connelly and Clandinin's narrative inquiry to accommodate the larger number of participants than is usually the case and amend the narrative findings to accommodate publishing the findings to inform a wider audience. This augmented the usefulness of narrative inquiry in nursing research in line with Clandinin's "so what" and "who cares" discourse. I published the article titled 'Narrative inquiry as a research methodology, exploring person centred care in nursing' in Collegian in 2018 and is presented below.*

*~~~*

## **PUBLICATION: NARRATIVE INQUIRY AS A RESEARCH METHODOLOGY EXPLORING PERSON CENTRED CARE IN NURSING**

*During my candidature, as I immersed myself in the usefulness of narrative inquiry as a methodology in research and explored the literature and learned more of narrative inquiry, I found it to be well suited to nursing research. The opportunity to use narrative inquiry to explore patients' illness experiences by listening to their stories and understanding what is important from their point of view highlighted the practicality of this methodology. Therefore, as I explored the utility of narrative inquiry and how well my participants responded to the inquiry, I found there was a need to inform fellow researchers and promote the usefulness of narrative inquiry in nursing research. This article titled 'Narrative inquiry as a research methodology, exploring person centred care in nursing' was published in Collegian in 2018 augmenting the usefulness of narrative inquiry in nursing and health research.*

### **The impact of the article**

At the time of thesis submission this article '*Narrative inquiry as a research methodology exploring person centred care in nursing*' has 13 citation Scopus, 120 in Google scholar and a Field Weighted Citation Impact of 6.9, and a Prominence percentile: 98.093

In ResearchGate this article has 4208 reads and 44 citations

### **Author contribution see appendix 13**

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# Narrative inquiry as a research methodology exploring person centred care in nursing

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## ABSTRACT

**Background:** Although, person centred care has for a long time been an important approach to nursing care, it is often not a reality in the clinical environment. The focus of health research has, until recently, been on the physical aspects of a persons' illness and this has influenced how care is delivered. There is a need to broaden the focus from the illness to the person who is ill. A holistic approach to the persons' social and cultural experience of their illness will aid health care professions to provide person centred care.

This paper will make the argument that narrative inquiry is a well suited to health care research in general and nursing research in particular as it focuses its inquiry on the individual person's experience of their illness – 'what matters' from the person's point of view. Narrative inquiry explores the narrative from a temporal, social and spatial view.

**Conclusions:** There is a need to find what is important from the patients' 'point of view' to optimise care. Narrative Inquiry is a methodology often used in education and sociology. It is a gentle relational methodology that has the capability to uncover what is important to the person in their situation. The research findings are presented narratively, that is, informally and engagingly for the consumer of the research.

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## 1. Introduction

Person centred care was first introduced by Kitwood (1993) who argued that categorising people with dementia in medical terms reduced them to objects, this resulted in them losing their personhood. More recently person centeredness has become an important approach to the delivery of care in all areas of nursing. Person centred approach to nursing focuses on the person's needs and goals, placing them at the centre of their care. The person's needs, as they define them, take priority. Person centred care values the involvement of the person in every stage of their health care. Just to allow someone to speak is not person-centred. Person centeredness means really listening and valuing what the person experiences and making their wishes central to decisions about care (Ekman et al., 2011).

People often feel a need to tell the stories of their illness and these narratives can be used to explore their experiences and

improve nursing care. Broyard (1992) asserts that "Storytelling seems to be a natural reaction to illness. People bleed stories, ..." (p. 21) and Frank reminds us (1995) "Whether ill people want to tell stories or not, illness calls for stories." (p. 55).

Although the concept of person centred care has been essential to the philosophy of nursing since the mid-nineties (Binnie and Titchen, 1999; Pence, 1997) clinical nurses have been slow to embrace it (Browne and Hemsley, 2008; Entwistle & Watt, 2013). Care decisions, to be person centred, need to acknowledge the unique individual person in care and not to undervalue their experience by objectifying and treating them as diagnostic labels. To include the person's illness and social narrative, and acknowledge their needs and wishes, contributes to person centred care (Ekman et al., 2011; Hsu & McCormack, 2012; Schwind, Fredericks, Metersky, & Porzuczek, 2016). Although person centred care was introduced as a gold standard for institutional care in the early 1990s (Ekman et al., 2011), there is limited evidence to guide nurses in what person centred care entails.

The relational properties of narrative inquiry provide both researcher and participant with a foundation to engage and to develop connections; hence a broader understanding of the phenomena under investigation is established. Narrative inquiry is a well suited methodology with its possibilities to gather rich data

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of personal experiences to explore what the recipient of care values. Though there is a body of literature exploring narrative inquiry (Clandinin, 2007, 2013; Green & Thorogood, 2004; Wang & Geale, 2015) there is still limited use in nursing research around the patients' experience of illness and care. The views expressed in this paper are informed by Connelly and Clandinin, 1990 and Clandinin (2007, 2013)

approach and argues for narrative inquiries usefulness in nursing research, especially when exploring person centeredness.

## 2. Background

Narrative inquiry, located in the interpretive paradigm, explores the experience of an individual and how their physical, social, and cultural environment impacts and shapes their individual experiences. There are different approaches or frameworks to narrative inquiry: for example, Riessman (2008) is prominent in sociology research and Czarniawska (2004) use narrative inquiry to explore organisational narratives.

Connelly and Clandinin's framework is informed by Dewey's (1938) 'theory of experience' and 'the criteria of continuity'. "... narrative inquiry is a way to understand experience and a way to study experience" (Clandinin, 2013, p. 15). Connelly and Clandinin's (1990, 2000) and Clandinin (2006, 2007, 2013) approach is unique in that they view the narrative as a whole, that is, it does not involve a dichotomy of separate themes or categories, instead threads of stories that are synthesised through a dimension of inquiry of temporality, sociality and spatiality – described in detail below.

Connelly and Clandinin's approach has been used successfully in sociology and educational research (Clandinin, 2006; Clandinin & Rosiek, 2007). Narrative inquiry research has supported curriculum development (Connelly & Clandinin, 1990; Lessard, Caine, & Clandinin, 2015), practice development in mental health (Grant, Biley, Leigh-Phippard, & Walker, 2012) and in exploring the therapeutic relationship in nursing (Haydon and van der Riet, 2014; Haydon, van der Riet, & Browne, 2015; Shields et al., 2015). Work environment for newly graduated nurses (Law and Chan, 2016; Lindsay & Schwind, 2016) communication and time management (Chan, Jones, & Wong, 2013) have also been explored. The use of narrative inquiry research into family members (van der Riet, Jitsacorn, Junlapeeya, Thursby, & Thursby, 2015) and the nurses' experience of a Fairy Garden for sick children in a hospital setting (van der Riet, Jitsacorn, Junlapeeya, Dedkhard, & Thursby, 2014) revealed how through narratives social, cultural and environmental surroundings shape the individual's experience.

In Connelly and Clandinin's approach to narrative inquiry a person's current experience, is viewed as a direct product of their previous experiences and is "Honouring lived experience as a source of important knowledge and understanding" (Clandinin, 2013, p. 17). Clandinin and Connelly first published narrative inquiry in the 1990s and they have continued to develop narrative inquiry as a methodology. From the beginning it was clear that narrative inquiry is a "way of understanding and inquiring into experiences" (Clandinin, 2013, p. 13) and they have, over time, highlighted the relational aspects of narrative inquiry (temporality, sociality and spatiality) including the relational aspect between the researcher and participant (Josselson, 2007). The narrative inquirer sees research as a puzzle whereby both researcher and participant add pieces to the 'whole' to create a clearer narrative of the experience under study.

There is a notion that experiences will change and that there is no absolute truth to be found (Clandinin, 2013). Understanding of experiences as narratives, and findings from these narratives will support and strengthen future knowledge, inform decisions and contribute to practice development (Clandinin, 2013). Clandinin

and Rosiek (2007) argue "... the focus of narrative inquiry is not only on individual's experience but also on the social, cultural and institutional narratives within the individuals' experiences of which are constituted, shaped, expressed and enacted. Narrative inquiry is the study the individual's experience in the world..." (p. 42). Using narrative inquiry to explore an individual's experience of healthcare can find where and what are the important parts of person centred care. The narrative of a person with a health problem is a recount of their individual experience of their situation, influenced both by surrounding, such as hospitals, homecare and GP surgeries, previous illness experiences, significant others and life experience. The connectedness between these dimensions is observable in the final narrative and can provide a rich detailed view of the person's illness experience.

## 3. Narrative inquiry

The inclusion of social, cultural and environmental influences on experiences makes narrative inquiry particularly suitable for research in health as it incorporates all dimensions that impact the person's experience. These human experiences are captured in the living and telling of narratives, and can be studied by listening, observing, reading and interpreting text. Narrative inquiry is a way to understand experience and a way to study experience (Clandinin, 2006, 2007, 2013; Clandinin & Connelly, 1990, 2000).

In narrative inquiry the researcher does not observe the participant objectively; instead they take a subjective position in connecting relationally with the participants' social and private world (Clandinin, 2006; Pinnegar & Daynes, 2007). Narrative inquiry can capture the experiences of people cared for by nurses, and thereby provide a better understanding of what the person sees as vital components of their care.

By using the narrative inquiry approach of Clandinin (2006, 2007, 2013) the researcher invites individuals to tell their stories and presents them, using a framework of temporality, sociality and spatiality, to allow a deeper understanding of their experience. These stories can bridge the gap of nurses' exposure to people's narratives and provide nursing staff with an understanding of the person's experience in their care. Ekman et al. (2011) illustrate the power of illness narratives when they argue that the narrative can consider the persons wishes and desires in planning future care. By narratively describing the person's situation, it becomes clear where their wishes collide with and bump up against the healthcare providers' view, and changes can be made to accommodate a person centred care approach.

## 4. Methods in narrative inquiry

'Relational' is a term used in narrative inquiry; it focuses on two different areas which can be confusing to one new to narrative inquiry. Relational refers both to the relation between researcher and participant as well as the relations between the interwoven dimensions of inquiry in to temporality, sociality and spatiality.

One of the characteristics of narrative inquiry is that, during the data collection phase of narrative inquiry, there are multiple meetings between participant and researcher. In health research, patients often are in a vulnerable position with their bodies exposed to vulnerable procedures. The challenge is to attain equality in the relationship. This relational perspective within narrative inquiry during the research process gives participants' time to build a relationship, importantly of trust with the researcher and share their story, resulting in greater depth and richness in the data/field text collected. In Clandinin's (2013) approach to narrative enquiry the term data is replaced with the term field text. Narrative inquiry has the potential to provide a connection that offers participants

the security needed to be truly open in sharing their narratives (Clandinin, 2013). This relationship provides a platform where exploration of the people's experience can help to discover the essential needs of person centred care. This relational element also recognises the influence the researcher has on the participants' narrative and there is visibility of the researcher in published findings (Clandinin, 2013).

Often narrative inquiry research has a few participants, sometimes only one but more commonly 4–6 participants. The in-depth collaboration between researcher and participant during data collection and processing of narrative inquiry limits the number of participants and the inclusion of the three dimensions in narrative inquiry creates a longer and detailed presentation of findings (Ely, 2007). Clandinin (2013) also highlights the absence of a research question and use the term research puzzle as there is no absolute answer or truth to be given. Cultural and environmental changes over time will undoubtedly change how individuals perceive their situation, and with that their narrative will change.

## 5. The building blocks of narrative inquiry

An important and central component in narrative inquiry as described by Clandinin and Connelly (1990, 2000) and Clandinin (2013) is the concept of the relation between temporality, sociality and spatiality. A narrative will be explored in relation to the three dimensions, sometimes revealing a stronger influence from one of these dimensions; however, importantly the interconnectedness of the dimension is always present. This creates a commonplace of a three-dimensional inquiry space of temporality, sociality and spatiality with the researcher attending to storylines of past present and future, inner and outer emotions and place (Clandinin, 2013).

### 5.1. Temporality – past, present and future

People live a continuous narrative and the narratives are often expressed as memories from the past. However, when narratives are told, the experience will be remembered and subtle changes are often being made to accommodate for new experiences. The temporal aspect will also involve the social change that happens over time; when people recall their stories they composed some time ago, social changes becomes obvious and what was socially accepted then might no longer be valid. Past experiences will also influence how future events are perceived (Clandinin, 2007, 2013; Clandinin & Connelly, 1990, 2000). In hospital settings, past experiences may have an influence of the person's expectations of future care, and these past experiences provide depth to the person's narrative.

### 5.2. Sociality – the personal, social and cultural

Societies use people's interaction, understandings and perception of their environment to build their social framework. Individuals' experiences are articulated in narratives; as social norms change so do their narratives. Depending on who the audience is, the narrative will change. Narratives are central to our identity and self, our experiences are understood through narrative – not necessarily as verbalised; people think and dream narratively. While telling and listening to narratives, people narratively construct, and repeatedly re-construct their identity and who they socially are connected to. People make sense of their experiences by telling narratives. An important part of a person's narrative includes the audience, be it the researcher, a family member or a stranger, and this will undoubtedly influence how the narrative is told.

### 5.3. Spatiality – environment and institution

The environment, spatiality, will also influence how the event is experienced by the person involved.

Past involvements from institutions, such as schools and hospitals, will also impact on the persons' experience. This might be reflected in their story and is often described in detail by participants in research. Later, when the experience is recounted and told, the environment where the narrative is told will also influence how it is presented to the audience (Clandinin, 2007, 2013; Clandinin & Connelly, 1990, 2000; Edvardsson, Rasmussen, & Riessman, 2003). Not everybody finds the hospital setting safe and comfortable. For many individuals the institutional experience can be overwhelming – it can be a harsh and an alien environment.

### 5.4. Emplotment

Emplotment is the merger of multiple dialogues/conversations into one narrative that encompasses the events conversed, though presented in a sequence that creates a narrative plot (Tropea, 2011). A narrative without a plot would be a string of words with no meaning (Mattingly, 1994; Tropea, 2011). A plot emphasises events and moves the narrative forward, highlighting both connections and tensions within the narrative.

The promotion, and collection, of peoples' narratives about their health could contribute to improved care and thereby patient satisfaction. The emplotment of these, often short narratives, will create informative narratives of the person's reality, improving patient-nurse communication. Emplotment offers a way of improving fragmented, scattered and sometimes contradictory communication to understandable narratives (Tropea, 2011). The therapeutic properties of storytelling should not be underestimated. Often a narrative is told more than once and for each time the 'reality' of the story becomes clearer, both for the narrator and the listener. For example, after a cardiac arrest there is memory gap that needs to be filled in order for the person to regain an embodied temporal feeling of reality. The retelling of the narrative could support the person in this endeavour and support healing (Mattingly, 1994). Often a narrative is told more than once and for each time the 'reality' of the narrative often becomes clearer, both for the narrator and the listener.

## 6. Presentation of findings

"Narrative enquiry provides powerful data to answer important research questions meaningfully" (Berry, 2016, p. 14). The presentation of findings by emplotment of the participant's stories constructs a narrative that is easy to comprehend for the reader of the research. The presentations include the researcher as a visible participant. Clandinin and Connelly's (2000) framework of narrative inquiry identify the importance of this relationship by including the researcher in the findings. Clandinin (2013) highlights this co-construction and argues that the collaboration with the participant as vital in the final presentation of the research narrative. Findings are presented as a narrative account shared between the researcher and participant. The presentation in a narrative form can be deceiving in its simplicity for the reader of research and be dismissed as a simple recount of an event. There is, however, a substantial amount of work preceding the narrative presentation to dismantle irrelevant data and allow the significant narrative to emerge.

### 6.1. Credibility of narrative inquiry in nursing research

To address the credibility of narrative inquiry as an appropriate methodology, the researcher needs to consider the suitability

of narrative inquiry in its ability to answer the research question/puzzle, how the data is collected, analysed and presented, and whether the findings and conclusion provides useable information (Leung, 2015). Narrative inquiry with its relational aspects provides an opportunity for the researcher to build a relationship with the participant over a longer period and thereby collect a richer and deeper story that can extract 'hidden' concerns not disclosed during a shorter data collection time. The relational dimensions between temporality, spatiality and sociality also explore how these dimensions influence the person's illness experience (Clandinin, 2013). This deeper understanding may inform future research, perhaps policy making and person centred care.

The longer data collection time also provides the participant with an opportunity to collaborate and confirm previous collected data. Regular checking of stories leads to rigour in narrative inquiry. Baillie (2015) together with Berry (2016) argues that this longer collaboration between participant and researcher could influence the data collection where the researcher unwittingly influences the participant. However, the value of this close relationship between narrative inquiry researchers and participants often outweighs the negative aspects (Clandinin, Murphy, Huber, & Orr, 2009). The use of a research diary as a strategy of reflectivity has been recommended as 'preventative' tool (Baillie, 2015) and, therefore ensuring credibility and rigour of the research.

## 7. Ethics

A concern with the relational and closer collaboration with the participants is an ethical dilemma, both on a relationship level with the participant and the use of the participant's narrative (Josselson, 2007). The narrative presentation of research findings can 'blur' who the author is; the participant or the researcher? In the narrative presentation of findings, it has to be clear where the participants' narrative is and where the researchers' findings are (Berry, 2016; Josselson, 2007). On the personal level the longer and often deep conversations can be misinterpreted by the participant as friendship. This becomes a dilemma, often highlighted at the end of data collection when the researchers end the collaboration. It is important to make it clear from the beginning and repeated during data collection what the purposes of these meetings are (Berry, 2016; Josselson, 2007). However, the benefit of this close researcher-participant relationship reduce this ethical concern of over attachment and involvement (Josselson, 2007).

Narrative inquiry is more than longer data collection. In Clandinin's (2013) view the researcher intentionally lives alongside the participant in their co-creation of their stories. This longer data collection time works well when exploring the person's experiences of chronic disease. However, the relational aspects between temporality, spatiality and sociality can be used with a single interview to explore an individual's experience (Crowfoot, van der Riet, & Maguire, 2016).

## 8. Discussion

There is an emerging trend to use narrative inquiry in nursing research, often used to explore nurses' experiences (Chan et al., 2013; Haydon & van der Riet, 2014; Haydon et al., 2015; Law and Chan, 2016; Edvardsson et al., 2003; Lindsay and Schwind, 2016; Shields et al., 2015; van der Riet et al., 2014), less exploring the individuals unique experience of illness and care (Hsu and McCormack, 2012; Schwind et al., 2016). Narrative inquiry is a suitable methodology for understanding individuals' experiences of illness and health care and thereby provides essential knowledge to develop person centred care directives. To deliver person centred

care, there is a need to identify what person centred care is from a patients point of view.

Narrative inquiry as a methodology takes account all dimensions that influence the narrative, such as hospital environment and social interaction. This gives the research a broad foundation and conclusions can be drawn on how to best introduce policies that promote person centred care. The influence of the hospital environment and social interaction from health care personnel could have a profound influence in the individuals' illness experience. Connelly and Clandinin (1990, 2000); Connelly and Clandinin, 1990 and Clandinin's (2007, 2013) framework for narrative inquiry is unique and has the potential to shine a light on nursing care from a different angle, giving new insights into a person's experience as a patient.

By using this framework the 'whole' narrative is analysed from the three different dimensions. Often in qualitative research the collected data is dissected into smaller parts to investigate and find themes and patterns. There is a chance that these smaller parts create a distorted conclusion; Such a process can be likened to a picture cut up, examined and reassembled in a way that distorts the findings. When using Connelly and Clandinin's framework the narrative stays intact and the data relating to the different dimensions is drawn from the whole narrative. These dimensions are then put together as the final result. This image focuses not only on the illness but includes the whole personhood; by learning from these narratives, measures can be implemented to deliver a higher standard of person centred care in the future.

The acceptance of a relationship between researcher and participant during the data collection also makes narrative inquiry unique. This relationship continues during the writing phase where the participant has an input into the finished product. The researcher is not silent, in the narrative presentation with both the researcher and participant actively present. Narrative inquiry accepts the influence the researcher (audience) has on the participants' narrative (Clandinin, 2007, 2013; Connelly & Clandinin, 2000). These factors create a finished product that is very different from commonly used methodologies in health care research. With few participants and long presentation of findings narrative inquiry could be viewed as purely descriptive interpretations of experiences. However, the narrative inquiry framework brings a different perspective through the narrative having been explored through the dimensions of temporality spatiality and sociality and thus creates deeper understanding of the participants' experience. There is also a notion that there is no absolute truth to be found, instead of a research question, the research is seen as a research puzzle, where each narrative contributes to a clearer image to be seen; as environment and social norms change over time so does the image (Clandinin, 2013).

## 9. Conclusion

The three dimensions of temporality, sociality and spatiality are interwoven in narrative inquiry and influence how the narrative is presented and received, with the narrative researcher constantly observing these relations and seeing the shift in balance and tensions between them. This awareness creates a narrative that holds the considered persons view; these findings formerly support future implementation of person centred care policies. The individuals' narrative needs to be expressed, listened to with humility and research should capture the vulnerability of these narratives. By capturing these narratives new knowledge can be provided to clinicians. To be able to share the experience of illness often allows the person to gain a better understanding of their situation and improve their quality of life (Bury, 2001; Frank, 1995).

Narrative inquiry presents the research findings in narrative form, encouraging more health professionals to engage with this

research. “These texts are intended to engage audiences to rethink and reimagine the way in which they practice and the ways in which they relate to others” (Clandinin, 2013, p. 51). By that, narrative inquiry can increase understanding and assist all health professionals redefine their practice to better cater for the needs of people during their illness experience, that is, provide and attend to person centred care. Importantly, the therapeutic properties and power of stories should not be underestimated, as stated above “Storytelling seems to be a natural reaction to illness.” (Broyard, 1992, p. 21). As an addition, the retelling of the illness narrative can potentially support the person in acceptance and understanding of their situation.

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## Summary of Chapter Three

*In the beginning of this chapter the methodology, background, contributing authors to narrative inquiry and the theoretical perspective were presented. The subsequent part of the chapter included a detailed account of how the participants were recruited for this study and how the field text was collected and analysed, as well as how ethical considerations and rigour of the research puzzle were maintained. The final part, a published article, highlights the usefulness of native inquiry in health research, and how person centeredness is an integral part of narrative inquiry.*

*The following chapter presents the findings from this narrative inquiry using three published articles. These articles follow the timeline of recovery after a cardiac arrest where the first article focuses on the immediate time before and after the cardiac arrest. The second article explores the transition from hospital to home after the cardiac arrest and the last article presents the findings from the long term survivors' experience.*

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# Presentation of Findings

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*In the previous chapter, Methodology and Method, background, contributing authors to narrative inquiry and the theoretical perspective were presented. The chapter also included a description of how the participants were recruited and how the field text was collected and analysed. Ethical considerations and rigour of the inquiry was also addressed. An article 'Narrative inquiry as a research methodology exploring person centred care in nursing' published in Collegian 2018 concluded the chapter.*

*This chapter presents the findings of my narrative inquiry using three articles. These articles follow the timeline of recovery after a cardiac arrest where the first article aims to explore survivors' experiences of surviving cardiac arrest in the immediate time before and just after the event. This is presented in an article titled 'A narrative inquiry of survivors' experiences of the time just before and after a cardiac arrest' experience' published in Collegian in 2020. The second article titled 'The experience of returning home after surviving cardiac arrest: A narrative inquiry' aimed to explore survivors' experiences of returning home after surviving a cardiac arrest published in Nordic Journal of Nursing Research in 2020. The aim of the last article was to explore how long-term survivors of a cardiac arrest adjusted to their new reality, expressed in their re-storied narratives presented in an article titled, 'Long-term survivors of cardiac arrest: A narrative inquiry' published 2019 in European Journal of Cardiovascular Nursing.*

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## INTRODUCTION

After completing my literature reviews there was ample research with a focus on the quality of life for survivors of a cardiac arrest, however, there was limited knowledge of the experience of surviving and waking up after the event. My narrative inquiry and research puzzle have therefore focused on the experience, seeking to find from the participants' "What is the experience of surviving a cardiac arrest?"

As pointed out in my introductory chapter there was a large interest in this inquiry and all 17 interested individuals fulfilled the inclusion criteria, therefore all were given the opportunity to tell their story in my study. No one withdrew from the study and there was a large amount of field text derived from my conversations with my participants.

To be able to handle such a large amount of field text using narrative inquiry I had to find a solution to how I could make meaning out of all these stories and find the threads without getting lost in all the material. Even with non-related sentences removed there was a very large amount of field text and I found it necessary to divide the field text into something more manageable and used Clandinin and Connelly's (1990, 2000) dimension of 'time' as a thread that weaved throughout this findings chapter. I chose 'time' as it is an often used structure in storytelling and brings a natural progression of my findings to the readers.

The study involved conversations with participants about sensitive subjects such as closeness to death and an existential dimension. For me it was important to build a relationship with each participant. Fortunately, I found Clandinin and Connelly's narrative

inquiry to suit this inquiry as they emphasise the importance of relationship between participant and researcher.

To use 'time' seemed a natural solution as the progression in stories often followed a timeline and an accepted occurrence in storytelling. I decided to break the field text in to three parts where the first part focuses on the immediate time before and after the cardiac arrest. The second article pays attention to the experience of returning home from the hospital and facing the mental and physical changes that are apparent as they return to their home environment. In the last article I present the findings from seven of the participants' experience who had survived longer than five years and their experience as they return to a new normality and acceptance of the experience of surviving cardiac arrest.

## **PUBLICATION: A NARRATIVE INQUIRY OF SURVIVORS' EXPERIENCES OF THE TIME JUST BEFORE AND AFTER A CARDIAC ARREST**

### **The impact of the article**

At the time of thesis submission, the manuscript titled: 'The experience of returning home after surviving cardiac arrest: A narrative inquiry.' has no citations in Scopus and 1 in Google Scholar. The article has no Field Weighted Citation Impact and no Prominence percentile as it is just recently published.

In Research gate the article has 7 reads

### **Author contribution see appendix 4**

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## A narrative inquiry of survivors' experiences of the time just before and after a cardiac arrest

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### ABSTRACT

**Background:** There is extensive research on factors influencing cardiac arrest, however, there is limited understanding of survivors' experiences of cardiac arrest.

**Aim:** To explore survivors' experiences of surviving cardiac arrest in the immediate time before and just after the event.

**Methods:** Using a narrative inquiry approach individual face-to-face interviews were held from November 2016 to June 2017. A convenience sample of four females and thirteen males were recruited from the community using a newspaper article and snowball sampling techniques. Participants were aged between 48 and 92 years and experienced a cardiac arrest between 3 months and 36 years ago. Collected field text were analysed adhering to Clandinin and Connelly's narrative inquiry exploring how physical, social and cultural environment, and time impact and shape individual experiences.

**Findings:** Narrative exploration of the experiences of cardiac arrest revealed survivors were unprepared and confused as a result of the event. Survivors found themselves in a liminal space, of between and between involving 'what was' and 'what will be'. Seven threads were identified: Ordinary to extraordinary, Cardiac pain, Waking up in chaos, Resuscitation pain, Drawing on spirituality, Luck, and Surviving death.

**Discussion:** The experiences of surviving a cardiac arrest influence follow-up care needed. Nurses and other clinicians need to have a holistic view of the survivor, as the experience of cardiac arrest is an extraordinary time in an individual's life, especially in the immediate period following the arrest.

**Conclusion:** A cardiac arrest transforms the ordinary to the extraordinary. Surviving a cardiac arrest is confusing, and survivors have to adapt to a new reality resulting in a liminal transition that is complex. Existential questions about luck, spirituality and survival are intense.

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### 1. Introduction

Globally, cardiac arrest (CA) is a large health problem. Published data report a combined annual total incidence of CA in United States, Europe and Australia as approximately 824,000 cases (Benjamin et al., 2017; Gräsner et al., 2016; Wong et al., 2019). Survival rates vary between in-patient and out-of-hospital CA. Survival rates after out-of-hospital cardiac arrest are low; estimated to be between 8% and 13% worldwide (Berger, 2017; Gräsner et al., 2016; Myat, Song, & Rea, 2018). A study involving 27 European countries exploring out-of-hospital cardiac arrest survival during October

2014, found a 10.3% survival rate after 30 days (Gräsner et al., 2016). In-hospital cardiac arrests have a higher 30 day survival rate ranging from 20% to 26% (Berger, 2017; Memar et al., 2018). Multiple factors influence CA survival, including hospital size and location (Del Rios et al., 2019) and technology, such as extracorporeal cardiopulmonary resuscitation (Chen et al., 2019). Still, the outcome after CA is capricious and spans from no physical or mental deficits to severe physical or cognitive impairment and death; how well an individual will recover is largely unknown (Kazaure, Roman, & Sosa, 2013; Wallin, Larsson, Rubertsson, & Kristofferzon, 2014). Nevertheless, with an increased awareness of CA symptoms, cardiopulmonary resuscitation (CPR) education, increased availability of automated external defibrillators and greater bystander participation, there is a positive survival trend (Benjamin et al., 2017; Karlsson et al., 2019; Myat et al., 2018). Nurses and other clinicians working in high acuity care environments and in cardiac rehabili-

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### Issue

• Cardiac arrest is well researched, however little is known about how the event is experienced by survivors. Exploring the experiences from cardiac arrest survivors' perspectives is important to optimise care, recovery and quality of life for this group of people.

### What is already known?

- During hospital stay, psychological, social and cultural needs influence patients' wellbeing and impact their ability to do everyday activities. Holistic care improves health outcomes by addressing patients' physical, emotional, social and spiritual needs and supports them to manage their ailments, thereby increasing their quality of life.
- Lack of support for survivors in the initial recovery, increases health problems, reduces employment and quality of life compared with the general population.

### What does this paper add?

- Surviving a cardiac arrest involves a transformation from the ordinary to extraordinary with a return to a reality engulfed in chaos and ambiguity, where 'luck' and 'spirituality' are questioned together with the knowledge of having survived a certain death.
- Cardiac arrest survivors find themselves betwixt and between, in a liminal space of chaos and confusion, in a vulnerable position as they face an uncertain recovery and future.
- Nurses and other clinicians need to have a holistic view of the survivor, acknowledging that this is an extraordinary time in an individual's life.
- Support services, such as cardiac rehabilitation should be routinely utilised for cardiac arrest survivors in the early stages of recovery to support the transition to their new reality.

tation services will encounter survivors of CA and with enhanced knowledge of the experience from the survivor's perspective can improve care provided.

Valuable knowledge to help support new CA survivors can be found in the stories of those who have survived the event. Narrative inquiry as a methodological approach provides an opportunity to explore dimensions that are noticeable in conversations and is well suited to health research where healthcare experiences are the focus (Haydon, Browne, & van der Riet, 2017). Using a narrative inquiry approach, conversational data collection provides participants following a CA with the opportunity to express their story as they return to a reality of what really mattered to them in their adaptation to this unexpected event.

## 2. Aim

To explore survivors' experiences of surviving cardiac arrest in the immediate time before and just after the event.

## 3. Methodology/method

### 3.1. Design

This qualitative research was informed by Clandinin and Connelly (2000) and Clandinin's (2013) approach to narrative inquiry where in-depth conversations were analysed using the dimensions of sociality, place and time.

### 3.2. Methodology

Medical outcomes and efficacy are supported by quantitative research, however, this rarely provides insight into individual experiences (Polkinghorne, 1988). Qualitative research provides an opportunity to give insight into individuals' perspectives and understandings of their experiences (Creswell, 1998; Riessman, 2008). Narrative inquiry is suitable for health research as it encompasses all dimensions of the event and gives participants an opportunity to tell their stories, highlighting what is important for them in their recovery (Haydon, Browne et al., 2017; Haydon, van der Riet, & Maguire, 2017). Health professionals have always had an interest in stories, highlighting the importance of attending to what patients tell them (Clandinin, Cave, & Berendonk, 2017). Clandinin and Connelly (2000) and Clandinin's (2013) narrative inquiry support the notion that humans are storytellers who as individuals and socially, lead storied lives. Hence, studying people's stories involves learning how people experience their world. Narrative inquiry's ontological stance reinforces an epistemological commitment that experiences provide knowledge (Clandinin & Connelly, 2000; Clandinin, 2013; Kim, 2016) and the described experiences collected from these participants are intended to engage the readers (Caine, Estefan, & Clandinin, 2013). The ontological responsibility of narrative inquiry research influences each stage, beginning with a personal interest in the experiences, and professional inquisitiveness about how participants are managing their experiences under inquiry (Clandinin, 2013; Clandinin et al., 2017). In this inquiry, the interest stemmed from the first author's experiences of working in intensive care as a nurse.

In this community-based research, recruitment of participants was through a single article in a local newspaper, introducing the female lead author and her research into stories of CA survival. The article stated where interested participants could find information about the inquiry and how to contact the researcher. This article led to twelve people contacting the first author for an interview. Recruitment of a further five participants was through snowball sampling, using word of mouth. The inquiry was open to anybody who had survived a CA, was living independently in the community and able to have a conversation in English. The authors did not know any of the participants before the inquiry commenced and no compensation was offered to participants. At the time of interview, participants were aged between 48 and 92 years and most were married. Participants reported a diversity of education levels from high school to doctoral studies, and a variety of employment including self-employed, home care, office work, academia and health professions. Their living environments ranged from metropolitan cities, to small towns and rural properties. They had experienced a CA between three months and 36 years prior, receiving care following their CA in a variety of hospitals, from metropolitan to smaller rural hospitals. Five participants experienced their CA in hospital, eight participants had their CA during exercise (surfing, playing golf, team sports, jogging and gardening) and four participants experienced their CA during sedentary activities at home or in the community. Characteristics of the participants are presented in Table 1.

### 3.3. Data collection

Individual interviews were held over a seven-month period from November 2016 to June 2017, at a time and place of shared convenience, lasting between one and four hours. Nine of the interviews were held in the participant's home, five in the town library and three via online video using Skype. Interviews were audio-recorded with permission and transcribed verbatim by the first author; no participants withdrew from the inquiry. Conversation starters such as 'What do you remember from the day of your CA?'

**Table 1**

Characteristics of participants who were interviewed about their experience of a Cardiac Arrest (n = 17)

No.	Gender	Marital status	Age <sup>a</sup>	Setting of cardiac arrest		Date of arrest	
				In hospital	Out of hospital	Month	Year
1	Male	Widower	92		Yes	June	1982
2	Male	Married	73		Yes	April	2001
3	Female	Married	51	Yes		May	2006
4	Male <sup>b</sup>	Partner	59		Yes	June	2008
5	Female	Single	63	Yes		October	2008
6	Male	Single	75	Yes		August	2010
7	Male	Married	64		Yes	December	2010
8	Male	Married	59		Yes	April	2011
9	Male <sup>b</sup>	Married	58		Yes	October	2014
10	Male	Married	48		Yes	December	2014
11	Female	Single	66	Yes		December	2014
12	Male	Married	57		Yes	April	2015
13	Male <sup>b</sup>	Married	71		Yes	November	2015
14	Female <sup>b</sup>	Married	76	Yes		December	2015
15	Male	Married	62		Yes	February	2017
16	Male	Married	64		Yes	February	2017
17	Male	Married	70		Yes	March	2017

<sup>a</sup> Age at time of interview.<sup>b</sup> Participated in a second interview.

and 'Tell me about your experience of waking up after the CA?' were used to get the conversation started and to keep the interview focused. Before and after the interview, contact was maintained by email and telephone calls to continue the relational aspects of narrative inquiry during data analysis. Interview transcripts were returned to participants who were invited to participate in a second interview. Four further interviews were held and included in the data collection. The second interview provided participants with the opportunity to clarify or add information and allowed the researcher-participant relationship to be extended (Clandinin & Connelly, 2000). Before data collection ethical clearance was given by the relevant human research ethics committee (HREC Number H-2015-0132) and included strategies for managing a participant if they became distressed while recalling their event. However, there was no observed distress among participants, therefore, no referrals were required to support services.

### 3.4. Data analysis

The first author transcribed, re-read and listened to all interviews multiple times. Using an iterative process from Clandinin and Connelly's (2000) three dimensional narrative inquiry framework of sociality, place and time, the analysis was shaped and emerging threads were identified. Narrative inquiry is defined by Clandinin (2013) and Caine et al. (2013) as the study of people's lives, honouring lived experiences that are presented into a narrative thread. Clandinin (2013) and Caine et al. (2013) state that participants are always within this three-dimensional space. Transcribed interviews and emerging threads were circulated among co-authors, ensuring the emerging threads were grounded within the narratives. The three dimensions were intertwined in the participants' stories. The 'social' dimension highlights how personal (feelings about their experiences), social and cultural experiences influence their narrative. 'Place' explores the environment and 'time' involving past, present and future, explores how past experiences influence the participant's current reality and their plans for the future (Clandinin & Connelly, 2000; Clandinin, 2013). Although 'themes' are commonly used in qualitative research, the narrative inquiry framework of Clandinin uses the term 'threads' to find and explore re-occurring thoughts and feelings in the participants' stories as they are intertwined and resonate within the three dimensions (Clandinin & Connelly, 2000; Clandinin, 2013). The dimensions of time, place and sociality need to be understood

and contemplated; however, they are not separate entities and commonly overlap (Caine et al., 2013; Clandinin, 2013; Clandinin et al., 2017).

In narrative inquiry the findings are presented in a narrative emplotment, creating a narrative where the selected threads are presented (Clandinin, 2013). There are influences in participants' narratives from sociality, place and time that provide structure to the presentation of the narrative emplotment of the CA event. In narrative inquiry "Final research text does not have final answers. These texts are intended to engage audiences to rethink and reimagine the ways in which they practice and the ways which they relate to others" (Clandinin, 2013, p. 51). In the findings below, the number within the brackets following the quotes denotes the participant represented in Table 1.

## 4. Findings

In exploring the dimension of time, the CA becomes the defining moment where life changes from ordinary to extraordinary and places the survivor in a liminal space of betwixt and between involving 'before' and 'after' the event that influences the survivor's future. The social dimension highlights their feelings of chaos and confusion. The CA was an unexpected event where both mind and body were dramatically intertwined. The body had a serious malfunction and the pain stemming from the CA and CPR was a reminder of the ordeal. Participants tried to comprehend new information from their unreliable body involving pain and surviving a certain death, placing survivors in a liminal space between what was and now an unknown future. A reaction to the unexpected event and to the confusion often generated questions of spirituality and a sense of being lucky to have survived. Most importantly at the crucial moment in time there were people in that space who have knowledge of CA and skills in CPR. These findings highlight how intertwined the three dimensions of sociality, place and time are in narrative inquiry. Seven main threads were identified from the narratives: Ordinary to extraordinary, Cardiac pain, Waking up in chaos, Resuscitation pain, Drawing on spirituality, Luck, and Surviving death.

### 4.1. Ordinary to extraordinary

Although some participants in this inquiry had health issues including cardiac problems, there was no premonition of an

impending CA, transforming their ordinary day into an extraordinary one. *"On the day I was feeling fine. Nothing to warn me that there was something sinister about to happen"*(13), *"There was nothing to indicate to me that there was something going on with my heart—it was a complete and utter surprise"*(5), and *"I saw myself as healthy—my background is in health and fitness. I have been passionate with this, a euphemism perhaps, obsessed about fitness"*(10).

Participants who experienced their CA out of hospital, and those who experienced it in hospital, reported an ordinary day that evolved into an extraordinary day. Participants who experienced their CA out of hospital were engaged in work or social events, blissfully unaware of what was about to happen. *"I was playing oldies rugby and I arrested on the field"*(6), *"I was out running"*(15), *"I had my CA in the back seat of the car"*(11), *"I fell over on the golf green"*(14), *"I remember doing my feet up in the straps and I just fell off"*(5), and *"Apparently I just keeled over and they could not get any response from me"*(1).

Participants who experienced an in-hospital CA did not report a premonition of an extraordinary event happening; it was described as an unexpected event: *"I was just lying there—feeling not too bad, and then everything all just went pear-shaped"*(4), and *"I can remember enjoying my lunch and then it was like a jackhammer hit my heart!"*(8). These quotes speak of unpreparedness, an unexpected event that changed their known reality and threw them into a liminal transitional space.

#### 4.2. Cardiac pain

The pain associated with the CA was described as excruciating, intense and sudden. *"The pain was just unbelievable"*(13), *"I was lashing out—I had so much pain"*(3), *"Cardiac pain is just mind blowing!"*(10), *"Crippling pain! I have never experienced pain like that in my life!"*(16), and *"Suddenly I had this like a train smash pain and compression. I did not have any indication of this before and it hit me really quickly"*(11). As with the unpreparedness of the event, the cardiac pain was intense with no warning, adding to the trauma and confusion.

Three participants did not have any indications of pain demonstrating the unpredictability of a CA. *"Prior to the event I had no pain or any symptoms—there was no indication of a forthcoming arrest"*(2), *"I had no signs or pain—not feeling different"*(5), and *"I did not have any pain—it just happened."*(15) For CA survivors who experienced no pain, the CA became surreal, without pain there was no warning of an impending CA.

#### 4.3. Waking up in chaos

To wake up after a CA was a surreal confrontation with reality. There was no memory except for waking up in chaos, regardless of whether the arrest occurred in hospital or out of hospital. The intensity of people around them together with sounds and light, made it a dreamlike experience. To comprehend what had happened became an overwhelming task. For the CA survivor, the confusion created a loss of reality where there was no control. *"When I came through I was in the recovery position—I had no idea what had happened. All I could see was the world from the ground—lots of feet and voices"*(13), *"I was trying to comprehend what was happening, whether I was clinging onto life or not"*(10), *"When I came around there was lots of people around me—I think I woke up with a couple of swear words and trying to fight my way out"*(14), *"I remember coming out of it—I came out of a dark chasm to light"*(16), *"When I came around—it was like what you see on TV! Never seen so many people in my life!"*(8), and *"You wake up and everyone else around you is in a panic"*(4). To wake up to the chaos of one's own cardiac arrest was in contrast to what went before. A major event had unravelled and unknowingly they had played a key part in the event. Not knowing the timeline, or

who participated in the event increased the feeling of chaos and uncertainty.

#### 4.4. Resuscitation pain

Many participants experienced pain from fractured ribs or sternum due to the CPR efforts, this was concerning as participants were not sure if the pain was from their fractures or their heart. *"I can remember telling the cardiologist that there is still something wrong because my chest is really sore and he said 'No, it's the result from your mates jumping on you'"*(5), *"The CPR cracked my ribs. I was very sore for a long, long time"*(4), *"They belted me and broke my ribs to keep me alive. The ribs were very painful"*(7), and *"They cracked the sternum—they cracked a couple of ribs as well"*(4).

Alongside the resuscitation pain there was also apprehension and resistance regarding rehabilitation. *"It was not that nice, it had only been three days and the nurses made me walk—the agony!"*(3), and *"They said they wanted me to get out of bed and I thought 'Hey, I am an invalid. Jesus NO!'"*(1). Fractures and memory of the cardiac pain discouraged participation in rehabilitation. They did not trust their now, unknown body, having pain and ailments that were not there before the event. In recovery the pain associated with the cardiac arrest influenced their transition across the liminal space.

#### 4.5. Luck

Participants' narratives often included comments of 'luck'—lucky that the CA happened when and where it did with people around them that could support their survival. This was common in narratives from both in hospital and out of hospital CA: *"I'm lucky to be here today"*(3), *"I am an extremely lucky lady"*(8), *"I was super lucky there was an ambulance not far away"*(13), *"I was very lucky — there are not too many people who survive"*(12), *"I was lucky because I was already hooked up"*(16), *"I was lucky because there was a paramedic I was playing rugby with and an intensive care nurse was there"*(6), *"The arrest happened in the hospital—I was lucky I was there"*(12), and *"She said in Australia there are around 32,000 cardiac arrests a year and of those slightly less than 6% of them survive, to me that was amazing — I am lucky to be one of them"*(5). The majority of participants in this inquiry referred to their survival as 'lucky' as they had no input over the outcome. External factors made their survival possible, something they were aware of and appreciated. The dimensions of sociality, place and time are strongly evident in this thread. Participants linked their fortunate survival to being in the right place, at the right time, as they were already in hospital and with the right people (sociality) nearby.

#### 4.6. Drawing on spirituality

Participants expressed a belief in a benevolent metaphysical power providing comfort. For some survivors the feeling of luck reaffirmed a belief of a higher purpose, a reason for their survival. *"It was not meant to be the end of me"*(14), *"I started to explore my spirituality and why am I here"*(9), *"I was not allowed to go—because it was not my time"*(7), *"Maybe somebody up there is not ready for me yet"*(11) and *"I have survived two cardiac arrests. I felt each time that there was some reason—I have been practically blessed"*(2). For participants, the knowledge of how close they had been to death had a profound influence. They were grateful and appreciated being alive. In their search for meaning and reasons for their survival they engaged in an existential discourse of spirituality.

#### 4.7. Surviving death

The realisation of how close they were to dying created an anxiety that a CA might happen again and also a feeling of calmness to have survived and to have experienced near-death. *"To realise how quick life can change and how fragile it is, is quite an eye-opener—those feelings of suddenly being confronted by my own mortality" (7), "While I was waiting for the ambulance I was just thinking—is this the day that I die? Like, a very strange sense of calmness came over me—life felt quite precarious" (13), "The realisation that I could have died shakes you. I think that realisation is what you are left with—the mortality you touched affects you" (2), "Feelings of suddenly being confronted by my own mortality, I basically died, I live with that feeling—I remember thinking 'Is this all there is?' (3), and "I was in intensive care and there were three other guys there and each of them died. I was the only one that survived. I kept looking around—thinking 'Am I going to be next?' (5). The close encounter with death left a powerful memory—the swiftness of death and the fragility of life became a certainty. The experience made participants feel that they had experienced something 'special', something most individuals would not be able to experience.*

#### 5. Discussion

The aim of this narrative inquiry was to explore survivors' experiences of surviving cardiac arrest in the immediate time before and just after the event. Seventeen cardiac arrest survivors told of their experiences and seven threads were identified: Ordinary to extraordinary, Cardiac pain, Waking up in chaos, Resuscitation pain, Drawing on spirituality, Luck, and Surviving death. These findings reveal a liminal space involving a chaotic ordeal that exposed the unpreparedness and the confusion immediately after the CA.

From the narratives, regardless of whether the CA happened in the community or in hospital, the event changed their lives, creating confusion for survivors about their future existence and health. Commonly before the CA, participants were alone, or with a few people around them. However, when they woke up, they were in a chaotic and changed landscape with a multitude of people and sounds around them. This transformation of reality was frightening and added to the feeling of loss of control and chaos. With this in mind, giving the CA survivor opportunities for conversation and time to ask questions is important, as it is a complex time where they might find it difficult to articulate their questions and concerns (Klint, Sjöland, & Axelsson, 2018). Nurses and other clinicians need to pay attention to the individual's response to the event and create information that is adapted to their needs where the survivor has time to formulate and ask questions (Klint et al., 2018).

The cardiac pain experienced by the participants is described as excruciating and sudden. The memory of this excruciating pain might linger as the individual recovers and should be considered in their recovery plan (McCabe, Murray, Austin, & Siddall, 2018). The pain caused by the chest compressions during CPR can also be intense where fractured ribs and sternum are common complications in adults. A study of 149 patients following CPR found that 47% had CPR-related injuries and 43% had multiple rib fractures (Setälä et al., 2018). Clinicians who are part of the care team need to inform and reassure the survivor that the pain they are experiencing may not be of cardiac origin, instead due to complications of CPR (Magliocca et al., 2019; Setälä et al., 2018). Poorly managed pain can delay recovery and it is important that nurses and other clinicians are able to assess and treat pain adequately (McCabe et al., 2018). The pain might also hamper participation in phase one rehabilitation. Attending cardiac rehabilitation should be encouraged, as early inclusive models of cardiac rehabilitation have significant long-lasting benefits (Gardiner et al., 2018; Hall, Murphy, & Scanlon,

2017). Delivering individualised education increases the motivation to participate in cardiac rehabilitation, therefore, information and education needs to be tailored to individual needs (Hall et al., 2017). McCabe et al. (2018) found that higher levels of meaning, purpose and satisfaction with life are associated with lower levels of pain, indicating that existential and spiritual factors may be helpful components of pain assessment and treatment.

Many CA survivors mentioned 'luck' as a factor in their survival. 'Luck' can be viewed as a cognitive illusion and a way to subjectively interpret experiences (Hales & Johnson, 2014). The contrast of being a survivor of CA compared to the fact that they could have died, made them 'survivors' rather than 'victims' of a CA; the focus changed from "why me" to "I could have died" making participants feel lucky. People exposed to a disaster are often resolute that they have been lucky suggesting that by comparing themselves with those who were less fortunate makes them feel better (Teigen & Jensen, 2011).

For the CA survivor, the event often evokes spiritual and existential questions. Nurses and other clinicians need to be aware of the emotional turmoil the event potentially creates. Spirituality can be described as a person's relationship with transcendent questions that confront us as human beings—it may, or may not, involve relationships with a God (Senreich, 2013). Nurses and other clinicians importantly need to acknowledge and support the survivor in their need for spirituality and not diminish the importance of it (Klint et al., 2018; Senreich, 2013; Wachelder et al., 2016). Spirituality can be used as a coping resource and may support individuals dealing with adversity (Wachelder et al., 2016).

The fear of dying is often deep, profound and not likely to change, unless the person has an experience such as surviving a CA (Forslund, Jansson, Lundblad, & Söderberg, 2017; Tassell-Matamua & Lindsay, 2016). For many it was a reality check and an appreciation of being alive. The experiences of 'dying' can diminish the fear as many of the participants in this inquiry expressed a feeling of relief that they had already experienced death. A CA could be a profound reality check, nurses and other clinicians need to be open in their conversations with survivors and encourage the person to talk about their experiences (Klemenc-Ketis, 2013).

Survivors' experiences of a CA influence care needed following the event. To optimise recovery and improve quality of life for survivors, nurses and other clinicians need to have a holistic view of the survivor, acknowledging that this is an extraordinary and chaotic time for the survivor. In healthcare research illness is often viewed as a trajectory where individuals transfer from diagnosis, treatment and recovery. Liminality is a reflective time during a life-changing process, with three phases of transition from an ending of the known reality and a beginning of a new reality with an empty or unknown time in between (Turner, 1969; Van Gennep, 1960). Survivors entered a liminal space, a state of 'limbo', where the survivor felt alienated and confused as they moved into an uncertain future. The liminal time while adapting to surviving a CA is less known and is important for nurses and other clinicians to recognize to support survivors' transition in this liminal period (Smith, Frazer, Hall, Hyde, & O'Connor, 2017). The first stage of transition contains the split from their everyday social reality toward a new reality, the second stage is the liminal experience of being in between their previous existence and the now changed, uncertain future. This liminal time includes skill-building tasks and acceptance to help prepare for the final stage, the return to their social reality with an altered future (Underwood & Rhodes, 2018).

It is important to consider the individual's experiences when providing care and the importance of holistic care in the immediate aftermath of a CA should not be underestimated (Haydon, Browne et al., 2017; Haydon, van der Riet et al., 2017; Verberne, Moulaert, Verbunt, & van Heugten, 2018). During the initial time after a CA while in hospital, and in the liminal transition, survivors may feel

unsupported by the healthcare system. Locked in a liminal space, their existence dramatically changed as they now live with internal chaos juxtaposed with an expectation of recovery. In the immediate period after CA when the projected life trajectory is altered, individualised healthcare can be vital to enable a positive outcome (Forslund et al., 2017; Verberne et al., 2018). While CA related factors are influential to recovery, there are also early functional related factors, subjective wellbeing and demographic factors influencing the individual's future perception of QOL (Bremer, Dahné, Stureson, Årestedt, & Thylén, 2019; Verberne et al., 2018). Participants in this inquiry did not disclose any indication of depression and anxiety immediately after the event, however this may in part be due to the time elapsed between the CA and the interview for some participants. Both depression and anxiety are common after a CA (Bremer et al., 2019; Verberne et al., 2018). Verberne et al. (2018) found in their research of 110 survivors that participants' QOL was improved when focus was on functional levels and less on CA related variables during the immediate time after the event. Drawing on strong conclusions regarding the QOL for survivors is difficult as there is a multitude of factors and a diverse range of assessment tools used to assess QOL (Green, Botha & Tiruvoipati, 2015; Haydon, van der Riet et al., 2017). Quality of life is a subjective term and what one individual might consider as a 'good QOL', could for another individual be viewed as a 'poor QOL'. Nurses and other clinicians need to take into account the individual's experiences of the event and provide time for the person to explore their story (Ewens, Hendricks, & Sundin, 2018; Klint et al., 2018; Wachelder et al., 2016).

## 6. Strength and trustworthiness

Research participants in this narrative inquiry represented a diverse purposive group, with a wide age span, comprising both professional and non-professional work experiences and experiences from large metropolitan to smaller rural hospitals. This breadth of experiences in the in-depth interviews ensured trustworthiness and reliability (FitzPatrick, 2019). The strength in this project was the participants' individual rich quotes (field text). Field notes were kept throughout the research process by the first author to prevent unintended bias and preconceived conclusions (Rettke, Pretto, Spichiger, Frei, & Spirig, 2018). All interviews and verbatim transcription were conducted by the first author, followed by involvement of the co-authors to analyse, evaluate and interpret the findings confirming that the identified threads were grounded within the narratives.

## 7. Limitations

Voluntary participation in this inquiry, where participants initiated contact with the researcher has limited the findings to cognitively intact individuals who regarded their survival with a positive outcome. There is possible self-selection bias and findings cannot be extrapolated to those who experienced cognitive impairment post CA (Portney & Watkins, 2014). This article focused on the immediate time surrounding the CA and is subject to recall bias especially for participants who experienced their CA more than 12 months previously. Recall is likely to be very different for participants who experienced their CA three months ago compared to 36 years ago. Survivors' recall of their experience of CA may be influenced by whether their expectations of recovery have been met as well as the time elapsed since the CA (Pasupathi, 2007). Treatment following CA has advanced over the time period that participants experienced their CA and length of hospital stay is also likely to have varied. These changes over time may have influenced recall and potentially other unmeasured factors. As with any conversa-

tion participants choose what they are willing to share, and they may alter their story over time and might adapt their narrative to present themselves in a more positive light. Survivors with less favourable outcomes may have a different story of their experiences.

This community-based study was undertaken with residents from coastal regions of eastern Australia in a society with high technological care. Therefore, surviving a CA in a society with limited access to care might have other circumstantial, social, religious, and cultural variations not found here. Findings are not broadly generalisable to populations following CA, however, the narratives provide an insight into CA survivors' experiences. In narrative inquiry, Clandinin and Connelly point out "interpretation of events can always be otherwise" (2000, p.31). This may create uncertainty about events and their meaning of experience and, therefore, this could be seen as a limitation of this study.

## 8. Relevance to clinical practice

Survivors of CA experience an instant change to their reality, which is unexpected with much to grasp. While survivors are in the liminal space, their need for support may be increased so they may move forward in their recovery. Evidence indicates that a prolonged liminal transition may result in ongoing reduction in employment, increased health problems and reduction in QOL compared to the general population (Ewens et al., 2018).

Providing flexibility and sensitivity around the hospital structures and practices can improve survivor satisfaction and a faster liminal transition to recovery (Underwood & Rhodes, 2018). Nurses and other clinicians need to consider the individual's experience of the event and provide time for the person to express their story. By listening to patients' stories nurses and other clinicians can gain knowledge to provide holistic care that can promote positive health outcomes and improve QOL.

## 9. Conclusion

Narrative inquiry's ontological position underpins the epistemological stance, stating that experiences provide knowledge, and the collected quotes from participants who survived a CA are intended to inform readers. The immediate time after a cardiac arrest is a complex time where existential questions about luck, spirituality and survival are intense. A prominent thread involved the immediate transition from an ordinary to extraordinary existence, thus entering a liminal space, of a chaotic illness experience. Nurses and other clinicians can gain knowledge through patients' narratives to provide holistic care that can promote positive health outcomes and QOL. This may help shorten the liminal transition to a new normality where the survivor becomes comfortable in their new life.

## Author contribution

The first author recruited and interviewed participants, managed data collection, undertook initial data analysis and drafted the manuscript. All authors contributed to the conception and design of the work, finalisation of data interpretation and finalisation of the manuscript.

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## Ethical statement

Ethical approval for this study was granted by the University of Newcastle Human Research & Ethics Committee (HREC Number H-2015-0132). Participants gave written informed consent stating their willingness to participate in the semi-structured interviews and the digital audio recording of the interviews.

## Conflict of interest

None.

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## **PUBLICATION: THE EXPERIENCES OF RETURNING HOME AFTER SURVIVING CARDIAC ARREST**

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# The experience of returning home after surviving cardiac arrest: A narrative inquiry

Gunilla Haydon , Pamela van der Riet and Kerry Inder

## Abstract

Surviving a cardiac arrest is a tumultuous experience. Although the incidence of cardiac arrest and influencing factors are well researched, little is known of survivors' experiences as they return home from hospital. This article aims to explore survivors' experiences of returning home after surviving a cardiac arrest. Four females and 13 males, all independently living cardiac arrest survivors, were recruited using purposive and snowball sampling techniques and participated in individual in-depth interviews over a six-month period. This inquiry follows COREQ guidelines and data were analysed using narrative inquiry where key threads were identified. Findings indicate that a cardiac arrest is a catastrophic event where the survivor has to accept and adjust mentally, physically and socially, often leading to insecurity about the future. The cardiac arrest impacts all aspects of life on return home, including the ability to work and to drive, accepting added medical appointments and medication regimens. Healthcare professionals can learn from survivors' narratives to support holistic care, considering survivors' experiences in their transition home and back to reality as a cardiac arrest survivor.

## Keywords

cardiac arrest, holistic care, narrative inquiry, qualitative, survival

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## Introduction

Cardiac arrest (CA) is a large public health problem, claiming approximately 300,000 lives in Europe and 3.7 million lives worldwide each year.<sup>1</sup> Global survival rates to discharge among out-of-hospital CA patients who received cardiopulmonary resuscitation (CPR) have increased from 8.6% in 1976–1999 to 9.9% in 2010–2019.<sup>2</sup> There are, however, differences in survival rates depending on location. Europe has an estimated survival rate of 11.7%, North America 7.7% and Asia 4.5%.<sup>2</sup> Although mortality remains high there are positive trends with better education in CPR, bystander participation and the availability of automated defibrillators, as well as improved medical interventions, increasing the number of CA survivors.<sup>3</sup> As the number of survivors rises, the exploration of the survivors' experiences in the transition between the hospital and the home environments becomes of interest.

Experiencing a CA is a defining moment in the life of the survivor, where their previous reality is compared with their current situation and an altered future. Commonly, survivors' physical and psychological capacities have changed and the adaptation to a new reality can be a challenge; frustration and dissatisfaction are common in adjusting to this new reality.<sup>4,5</sup> Although survivors are considered to have an acceptable quality of life (QOL),<sup>6,7</sup> it has long been known that many CA survivors experience anxiety<sup>8</sup> and that insufficient care after the event can

amplify the problem.<sup>9</sup> Many survivors of CA have cognitive impairment<sup>10</sup> and experience psychological distress.<sup>8</sup>

Often, quantitative research is used to explore QOL using validated tools<sup>6</sup> and survivors report an acceptable QOL.<sup>7,11</sup> In comparison, qualitative explorations of the phenomena of surviving CA are few.<sup>6</sup> Qualitative research gives the participant an opportunity to express their views without the constraint of questionnaires and allows depth of experience to come to light that is not exposed in quantitative research. Knowledge about survivors' experiences will benefit nurses and health professionals in supporting their patients in their transition to the home environment. This article explores the narratives of 17 CA survivors with the aim of exploring their experiences of returning home after surviving a CA.

## Methods and design

Stories are an integral part of human life; they create order and string together experiences to form an understandable and meaningful whole.<sup>12,13</sup> By telling and re-telling

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experiences, a greater understanding of the phenomena under study occurs.<sup>14</sup> Clandinin and Connelly<sup>14</sup> and Clandinin's<sup>15</sup> framework of narrative inquiry (NI) informed this study, as NI is well suited to explore health-related topics with a focus on the individual's experience of illness.<sup>16</sup> In this framework, the three dimensions of *time* (where past and present experiences are explored as well as the influence they may have on future experiences), *place* (where the event happened and where the story is told), and *sociality* (personal circumstances, feelings, desires and hopes, as well as cultural, social and institutional knowledge), influence the individual's story.<sup>14,15</sup> These three dimensions need to be understood and contemplated; they intertwine and are not separate entities.<sup>15,17</sup> Themes are commonly used to describe findings in qualitative research; however, Clandinin's NI framework replaces themes with the term *threads* to explore re-occurring feelings and thoughts in the participants' stories, and like threads they are intertwined and woven within the three dimensions.<sup>14,15</sup> The ontological stance of NI reinforces the epistemological assurance that experiences, through the telling of and listening to stories, provide knowledge.<sup>14,17-19</sup> Narrative inquiry aims to create an engaging text that '...resonates with readers so that they reflect on their own lives, their own values and beliefs',<sup>15(p.xii)</sup> therefore findings from this research provide health professionals with an opportunity to engage in reflection over CA survivors' experiences and, most importantly, their care needs. This research follows the consolidated criteria for reporting qualitative research (COREQ) checklist.<sup>20</sup>

### Sampling and recruitment

The study was open to adults who had survived a CA, were living independently in the community and were

proficient enough in English to provide written consent and have a conversation. Twelve participants contacted the first author after an article introduced the first author and her interest in survival of CA. A further five participants were recruited through snowball sampling.<sup>21</sup> The number of people expressing interest in participating was more than expected and more than what would be required for NI. However, as all participants fulfilled the inclusion criteria, no participant was denied inclusion in this study. All participants initiated contact with the first author, ensuring their participation was voluntary, and all received a printed information pack, which included information about how to contact support services should they be needed following the interview.

### Participants

The study included four females and 13 males, aged 48 to 92 years at the time of interview. Level of education spanned from high school to doctoral studies, and employment was equally broad, including self-employment, home care duties, office work, academia and health professions. The experience of a CA had occurred between three months and 36 years prior to the interview. Twelve participants had experienced an out of hospital CA: eight during exercise (gardening, jogging, surfing, playing golf and team sports) and four during sedentary activities at home or in the community. Five participants experienced their CA in hospital. The participants' characteristics are presented in Table 1.

### Data collection

The first author, who has experience in intensive care and education, conducted the individual interviews during November 2016 and June 2017. The duration of first interviews ranged between 52 minutes and 3 hours 49 minutes

**Table 1.** Characteristics of participants who were interviewed about their experience of a cardiac arrest ( $n = 17$ ).

No.	Gender	Marital status	Age* (years)	Setting of cardiac arrest		Date of arrest Month	Year
				In hospital	Out of hospital		
1	Male	Widower	92		Yes	June	1982
2	Male	Married	73		Yes	April	2001
3	Female	Married	51	Yes		May	2006
4	Male**	Partner	59		Yes	June	2008
5	Female	Single	63	Yes		October	2008
6	Male	Single	75	Yes		August	2010
7	Male	Married	64		Yes	December	2010
8	Male	Married	59		Yes	April	2011
9	Male**	Married	58		Yes	October	2014
10	Male	Married	48		Yes	December	2014
11	Female	Single	66	Yes		December	2014
12	Male	Married	57		Yes	April	2015
13	Male**	Married	71		Yes	November	2015
14	Female**	Married	76	Yes		December	2015
15	Male	Married	62		Yes	February	2017
16	Male	Married	64		Yes	February	2017
17	Male	Married	70		Yes	March	2017

\*Age at time of interview. \*\*Participated in a second interview.

with a median time of 73 minutes. Second interviews ranged from 44 to 63 minutes. These interviews were held at a time and place chosen by the participants: fourteen were face to face and three on video chat using Skype (Skype Communications). All interviews were audiotaped with participant permission and field notes were completed after the interview. The first author transcribed all interviews verbatim. Questions such as ‘Tell me about coming home?’ and ‘What was the biggest difference in “before” and “after” the CA in returning home?’ kept the conversation focused. Before and after the main interview contact was maintained via email and phone calls, consistent with the relational aspects of NI.<sup>14,15</sup> Participants were offered a second interview, however, they were advised that there was no obligation to take part in this. Four participants took part in a second interview, providing them with the opportunity to add information included in the inquiry, and a chance to extend the researcher–participant relationship as recommended by Clandinin and Connelly.<sup>14</sup> Transcribed material was returned to the participants for review before analysis commenced. Due to the large amount of field text, data obtained from the interviews were divided into three sections: The immediate time before and after the CA, Transition from hospital to home, and Long-term survival. Each section has been analysed and presented separately. This analysis focuses on the transition from hospital to home and findings are presented below.

**Data analysis.** The analysis of collected narratives using Clandinin and Connelly’s<sup>14</sup> three-dimensional framework of time, sociality and place, was central in identifying the narrative threads and answering the research question of the survivors’ experiences of returning home after surviving CA. Participants were assigned pseudonyms to maintain confidentiality. Language used and highlighted words were closely checked to determine their fit with potential threads.<sup>22</sup> In line with the dimension of sociality and its personal conditions, participants’ statements about their feelings and their hopes for the future were examined carefully. The first author observed the body language and other non-verbal communication of the participants during the interview to enhance the interpretation of the narratives and noted these in a journal. The transcribed stories were read, re-read and listened to multiple times and field notes were included to create a narrative of the experience for each participant. Analysis was a prolonged iterative process where the three dimensions were central in identifying emerging threads.<sup>15</sup> Before meetings with co-authors, transcribed interviews and emerging threads were circulated among the authors checking that the threads stemmed from the transcribed material. In NI, findings are fluid and experiences change over time, therefore ‘final research texts do not have final answers’.<sup>15(p.51)</sup> The findings are intended to engage the reader ‘to rethink and reimagine the ways in which they practice and the way they relate to others’.<sup>15(p.51)</sup>

**Ethical considerations.** This inquiry conforms to the principles outlined in the Declaration of Helsinki<sup>23</sup> and before recruitment of participants, ethical approval was received from the authors’ university human research ethics committee (reference number: H-2015-0132). Given the potentially sensitive nature of the inquiry, the interviewer was alert to any signs of distress from participants during the interviews. Written consent was obtained from participants and no reimbursement for time was offered. The researchers did not know any of the participants prior to the interviews and no participant withdrew from the inquiry during or after the interviews.

## Findings

Five threads emerged from the data analysis: A new reality in coming home, Emotional turmoil, Restrictions both internal and external, Navigating medication regimens and Support systems. The three dimensions were closely intertwined<sup>14,15</sup> and central in identifying the narrative threads. For the dimension of *time* survivors recalled the past, before the CA and what was a known reality, and then faced the time of coming home, a transition to a new reality and an unknown future. The social transition from being, what many of the participants considered a healthy person, to a CA survivor with prolonged health concerns was mentally challenging. Questions of future employment and health were central, with the threads emerging from the *sociality* dimension. The final dimension, *place*, highlighted the change from hospital to home and was a stark reminder that their reality had changed. What they used to be able to do at home with ease was now a tiresome task.

The presentation of findings related to each thread uses quotations from the participants, creating an ongoing narrative starting with the transition from the hospital to home. The number within the brackets immediately following a participant’s quotation represents the participant number listed in Table 1.

### A new reality in coming home

To leave the hospital routine and return home after a CA was often daunting. The external aspects of independence, work and participation in society were now apparent. There was a realisation that they were different from before the CA. The following quotations reflect the difficulty of and adjustments to a changed life. Participants reflected on the sociality dimension of inquiry with a specific focus on personal conditions involving feelings and emotions.

You have your CA and all that hospital stuff — and you think, that is it. I have survived all of that. The hardest part is afterwards, to come home. (12)

It was difficult to come home. (5)

Adapting to a new reality, with an uncertain future, was a challenge. Questions over future health and ability to work were common. ‘

Wondering what does this mean for me in terms of my future and how my life might be compromised. (3)

I was out of hospital, but I was still slow mentally and physically. (9)

I had to re-evaluate a lot of things, including work. (4)

I used to run a community centre for 25 years and within four weeks I went from actively working to nothing. (10)

Coming home emphasised this change; their working life was on hold, and their body was not what it used to be, creating insecurity and uncertainty.

### *Emotional turmoil*

As the survivors came to terms with the reality of surviving a CA, it became an emotional roller coaster. There was a joy of survival.

I am amazed I survived. (5)

A happy ending is a good cure for trauma. (2)

However, more dominant were the personal conditions with feelings of fear and anxiety.

Some nights you lay there thinking about it – listening to your heart beat. It is just fear. (10)

I was in a spiral of more anxiety. (13)

To have a CA is to be very close to death – it is not that easy just to get over it, or told it will be alright. (16)

The internal distress was not easy to accommodate and lingered for a long time. A CA is a life-changing event. Although life returns to a new normal there is an underlying doubt.

I know this is a life event and people go through it. (2)

The biggest obstacle is not knowing what might happen next. (6)

I thought your heart broke, you get something fixed and everything is right again. (9)

I don't like the concept of being defined by an illness and the sick role. (4),

I want to get to the end of this, I want to get back to normal! (17)

From the sociality dimension participants described a desire to return to what was known, back to the reality of their normal previous life.

Once home, during the early recovery period, participants described a vulnerability in their encounters with the healthcare system where the many medical appointments participants attended reminded them of their ordeal.

I was so sick, I would be in hospital every three or four days. (10)

I sat there waiting and said ‘if I die here is that all right?’ They replied ‘Don't die here – too many forms to fill out!’ (12)

I live rural, it was an issue! Because the cardiac support was in town. (5)

The disruption CA caused in their lives created a need for support and information, and some of the participants found the lack of information stressful.

After the CA I remember no one had the answers, which meant I felt this could happen again. (4)

I was trying to read everything I possibly could. (8)

They gave me a pack of brochures – read this, do this. (11)

Often, encounters with health professionals made them feel vulnerable and that no one understood the enormity of the event. These feelings of vulnerability and a sense of being dismissed by others, point to those embodied feelings of a new reality that things are now very different.

A recurring thread in the survivors' narratives was the importance of fitness for their survival and their surprise that they had actually had a CA.

I have been healthy my whole life, I thought that would be enough to keep me on the safe side. (7)

I do not think you find many individuals more health conscious than me, more pedantic about health and diets, to the point to having blood tests done every six months, so for this to happen to me it was a surprise, I was quite angry for a while. (10)

I had a fit body, I was returning to normal. Look after your body! (1)

They attributed their survival to their fitness level and their ability to recover as well, but they also expressed disappointment that their body had failed them.

### *Restrictions both internal and external*

Participants realised that their lives were not the same as before their CA, their bodies had new limitations.

I felt completely entrapped in illness within myself. (4)

I got back to my job, but I could not handle it. (9)

I was chomping at the bit to do things. That was the hardest thing. (14)

I was out of hospital but I was still slow mentally and physically. (9)

I never felt old before the CA. (17)

At the moment I am sort of half treating myself as an invalid. (13)

To accept that their body was not performing as it used to was for many a troublesome experience. Adjusting to a slower tempo both mentally and physically was difficult, along with the realisation that recovery takes time.

A leading restriction coming home was the driving ban, causing the participants to depend on others.

The worst – I was not allowed to drive! To me driving is essential! If I can't drive, who am I then, I'm no help to anybody. (9)

I thought the ban was excessive, I couldn't get around. (4)

It just hurts – I cannot just duck into town and do something. (6)

It was difficult to all of a sudden to have to rely on other people, especially with the driving. (10)

To lose independence and depend on others for an activity that previously was taken for granted was difficult.

### *Navigating medication regimens*

For many of the participants there was a drastic change from no, or few, medications, to multiple medicines.

I came from having hardly any medication to having a plethora of bloody pills. (12)

I never took a tablet before, I am 70 years old! It is bloody terrible. I went from sublime to ridiculous – a massive lifestyle change. (17)

I was on no heart medication. Now I am probably on more medication than most people. (2)

They described frustration over a lifestyle change that was a daily reminder of the event, and although they had previously viewed themselves as healthy, their bodies now needed help to function. For some participants medication was an important part of their recovery.

I was out and I had forgotten my tablets so I turnaround. (10)

Maybe it is fear – I will not miss a dose of my medication. If I can do something to promote a longer life, I can do all the soul-searching, but if I don't follow the strict medication regimen, all of the other things are pointless to some extent. (4)

In contrast, some questioned the effectiveness of their medication.

My GP told me I would be on aspirin for the rest of my life. I stopped probably after nine months. I take no tablets! (7)

I wrote down every time I had a painkiller. I knew they could be dangerous so I stopped taking them, but I kept them, if I don't feel good I can take them. (13)

Participants' views of their medication regime varied; some were not taking medication, others questioned the value of taking medication, and others followed their medication regime strictly. These findings indicate that medication was a central focus for survivors.

### *Support systems*

To adjust and navigate their way through the health system was, for many, a stressful experience and there was often a disjointed relationships between survivors and support services after the event.

A lot of frustration was battling the health system. I am spending a good part of my life sitting in the waiting room, waiting for something to happen and I get frustrated. (17)

Nothing was smooth, you become involved in a health fight. I just had this major CA and they say 'Two weeks from "someday" we have an appointment'. (16)

I was lucky, I knew the system – I have been helping others through the system. (12)

Participants described feelings of frustration, as they felt that the enormity of their survival was not reflected in the engagement with health professionals during appointments.

Part of the support system offered to survivors following CA was rehabilitation sessions. There were mixed feelings over the benefits of attending cardiac rehabilitation (CR).

I went to rehab. I tried to be a good patient and do all the things I was supposed to do. (2)

It was only exercises. They lecture you! Very similar in what they did on the ward. (5)

There is a group at community health. It was supportive. (8)

They wanted me to go to rehab. I did not see myself needing it, I felt fit and healthy. (7)

Some participants felt that cardiac rehabilitation was not at their level and they did not foresee the long-term benefits from attending the rehabilitation sessions.

## Discussion

To survive a CA is an unexpected experience and the consequences for the individual and society are huge.<sup>2</sup> This inquiry explored how survivors experienced the transition from hospital to home and how they settled into their new roles as CA survivors. Using Clandinin and Connelly's<sup>14</sup> three-dimensional NI framework of time, sociality and place, this study explored the narratives of four female and 13 male CA survivors about their experiences of leaving hospital and returning home. The main findings highlight the disruption of participants' lives and how the return home made the changes palpable both mentally and physically.

The participants expressed a positive attitude towards their survival, although they viewed the transition from hospital to home as uncoordinated. Our findings indicate that nurses and health professionals need to have a broad knowledge of support services available for the survivor, and the ability to guide the patient to engage with the most relevant services. The geographic location of their home was an important factor in the level of support available, as those in rural areas expressed frustration that living in a rural area meant support was limited. This is not only a rural dilemma; available support for CA survivors varies among health services and often there are limits to follow-up treatment after a CA.<sup>24</sup>

Although there was support for CA survivors as they returned home, long waiting periods and miscommunication between different support services created a feeling of frustration, possibly creating emotional barriers to the willingness to implement changes in practice as part of a daily routine. There was a perceived lack of information, which could be magnified by the survivors' state of recovery, as memory is often affected after a CA.<sup>24–26</sup> Information needs to be provided in such a manner that the survivor can comprehend the information and may need to be repeated or provided in writing. The survivor's response should guide the information provided so that the content is adjusted to the individual's requirements.<sup>27</sup>

The restrictions that survivors experience, both internal and external, highlighted the enormity of the event. The CA survivor had to adapt to a different lifestyle and the uncertainty of physical limits created insecurity. Not to be able to carry out common everyday activities at the same level as before was a new experience; this is also described by Swedish research.<sup>25,28</sup> Driving restrictions, especially for men, were a limitation causing frustration among survivors as they became dependent on others for transport – the loss of independence was mentally distressing and difficult to accept. Nurses and health professionals need to take into account that the male stereotype of independence, strength and as a provider may influence how male CA survivors perceive the care given.<sup>5,28</sup> The new increased medication regimen was a daily tangible

reminder of the CA and of a failing body; it could be burdensome for respondents to accept that they now had a chronic illness. This was more prominent among male survivors and might also be influenced by the male stereotype.<sup>5</sup> Often the CA survivor felt that health professionals did not understand the enormity of surviving a CA for the individual, there was a perceived lack of empathy and understanding from health professionals. Survivors felt dismissed, this was not only described by participants in this study but is a common theme in qualitative research exploring CA survivors' experiences.<sup>4,24,28–30</sup>

Mostly research about CA focuses on the actual event<sup>31</sup> and less is known about how best to provide care for survivors. Acknowledging the internal and external difficulties experienced by the CA survivor and providing essential services to meet these needs will allow them to return to an optimal level of activity. Cardiac rehabilitation (CR) encompasses all cardiac conditions including acute myocardial infarction and acute coronary syndromes. There is limited research focusing solely on rehabilitation for CA survivors. However, with similarities in recovery, the benefits of CR are transferable to CA survivors.

Individuals' perceptions of health levels influence participation in CR as seen in participants' conversation fragments. Opinion about the importance of participation in rehabilitation was divided, as some participants did not find it to be an important part of their recovery. Factors such as physical, logistical (for example, driving bans), and health system factors influence participation in CR.<sup>27</sup> There is a need to personalise information to CA survivors as those who did participate in CR expressed that the sessions were not aimed at their level of recovery. Increased knowledge of the benefits of CR and support from health professionals to coordinate strategies to achieve efficient care and follow-up for CA survivors should increase CR participation.<sup>32,33</sup>

Holistic care is important in the recovery after a CA and has positive outcomes for the individual.<sup>7,30</sup> Holistic care involves the whole person, their physical, emotional, social, economic, and spiritual needs,<sup>34</sup> and is inclusive with a focus on the interaction between health services and the patient.<sup>35</sup> Often, nurses are the health professionals that communicate most frequently with patients and have a coordinating role in planning care. As such nurses need to be familiar with other health professionals' different roles.<sup>35</sup> Research indicates that individuals who received holistic care had an increased physical activity level, returned to work to a greater extent and reported a higher QOL.<sup>36</sup> A holistic care approach improves the partnership between nurses, other health professionals and their patients, which leads to an improved patient experience of care.

Empowering the CA survivor enables them to take a larger part in the decision-making process.<sup>33</sup> For the individual experiencing a CA it is a life-changing event.<sup>24,28,37</sup> Learning from CA survivors' narratives, an understanding of CA survivors' experiences of returning home should influence the holistic care needed to improve the transition

from hospital to home.<sup>38,39</sup> Often the full extent and reality of the CA is not obvious for the survivor until they have returned home. Participants' home routines were altered, and the experience of coming home was a daily reminder that their life had changed. The realisation that their heart had failed, and their body was no longer functioning as usual, created feelings of insecurity and fear. While health professionals often place emphasis on medical knowledge, the person's feelings about their changed body need to be central to provide holistic care.<sup>40,41</sup> Leaving hospital, some participants worried that they might experience another CA, creating insecurity and although they might have lived alone before the CA, they now had family or friends living with them. This feeling of insecurity during the transition to home is common<sup>4,25,28</sup> and must be considered when care is planned. There is evidence that lifestyle changes and medication adherence are important in CA survivors' recovery, and the support provided in CR increases the likelihood of both lifestyle changes and medication adherence.<sup>25,42</sup> Therefore, recovery plans after a CA should include an automatic referral process to CR and a plan that clearly emphasises the benefits of participation to the survivor.

### **Strengths and limitations**

There are limited findings exclusively from CA survivors' rehabilitation experiences, and often research includes all cardiac ailments such as myocardial infarction (MI) and acute coronary syndromes. In an article comparing QOL between CA and MI there was no difference between the two groups,<sup>43</sup> suggesting the generalisation of findings among cardiac conditions. Participants in this inquiry included both genders across a wide age span, with broad education levels, working experience and living conditions, providing validity and reliability of the data.<sup>44</sup> This inquiry's rigour, trustworthiness and validity is founded on the reflexivity of the researchers' open approach and thoughtfulness towards the participants' narratives, supported by Clandinin's<sup>16</sup> and Clandinin and Connelly's<sup>15</sup> framework. Further to reflexivity, a reflective journal was kept throughout the research process by the first author to prevent unintended pre-conceptions and conclusions.<sup>44</sup> To uphold rigour and ensure credibility and dependability, meetings with participants were held over a prolonged time and included emails and phone calls to support accuracy in the study.<sup>16,44</sup>

Although participants with a less favourable view of their survival were eligible to participate, only participants who regarded their survival with a positive outcome contributed. Survivors with less favourable experiences may have told a different story. Participants selected what they were willing to share in the conversation with the researcher and may have adjusted their stories to include only what they perceived as important. The generalisability of these results is limited as the participants in this study lived in a society with a high level of technological hospital care. CA survivors living in a society with reduced access to care

might have other social and cultural narratives not found in this study.

### **Clinical implications**

Nurses and health professionals need to consider the enormity of surviving a CA as it has broad consequences for the individual. Survivors may need extra encouragement and support in the transition home when confidence over their ability to participate in society might be low. Both clinical and logistical needs must be taken into account to provide opportunities for participation in suitable activities. Interdisciplinary holistic care may support survivors to cope with the transition to home, increase survivors' QOL and improve health outcomes. The perceived lack of support from health professionals during the survivors' transition to home life could be resolved through transition programmes in hospitals, where dedicated nurses and health professionals follow the CA survivor during the transition from hospital to home.<sup>4,33,35</sup>

### **Conclusion**

Returning home after surviving a CA is an emotional roller coaster experience, where survivors have to accept that their bodies may not be as capable and dependable as before. The realisation that their bodies had unexpectedly failed them made them anxious when they returned home, indicating a need for support from health professionals, including information addressing their concerns and available support services. The transition home was a stark reminder of their new reality where they could not perform at the same level as they previously did, questioning their sense of being. Nursing interventions and support need to address the time of transition home and nurses need to emphasise the importance and benefits of participation in CR. Returning home may be a chaotic and bewildering time; however, nurses and health professionals can learn from survivors' stories and play an important part in optimising the transition back to a new normal life by providing holistic care.

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### **Conflict of interest**

The authors declare that there is no conflict of interest.

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### **Supplemental material**

The supplementary material is available online with the article.

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## **PUBLICATION: LONG TERM SURVIVAL FOLLOWING CARDIAC ARREST: A NARRATIVE INQUIRY**

### **The impact of the article**

At the time of thesis submission, the publication titled: 'Long-term survivors of cardiac arrest: A narrative inquiry' has 2 citations Scopus and 24 in Google Scholar. The article has a Field Weighted Citation Impact of 1.58, and a Prominence percentile: 76.181

In ResearchGate this article has 145 reads and 8 citations

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This article explores the long term survivors' experience and is a sub-analysis of the whole cohort of participants. Therefore some presented findings are repetitive and included in the first article named 'A narrative inquiry of survivors' experiences of the time just before and after a cardiac arrest.'

# Long-term survivors of cardiac arrest: A narrative inquiry

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Gunilla Haydon, Pamela van der Riet and Kerry Inder

## Abstract

**Background:** Despite extensive knowledge and research in cardiac health there is limited understanding in how a cardiac arrest influences the life of long-term survivors.

**Objective:** The aim of this study was to explore how long-term survivors of a cardiac arrest adjusted to their new reality, expressed in their re-storied narratives.

**Methods:** Seven individuals surviving a cardiac arrest 5–26 years ago were interviewed through in-depth conversations over a six-month period. These interviews were analysed using Clandinin and Connelly's framework of narrative inquiry.

**Results:** Seven threads were found: Disbelief, Surveillance of their body, Loss of control and desire for normality, Keeping fit and informing others, Gratefulness, Spirituality – luck and fate, and Fragility of life and dying.

**Conclusions:** All seven long-term survivors of cardiac arrest expressed a positive attitude. Despite the nature of the cardiac arrest and the hurdles that followed, they have a heightened appreciation for life. This indicates that after the adaptation to their new reality of being a cardiac arrest survivor life returns to a new normality.

## Keywords

Qualitative research, narrative, cardiac arrest, heart arrest, long-term survival

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## Introduction

Narratives, or stories, are a way of creating structure and order to experiences<sup>1–4</sup> and can make experiences easier to understand for both narrator and listener<sup>3</sup> as they organise complex experiences, providing meaning and purpose to events and memories.<sup>4</sup> By exploring the narratives of cardiac arrest survivors, a deeper understanding of their experience can support healthcare professionals to provide personalised care, especially during the first year of recovery where significant improvement can be seen.<sup>5,6</sup>

Cardiac arrest is a large health problem in the western world. Recent published data has the combined annual total incidents of cardiac arrest in Europe, USA and Australia as 810,000 cases<sup>7,8</sup> and worldwide the number of survivors remains low (10% to 13%).<sup>7,9–11</sup> Nevertheless, with improved education in signs and symptoms of cardiac arrest and more training in cardiopulmonary resuscitation (CPR), there is an increased possibility of not just surviving a cardiac arrest, but surviving with a good outcome.<sup>12–14</sup> This has led to interest in the quality of life (QOL) of cardiac arrest survivors and findings indicate that survivors

were mostly content with their QOL.<sup>15–17</sup> There are often initial issues such as anxiety and depression<sup>5,6</sup> and cognitive impairment.<sup>18</sup> However, there is limited qualitative research available exploring the long-term experience of cardiac arrest survivors, hence a need for a deeper understanding to tailor more person-centred care for cardiac arrest survivors.

This study explores the re-storied narratives<sup>19</sup> of seven individuals who survived a cardiac arrest between five and 26 years ago. Re-storied narratives are when one's projected life-story changes due to an unexpected event.<sup>19</sup> As we found no consensus to the definition of 'long-term' after surviving a cardiac arrest<sup>7–9</sup> we have classified a long-term survivor as someone who has survived a cardiac arrest more than five years after the event. This study provides

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insight from the experience of long-term survivors, as surviving a cardiac arrest may be a chaotic and potentially traumatic event where early support may provide long-term benefits for the survivor.

## Aim

The aim of this study was to explore how long-term survivors of cardiac arrest adjusted to their new reality expressed in re-storied narratives.

## Methodology and method

Narrative inquiry is well suited to the exploration of health related issues because it places the individual, their experiences and their narrative at the very centre of the inquiry.<sup>3,20-24</sup> The narrative inquiry researcher takes a subjective position, emotionally engaging in connecting relationally to the participants' social and private world and attends to the phenomena of the 'storied' experience, thereby providing a deep understanding of their unique story.<sup>1,20-24</sup>

## Ethical considerations

Ethics approval was granted (reference number H-2015-0132) from the University of Newcastle human research ethics committee to explore the experience of surviving a cardiac arrest as part of a larger qualitative study involving 17 survivors of cardiac arrest. Ten survivors recently had a cardiac arrest, whereas this study focuses on seven participants who had their cardiac arrest five to 26 years ago. Participants were provided with information and written consent was obtained from all participants.

## Recruitment and data collection

Survivors of a cardiac arrest who lived independently and could speak English were recruited through snowball sampling – word of mouth – where interested people (nurses, colleagues other participants) spoke about the study and this was bolstered by an article in a local newspaper. This newspaper article introduced the main researcher, and interested participants could find information about the research. It also encouraged people who did not experience a positive outcome after a cardiac arrest to approach the researcher. Participants were asked to contact the main researcher and individual interviews ranging between one and four hours were undertaken at a time and place of mutual convenience. No participants were known to the researchers before the study. These interviews were audiotaped with permission and no participant withdrew from the study. An interview schedule was developed and an open-ended question such as 'Tell me about the experience of waking up after the event' started the conversation. Within the relational aspects of narrative inquiry, the conversation was not limited to the

experience of the cardiac arrest but tangential narratives were also included to give a holistic view of the cardiac arrest experience. The interviews were held at a place chosen by the participants and comprised six face to face and one via Skype. Prior to, and after, the main interview, contact between the main researcher and the participant continued by emails and phone calls, consistent with the relational aspects of narrative inquiry.

## Data analysis

The three-dimensional framework response to this question of Clandinin and Connelly's<sup>3</sup> narrative inquiry involving time, sociality and place were central to the analysis and in identifying various narrative threads. This framework emphasises that participants' narratives are always situated and intertwined within this three-dimensional space and should be considered in relation to each other.<sup>1-3</sup> The temporal dimension, past, present and future, explores how past experiences influence participants' current reality and their plans for the future.<sup>1-3</sup> The social dimension explores how the personal, social and cultural experiences impact on their narrative<sup>1-3</sup> and place explores how the environment frames each experience because where the event occurred may impact the narrative.<sup>1-3</sup> Though 'themes' are commonly used in qualitative research, the narrative inquiry framework uses the term 'threads' to identify and examine re-occurring thoughts and feelings throughout the narratives as they are intertwined within the three dimensions.<sup>2,3</sup>

Each interview was transcribed, re-read and listened to multiple times by the lead author. This was an iterative process using the three-dimensional inquiry space as a framework to guide the identification of emerging threads and analysis. These emerging threads were circulated among the co-authors to ensure the threads were accurate and to finalise findings.

## Findings

The seven participants were all living independently: two female participants and five males spanning from 48 to 92 years of age. The individual participants are listed in Table 1. The numbers link quotes to individuals. The presentation of findings begins with the three dimensions, followed by the narrative threads.

## Three dimensions in these re-storied narratives

### Time

None of the participants in their re-storying following cardiac arrest survival had ever considered that they might be a candidate for a cardiac arrest. They all lived lives filled

**Table 1.** Participant characteristics.

Participant no.	Pseudonym	Sex	Age at interview	Year of cardiac arrest
1	Mary	Female	51	2006
2	David	Male	59	2008
3	Thomas	Male	59	2011
4	Betty	Female	63	2008
5	Steve	Male	64	2010
6	Arthur	Male	75	2010
7	Paul	Male	92	1982

with family, work and leisure. Although four of the participants had health issues, the arrest took them by surprise. Though the cardiac arrest happened in the past, and many years have gone by, the event greatly impacted on their lives, as presented in the narrative threads. The cardiac arrest was a catalyst for change and required them to re-define themselves: to adopt and promote a healthier lifestyle, to leave an abusive relationship, to write a book, or to change career. All these changes came about because of their cardiac arrest. Life inevitably returned to a new normality but it is a re-storied life. Initially there was trepidation and uncertainty before settling back into lives of family, work and leisure. The cardiac arrest is always in the background of living, repressed perhaps, but never forgotten.

### *Sociality*

The social implications of a cardiac arrest are broad and the survivors' narratives highlighted how enormously the people around them influenced their re-storied lives. The support they received from friends and family was invaluable and influenced the re-storying of their social life. Frequently vocalised was a certain amount of frustration with the oblivious, or disinterested, attitude in society about the serious ramifications of a poor lifestyle. Perhaps their zeal can be attributed to their perception that they had survived because they felt they were generally in good physical condition before the cardiac arrest. The participants did not have great knowledge concerning cardiac illnesses, or cardiac arrest, thus their cardiac arrest was unexpected and created chaos in their social environment that lingered for a long time.

### *Place*

Place, both where the cardiac arrest occurred and where they live now, was of great importance for the participants. The place for the immediate recovery was important – a need to feel safe and have access to support during this initial critical period. For these long-term survivors, the current dwelling place, and their relationship to it, influences and contributes to their re-storied life, providing a

feeling of security, gratitude and appreciation for being alive. They were conscious about the need to be close to help and chose to live in a place where support is available. The place where the cardiac arrest occurred had a tremendous impact on the participants' survival. It was the environment in which immediate response took place, where the knowledge of bystanders and their actions may have meant the difference between survival and death.

### *Narrative threads*

Seven threads were intertwined in the three dimensions of time, sociality and place revealed in the re-storied narratives: Disbelief, Surveillance of their body, Loss of control and desire for normality, Keeping fit and informing others, Gratefulness, Spirituality: luck and fate, and, last, the Fragility of life and dying.

#### *Disbelief*

There was a strong thread of disbelief expressed by participants. They did not perceive themselves as potential candidates for a cardiac arrest. Indeed, they considered themselves to have an average lifestyle, had none of the perceived serious risk factors for cardiac arrest such as being a smoker, heavy alcohol consumption, obesity or a sedentary lifestyle. Comments such as, 'I was not overweight or drank or smoked. And yet it happened!' (6), 'I thought I would definitely not be a candidate for a [cardiac arrest] because I was healthy, in good condition and not overweight' (5), 'I think everybody that has a [cardiac arrest] is unprepared for it' (3) and 'I was certain I wouldn't have a [cardiac arrest]! (1)' all convey their unpreparedness for the event, which in turn generated feelings of doubt and insecurity when it occurred. This insecurity intensified as they realised their body was not as reliable as previously imagined, leading to surveillance over their body.

#### *Surveillance of their body*

After the event, there was mistrust and apprehension regarding their bodies, creating a need for surveillance to ensure their bodies were working well, monitoring diet

and exercise. 'Keeping a record of my heart' (7), 'I monitor my lifestyle, diet and exercise' (5), 'The left ventricle was struggling to work so I lost weight' (1), 'I am doing my best to keep my heart as healthy as possible' (4) and 'Your diet is everything' (3). The participants paid attention to their body and any deviation from *their* normal was examined to ensure it was not a prelude to another cardiac arrest. These comments express their need to regain control over their bodies and their future reality, to redefine themselves as survivors. This need lessened as time passed and they adapted to their re-storied life.

### *Loss of control and desire for normality*

The cardiac arrest was a chaotic event in which participants felt they had lost control over their lives and it took time to adjust to a new reality. 'I had lost control' (4), 'I did not know how to react, I had never been subjected to such illness before' (5), 'The [cardiac arrest] was completely out of my control' (6), 'My greatest fear, would it happen again?' (7) and 'I remember craving normality, not involving doctors or appointments; a desire to be in the herd again' (2). These remarks indicate their need to return to normality and regain control of their own re-storied lives and to influence others in a positive way.

### *Keeping fit and informing others*

One of the motivators for participants to tell their re-storied narratives was to broadcast to others the importance of keeping fit and looking after their health. Although participants had not seen themselves as candidates for a cardiac arrest before the event, their belief in attitudes and behaviours regarding their health consolidated their commitment to looking after their bodies following the cardiac arrest. In their realisation that life was fragile there was a degree of frustration about the relaxed attitude of others regarding their health and failure to embrace the need to change to a healthier lifestyle. 'If you are unfit and overweight, perhaps you should expect the worst if you do not look after yourself and continue to smoke, carry big bellies and not exercise' (5), 'Maybe I am a little bit harsh on people, once you experienced it, you want to shake them!' (6), 'Do what you can to prevent it from happening again' (1) and 'I emphasise this, look after your body' (3) conveyed that they had developed a strong desire to increase general knowledge that a cardiac arrest can happen to anybody.

### *Gratefulness*

After the cardiac arrest, the re-storying of their lives included a new appreciation for life and a mindful relationship to their own physicality, leading to doing what felt right and not pressing to over-achieve. These participants had a positive attitude to their survival; there was an

underlying gratitude toward the people and circumstances which made their survival a reality. 'I feel particularly fortunate' (7), 'A wakeup call to appreciate life and what you have' (3), 'There was a meaning in my survival' (1), 'I have a second chance here and I having another go' (6) and 'How can you thank somebody for saving your life?' (2) In re-storying their lives, they experienced a contented presence and appreciation for living in tune with family, friends, their surroundings and themselves.

### *Spirituality: luck and fate*

To survive a cardiac arrest is to be very close to death; it is a life changing experience where survivors' fundamental existential and ontological beliefs and values are challenged. For participants, knowing that most people do not survive a cardiac arrest made them feel very fortunate. Comments such as 'I feel lucky to be here today' (7), 'I am so fortunate' (3), 'I was at the right place at the right time' (4) and 'the stars aligned to help me survive' (2) describe the participants' belief that luck and fate were involved in their survival; the cardiac arrest happened where people around them could act accordingly. Their survival gave them a feeling of purpose. The statements 'It was not meant to be the end of me' (7), 'I started to explore my spirituality and why am I here for?' (1), 'I was not allowed to go, because it was not my time' (5) and 'Maybe somebody up there is not ready for me yet' (4) all express a belief in a benevolent metaphysical power and this provided meaning and comfort to the participants.

### *Fragility of life and dying*

The experience of a cardiac arrest and realisation that life is fragile and can end abruptly caused participants not only to appreciate life, but also accept that they will die one day. The cardiac arrest experience, with the closeness to death, changed their view of dying as they expressed they had already experienced it. 'I am not frightened about dying. Before this I was terrified of dying' (1), 'I don't mind. It was pretty quick' (4), 'I am not scared of dying' (7) and 'It is a good way to go, if you've got to go' (6). This experience of near-death as a reality provided participants with an awareness that seems to be comforting for them.

## **Discussion**

This study aimed to explore the experience of long-term survivors of cardiac arrest and to describe how they adjusted to their new reality using re-storied narratives. Seven participants' narratives of long-term survival after a cardiac arrest were analysed using the dimensions of time, sociality and place.<sup>1-3</sup> In the unpacking of life before the cardiac arrest participants tell about a life where cardiac problems did not exist and they viewed themselves not to

be at risk of cardiac arrest. The cardiac arrest was an unexpected life changing event where they had to adapt to an unforeseen future, to be re-storied. The social dimension includes the difficulties after the cardiac arrest. They had to adjust to a life with hospital appointments and limitations before settling into a new re-storied life. Although progress is seen throughout the first year, evidence in research indicates improvements in the first three months after cardiac arrest.<sup>5,6</sup> While the physical function level is steadily improving, emotionally anxiety and depression can still influence recovery.<sup>5,6</sup> The long-term survivors in this study did not specify a timeline as to when they felt they had adjusted to their new re-storied life.

For some participants the cardiac arrest became a strong motivator to inform others of the implications of cardiac arrest and how to prevent and improve chances of survival. All participants were aware of the importance of where the cardiac arrest happened. Place greatly influenced their survival along with sociality, as people with skills and knowledge were involved in their resuscitation. The immediacy of help, resources and facilities played a huge role in their survival in their narratives. The place where they now live has a strong influence of how they adapted to a life after cardiac arrest, living in a place where support is available.

There was a strong disbelief among participants and all spoke of the unpreparedness they felt after the event, creating a feeling of insecurity. This insecurity is expressed as they realise their body is not what they thought it was. Earlier research describes the cardiac arrest event as a sudden and unexpected event for the survivor.<sup>25,26,27</sup> After cardiac arrest there was a need both to regain control over their body and to re-story their future life; they did not trust their body. They took on a surveillance discourse and they redefined themselves through this surveillance along with a desire to reconnect with their unknown body. Forslund and colleagues<sup>28</sup> in a mixed methods study of 15 interviewed participants found that participants chose to some extent to ignore risk factors and 'preferred living a "good life", where risk factor treatment played a minor part' (p.7). This was not reflected among these long-term survivors, as through their surveillance discourse they all adapted to a healthier lifestyle.

The loss of control after the cardiac arrest and realisation that life is now different, a re-storied life, took into consideration factors such as diet, less stress, where they live, closeness to healthcare and support. Participants tried to regain control by creating meaning from their cardiac arrest experience and this has continued over the years. Research undertaken closer to the cardiac arrest event found that recovering after an unexpected life threat becomes possible by searching for the logic and reflecting over the experience of the event, where plans for a future life become visible.<sup>25,26,27</sup>

All participants were grateful for their survival and, with a positive attitude, their narratives emphasised the

importance of living, to enjoy the benefits of family friends and environment. There was a strong appreciation for life, adapting to their ability and not trying to over-achieve. There is an underlying gratitude to the people and circumstances that made their survival a reality. This new-found appreciation for living became a touchstone for decision-making, something that was not in the forefront of their minds before the cardiac arrest. Appreciation of the little things in life is also apparent from previous research.<sup>26-29</sup> Participants' knowledge that most people do not survive a cardiac arrest made them feel extremely lucky and they expressed belief that both luck and fate were involved in their survival. The location of the cardiac arrest meant they could obtain immediate help. Bremer and colleagues<sup>25</sup> indicate that survival depends on circumstances where commencement of immediate life-saving measures is crucial. The participants' re-storied narratives tell of the influence their current surroundings have on their present wellness as they have chosen environments that provide a quiet life with less stress.

Their survival caused them to think of the fragility of life; for many the experience gave them a feeling of a purpose for their survival. To survive a cardiac arrest is to be very close to death and this reality can be a life changing experience where the survivors' fundamental existential and ontological beliefs and values are changed.<sup>25,27-29</sup> For these long-term survivors there is an acceptance of death and the participants expressed they had already confronted dying. This experience of death as a reality provided them with a knowledge that seems to be comforting.

Long-term survivors of a cardiac arrest in this study have a positive attitude and want to convey their re-storied narratives to inform others of the importance of keeping fit and looking after their health. With their experience of survival, and their own ignorance of the dangers of a cardiac arrest before the event, they expressed frustration over their perceived relaxed attitude others have of their health and willingness to change to a healthier lifestyle. There was a will to support and increase the public's knowledge that a cardiac arrest can happen to anybody and the importance of knowing CPR. To survive a cardiac arrest is a chaotic experience; however, survivors with limited ailments can expect to return to a regular lifestyle.

The healthcare professionals' influence on recovery should not be underestimated. The first year after the event influences how well the survivors recover. Long-term cardiac rehabilitation and follow-up are essential to prevent readmission and improved QOL.<sup>30</sup> Depression<sup>5,6</sup> and cognitive impairment<sup>18</sup> are common after surviving a cardiac arrest. Healthcare professionals should take into account the chaotic and life changing experience that a cardiac arrest can be for the survivor and monitor survivors for indicators of both physical and psychological signs of distress.

## Trustworthiness, rigour and strength

Included participants represent a diverse purposive group, whereby the depth and breadth of experiences ensured rigour and trustworthiness. This project's rigour is based on the researchers' open attitude and sensitivity to the participants' re-storied narratives, supported by Clandinin and Connelly's<sup>3</sup> framework. The first author conducted all the interviews and transcribed them verbatim, the co-authors collaborated to discuss and review threads present in the re-storied narratives.

To uphold the rigour of the study<sup>31,32</sup> interviews with participants were held over time and included both before and after emails and phone conversations. All authors were involved in the analysing, evaluating and interpretations confirming that findings were grounded within the narratives. Included participants came from diverse backgrounds and ages, ensuring a broad and deep pool of experiences, facilitating rigour and credibility.

The strength in this project is the cardiac arrest survivors' in-depth narratives, describing their experience, which contributes to the understanding of long-term cardiac arrest survivors' lives.

## Limitations

As with any conversation there is a possibility that participants selected what they were willing to share and might have adapted their narrative to present themselves in a more positive light, therefore, a self-selected bias might be present in their narrative. This project was limited to a society with high technological care, therefore surviving a cardiac arrest in a different society or geographical location might have other circumstantial, social, religious and cultural variations not found here. Although this study was open to all English-speaking survivors of a cardiac arrest living independently, and the newspaper article encouraged people who did not experience a positive outcome after a cardiac arrest to approach the researcher, only participants who did not see themselves as having any severe residual complications from their cardiac arrest shared their re-storied narratives. Long-term cardiac arrest survivors with life limiting outcomes did not participate and their experience may be different, especially those who have not adjusted as well as the seven participants presented in this study.

## Conclusion

In-depth exploration of seven narratives gives an insight into the long-term survival of cardiac arrest. All participants expressed a positive attitude to life. Although they viewed the cardiac arrest with disbelief and as a hurdle to be overcome, after the ordeal they found a new appreciation of life and an acceptance of life's fragility and death. Survivors of a cardiac arrest with a positive outcome can

expect to return to a regular lifestyle after the initial turmoil after the event and an adaptation to their new re-storied life has been made. Participants voiced a desire to share their knowledge to help increase the possibility for others to survive a cardiac arrest. Their experience may be useful to support recent survivors of cardiac arrest while in rehabilitation. As all participants survived with limited consequences from the ordeal, there is a need to explore the experience of less fortunate survivors of cardiac arrest to obtain a more inclusive experience of all survivors of a cardiac arrest.

## Implications for practice

- Long-term survivors of a cardiac arrest with a positive outcome can expect to return to a regular lifestyle.
- Participants expressed a positive attitude and although they viewed the cardiac arrest with disbelief and as a hurdle to be overcome, after the ordeal they found a new appreciation of life and an acceptance of life's fragility and death.
- Participants voiced a desire to share their knowledge and thereby increase the possibility for others to survive a cardiac arrest; their knowledge should be used to support recent survivors of cardiac arrest while in rehabilitation.

## Declaration of conflicting interests

The authors declare that there is no conflict of interest.

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## Summary of Chapter Four

*This chapter presented the findings of my narrative inquiry study using three articles. These articles follow the timeline of recovery after a cardiac arrest where the first article focuses on the immediate time before and after the cardiac arrest. This is presented in an article titled ‘A narrative inquiry of survivors’ experiences of the time just before and after a cardiac arrest’ experience’. The second article titled: ‘The experience of returning home after surviving cardiac arrest: A narrative inquiry’ explores how the survivor experienced the transition home from hospital. The last article ‘Long-term survivors of cardiac arrest: A narrative inquiry’ presents the findings from the long term survivors experience.*

*This following chapter begins with a discussion of the importance of story, and a recapitulation of Clandinin and Connelly (2000) and Clandinin’s (2013) ontological and epistemological stance of embodied learning from experiences, and the dimensions of time, place and sociality. This is followed by a summary of the findings using narrative inquiry. The threads found in this narrative inquiry exploring the experience of surviving a cardiac arrest will be discussed including the latest research in this area. The Discussion Chapter also holds the summary of my experience as a researcher using narrative inquiry at the end of the chapter.*

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# Discussion

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*The previous chapter presented three articles published from my narrative inquiry study. These articles follow the timeline of recovery after a cardiac arrest and the first article, titled 'A narrative inquiry of survivors' experiences of the time just before and after a cardiac arrest', found that the experiences of surviving a cardiac arrest strongly influence the care needed, and that healthcare professionals need to have a holistic view of the survivor. The experience of cardiac arrest is an extraordinary event for the individual, changing the ordinary to extraordinary where they adapt to a new reality resulting in a complex liminal transition.*

*The second article entitled 'The experience of returning home after surviving cardiac arrest: A narrative inquiry', found that a cardiac arrest is experienced as a catastrophic event where the survivor has to accept and adjust mentally, physically and socially, leading to insecurity about the future. The cardiac arrest impacts all aspects of life on returning home, including the ability to work and to drive, and accepting added medical appointments and medication regimens.*

*The last article, 'Long-term survivors of cardiac arrest: A narrative inquiry', presents the findings from the long term survivors experience. This group expressed a positive attitude. Although there were hurdles that followed the cardiac arrest, they had an appreciation for living, indicating that after the adaptation to the reality of being a cardiac arrest survivor, life returns to a new normality.*

*This chapter begins with a discussion of the importance of story and a recapitulation of Clandinin and Connelly (2000) and Clandinin's (2013) ontological and epistemological*

*stance of the learning from experiences, and the dimensions of time, place and sociality. Thereafter is a discussion of the inquiry and the findings using narrative inquiry as a methodology and with eleven headings the plotlines are further explored. The literature review in Chapter Two was limited to the literature published before 2015, therefore, inclusion of recent published literature is also included. Finally, the synthesis and conceptualisation of my study will be presented.*

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## THE IMPORTANCE OF STORIES

This inquiry has sought to find “What is the experience of surviving a cardiac arrest?” with the starting point ‘telling and listening to stories’. This thesis presents the retelling of these stories adapted to the journal requirements for publication.

Stories are a universal and the most common and widely used means of human communication, stories are used by everybody in daily conversations as well as in science, politics and the arts. Therefore, stories are the most likely source of communicable understanding of subjective experiences. Stories bring both richness and depth of experience and are probably the best opportunity there is to explore the subjective illness experience (Little, Jordens, Paul, Montgomery & Philipson, 1998).

The importance of story in our society should not be underestimated. Stories are how we make sense of our experiences, as we retell our endeavours at the end of the day. We reconnect with people (our audience) as we exchange our stories, we share the experience with each other and build connections that bind us together (Clandinin, Caine, & Lessard, 2018). Therefore, the richness of our story has multiple purposes in our daily lives, and it provides the storyteller with an opportunity to make sense of the event that happened, especially if it was an unusual or an unexpected event. By sharing the story, it provides the listener with an opportunity to learn from events and may provide the storyteller with an opportunity to reflect. Storytelling strengthens the bonds between the teller and listener and a mutual understanding of experiences occurs. The story creates memories from the past and learnings for the future. Reminiscing of stories from the past

often highlights social changes that have occurred and how experiences have influenced the future (Clandinin, 2013, 2016; Clandinin, Caine, Lessard & Huber, 2016).

Connelly and Clandinin (1990, 2000) were inspired by one of the most eminent educational theorists, John Dewey. In his book, 'Experience and Education' (1938), Dewey highlights the importance of learning through experience. Clandinin and Connelly (1990, 2000) and Clandinin (2013) use Dewey's ontological and philosophical stance on experience in their commitment to narrative inquiry describing the narrative inquiry as a way to study experience where "People shape their daily lives by stories of who they and others are, as they interpret their past in terms of these stories. Story, in the current idiom, is a portal through which a person enters the world and by which their experiences of the world are interpreted and made personally meaningful." (Connelly & Clandinin, 2006, p. 375).

This statement indicates that as an individual tells and retells their story, the event/plot of the story becomes clearer and the storyteller creates order into their experience. The story that is told will also depend on the 'audience' for whom the story is told. For example, the young teenager may tell a different story to that of their parents compared to their friends of what happened during a Saturday evening event. Both versions will be a truthful recount of the event, but the teenager will highlight different aspects and perhaps omit other aspects, in order to appeal to their 'audience'. Hence there is no absolute truth to be found, only the storyteller's and audience's interpretation of the event. Dewey's (1938) ontology is described as 'transactional' (a process of negotiating contact between two or more people) indicating the epistemological implication that the ideal intent for a narrative inquiry is not to produce a faithful description of a reality independent of the storyteller. Instead, it is a pragmatic view of knowledge where findings stem from the

experience and return to that experience for authentication (Clandinin, 2013, Clandinin et al., 2016). In narrative inquiry there are four terms regarded as foundational: telling and living followed by retelling and reliving (Clandinin et al, 2016). Connelly and Clandinin (2000) explain that there are two starting points of a narrative inquiry. The inquiry can start by participants 'telling stories' and the inquirer listening to the stories. Or by 'living stories', as in the inquirer living alongside the participants for a period of time. This leads the researcher to 're-telling' or 're-living' the presentation of findings in the inquiry (Connelly & Clandinin, 2000).

Clandinin (2013, p. 44) states "*Narrative inquiry always begin and ends in the midst of ongoing experiences.*" Therefore, as time moves on and our experiences expand, the answer to a research question may change. Hence, narrative inquiry does not have a research question asking for a definite answer but rather considers the inquiry to be a research puzzle, where the "*narrative inquiry does not have an explicit research question leading to acceptance of a specific answer. Narrative inquiry is a research puzzle in which the lived experience is revealed and is described as "an experience of an experience"*" (Connelly & Clandinin, 2000, p. 189). The reality that stories change over time, as exploring stories from bygone years highlight the change in social norms, also implies the notion that there is no exact answer to find as we are all in a transition in time.

The ontological and epistemology stance in narrative inquiry that is learning from experience was an important part of my involvement throughout this research. Feelings associated with a traumatic event, such as a cardiac arrest, can be explored through an embodied approach. Healthcare should utilise the embodied experiences of both patients and healthcare professionals providing care in order for person-centred care to take place

(Fernandez, 2020; Ray, 2006). Embodiment highlights a conceptual approach to holistic care, allowing exploration of time, place and social (emotional) aspects of illness, including how well we as healthcare professionals relate to others (Fernandez, 2020). Through listening to the telling and retelling of patients stories healthcare professionals could be better able to empathise with their patients and thereby engage with them in more meaningful ways (Fernandez, 2020). The awareness of embodiment provides opportunities for patients to describe and understand their experiences of illness and healthcare. Providing an opportunity to describe some bodily experiences, or formulate questions, that they experience during their illness.

The opportunity to explore experiences that we cannot (or hope that we will not) experience, such as surviving a cardiac arrest, provide a window of knowledge to the event under inquiry. We can, however, learn through stories from other peoples' experiences. Having conversations with these survivors of a cardiac arrest was a privilege, the stories they told me were colourful and engaging. The reality of compressing all these in-depth and engaging threads into journal articles with the restrictions of word limits was a challenging task. However, with the ontological and epistemological stance of learning from experience and education in narrative inquiry, I felt it was important to have these findings published as scholarly work, although much of the vibrancy from the narratives was removed to meet the journals requirements.

This research using narrative inquiry was part of the qualitative realm of research and, therefore, there was no attempt to claim that these narrative findings hold an absolute truth. Instead, the presented narratives from my analysis represent multiple truths (Clandinin, 2013) as experienced by the participants and analysed by me, the researcher,

and finally the readers of this research puzzle. However, there is no assurance that readers of these narrative findings will interpret the findings in the same way, as each reader will have their own previous experiences and thereby interpret the findings from their own ontological stance. I would reason that this is a positive notion whereby each reader of this research puzzle engages in the experience of others and thereby increases their own knowledge and understanding of the participants' experiences.

### **THE FOCUS OF THIS NARRATIVE INQUIRY**

Stories are an integral part of life and when people are ill, they often feel a need to tell stories of their illness experience. Frank (1995, p. 55) stated that “*Whether ill people want to tell stories or not, illness calls for stories.*” For Broyard (1992, p. 21), “*Storytelling seems to be a natural reaction to illness. People bleed stories, . . .*” highlighting the need for people to tell their story of illness. This could explain the large number of interested participants. To survive a cardiac arrest is a life changing event and generates a lot of internal reflection that is expressed in their stories. As narrative inquiry's focus is on storytelling and illness generates stories, this makes narrative inquiry well suited for health research (Haydon, Browne & van der Riet, 2018).

I entered this inquiry as a result of listening to stories of surviving a cardiac arrest that sometimes were not a positive experience. My own experience working in an intensive care unit was an impetus for the inquiry. I felt there was a misconception about a cardiac arrest and wanted to explore what survivors of a cardiac arrest experienced. I had this wonder about what it was like to experience such a close encounter with death, knowing

that without intervention you would be dead. During this time, listening to stories where survivors had a less positive experience of survival, I asked myself, was there something in our rescue attempt that changed the outcome? Unfortunately, that wonder still remains as all the participants in this inquiry had a positive story to tell.

I was drawn to narrative inquiry, with its relational aspect between participant and researcher and the opportunities for multiple meetings that would provide opportunities to get to know the participants. In that respect the methodology was well chosen as I had a good connection with all participants even though most participants chose to only meet once face to face.

Although, the whole spectrums of experience were invited, only participants with a positive story to tell participated in the study. Their stories were not without tensions and distress, however, the participants were content with their life after the cardiac arrest indicating it was with a good outcome in the end for them.

As I look back on this time as a PhD candidate and venture back to the beginning of being in the midst of living alongside this research puzzle for many years, I have become aware how well Clandinin and Connelly's (2000) and Clandinin's (2013) notion of the three-dimensions of time, place and sociality help explore the phenomena of people's lives. As I continued my inquiry I travelled to many places, from the inner city to rural towns, farms and beach cottages, where I met with my participants. The participants were a diverse group; single, married, divorced, widowed, heterosexual and gay, all with a variety of backgrounds in personal and career achievements including home carers, academics, white and blue colour workers, health professionals and a PhD. I truly met a diverse group of survivors of

cardiac arrest, highlighting that a cardiac arrest does not discriminate, it can happen to anybody, regardless of age, gender, education or social status.

The importance of stories can also explain the unexpectedly high number of interested cardiac arrest survivors who wanted to share their story. In a very short time span I had more participants than I had expected and more than I needed for narrative inquiry methodology. Many of the participants were encouraged by their loved ones to contact me for a meeting. To honour their willingness to participate and accept that this was an important story for the participants to tell, I did not deny any eligible participants' the opportunity to tell me their story. The participants' willingness to share their stories with me, the depth of detail and the broad inclusion of other details, perhaps not always relating to the cardiac arrest but giving me a greater knowledge of them as individuals, was for me a privilege. In the end I had seventeen participants, all had survived a cardiac arrest, with a good outcome. I received no contact from survivors living independently with a less than positive experience, although I hope that in the future, I can make such contacts and listen to their stories. There is a need to gain knowledge from all groups in order to provide care that is aimed at all levels of recovery after survival.

A single meeting with a participant could last for close to four hours and was never shorter than one hour. I will treasure times spent with my participants as their stories have left lasting memories. Although there were still hurdles to overcome, adjustments to make and acceptance of surviving a cardiac arrest, none of the participants described a miserable or negative existence. They were all very happy and grateful that they had survived.

Connelly and Clandinin (2000) as well as Clandinin, Caine and Lessard (2018) emphasise the relational aspects of narrative inquiry between the researcher and

participant. Often, the first contact I had with a participant was over the phone. Of note, for the initial contact the newspaper article had the wrong contact phone number listed for me, therefore, interested participants had to find the correct phone number, a factor that indicated a keen interest to participate. This was followed by emails and further phone calls before the face-to-face meeting occurred. I was surprised by the warm welcome I received and their frankness and openness in discussing their experience. When I met them in their home there was time for a cup of tea and general conversation before the voice recorder was started and the conversation focused on the actual reason for the meeting. The meetings in the library were more formal, although there was still time for general conversation before and after the recorded conversation. The Skype conversations followed the same pattern of general conversation followed by the recorded cardiac arrest story. Krouwel, Jolly and Greenfield (2019) as well as Janghorban, Roudsari, and Taghipour (2014) compared face to face interviews with Skype interviews and found that both interview methods gave a similar number of words and topics discussed and, therefore, can be acceptable to use in qualitative research. This was also my experience, as I did not notice any hesitation in my conversations via Skype.

The stories shared with me included much more than just the cardiac arrest and the influence these stories had on me was quite profound. They were not only about the cardiac arrest; they included vulnerable embodied stories of hardship, domestic violence, mental health, comorbidities, death of family members and loved pets. As well as joy over survival, there was an appreciation of nature and being alive. The relational aspect is not a one-way transaction. Their stories had a stronger influence on me as the listener of their stories. The time for reflection during verbatim transcription and during the exploration of

the metaphorical three-dimensional space to find the threads was a demanding time but also exciting and privileged. To find the common threads among the large amount of field text and keep the essence of the thread by using only a few quotes in the published articles was a challenge. The stories I was told will remain with me after this narrative inquiry is completed and I feel I have also learned to appreciate life and living more than before.

The topic of the inquiry made the conversations with the participants special. To let the participants' tell their story of surviving a cardiac arrest, the certainty of death and living revealed much of their ontology. They told of their hopes and worries for the future and the feeling of having experienced something very special. The participants were well aware of the low number of survivors after a cardiac arrest. This created ontological and existential questions of 'Why did I survive?' and 'Is there a meaning with my survival?' It also made them feel 'special', as they are now members of a very select group of survivors. This proud feeling of survival was embodied in their conversations with me. While telling me their stories they all had a sense of purpose, they wanted their story to be known. All the stories had an amazing depth and included many details of the place and the people around them, both as it happened and during their recovery. Each story was special and added depth to the study, it was a special time to live and listen to the participants, being part of their life and for a short while, being in the midst of their living. Reflecting on that period of this PhD project makes me feel very special as I had the privilege to be part of their experience and in this thesis create a narrative of their experience of surviving a cardiac arrest. The stories they told me were like a valuable gift, a gift that I will treasure.

## DIMENSIONS OF NARRATIVE INQUIRY

People are storytellers who as individuals and together lead storied lives, therefore, by studying people's stories we can learn how people experience their world (Clandinin & Connelly, 2000; Clandinin, 2013, 2016). The ontological stance of narrative inquiry underpins an epistemological commitment that experiences provide knowledge (Clandinin & Connelly, 2000; Clandinin, 2013; Kim, 2016). This framework of narrative inquiry states that people's stories are always within and intertwined with a three-dimensional space of time, place and sociality and therefore, need to be considered in relation to each other (Clandinin, 2006, 2013; Clandinin & Connelly, 2000).

In my analysis the three-dimensional framework of narrative inquiry was important to the significance and depth of experience since each is a component of a totality of experience. Unlike themes that focus upon areas of experience, threads allow the researcher to see how thoughts and feelings interact over time, place and social events in a relational way (Clandinin, 2013; Clandinin & Connelly, 2000).

When the three-dimensions are described, 'time' is probably the easiest to define. 'Time' is the present, when the story is told about a past event that will give us experience for the future (Clandinin & Connelly, 2000; Clandinin, 2013). Place includes both the place where the event 'happened' and where the story is told. As Connelly and Clandinin (2006, p.481) explain, "*all events take place some place.*" Places are often well described in stories and highlight how strongly the environment can influence experiences especially institutional places such as schools and hospitals, which also include the 'social' dimension. The social dimension includes both internal and external conditions. Internal conditions

include “... *the feelings, hopes, desires, aesthetic reactions and moral dispositions*” (Connelly & Clandinin 2006, p.480) of both participant and researcher. External conditions include the cultural, social, institutional and linguistic influences of the story.

### **TIME AS SEEN BY THE PARTICIPANTS**

Participants define the time of the cardiac arrest as the moment when what they thought was a predictable future, changed their reality from the well-known to the un-known and an uncertain future creating a liminal space. A cardiac arrest is an unexpected event, and some participants in this inquiry had no indication of a cardiac health problem whereas some already had health and cardiac issues.

The cardiac arrest is described as a ‘before and after’. The life ‘before’ was assumed as foreseeable; family, work and leisure were part of the ‘normal’ and the trajectory of living well followed their expectations. After the event, what the participants had taken for granted is now uncertain. Multiple questions of health, work and family are common, the time closely after the cardiac arrest is filled with doubt and apprehension. As time moves on, life returns to a new, but different, normal. The cardiac arrest is part of their life and experience, not forgotten but accepted as part of their life. The disruption of the continuum of time, as survivors’ predicted future is altered is reflected in the findings in the literature review (Chapter four). Five of the included articles (Bremer et al., 2009; Forslund et al., 2014; Ketilsdottir et al., 2014; Lau et al., 2010; Palacios-Ceña et al., 2011) in the systematic review (Haydon et al., 2017) describe the event as frightening and chaotic. There was a need to find out what had happened and to find a reason for the cardiac arrest. The

finiteness of life where time is limited was highlighted both in the found articles as well as described by the participants in my inquiry.

## **PLACE AS SEEN BY THE PARTICIPANTS**

When the participants' described their experience of survival, the place where the cardiac arrest occurred was an important part of their story. They were aware of the influence place had as it greatly influenced their survival. The place and people (sociality) with skills and knowledge of CPR made their survival possible.

Regardless of the place where the cardiac arrest happened, regaining consciousness after the cardiac arrest was a dreamlike clash with reality. They had no memory of the incident, however, woke up in embodied chaos of liminality. Before the event, they were alone or with a few people around them. Returning to consciousness, they are in a drastically changed environment, surrounded by people and sounds. The changed reality was confronting as well as frightening, adding to a feeling of loss of control and chaos.

The hospital recovery experience varied from excellent to harrowing. A hospital, for many, is an alien environment where the survivor may not be able to care for themselves (Brännström, Niederbach & Rödin, 2018). The survivors who recovered quickly had a desire to be discharged early and felt that the hospital hampered their recovery. Although, leaving hospital could be worrisome, as they felt they could no longer trust their heart and worried that they might have another cardiac arrest. They preferred company even if they had lived alone, or they used technology such as smart watches or mobile phones to create

a feeling of security. The return home was also a reminder that life had changed. Their home routines had changed, realising the everyday activities such as climbing stairs or showering, were now a challenge.

## **SOCIALITY AS SEEN BY THE PARTICIPANTS**

The social dimension includes their experience of further liminality with feelings of chaos and confusion as well as feelings of astonishment and joy. They survived an unexpected event where body and mind were disrupted, as their heart malfunctioned and the discomfort from the CPR could be a painful reminder of what went before. Their minds attempted to understand information about their unreliable heart, their pain and surviving a certain death. This cacophony of information often led to existential thoughts and questions of spirituality. This brings us back to the importance of embodiment, where an increased focus on embodied practice will assist healthcare professionals to pay attention to the illness experiences of the patients (Draper, 2014).

The survivors, while they are in a liminal transition, are also dealing with the embodied experience of surviving a cardiac arrest. Understanding and having an awareness of liminality, assists healthcare professionals to understand what support survivors of cardiac arrest want from the healthcare system, not only in the initial acute phase of their survival (Little et al., 1998), but also in the post recovery phase. When healthcare professionals do not take liminality and the embodied experience into account in their interactions with the patient, integral conflict may be created in the nurse-patient interaction (Mason, 2014). Healthcare professionals need to take into account the

embodied experience of the survivor, exploring their personality and what makes the patient who they are and as a result, how they are seeing their future (Dauphin et al., 2020; Draper, 2014; Mason, 2014). This is especially important while the patient is in the liminal space after the event (Dauphin et al., 2020; Smith, Frazer, Hall, Hyde & O'Connor, 2017). When healthcare professionals utilise body and verbal language and critical thinking, they can do what no machine or test can do; explore the primary meaningfulness and internal reasoning of the patient (Mason, 2014). Technology by itself does not distract the focus away from the body, it is the way the technology is used and interpreted. Therefore, healthcare professionals should not solely rely on technology and neglect embodied skills. As healthcare professionals we should use all our senses, our bodies and minds as the primary tools of practice (Draper, 2014). "Our bodies are significant for how we go about our everyday lives. We conduct our daily business in and through our bodies" (Draper, 2014, p.2237).

The homecoming was an emotional experience where they spoke of having to accept some restrictions, both from within their body and mind as well as from society. Not only was the internal emotional turmoil creating restrictions, external aspects of independence, work and participation in society was also greatly limited. To find, adjust and navigate the support of the health system was also a stressful time since the relationship between survivor and support services following discharge was more commonly disjointed, lacking in ease of use for the survivor. Coming to terms with the reality of surviving a cardiac arrest and realising the odds of survival was an emotional roller coaster ride. There were mixed feelings of joy, luck, fear, insecurity and anxiety. Surviving a cardiac arrest was a life changing experience where the survivors' existential beliefs and values were

challenged. Survival became a reality check and now more than ever an appreciation of being alive, realising the fragility of life. The experience of being close to death gave the participants an awareness of death that was confronting. This reality check created an appreciation for still being alive. For many, the experience gave them a feeling of a purpose, one that they often used to educate others about their experience.

## **PLOTLINES AND NARRATIVE THREADS**

In the following section I have further explored the findings from my two literature reviews in chapter two and the threads that were presented in the findings chapter. Clandinin and Connelly (2000) describe the plot as an overarching narrative, where the intertwining threads create a plotline that is situated in a three-dimensional space of time, place and sociality. The interaction between personal and cultural norms and space refers to the context in which the experience story was experienced. As further field text is collected, plotlines are adjusted to consolidate further findings from the revised threads (Clandinin & Connelly, 2000).

In the plotlines below I have included the names of the earlier found threads in my research that relates to each plotline. Additional exploration of recent literature relating to the plotlines exploring the experience of surviving a cardiac arrest included in this section.

## **PLOTLINE: CARDIAC ARREST—AN UNEXPECTED EVENT**

**Threads:** ‘Ordinary to extraordinary’ and ‘Disbelief’.

In conversation with participants, they all expressed the unexpectedness of the cardiac arrest. Even if the participant was in hospital due to a cardiac illness, they were unprepared for the event. To wake up after the cardiac arrest was often retold as a frightening, confusing, chaotic experience (Haydon, van der Riet & Inder, 2017, 2019, 2020 a,b). The drastic change of environment, often going from solitude and ordinary calmness to loud noises, sharp lights and a multitude of people, even in hospital, was challenging and threw the participants into a liminal space. The stark contrast between the ‘before’ and ‘after’ consciousness was frightening for the survivor and created feelings of a loss of control over their life. This is previously described by survivors (Bremer et al., 2009; Brännström et al., 2018; Forslund et al., 2014; Palacios-Ceña et al., 2011; Whitehead, Tierney, Biggerstaff, Perkins & Haywood, 2020). Although intensive health support is necessary during the immediate time of the cardiac arrest, perhaps an awareness of the survivor’s situation and a calmer environment could lessen the shock when a person gains consciousness after the event.

## **PLOTLINE: HEALTH RELATED QUALITY OF LIFE**

**Threads:** ‘Cardiac pain’ and ‘Resuscitation pain’.

Quantitative research uses statistical and mathematical tools to deliver results which may be generalised to the broader population. In health quantitative research is often used

to measure outcomes, behaviours and opinions using questionnaires. Commonly, quantitative research uses a larger group of participants, thus trends can be seen, and the result can be predicted to a larger similar population (Thompson et al., 2018). Therefore, the results seen in Haydon et al. (2017) integrative review could be transferable to other cardiac arrest survivors. In health research the question of quality of life is commonly used to explore the experience of health-related events and this includes the interest in quality of life among survivors of a cardiac arrest. Quantitative research dominates this research field where a large number of survivors' answer questionnaires such as the EuroQol-5D (Brooks, 1996), and 12-Item Short Form health survey (Ware, Kosinski & Keller, 1996). The literature review that commenced this narrative inquiry identified 36 articles with more than 50 different tools used to explore the quality of life for cardiac arrest survivors (Haydon, van der Riet & Maguire, 2017b). The tools used are often generic and are not specifically aimed at cardiac arrest survivors. Although the Utstein template, (Jacobs et al., 2004), is the international standard for the reporting of cardiac arrest and CPR, this reporting standard was not followed in the majority of the papers included in the integrative literature review (Haydon et al., 2017b). There is often a focus on the cardiac arrest, to the exclusion of comorbidities. This might influence the outcome as the 'holistic' view of the participants is lost. A recent article comparing health-related quality of life among 1369 in-hospital cardiac arrest survivors and 772 out of hospital cardiac arrest survivors found that in-hospital cardiac arrest survivors had more problems with pain, discomfort mobility and self-care (Djäv et al., 2020). The difference in outcome between in-hospital and out of hospital cardiac arrest survivors could possibly be because those in hospital had comorbidity that

influenced their general wellbeing (Djärv et al., 2020). There was, however, no difference between the two groups in rates of anxiety and depression.

The use of structured questionnaires limits the opportunity for the participants to provide information not contained in the questions. Hence, qualitative research provides the participant with the opportunity to tell their story, emphasising what is important for them in their views of quality of life. Although quality of life was not the focus of this inquiry, it is part of the experience of survival. For survivors of out-of-hospital cardiac arrest, health related quality of life is comparable to the general public in the same age group, however, some decline in emotional and physical domains were found among the cardiac arrest survivors (Bohm et al., 2019, Tiainen et al., 2018). Female cardiac arrest survivors often reported a lower satisfaction in health-related quality of life (Bohm et al., 2019; Nehme, Andrew, Bernard & Smith, 2019).

Qualitative research allows the participant to elaborate their situation in detail. Recent qualitative research among cardiac arrest survivors found that there is a longing for 'normality'— to return to an 'everyday' reality as before the cardiac arrest (Bremer et al., 2019, Haydon et al., 2019, 2020b). The survivor strives to find their identity as a survivor, searching for emotional wellness and lost abilities (Bremer et al., 2019, Haydon et al., 2019, 2020b; Whitehead et al., 2020). Recovery can be delayed by social, physical, cognitive, emotional and spiritual distress that can interfere with the perceptions of 'normality' (Bremer et al., 2019; Whitehead, et al., 2020). To achieve pre-cardiac arrest ability is a gold standard for survivors, however, the impact of a cardiac arrest is significant and wide-ranging, and the gold standard may not be achievable. Acceptance of the reality and consequences of the event may improve quality of life. Holistic assessment should support

the acceptance of a new reality rather than aiming for a pre-cardiac arrest ability. Throughout their recovery, the survivors should have the opportunity to highlight to their treating health professionals which health outcomes are the most important for them (Bremer et al., 2019, Haydon et al., 2020b; Whitehead et al., 2020).

### **PLOTLINE: ADAPTATION TO A NEW REALITY**

**Threads:** 'Waking up in chaos' and 'A new reality in coming home'.

The cardiac arrest survivors had to adapt to a new reality that frequently included restrictions, both internal and external, that impacted their life on multiple levels. The uncertainty of physical limits creates insecurity and the survivor might have to adapt to a different lifestyle (Bremer, et al., 2019; Haydon et al., 2019, 2020 a,b; Kearney, Dyson, Andrew, Bernard & Smith, 2020; Whitehead et al., 2020). Their ability to complete common everyday activities at previous levels could be limited, causing distress (Bremer et al., 2020; Haydon et al., 2020b; Whitehead et al., 2020). The driving restrictions caused frustration as the loss of independence was difficult to accept (Bremer et al., 2019; Haydon et al., 2020b; Timmermans et al., 2018; Uren & Galdas, 2015). The capacity for cardiac arrest survivors to return to work is often influenced by fatigue and mild cognitive impairment (Kearney et al., 2020) as well as depression and restricted mobility (Lilja et al., 2015). The transition from hospital to home, is for many, an uncertain time, where the survivor may feel vulnerable and abandoned (Bremer et al., 2019; Brännström, et al., 2018; Haydon et al., 2020b) The home environment is the same, but the survivor has changed in ability and may need support to adjust to their new limitations. The survivor may also need support in

accepting that their mental and physical abilities may not return to the same level as that prior to their cardiac arrest (Brännström et al., 2018; Kearney et al., 2020; Whitehead et al., 2020). Survivors in previous findings described redefining their attitude to life, where an evaluation of habits and priorities to reduce stress and live a healthier life became important (Haydon et al., 2017; Ketilsdottir et al., 2014).

### **PLOTLINE: ANXIETY, DEPRESSION AND POST-TRAUMATIC STRESS DISORDER**

**Threads:** 'Emotional turmoil' and 'Loss of control and desire for normality'.

Although none of the participants in this narrative inquiry expressed issues with anxiety, depression or post-traumatic stress disorder (PTSD), it is not uncommon among survivors of cardiac arrest to experience mental health conditions (Larsson et al., 2014; Presciutti et al., 2018; Verberne et al., 2018). These three conditions may have a strong influence on the survivor's quality of life and should be investigated and supported to minimise the burden (Miller et al., 2019; Presciutti et al., 2018). Anxiety and depression seem to be the most prevalent while the person was in hospital (Larsson et al., 2014; Presciutti et al., 2018; Verberne et al., 2018). Unless attended to, the person is at an increased risk for long-term distress (Miller et al., 2019; Whitehead et al., 2020; Wilder Schaaf et al., 2013). As in this inquiry, a study by Nichol et al. (2015) found that many participants had no cognitive impairment or depression. However, people with cognitive impairment or depression may be less likely to volunteer to participate in research. Importantly, those participants with cognitive impairment may not have been able to verbalise or communicate their story and I would have been left with a lot of wonderings.

Substantial research suggests that PTSD has a diverse aetiology, although it is mostly being treated as a singular aetiology (Presciutti et al., 2019). PTSD after a cardiac arrest is not unusual. As most survivors have no recollection of the event, it is unclear why and how PTSD occurs and that it may be different compared to other medical traumas such as motor vehicle accidents (Presciutti et al., 2019). As anxiety, depression and PTSD can severely affect quality of life, they should not be overlooked in the assessment of cardiac arrest survivors (Miller et al., 2019; Presciutti et al., 2019; Verberne et al., 2018). PTSD and depression can develop over time; they are not always instant and therefore, may be assessed at a point in time when the person does not meet criteria. The person's symptoms may not be apparent in hospital or at a 6-week specialist follow-up. These problems may develop later and can be missed, therefore, the most appropriate timing for assessments needs consideration (Miller et al., 2019; Presciutti et al., 2019; Verberne et al., 2018).

## **PLOTLINE: REHABILITATION**

**Threads:** 'Restrictions—internal and external' and 'Navigating medication regimens'.

The participants in this inquiry had mixed views of cardiac rehabilitation, as most of them did not feel it was aimed at their level of ability (Haydon et al., 2019, 2020a,b). Cardiac rehabilitation is an integral part of the care of individuals who have experienced a cardiac event (González-Salvado et al., 2017; Kearney et al., 2020; Nakayama et al., 2020). Comprehensive cardiac rehabilitation includes exercise, nutrition support, smoking cessation support (if needed), and education on cardiac diseases following a cardiovascular event (Nakayama et al., 2020). Cardiac rehabilitation has a wide-ranging approach towards

secondary prevention with the aim to empower the patient, to become independent and aware of the health-related choices they can influence (González-Salvado et al., 2017; Kearney et al., 2020; Nakayama et al., 2020). Cardiac rehabilitation is known to improve mortality and quality of life, as well as prevent recurrence of adverse cardiovascular events and reduce cardiac re-admissions (Sjölin et al., 2020). Cardiac rehabilitation is typically offered to all patients who have experienced a cardiac event within a six-month period (Nakayama et al., 2020). Though cardiac rehabilitation is internationally recommended, participation rates and adherence to recommendations remain low (Ruano-Ravina et al., 2016). The willingness of patients to consider cardiac rehabilitation is influenced by the relationship between perceived self-efficacy and their intention to participate in cardiac rehabilitation (Jahandideh et al., 2019).

There is currently no specific cardiac rehabilitation program aimed at cardiac arrest survivors and it could be an issue as many survivors often suffer from mild cognitive problems that can influence their ability to participate in the rehabilitation program (Boyce-van der Wal et al., 2015). Although participants in this inquiry knew of the importance of cardiac rehabilitation, they stated that they did not feel that it was aimed at their level of ability. Cardiac rehabilitation encompasses all cardiac illnesses and is not specifically aimed at cardiac arrest survivors. However, Thomson et al. (2020) found that there is a need to focus on specific illness perceptions and beliefs about cardiac rehabilitation. Early in the rehabilitation process a focus on the individual's requirements might help to improve participants' physical and mental health. In the end it is the survivor's perception of their illness and of cardiac rehabilitation that will influence participation and adherence to the program (Jahandideh et al., 2019; Thomson et al., 2020).

## **PLOTLINE: TO INFORM OTHERS ABOUT HEALTH FITNESS AND CARDIOPULMONARY RESUSCITATION**

**Threads:** 'Keeping fit and informing others' and 'Support systems'.

For the survivor it was not only important for them to be able to tell their story, it was also important for them to inform society of their experience and to educate others through their experience (Haydon et al., 2019). The benefits of a healthy lifestyle were a focus for many, describing a frustration over friends and family who continued their unhealthy lifestyle and not taking the advice from the survivor. As well, they were concerned over society's general lack of a healthy lifestyle (Haydon et al., 2019). Some participants went to considerable lengths to educate the public; one participant wrote a book about the cardiac arrest experience, providing advice, not only of the recovery but also prevention mentally and physically including the economic downfall of a cardiac arrest (Czerny, 2014). This participant also created a 'snakes and ladder' game for school children to teach the importance of knowing how to perform CPR as well as attending conferences to tell others of the experience. Other participants used newspaper articles, radio and social media to tell their experience of surviving a cardiac arrest. A survivor living in a retirement village organised for St John's Ambulance to come and teach the fellow retirees the art of CPR. Another participant noted that the Australian and New Zealand Association of Bellringers should always have a defibrillator on site and at least one member should have a certificate in CPR. Webpages such as Australia's Heart Foundation (<https://www.heartfoundation.org.au/>) and the American Heart Association (<https://www.heart.org/>) are places where many survivors present their stories of cardiac arrest. Informing others about health fitness and cardiopulmonary resuscitation, involved

the participants' engagement in telling and retelling of their stories and was part of their recovery. Also, this was their embodied stories to live by and move them forward. As (Clandinin, 2013, p. 53) explains “‘*Stories to live by*’ allow us to speak about the stories that each of us lives out and tell of who we are and are becoming.” Each story highlights the diversity of all people’s lives. Experiences are ongoing and these experiences are live out, told and re-told with various plotlines over time in different relationships and different environment (Clandinin, 2013).

Although there is no research available, exploring this interest among cardiac arrest survivors of informing others, it was evident among this cohort of participants’ in this inquiry, that this phenomenon was an important part of their recovery. Even though there is no published research, there are articles in academic journals exploring accounts of survival stories (Anthony, 2020; Hausheer, 2020; Stausmire, Greenbaum & Morelli-Greenbaum, 2018).

## **PLOTLINE: LUCK**

**Threads:** ‘Luck’ and ‘Luck and fate’.

Many of the stories included circumstances and sections of ‘luck’ that made their survival possible. This feeling of luck made them feel special but also that there is a meaning for their survival. This could explain the need to inform others of their experience (Haydon et al., 2019). In Australia almost 20,000 people suffer an out of hospital cardiac arrest and about 10% will survive (Victor Chang Cardiac Research Institute, 2020). In the participants stories many of them recited the low number of survivors with some variation.

The knowledge that they did survive, creates a cognitive impression and a subjective interpretation of the experience as 'lucky' (Hales & Johnson, 2014). To survive the cardiac arrest made them 'survivors' instead of 'victims' and changed the view from 'why me?' to 'I could be dead!' By comparing themselves to other people experiencing the same situation, they often suggest that they are lucky in comparison to those who were less fortunate (Teigen & Jensen, 2011).

Prasad (2020) suggest there are three features that characterise medical events that are associated with good or bad luck. First, there is no control over the event; second, the event occurs through chance or accident and finally, the event is of significant interest. All three features of luck are represented in my participants' cardiac arrest event. Medical events can be helpful to understand good and bad luck, as they are non-fictional, are variable and often generate considerable interest. Luck is often given to either the event or the individual, if instead luck is seen as a 'relationship' between the event and individual, where opportunities for interventions can be established, the amount of good versus bad luck can be determined (Prasad, 2020). With this definition of luck where the event and the survivor are combined, these survivors had a large amount of good luck. For these survivors, who told me their story, they were at the right place, at the right time and with the right people who had the skills to enable them to survive. This highlights how the three-dimensions of place, time and social are intertwined in our experiences. If any of these dimensions had been different, such as time, "If I had been surfing on Wednesday instead of the Friday..." or place, "I was already in hospital" or social, "I was among people who knew CPR", knowing the circumstances and how these dimensions influenced their survival created strong feelings of wonder and, indeed, 'luck'.

## **PLOTLINE: SPIRITUALITY**

**Threads:** 'Drawing on spirituality', 'Spirituality' and 'Gratefulness'.

After the event, many questions of spiritual and existential nature arose. These questions should not be neglected or diminished by health carers. The recovery from a cardiac arrest involves both body and mind (Whitehead et al., 2020). A person's spirituality can be explained as the transcendent questions that confront us as human beings and may, or may not, involve relationships with a 'God' or 'Gods' (Senreich, 2013). The emotional turmoil the event potentially created for the survivor has to be taken into account when care is planned, providing person-centred care during this time is vital. Acknowledgement and support for the survivor is needed in their search for spiritual answers and the importance of it should not be ignored (Klint, Sjöland & Axelsson, 2018; Senreich, 2013; Wachelder et al., 2016). A systematic review involving 15 articles that explored the association between spirituality, faith and quality of life found that higher levels of spirituality or faith lead to better quality of life among patients with cardiovascular disease (Abu et al., 2018). This was supported by Counted, Possamai and Meade (2018) who found evidence that spirituality and faith, direct or indirect, affected quality of life and was associated with health benefits across all quality-of-life areas.

Spirituality is important and can be a coping resource that supports individuals dealing with the reality after the cardiac arrest (Wachelder et al., 2016), and healthcare professionals should take into account that faith and spirituality may assist with coping and can support the survivor in the healing process (Haydon et al., 2020a,b).

## **PLOTLINE: CLOSENESS TO DEATH**

**Thread:** 'Surviving death'.

Not only was this 'Surviving death' a well-supported thread among the participants, this was also found in previous literature (Bremer et al., 2009; Haydon et al., 2017; Palacios-Ceña et al., 2011). The close encounter with death created an awareness of life and death for survivors, where the fragility of life became apparent. To survive a cardiac arrest is to know that without external support you would not have survived; death would have been certain. Although the cardiac arrest was unexpected, the experience was 'special' as many other individuals do not survive a cardiac arrest (Haydon et al., 2017, 2019, 2020a, b). This reality of low survival numbers is quite confronting for the survivor (Chen et al., 2019). For the survivor, this reality, especially shortly after the cardiac arrest, created multiple questions of luck, spirituality and 'why me' (Haydon et al., 2020a). Many of the participants in this inquiry wrote letters to the hospital, writing of their gratitude to be alive and the admiration of the professionalism of the healthcare team and others that kept them alive. Affirming the feelings were statements such as "How can you thank anybody for saving my life?" Unfortunately, many of them did not receive a response and that was disappointing as it made them feel less valued, as the enormity of the event was not perceived as being acknowledged from the healthcare sector. The importance of person-centred care was highlighted by the participants in that the healthcare professionals needed to adopt holistic care of the survivor (Fernandez, 2020; Jasemi, et al., 2017).

The enormity of the event is overwhelming, making it difficult for the survivor to grasp and comprehend. This realisation of how close they were to death, created worrying

feelings over the possibility of another cardiac arrest, but is also juxtaposed with feelings of calmness to have experienced a close encounter with death (Brännström et al., 2018; Haydon et al., 2019, 2020b).

## **PLOTLINE: DEATH AND DYING**

**Thread:** 'Fragility of life and dying'.

The realisation that they had survived a life-threatening event often changed their perception of death and dying. Most individuals in our western culture have a fear of dying; it is often profound and not likely to change or be spoken about (Tassell-Matamua & Lindsay, 2016). Although, if an individual has a close encounter with death, such as a cardiac arrest, the fear seems to lessen (Forslund, Jansson, Lundblad & Söderberg, 2017; Tassell-Matamua & Lindsay, 2016). One of the participants in this inquiry spoke about a near death experience, seeing a relative waiting for him. Although the majority of survivors have no memory of the event, about 10% experience and recall near death events (Parnia & Fenwick, 2002; Parnia, Spearpoint & Fenwick, 2007). To survive a cardiac arrest is a close encounter with death. Contemplating and making meaning of near-death events is a stressful time and healthcare professionals should not avoid those conversations. Healthcare professionals should encourage retelling of the experience, thereby providing a social validation of the experience and accepting the internal difficulties encountered by the survivor who have been through the experience (Bianco, Sambin & Palmieri, 2017). The experience of being close to death creates an increased appreciation for spirituality and life and lessens the fear of death and dying (Haydon, 2019, 2020b; Tassell-Matamua, Lindsay,

Bennett, Valentine & Pahina, 2017). This was confirmed by the participants in this inquiry as they expressed no increased fear of dying. They had a feeling of relief that they had already experienced dying after the cardiac arrest and that gave them a greater appreciation of life and living (Haydon et al., 2019, 2020b). The participants' willingness to talk about death and dying indicates that healthcare professionals need to be open in their conversations with survivors and encourage the person to talk about their experience of closeness to death (Brännström et al., 2018; Klemenc-Ketis, 2013).

### **PLOTLINE: THE LIMINAL TRANSITION**

This final plotline “the liminal transition’ focus on the interrelationship among the threads that are presented above and highlight the importance of liminality in the cardiac arrest survivor’s experience.

Little is known of the liminal time for the survivor as they adapt to be a survivor of a cardiac arrest, yet it is important for all involved in their care to recognise this transition and support survivors in this liminal period (Smith et al., 2017). For the survivor, the cardiac arrest is a defining moment, their life changed from their ordinary reality to a new extraordinary and unknown reality; the survivors entered a liminal space of ‘betwixt and between’ involving a ‘before’ and ‘after’ the event (Haydon et al., 2020a). ‘Liminality’ is described as a reflective time during a life-changing process and is described as having three phases of transition from 1) an ending of the known reality, 2) a beginning of a new reality and 3) an ‘empty’ or ‘unknown’ time in between (Turner, 1969; Van Gennep, 1960). The first liminal transition stage represents the abrupt split from their known reality (Little et

al., 1998), and the survivor may experience disorientation, uncertainty, sense of loss and loss of control over what the future might hold, as they entered the liminal space. A state of 'limbo' where they felt isolated and confused as they attempted to move towards an uncertain future.

The second stage of the liminal experience is one of being wedged in between their previous well-known existence and what the future might hold. The second stage becomes a time of skill-building tasks and acceptance to prepare for the final stage, a return to a new but accepted altered future reality (Underwood & Rhodes, 2018).

When providing care, the psychological state the survivor is in as they accept their new reality is an important consideration. Provision of holistic care in the immediate aftermath of a cardiac arrest cannot be underestimated (Bremer, Dahne, Stureson, Årestedt & Thyle'n, 2019; Haydon et al., 2017; Verberne, Moolaert, Verbunt & van Heugten, 2018). While in hospital, and when they leave hospital, the survivor is in the liminal transition and they may feel unsupported by the healthcare system. While in a liminal space, the survivor's existence has dramatically changed. They may now live with internal chaos juxtaposed with an expectation of recovery. After the cardiac arrest, as the survivor realises that their projected life trajectory is altered, individualised healthcare can be vital to enable a positive outcome (Brännström et al., 2018; Forslund et al., 2017; Verberne et al., 2018). Not only cardiac arrest related factors influence recovery, personal wellbeing and demographic factors influence the survivor's perception of future quality of life (Bremer et al., 2019; Verberne et al., 2018).

An understanding of liminality influences how healthcare professionals prompt and listen to the patient's stories. These stories often do not fit into the format that is common in

healthcare environments. An awareness of the liminal space the patient lives in comes with opportunities to strengthening holistic and person-centred care, leading to a better understanding of the possibilities that exist for patients (Bruce et al., 2014; Dauphin et al., 2020). Healthcare professionals need to actively listen to survivors' stories, to gain knowledge of how to best support survivors to continue to be active, contributing members in society. An awareness and understanding of the individual's liminal experience will support healthcare professionals in developing support structures and resources to improve quality of life for the patient (Bruce et al., 2014). Liminality also encompasses the embodiment of the persons illness experience and any illness experience is extremely complex, varied and personal (Dauphin et al., 2020).

Knowledge of the liminal transition will give further insight into the illness experience. The focus on organs and body systems often neglects the embodied experience of illness. Liminality can be the link between the focus on the body and the embodied experience of the survivor. The concept of liminality makes it a powerful and translatable tool for clinical knowledge and practice (Little, Sayers, Paul & Jordens, 2000).

'Uncertainty' is central in illness experiences, as patients find it difficult to find meaning in their ailment (Mishel, 1981). After surviving a cardiac arrest there is an acute awareness of the fallibility of their body and its mortality. The heart they once trusted is no longer reliable and as it malfunctioned once, it could do it again! There is an awareness that they have survived an extreme event and often feel alone, as they find it difficult to comprehend and describe the experience (Little et al., 2000). The creation of their story helps them make sense of the event and the story is often re-created multiple times. The

awareness of being close to death can be difficult to express in words to others who have not experienced a cardiac arrest.

In this study, cardiac arrest survivors experienced an instant change to their reality; it was unexpected and there was much to comprehend (Haydon et al., 2019, 2020 a, b). This situation is also confirmed by Bremer et al. (2019) and Whitehead et al. (2020). For the survivor to move forward in their recovery there is an increased need for support while survivors are in the liminal space 'of betwixt and between'. Research shows that prolonged time spent in liminal transition can result in continuing reduction in employment, increased health complications and a reduction in quality of life compared to the general population (Ewens, Hendricks & Sundin, 2018). The survivor needs to have a meaning and an existential path as they recover from the cardiac arrest. Not addressing existential matters can interfere with the survivors' recovery and quality of life (Aristidou, Vouzavali, Karanikola, Lambrinou & Papathanassoglou, 2018; Bremer et al., 2019).

To create an opportunity for the survivor to have conversations, listening to people who were involved in their rescue and to ask questions will support the survivor in creating order and reason in their survival (Driessnack, 2017; Olsthoorn & Thompson, 2018). Although it is a difficult time where cardiac arrest survivors might find it difficult to articulate their questions and concerns, it is important for the healthcare professionals to provide opportunities for conversations where both health professionals and the survivor have time to ask and answer questions (Driessnack, 2017; Klint et al., 2018; Whitehead et al., 2020). Nurses and health professionals need to pay attention to the survivor's demeanour, supplying information adapted to their needs, providing time to verbalise and ask questions

(Klint et al., 2018). Importantly, healthcare professionals should not shy away from existential issues if the survivor brings it up in conversation (Brännström et al., 2018).

Understanding and having an awareness of liminality support, healthcare professionals need to understand what support survivors of cardiac arrest want from the healthcare system not only in the initial acute phase of their survival but to ongoing or future care (Bruce et al., 2014; Dauphin et al., 2020; Little et al., 1998). The experience of a liminal transition has also been explored among cancer survivors and other chronic disease patients. Therefore, the knowledge of the transition within the liminal space in long term illness is important for healthcare professionals and educators as well as for those using outcomes as administrative and policy making instruments (Bruce et al., 2014; Dauphin et al., 2020; Little et al., 1998).

The liminal transition highlights the isolation, alienation and uncertainty the survivor often feels about their roles in society and future life opportunities. Healthcare professionals should endeavour to have a complete view of the patient's diverse and changing experiences of uncertainty while in the liminal space (Dauphin et al., 2020). While in the liminal state healthcare professionals need to understand and support the survivors as "life must be lived forward but understood backwards" (Little et al., 1998, p. 1491).

Among the findings from this study the threads of 'Liminality' and 'Keeping fit and informing others' have not previously been described among the searched literature. For the participants in this study liminality and the importance of keeping fit and informing others was a recurring thread in their stories. They described their desire to help others and teach about CPR as an important part of their recovery. The importance of informing others of their experiences as a cardiac arrest survivor may also be a way to express their







gratitude to be alive as most people do not survive a cardiac arrest. This desire to support and educate other people should be encouraged and opportunities provided to the survivor to contribute, if they so wish, in rehabilitation programs and community settings.

## **RESEARCH PUZZLE**

This narrative inquiry focused on the experience of surviving a cardiac arrest and does not have a research question with an expectation of a definite answer. Instead, this narrative inquiry formed a research puzzle that included “a sense of search, a re-search, a searching again... a sense of continual reformulation” (Clandinin & Connelly 2000, p. 124). There is a sense of wonder at the survival in the human experience; the knowledge gained after surviving a close encounter with death is thought-provoking. As we are all in a transition in time where social norms and places change, these findings, using narrative inquiry, do not claim that these findings hold an absolute truth. Instead, the presented narratives and analyses represent multiple truths (Clandinin, 2013) as experienced by the participants and analysed by me, the researcher. The findings are intended to “engage audiences to re-think and re-imagine the ways in which they practice and the ways in which they relate to others” (Clandinin, 2013, p.51). There is no assurance that readers of this thesis will interpret the findings the same way, each reader has their own earlier experiences and, therefore, interpret the findings in their own way. I would reason that this is a positive concept whereby each reader of this research puzzle engages in the experience of others and thereby increases their own knowledge and understanding of the participants’ experience.

## PUZZLE PIECES I FOUND IN THIS NARRATIVE INQUIRY

In this thesis I have explored the stories from 17 individuals who survived a cardiac arrest. In collecting and analysing these stories using Clandinin and Connelly's narrative inquiry framework, I have presented my narrative findings based on the time course following the participant's cardiac arrest. My ontological and epistemological perspective on the survivors' experience of surviving the event are the puzzle pieces found and are listed below.

-  The cardiac arrest is an unexpected and frightening event, even for the person who knows they have a cardiac illness.
-  As the survivor regains consciousness, they enter a liminal space where they are in limbo, 'betwixt and between' what was their known reality and a new and unknown future.
-  The return to reality can be a painful embodied reminder of the ordeal with a sore chest or fractured ribs and sternum.
-  The knowledge that their heart stopped created insecurity and mistrust of their own body, and they needed reassurance from loved ones or the use of technology such as smart watches to monitor their heart.
-  The acceptance that they were close to a certain death created existential and spiritual questions that can be difficult to comprehend and grasp.
-  The return home is a stark reminder that their reality has changed; what was taken for granted, physically and mentally can now be a difficult task.

- ❏ Some survivors found the health service and rehabilitation support systems were not aimed at their physical or mental capacity and access to support could depend on locality and home address.
- ❏ As the survivor adjusted to their new reality, many used their experience to inform others of their experience and highlighted the need to know how to perform CPR.
- ❏ Once the survivor accepted their new reality, they expressed an appreciation for the 'smaller' things in life, such as good friends and closeness to nature.
- ❏ Their experience of surviving a cardiac arrest and being close to death seemed to remove the anxiety of death and dying, as they had already 'faced death up close.'
- ❏ Considering that the survivor's realisation on how life-changing and close to death they have been, nurses' and health professionals' support and knowledge is needed to support the person while they are in the liminal space. Nurses and healthcare professionals can have a profound influence on the survivor's future ability to navigate their new reality.

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## SUMMARY OF CHAPTER FIVE

*This chapter began with a discussion of the importance of story and a recapitulation of Clandinin and Connelly (2000) and Clandinin's (2013) ontological and epistemological stance of the learning from experiences. Following the discussion, time, place and social dimensions in the thesis were presented. In 11 headings, the threads found in findings and reported in the three published articles exploring the experience of surviving a cardiac arrest were discussed and further explored. A search for current literature relating to the different threads in this area was conducted and included.*

*The last thesis chapter describes the strengths and limitations of this narrative inquiry, the relevance of the findings to clinical practice and recommendations for further research. A reflection of my research experience at the end of this inquiry and an overall thesis conclusion are provided.*

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# Conclusion

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*The previous chapter began with an exploration of the importance of story, and a recapitulation of Clandinin and Connelly (2000) and Clandinin's (2013) ontological and epistemological stance of learning from experiences, and the dimensions of time, place and sociality. Following the exploration was a discussion of the findings in this narrative inquiry that used a modified Clandinin and Connelly approach. The threads and plotlines in exploring the experience of surviving a cardiac arrest were discussed, including current literature in this area. This final thesis chapter contains the strengths and limitations of this narrative inquiry, relevance to clinical practice, recommendations for further research, a reflection of my research experience and the conclusion.*

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## STRENGTHS

Narrative inquiry using Connelly and Clandinin's (1990, 2000) approach commonly have a small number of participants, therefore I had to modify my narrative inquiry approach to accommodate the larger number of participants who participated in this inquiry. This may in itself strengthen my findings as a more varied representation of the experience is explored and I feel I have captured a broad range of experiences and meanings from the participant's stories. A larger number of participants can increase the transferability of the findings (Kim, 2016; McAlpine, 2016). A key strength of this research puzzle is the broad view of the experience of surviving a cardiac arrest that this participant group provided. The group included both genders across a wide age span, ranging from 48 to 92 years and education including high school to doctoral studies. Employment was equally broad and living conditions were from inner city, beach towns to rural properties. Participants experienced a cardiac arrest from three months ago to 36 years before having the conversation. Twelve participants experienced an out-of-hospital cardiac arrest and five participants had their cardiac arrest in hospital.

A further strength in this inquiry is the volume and depth of participants' individual stories collected from field text, emphasising what each participant thought to be the most memorable aspects of their story. The participants' keen interest to contribute to this inquiry and tell their story, contributed to the relational aspect that is important in narrative inquiry (Connelly & Clandinin, 1990, 2000; Clandinin, 2013). The in-depth conversations, as well as the contact both before and after the main conversation, provided me with a detailed description of their experience, which supported the fidelity of this inquiry and helped to

ensure credibility and dependability. This inquiry's rigour, trustworthiness and validity is grounded in the long period of interaction supported by my reflective journal, my own verbatim transcription of all the conversations and my open approach and thoughtfulness in attending to the participant's stories. The transcripts were analysed, evaluated, interpreted and supported by my field notes, along with my reflective journal where I searched for the main threads using Clandinin's (2013) and Clandinin and Connelly's (1990, 2000) three-dimensional framework of time, place and sociality dimensions. During conversations with my supervisors the confirmation of interpretations and found threads were grounded in the narratives.

A strength of narrative inquiry as a research methodology is the presentation of findings, as it invites the reader to engage and find their own view of the findings. In this thesis, the key findings are presented using published articles, where the readers may be nurses, other health professionals or researchers. They will have an interest in the cardiac arrest survivors' experience and may well have encountered patients following cardiac arrest. Reading about survivors' experience will invite the reader to explore and find their own view of the discoveries and may influence their future clinical practice. When they **encounter** a cardiac arrest survivor, their actions will be informed by their own experiences and by the conversation fragments and threads presented in this thesis, thereby making the findings transferable to their own situation.

My conclusions might be different to that of other readers of these narratives as we all have different prior experiences that may influence how we interpret the findings. Narrative inquiry allows for the findings to be shared, open to interpretation and re-interpretation and revisited over and over again as we are in a transition of time and our

experiences change. This inquiry will contribute to a holistic perspective and highlight the importance of person-centred care, with the knowledge of these survivors' experiences of their cardiac arrest as they transition through the liminal space towards their reality as a cardiac arrest survivor.

## LIMITATIONS

Narrative inquiry as a research methodology has limitations. All stories are "*incomplete, partial, and selective*" (Riessman, 1993, p. 11). Therefore researchers using narrative inquiry methodology can only represent an incomplete view of the experiences of others (Josselson, 2011) and what is presented to us as researchers in storied form is not the lived experience as it happens, but the experience presented as a narrative (Plummer, 2001). Polkinghorne (2007), as well as Clandinin et al. (2016), argues that stories represent a personal meaning and experience of the event, hence researchers are provided with a 'narrative truth' and not an exact 'historical truth' in narrative inquiry. Therefore, it is important that narrative inquiry findings of experiences are understood with this in mind.

Narrative inquiry provides a valuable perspective when exploring people's experiences that cannot be observed or understood unless told by a person who experienced the event. After such an event, an interview by a researcher will be the main method for collecting data. However, there are no universal rules on how to collect and analyse narrative data (Kim, 2016; Yee Khong Loong, 2019). Narrative research recognises that the stories people tell represents life and storytelling is a way to create meaning of life (Kim, 2016; O' Toole, 2018; Yee Khong Loong, 2019).

Therefore, in my research I can only make claims that the findings from this narrative inquiry may be transferable to settings that are similar in culture and advanced healthcare as in this study. The findings increase the understanding of the experience of a cardiac arrest and the influence of surviving the cardiac arrest had on their lives. These findings may or may not be applicable for other survivors of cardiac arrest. As in any conversation, participants in this inquiry selected what they were willing to share in their story and may have adjusted their story to only include what they perceived as important. They might have adapted their story to present themselves in a more positive light. For some of the participants the cardiac arrest happened a long time ago and their memory of the event might have changed with time. For the participants who recently had their cardiac arrest, the memory deficit that can be part of the cardiac arrest may also influence their recall of the event. In both these situations there may be parts of their story that remain untold. These untold fragments of their experience may have influenced the findings, however, the stories told would be what was the most memorable and important in the participants' experience of the event at that time. I am left wondering what stories I would have been told and what my findings would have looked like if my participants had not had the support systems of family and friends as well as access to high medical care.

This narrative inquiry was open to voluntary participation, where the participants initiated the contact with me, the researcher. I had a large number of interested participants for a narrative inquiry, all were cognitively intact individuals who regarded their survival as a positive outcome, became part of the inquiry. Therefore, the findings from this inquiry may not be transferrable to cardiac arrest survivors with cognitive impairment or to those who viewed their outcome as less than positive. Survivors with less favourable experience may

have a different story to tell, thereby providing a more diverse and varied narrative of the phenomena I explored. In an attempt to reach individuals that may not come forward to participate in research, snowball sampling was one of the methods used to reach participants. Snowball sampling is useful when the characteristics of the sought-after experience are not easily reachable and can be a purposeful method to enlist participants in qualitative research (Ghaljaie, Naderifar & Goli, 2017). The use of snowball sampling as a recruitment tool was intended to allow survivors with less favourable experience to contact me. Although snowball sampling was useful, it did not aid in the recruitment of participants with a less favourable experience.

While the group of participants was diverse in the ways mentioned above, in other ways the group was limited. All participants were Caucasian, living in stable environments and relationships. They all had available social support systems with family and friends, as well as living in a society with access to high medical care. All had good outcomes following their arrest and were left with minimal physical or mental / cognitive disability. Those who live in a society with reduced access to medical care, such as remote areas, as well as different living standards, social security, ethnicity and different cultural norms might have other circumstantial, social, religious and cultural variations that were not revealed in these participants' stories. Interpretation of the findings needs to take this perspective into account.

The basis for qualitative research involves multiple truths to be explored and in turn constructed as embodied knowledge. The participants in this inquiry shared freely their experiences as an embodied way of knowing, creating new knowledge of the phenomena of surviving a cardiac arrest. In qualitative research the researchers are not detached from

the researched phenomenon as they come with, and bring their subjective experiences (Arghode, 2012). This thesis aims to answer the ‘what’ of the experience of surviving a cardiac arrest. As Clandinin and Connelly (2000, p.31) point out, “interpretation of events can always be otherwise”. This may generate ambiguity about the presented findings and their meaning of experience. Consequently, this places a limitation on the interpretation of the findings of this inquiry.

Connelly and Clandinin’s (1990, 2000) narrative inquiry usually only has a small number of participants. In my inquiry there was unexpected interest from people to participate and contribute their experience resulting in a large number of participants. With 17 participants, all with interesting stories to tell, the ability to provide in depth descriptions of the participants re-storied narrative was limited. The essence of each story that I heard is presented in the findings of my study as short quotes, collected in threads that describe the experience of the cardiac arrest.

## **RELEVANCE TO CLINICAL PRACTICE**

Findings from this research will assist nurses and other clinicians during clinical practice encounters with the recovery and rehabilitation of cardiac arrest survivors. Clinicians need to keep in mind that experiencing a cardiac arrest is an unexpected and tumultuous event that has broad consequences for the individual’s future and wellbeing. Cardiac arrest survivors experience an instant change to their embodied reality, which is unforeseen and can have a major impact on their future.

This unexpected event, where the individual enters the liminal space, the transition from their known reality to the unknown future, may be prolonged if they do not have enough support. In the liminal space, survivors need an increased level of support to move forward in their recovery. Flexibility and sensitivity around the hospital structures and practices may need to improve to increase the survivors' satisfaction and a faster liminal transition to aid recovery.

As the liminal space encounter does not end as the survivor leaves the hospital, it is important for cardiac rehabilitation team and family members to keep supporting the person. When the survivor returns to the home environment, it can be a chaotic and bewildering time where the security from the hospital is no longer available and the survivor may feel abandoned with no clear path to follow. Returning home, they need support as they might not feel confident in their ability to participate in society as they did in their life before the cardiac arrest. Both clinical and logistical hurdles need consideration when opportunities for participation in suitable activities are planned. Interdisciplinary cooperation can support the survivor to cope with the transition to home, improve health outcomes and increase the survivor's quality of life. The perceived lack of support, the participants in this inquiry disclosed, from health professionals in the transition to home, could be resolved through transition programs in hospitals, where dedicated nurses and health professionals follow the cardiac arrest survivor during the transition from hospital to home. This may be facilitated through cardiac rehabilitation. A shorter liminal transition to a new normality is desirable where the survivor becomes comfortable and not stressed in their new lived landscape of being a survivor of a cardiac arrest. Follow up by cardiac rehabilitation teams

with health interventions that support and address the individual's needs is important during this time.

Many of the participants in this inquiry found the cardiac rehabilitation was not aimed at their level of recovery. Health professionals need to support the survivor and emphasise the importance and benefits of participation in cardiac rehabilitation. As the participants in this inquiry had a desire to share their experience and knowledge, it could be valuable to encourage them to participate in support groups where they can assist with the rehabilitation of recent survivors.

By gaining a broader knowledge of survivors' experience, nurses and clinicians can better provide person-centred and holistic care, promoting positive health outcomes and quality of life. The person centred task of responding to thank you letters from the cardiac arrest survivors should be a priority as it can make a big difference in the life of the survivor. The letters may not reach the ward but perhaps a standard letter could be sent to the survivor acknowledging that their message was received by the ward administrator. As the survivor often has some memory deficiency closely after the cardiac arrest and may not remember the involvement from the hospital discharge planning and follow up, it may be that there needs to be a second follow up, preferably with somebody who has been involved in their care. My findings from the participants' stories express a wish to have a closer relationship with their health professionals. Nurses and clinicians can gain knowledge of survivors' experience and wishes by providing time for survivors to tell their story promoting a positive health outcome and improved quality of life.

## **RECOMMENDATIONS FOR FURTHER RESEARCH**

Qualitative research in this area, including findings from this narrative inquiry, is limited to western cultures. The participants in this inquiry were in many ways diverse, however, they were all Caucasians, with good health literacy and living where they had access to good quality healthcare. Further research of the experience in other cultures is lacking and may help improve the experience of people from different cultural backgrounds.

My findings in this inquiry indicate that participation in cardiac rehabilitation is mixed, and perhaps cardiac rehabilitation tailored for cardiac arrest survivors and their specific needs may improve participation. The cardiac rehabilitation experience from cardiac arrest survivors should be further explored to investigate if there are unique needs for these cardiac arrest survivors.

Survivors with a less positive experience of their survival were not part of my group of participants and their voices are still to be heard. People with a less than favourable outcome can be challenging to engage in research, as they might be hesitant to explain that survival was not what they wanted or unable to communicate their stories due to cognitive deficit. There is also limited research with a focus on individuals who survived with life limiting ailments after the cardiac arrest, such as those who survived a cardiac arrest with limited cognition or dementia, who usually live in an institution, but may be looked after at home with exceptional family effort. This group of survivors who have survived with life limiting complications after the cardiac arrest need to have their voices heard. There is a gap in the research literature from the survivors and their loved ones' perspectives, as well as from clinicians.

There is a general acceptance by the public that CPR should be attempted, and that survival of the individual is a good outcome (Ouellette et al., 2018). However, the quality of life for the survivor should be a key part of the measurement of a successful resuscitation. An article by Karlsson, Karlsson and Hilli (2017) explored the difficult balancing act in decision making where the nurses have to equate the patient's chance for survival and quality of life against the possibility of a natural, peaceful and dignified death.

## **REFLECTION OF MY RESEARCH EXPERIENCE**

As this narrative inquiry draws to an end, it is time to reflect on my experience. It was an absolute privilege to meet with the participants' and as Clandinin states, "Narrative inquiry does not allow each of us to walk away unchanged from our experiences alongside each other and alongside our participants" (2013, p.142). Although this has been a very long endeavour with its ups and downs, I do feel I have made a difference. I know I am now a different person compared to the autobiography in Chapter 1 that I wrote some years ago now. Little did I know the strength of influence the participants' stories would have on me, both professionally and personally. As I venture back and re read the transcripts, memories come back from each and every one of the storied conversations. I did not expect to have so many interested participants willing to let me enter into their life. The stories they told me about were often initially of a traumatic experience but as the stories unfolded there were relatively positive outcomes. I wonder how their life has continued since our meetings. My encounter with these survivors left me wondering what life is like for them now. Some of the stories they told me were beginnings of new endeavours in their life, with plans of travel,

seeing their grandchildren, buying a dog. There were modest plans and desires of getting their strength back and returning to work or to being able to participate in their favourite hobby. As my life continues, so do the participants' lives. We were meeting in the midst of living and reliving in the experience of surviving a cardiac arrest.

The large number of interested participants was a pleasant surprise. As all participants fulfilled the inclusion criteria and wanted to tell me their story, I decided to listen to them as I was both curious to hear their story as well as honoured that they wanted to tell me their experience. I also felt a responsibility to listen to their story as they had approached me, indicating that this was important to them to be able to tell their story. To be denied the opportunity to have a conversation could possibly create detrimental feelings as this could be a sensitive topic that they were willing to share with me. There was also the possibility that the next person interviewed would have a totally different story to tell.

The verbatim transcription gave me an opportunity to immerse myself in the stories as well as the search for threads using the three-dimensional space. Even now some of their stories evoke an embodied response of tears to my eyes and some bring big smiles. None of their stories leave me untouched. The relational aspect of narrative inquiry allowed me to build relationships with my participants, although many of them were happy with just one meeting to tell their story. However, they did keep in contact by text messages and emails afterwards until the transcripts were finalised. They all gave me a treasured gift, which I will keep with me for a long time even though this inquiry has come to an end.

With so many participants it was difficult to present my findings as a traditional narrative inquiry thesis, involving Clandinin and Connelly framework, where only a few participants are involved in the inquiry. It became apparent that I had to consider another

way of presenting the findings from my inquiry. With the ontological and epistemology stance of narrative inquiry, stating that experiences provide knowledge, publishing my findings during the PhD candidature allowed me to disseminate and inform readers about my embodied knowledge of participants' experience during this time. I felt a need to share my findings not only in a thesis but to a wider audience. However, that came with a cost of losing some of the features of narrative inquiry. Most peer reviewed nursing journals limit the length of each article, therefore, to tighten and reduce the findings was essential. For me it became a conundrum of publishing the findings or being true to narrative inquiry where the findings are presented narratively creating a long manuscript. The published articles presented in Chapter 4 are written from Clandinin and Connelly's (1990, 2000) narrative inquiry viewpoint within the limits of the journals' word count. The narrative threads in each paper are a continued narrative where 'time' follows the participants from the moment of the cardiac arrest to the long-term survivors' experience of the present moment.

The findings in this narrative inquiry are intended to engage the readers and to awaken their curiosity of what it is like to have a very close encounter with death. Their experience of survival and liminality is described as a chaotic and bewildering experience, where health professionals play an important role in providing support as the survivor enters a liminal transition back to a new reality and normal life. This narrative inquiry is intended to inspire health professionals to learn and reflect on the survivors' embodied stories and thereby create and engage in improved holistic person-centred care for cardiac arrest survivors.

This group of participants were all survivors with a good outcome, although some had hurdles to overcome. One striking observation was, not only their willingness to tell their story, but also their discourse of being a survivor. To be a survivor of a cardiac arrest makes them members of a very special and lucky group of people. The knowledge that most people do not survive made them feel special, but it also comes with the ontological questions of 'Why did I survive?' and 'Is there a meaning associated with my survival?' This may explain their willingness to tell their story for the living and to the people who made their survival possible.

One aspect that I found comforting in my conversations with participants was their comfort with death. Many of them expressed the feeling that they had already experienced death and now felt comfortable with the concept of dying. This gives me comfort, to know that those who had experienced near-death are no longer afraid of dying. Instead they have a greater appreciation of living, enjoying friendships and the nature around them.

Looking back, I had two research aims when I started this study. The first aim was:

*To seek knowledge from people who have experienced a cardiac arrest and from their stories, seek to find pieces to build into my research puzzle, using the dimensions of time, sociality and place to explore threads found in the participants' stories. Using my findings I aim to transfer the knowledge I have gained to publish articles and to present at conferences.*

I was successful in this aim. I gained much knowledge from the cardiac arrest survivors I met and was able to publish, as well as present at conferences, my findings from this research puzzle. My second aim was:

*To inform nurses, other healthcare professionals and the general public about the reality of a cardiac arrest from the survivors' point of view and what matters to them. My purpose in publishing my findings during this candidature is to present nurses and healthcare professionals with information to encourage a holistic and person-centred approach to the individual who survived a cardiac arrest.*

The second aim is not as easy to evaluate. The publications are in both national and international journals, where the numbers of citations give an indication of how well the publications are received and referred to. The citation metrics to date indicate that there is interest in the findings of this narrative inquiry.

My personal aims and ontological stance for completing this inquiry are multifaceted. The decision to complete a PhD is not an easy decision to make. Undertaking a PhD is a long-term commitment with unknown challenges and rewards. I like to study, I am curious, I like to find out things and as I have written above, I am passionate about the area of research I have chosen that is the experience of surviving a cardiac arrest.

My personal aim has been accomplished. I remain passionate about my research subject which was to meet the survivors in the midst of living; mine as a researcher and theirs as a survivor. Their stories exist in an ongoing social environment where previous experiences and knowledge influence the ontological interrelationship expressed in the stories of life and living as a cardiac arrest survivor. Epistemologically, the nature of knowledge, can be found in the participants' experience as told to me and presented in the articles. This will increase knowing and learning from the survivors' experience.

A one sentence summary of my learning from this research puzzle would be: To survive a cardiac arrest is a chaotic experience where the predictable and known future changes in an instant, to an unknown future where the survivor, through a liminal space, navigates and transits to a new reality.

This narrative inquiry provides an insight into the survivors' experience, expressed as stories. The common threads gave me, the researcher, and readers of the published articles, an understanding of the liminal and embodied experience that cardiac arrest survivors have encountered. This knowledge, if acted upon, such as listening and affirming their experience, will progress the person-centred care provided to survivors of cardiac arrest. Furthermore, the area of liminality in the illness experience has been researched, in cancer patients but not for the survivors of a cardiac arrest.

## CONCLUSION

Narrative inquiry is useful in examining the subjective experience of those who suffered a cardiac arrest. The in-depth exploration of the 17 participants' stories provides insight into the experience of surviving a cardiac arrest. Individual fragments of conversation, presented as collective narrative threads, provide a narrative that spans the experience from when the cardiac arrest happened, the realisation of surviving, the transition from hospital to home and the long term survivors' experience. Surviving a cardiac arrest is a watershed moment in the life of the survivor.

The participants told of an awareness of limits to space, empowerment and available time, areas that resonate with the three-dimensions in narrative inquiry. The survivors' experience can be understood as a liminal transition. The unexpected cardiac arrest throws the survivor into a new lived landscape where they experience liminality, a transition from what was known to the unknown. This is followed by an adaptive, long lasting time of suspended liminality, where the survivor creates and re-creates their story of survival in an attempt to create meaning of the experience. This transitional state of liminality could be explained by the unexpected, embodied event where the body houses an unreliable heart as well as the conscious self.

Participants in this inquiry described the cardiac arrest as 'surprising' and 'unexpected'. Even if they had underlying health issues, they did not see themselves as candidates for a cardiac arrest. For those participants who were involved in sport and identified themselves as health conscious, it was a disheartening experience. But they also attributed their health consciousness to their survival. The knowledge that it was their heart,

metaphorically the symbol for life, love and living, that had unexpectedly failed them, created insecurity and the knowledge that they could not trust their own body. When they regained consciousness after the cardiac arrest, they found it to be confronting as their environment has drastically changed. Often there were a limited number of people around them before the arrest, but as one participant described on waking up, they were the 'star attraction' with multiple people around them. This was, however, without the pleasantries of what would normally be experienced as 'a star'. This was an embodied experience of confusion and embodied physical pain after the cardiac arrest and having chest compression during CPR. This stark contrast from 'before' and 'after' adds to the feeling of participating in a surrealistic event. Cardiac arrest is a confusing event where the survivor must adapt to a new reality in a short time span, a transition from an ordinary to extraordinary existence, where the survivor enters a liminal space as they adjust to their new reality as a cardiac arrest survivor. This led to a chaotic ontological experience of existential questioning about their luck in surviving. There was also a spirituality discourse evident in their stories that played on their mind.

The realisation that they survived a critical event, where feelings of joy over their survival are juxtaposed against the confusion and worrying about their future. As the survivor returns home after surviving the cardiac arrest, it was an emotional roller coaster experience, when the home environment becomes a reminder of their previous abilities and well-known life. For the survivors it was a confronting experience not to being able to perform at the same level as before the cardiac arrest, leading to an ontological stance of questioning their sense of value and being. They had to accept that their body was not as capable and dependable as before. On leaving the hospital environment where they had

support and surveillance from nurses and other healthcare professionals, there was a period where the survivor experienced anxiety. They sought reassurance by having friends or family close, as well as reliance on smart watches and mobile phones. The knowledge that their heart had unexpectedly malfunctioned worried them, and there was a need for support from nurses and health professionals to provide information addressing their concerns and pathways to available support services. Although cardiac rehabilitation commenced during the hospital period, it was not always seen as important by the survivors and they disclosed that they often felt it was not aimed at their level of physical ability.

In this inquiry all participants expressed a positive attitude to life after the cardiac arrest. While they viewed the cardiac arrest as unexpected and a hurdle to be overcome, once they adapted to their new reality, they had an increased appreciation of living and an acceptance of life's fragility, and death. The realisation that life can unexpectedly and dramatically change in an instant was a reality check. Participants adapted a gratitude and appreciation discourse. They appreciated the 'smaller' things in life, such as good friends, family and the place where they now live. For the participants in this inquiry, it was important to share their stories as they wanted to let other people know what it was like to survive. The knowledge provided in the published articles may support healthcare professionals in their decision making and future care of cardiac arrest survivors and this shared knowledge may also influence future cardiac arrest survivors' experience.

The participants also told of the difficulties they experienced in communicating with and understanding healthcare workers. Further knowledge and education of the complex liminal transition that survivors experience provides insight that can support healthcare workers to understand survivors' experiences and their behaviour at certain times. In

understanding the complexity of liminality and embodiment, person-centred care will be imbedded in the care of each individual.

This inquiry provides further understanding of the dynamic progressions and adaptation that survivors experience as they adapt to becoming a survivor of cardiac arrest. The extracts from the survivors' stories highlight the individual's experience, and provide a broad and framework with which to understand their experience. The extracts from the survivors' stories highlight the individuals' experience of the phenomena of surviving a cardiac arrest. The three-dimensional space of narrative inquiry involving temporality, sociality and place, which is informed by Dewey's philosophy of experience, has guided my theoretical framework through which I have been able to analyse and delve deeper into participants' experience of surviving a cardiac arrest. The participants' stories of the experience after the cardiac arrest reveal their subjective experience of health care. The needs they expressed were commonly not available in the healthcare settings available to them and were seen as a serious problem by the survivors. Liminality captures what is told in illness stories and for healthcare professionals it is important to have an understanding of influence liminality has on the cardiac arrest survivors experience and adaptation to a life as a cardiac arrest survivor.

## **Summary of Chapter Six**

*This chapter contained the strengths, limitations, relevance to clinical practice, recommendations for further research, a summary of my research experience and the conclusion.*

*This is the last chapter and concludes my thesis using narrative inquiry to explore the experience of surviving a cardiac arrest.*

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# Appendixes

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## Appendix 1 Conference abstracts and posters

### **Using narrative inquiry to explore the experience of surviving a cardiac arrest.**

*Gunilla Haydon, Pamela van der Riet & Kerry Inder.*

*Nordic Conference in Nursing Research "Methods and Networks for the future." June 2020, Copenhagen, Denmark. Oral presentation*

Background: Surviving a cardiac arrest is a tumultuous experience. Although the incidence of cardiac arrest and influencing factors are well researched, little is known of survivor's individual experience.

Objective: To explore the survivors' individual experience of surviving a cardiac arrest.

Method: During November 2016 to June 2017, four females and thirteen males, living independently, who survived a cardiac arrest between 3 months and 32 years ago were purposively recruited and participated in individual in-depth interviews. Narrative inquiry were used to analyse these interviews as it is well suited to explore health related issues as it places the individual in the centre of the inquiry.

Narrative inquiry combines time (past, present and future), place (not only where it happened but also where the narrative is told) and sociality (culture and institutional influences) as a conceptual framework in the analysing of the collected data, exploring how it influences the person's illness experience. The relational aspect of narrative inquiry, where researcher and participant enter a shared relationship during the research period,

potentially creating trust and deeper shared understanding, revealing details not accessible in a single in depth interview.

Results: To survive a cardiac arrest is an emotional roller coaster — to accept that the body is not as capable as it used to be, and to find a new identity as a survivor. The cardiac arrest often affects all aspects of life — limitations both internal and external influences quality of life. Healthcare professionals can learn from survivors' narratives to better support holistic care.

Conclusion: The use of narrative inquiry as a methodology provided the participants with an opportunity to engage with the researcher and the collected data provided a deep insight in the individuals' experience of surviving a cardiac arrest. The narrative presentation of findings narratively also encourages engagement from the reader of research.

## ***Nursing Research and Narrative Inquiry a great fit.***

*Gunilla Haydon, Pamela van der Riet & Kerry Inder.*

*Qualitative Methods Conference, “Qualitative Methods in a Time of Change”*

*May 2019, Brisbane, Australia.*

*Oral presentation*

By telling stories, people with illness try to create coherence between their lives before they became ill and their present lives with the illness, thereby making sense of their illness experiences and reconstructing the split between their prior and present known self as it interacts with others in the world, i.e. their disrupted biography (Murray, 2000; Williams, 1984).

Humans use stories continuously; we live and tell stories; we dream in stories — it is part of being human and how we express ourselves. By telling and retelling complex events we create order and ‘reasons’ as to why situations unfold as they do.

The saying ‘Ill people bleed stories’ makes narrative inquiry suitable for health research — it can also support participants’ in their understating of their illness. The narrated experience of illness is the interest of narrative inquiry in health research.

Narrative inquiry explores and explains actions by listening to and exploring stories. Therefore, when the experience of illness is expressed narratively, it can be studied and findings presented through the view of time (past, present, future), place (where the event took place and where the story is told) and social (influence from people and social norms) perspectives.

In narrative inquiry the researcher is not a silent observer and the relational aspect between researcher and participant are central in this methodology. The opportunity for multiple meetings creates trust and can reveal details not accessible in a single in-depth interview.

Narrative inquiry uses fewer participants and a longer period of data collection, the presentation of findings narratively creates a longer empirical narrative that is informal, holding a true and deep understanding of the participants' experience. This informal presentation may well encourage health colleagues to become more engaged in research consumption.

# ***Cardiac arrest survivors experience immediately before and after the event: A narrative Inquiry***

*Gunilla Haydon, Pamela van der Riet & Kerry Inder*

*Research week School of Nursing and Midwifery*

*Newcastle, Australia September 2019*

*Poster presentation*

Background: Cardiac arrest has been well researched in terms of prevalence, indicators, influencing factors and outcomes as well as the experience from health professionals and family members, however, little is known about the survivors' experience.

Aim: To explore survivors' experience of surviving cardiac arrest in the immediate time before and after the event, thereby providing an insight into their survival that could influence care from health professionals.

Methods: Snowball techniques, word of mouth, were used to recruit participants from the community for individual interviews. Four females and 12 males individually met with the interviewer. The collected field text were analysed using Clandinin and Connelly's (2000) methodology of narrative inquiry where the individual's lived experience was analysed using the three-dimensional of time, place and sociality - how the physical, social, and cultural environment as well as how time, impacts and shapes experiences.

Findings: The interview participants were aged between 48 to 76 and experienced their cardiac arrest 3 months to 17 years ago. The narrative exploration of the cardiac arrest revealed an unpreparedness for the event and confusion immediately after the event Seven

treads were establish; Turning point, Confusion, Cardiac arrest pain, Cardiopulmonary resuscitation pain, Luck, Faith and Surviving death.

Conclusion: The immediate time after surviving a cardiac arrest is confusing where the survivor has to adapt to a new reality. For the survivor it is a complex time where existential questions about luck, faith and survival are intense and at the same time, pain might be a strong reminder of the ordeal. Health professionals should have a holistic view of the survivor, taking into account the knowledge that this is often a major turning point in a person's life.

# Poster 2019 Cardiac arrest survivors experience immediately before and after the event: A narrative Inquiry



## Cardiac arrest survivors experience immediately before and after the event: A narrative Inquiry

Gunilla Haydon RN PhD (Nursing) Candidate Associate Professor Pamela van der Riet Associate Professor Kerry Inder  
University of Newcastle School of Nursing and Midwifery Gunilla.Hydon@newcastle.edu.au

**Aim:** To explore survivors' experience of surviving cardiac arrest in the immediate time before and after the event.

**Findings:** Narrative exploration of the cardiac arrest revealed unpreparedness and confusion surrounding the event. Seven threads were established: Ordinary to extraordinary, Cardiac arrest pain, Waking up in chaos and confusion, Resuscitation pain, Luck, Spirituality and Surviving death.

**Method and methodology:** Snowball techniques, word of mouth, and a newspaper article were used to recruit participants from the community for individual interviews. Collected field text were analysed using Clandinin and Connelly's methodology of narrative inquiry where individuals' lived experience were analysed using the three-dimensional framework of time, place and sociality.

Clandinin, D.J., & Connelly, F.M. (2000). Narrative inquiry: experience and story in qualitative research. San Francisco: Jossey-Bass

**Ordinary to extraordinary:** There was no premonition of an impending CA, transforming the ordinary to extraordinary. "On the day I was feeling fine. Nothing to concern me—nothing to warn me that there was something sinister about to happen"(13); "My background is in health and fitness. I have been passionate with this, a euphemism perhaps, obsessed about fitness"(10); "I thought I was feeling a bit faint, but there was no pre warning"(1).

Participants experienced an ordinary day that evolved into an extraordinary day—the out of hospital CA participants were engaged in work or social events, blissfully unaware of what was about to happen. "I was playing oldies rugby and I arrested on the field"(6); "I was out running—getting rid of some stress"(15); "I had my CA in the back seat of the car"(11)

As well the participants who experienced an in hospital CA did not report having a premonition of an extraordinary event happening. It was described as an unexpected event. "I was just lying there—feeling not too bad. The heart monitor when bip, bip, bip really fast"(4); "I can remember enjoying my lunch and then it was like a jackhammer hit my heart! I remember pushing the button"(8)



**Cardiac Pain:** When the arrest occurred, the CA pain was described as excruciating, intense and sudden. "In the ambulance, the pain was just unbelievable" (13); "Massive pains in my chest, crippling pain!"(16); "I was lashing out—I had so much pain"(3); "Cardiac pain is just mind blowing!"(10); "Crippling pain in my chest! I have never experienced pain like that in my life!"(16)

However, three participants did not recall having any pain. "Prior to the event I had no pain or any symptoms—there was no indication of a forthcoming arrest"(2); "I just did not have any pain—it just happened"(15); "I had no signs or pain—not feeling different"(5).



### PARTICIPANTS

No, gender, age, in hospital (IHCA) or out of hospital (OHCA) cardiac arrest, date of the arrest

|    |        |         |               |
|----|--------|---------|---------------|
| 1  | Male   | 73 OHCA | April 2001    |
| 2  | Male   | 59 OHCA | June 2008     |
| 3  | Female | 63 IHCA | October 2008  |
| 4  | Male   | 75 IHCA | August 2010   |
| 5  | Male   | 64 OHCA | December 2010 |
| 6  | Male   | 59 OHCA | April 2011    |
| 7  | Male   | 58 OHCA | October 2014  |
| 8  | Female | 66 IHCA | December 2014 |
| 9  | Female | 51 OHCA | December 2014 |
| 10 | Male   | 57 OHCA | April 2015    |
| 11 | Male   | 71 OHCA | November 2015 |
| 12 | Female | 76 IHCA | December 2015 |
| 13 | Male   | 48 IHCA | May 2016      |
| 14 | Male   | 64 OHCA | February 2017 |
| 15 | Male   | 62 OHCA | March 2017    |
| 16 | Male   | 70 OHCA | February 2017 |

**Waking up in chaos and confusion:** Waking up after a CA is a surreal confrontation with reality; their experience was one of chaos. For the survivor the confusion creates a loss of reality where they have no control. "When I came through—I had no idea what had happened. All I could see was the world from the ground—a lot of feet and lots of voices"(13); "I was trying to comprehend what was happening, whether I was clinging onto life or not"(10); "When I came around there was lots of people around me—I think I woke up with a couple of swear words and trying to fight my way out"(14); "The paramedics said 'Your partner, she will meet you at the hospital' and my comment was 'Is there something wrong with her?' Why is she in the hospital? I had no idea"(5); "When I came around—it was like what you see on TV! Never seen so many people in my life!"(8); "You wake up after this event and everyone else around you is in a panic"(2).



**Resuscitation pain:** Many participants experienced pain from fractured ribs and sternum. The participants were not sure if it was their fractures or their heart that was causing the pain. "I can remember saying to the cardiologist is something wrong because my chest is really sore"(5); "I woke up so sore that my first thought was that I must have been bounced around on a car"(2); "They broke my ribs to keep me alive. The ribs were very painful"(7)



**Luck:** The participants' narratives often include comments of 'luck'. "I am an extremely lucky lady"(8); "I was super lucky there was an ambulance not far away"(13); "I was lucky it happened when I was out and about"(7); "I was very lucky — there are not too many who survive"(12); "I was lucky there was a paramedic I was playing rugby with"(6); "Luckily I was running in an area where there were people living nearby"(15); "The arrest happened in the hospital—I was lucky I was there"(12); "She said in Australia there are around 32,000 cardiac arrests a year and of those slightly less than 6% of them survive—I am lucky to be one of them"(5).



**Spirituality:** Participants expressed a belief in a benevolent metaphysical power providing comfort to the survivors. For some survivors the feeling of luck also reaffirmed a belief of a higher purpose, a reason for their survival. "It was not meant to be the end of me"(14); "I started to explore my spirituality and why am I here"(9); "I was not allowed to go—because it was not my time"(7); "Maybe somebody up there is not ready for me yet" (11); "I have survived two cardiac arrests. I felt each time that there was some reason—I am practically blessed"(1).



**Surviving Death:** The realisation of how close they were to dying created an anxiety that it might happen again, juxtaposed however with a feeling of calmness to have survived and experienced death. "Often we take life for granted—we just move along"(9); "To realise how quick life can change and how fragile it is, is quite an eye-opener—those feelings of suddenly being confronted by my own mortality." (7); "While I was waiting for the ambulance I was just thinking—is this the day that I die? A very strange sense of calmness came over me. Life felt quite precarious"(13); "I think that realisation is what you are left with—the mortality you touched affects you"(2); "Being confronted by my own mortality, I basically died and was brought back again. I live with that feeling—I still remember thinking 'Is this all there is—is this it?'"(3); "I was in intensive care and there were three other guys there and each of them died. I was the only one that survived. I kept looking around—it was pretty heavy stuff—I was just thinking, 'I'm not going to be next—surely not'"(5); "The heart monitor tells you that you are alive. It also tells you are dying and you are listening to it and I was thinking 'Well, this is it...'"(10); "I dare say, when my time comes—it is the best way to go. I don't remember anything"(8)



### CONCLUSION

Surviving a cardiac arrest is confusing as the survivor has to adapt to a new reality. It is a complex time where existential conversations about luck, spirituality and survival are intense. This inquiry describes the participants' survival of a cardiac arrest to create a narrative with prominent threads involving the immediate transition from an ordinary to extraordinary existence leading to a chaotic illness experience. Findings from this inquiry are intended to engage the reader to consider survivors' complex experience. There are many aspects to comprehend and the predicted trajectory of the survivor's life is seriously altered and a new reality emerges. It can be a confusing time, where spirituality and closeness to death influence a person's life and recovery. It is important for healthcare professionals to gain knowledge through patients' experiences to be able to provide individualised care.



# **Narrative Inquiry in Nursing Research: Tensions, Bumps, and the Research Puzzle.**

*Gunilla Haydon, Pamela van der Riet & Kerry Inder.*

*Qualitative Methods Conference,*

*“Qualitative Methods in a Time of Change”*

*May 2018, Banff, Canada.*

*Oral presentation.*

Narrative inquiry has traditionally been used in social science and education research, and increasingly used in health research. It is well suited to health research, and nursing research in particular, as it focuses the inquiry on the person's experience of their illness - 'what matters' from the person's point of view. Narrative inquiry explores the narrative from a temporal, social and place point of view, providing a holistic approach to the persons' illness experience.

The adaptation of narrative inquiry to nursing research can create a tension in the nature of inquiry as a result of the differences between narrative inquiry and more traditional qualitative nursing research. Narrative inquiry data collection is characterised by multiple meetings, a relational aspect between the researcher and participant, the presence of the researcher in the findings, that sets narrative inquiry apart from other more traditional explorations and expectations within nursing research. The unique way in which narrative inquiry presents findings in addressing the research puzzle. The depth of analysis, that accrues from the multiple levels of inquiry can result in tensions with the more traditional methods of qualitative research. Findings bump and collide as narrative inquiry presents longer and relational narratives.

This presentation will use the experience from a narrative inquiry I study of how seven survivors of cardiac arrest, and how they have adapted to their new reality of self-surveillance (embodiment) and existential discourse. It will do this presentation from the inquirer's perspective, and, elaborate how temporal, social and place frames the inquiry process and presentation.

## ***Long term survivors of cardiac arrest: Re storied narratives***

*Gunilla Haydon, Pamela van der Riet & Kerry Inder*

*Research week School of Nursing and Midwifery,*

*Newcastle, Australia. September 2018*

*Poster presentation*

There is limited knowledge of how a cardiac arrest influences the embodiment for long term survivors and how these individuals' re-story their life. This presentation aims to explore how long term survivors of a CA adjusted to their new reality after the event.

Eight individuals who survived a cardiac arrest 5 to 26 years ago, were interviewed using in-depth conversations over a six-month period and these interviews were analysed using Clandinin and Connelly's (2000) framework of narrative inquiry (NI). Narrative inquiry, a qualitative methodology, is well suited to explore health related issues as it places the individual in the centre of the inquiry, combining all three-dimensions as a conceptual framework of NI that influence the person's illness experience: temporality (past, present and future), sociality (culture and institutional influences) and spatiality (place - not only where it happened but also where the narrative is told). Narrative inquiry also includes the researcher's influence of how the narrative is presented.

Narrative threads (themes) found during this exploration include; Experience of illness as a disbelief, Importance and wakefulness to keep fit, Surveillance/vigilance and practising wakefulness of the body (embodiment), Spirituality, and Gratefulness. Collectively, these eight survivors of CA have a very positive attitude to their experience and survival of a CA, conveyed through their narratives. None felt that the CA had impeded their future life as

such and saw it as an opportunity to take stock of their life. Their close encounter with death made them appreciate living and realise how fragile life is and how easy it is to die. It also removed their fear of dying as they felt they had experienced death.

For nursing these stories can bridge the gap between knowledge and experience. Nurses now have an exposure to people's narratives providing nursing staff with an understanding of the person's experience in their care.

# Poster 2018 Long term survivors of cardiac arrest: Re storied narratives

## Long term survivors of cardiac arrest: Re storied narratives

Gunilla Haydon RN PhD (Nursing) Candidate Associate Professor Pamela van der Riet Associate Professor Kerry Inder  
University of Newcastle School of Nursing and Midwifery

### Aim

To explore how long term survivors of a Cardiac Arrest (CA) experienced their lives.

### Method

Recruitment by snowballing technique, in- depth interview conversations over a six-month period.

Seven community dwelling individuals who survived a CA 5 to 26 years ago (5 men and 2 women) aged 43 —92 years.

### Methodology

Interview data were analysed using Clandinin and Connelly's framework of narrative inquiry, exploring how temporality, sociality and place influence the individuals' re-storied narrative.

## Preliminary Findings of Seven threads (themes)

### 1: Disbelief

There was disbelief among participants. They did not see themselves as candidates for a CA, they considered themselves as having a common lifestyle, with no extreme alcohol consumption, overweight or sedentary lifestyle. Comments such as:

"I was certain I wouldn't have a CA!"  
"I never thought it would happen to me"  
"I was not overweight or drank or smoked"  
"I think everybody that has a CA is unprepared for it"  
"I did not have any pre-warnings that I had a 'broken' heart"  
"I thought I would definitely not be a candidate for a CA because I was healthy, in good condition and not overweight"

confirmed the unpreparedness after the event, creating a feeling of insecurity. This insecurity is further expressed as they realised their body is not what they thought it was, leading to an increased need for surveillance over their body.

### 2: Surveillance/vigilance and practising wakefulness of the body (embodiment)

After the event they have a distrust in their body, creating a need for surveillance, making sure their body was working well, monitoring diet and exercise.

"Keeping a record of my heart"  
"I monitor my lifestyle, diet and exercise"  
"I am doing my best to keep my heart as healthy as possible"  
"Your diet is everything. The body is an amazing thing"  
There is a need to regain control both over their body and their future reality.

### 3: Loss of Control/ desire for normality

CA was tumultuous where participants felt they lost control over their life and it took time to adjust to a new reality

"I had lost control"  
"My greatest fear, would it happen again?"  
"The CA was completely out of my control"  
"I miss it dreadfully not being able to surf everyday"  
"I did not know how to react, I had never been subjected to such illness before"  
"I remember craving normality, not involving doctors or appointments. A desire to be in the herd again".  
To regain control, to return to a re-storied future was important for the participants, where they could make an impact, both in their own re-storied life but also by influencing others.

### 4: Importance of keeping fit and informing others

One of the driving motivators for participants to tell their re-storied narratives was to inform others of the importance of keeping fit and looking after their health. After the CA there was frustration over the relaxed attitude many people have over their health and willingness to change to a healthier lifestyle not realising how fragile life can be.

"I emphasise this, look after your body"  
"Do what you can to prevent it from happening again."  
"If you are unfit and overweight, perhaps you should expect the worst if you do not look after yourself and continue to smoke, carry big bellies and not exercise. Maybe I am a little bit harsh on people, once you experienced it, you want to shake them!"

There is strong will and attitude to support and increase the knowledge that a CA can happen to anybody and the importance of fitness

### 5: Gratefulness

After the CA the re-storying of their life included a new appreciation of life and how they are mindfully listening to their body, doing what feels right on the day, not pressing to over-achieve. All participants have a positive attitude to their survival. There is an underlying gratitude to the people and circumstances that made their survival a reality.

"I feel particularly fortunate"  
"A wakeup call to appreciate life and what you have"  
"There was a meaning in my survival"  
"I have a second chance and I am having another go"  
"How can you thank somebody for saving your life?"  
In their re-storying they are also expressing a newfound mindful appreciation of living, where family, friends and their surroundings are more important than before the CA.

### 6: Spirituality: Luck and fate

To survive a CA is to be very close to death, this reality can be a life changing experience. Knowing that most people do not survive a CA made them feel extremely lucky. It caused them to think of the fragility of life, how easy it is to lose it.

"I feel lucky to be here today"  
"The stars aligned to help me survive"  
"I was at the right place at the right time"  
"I was not allowed to go, because it was not my time"  
"It was a realisation it was not meant to be the end of me"  
The participants' belief that both luck and fate was involved in their survival; that the CA happened where it did with people around them who could act accordingly. Their survival also gave them a feeling of security and purpose.

### 7: Frailty of life and dying

The experience of a CA and realisation that life is frail and can end abruptly caused the participants, not only to appreciate life, but also accept that they will die one day. However, the CA experience, with the closeness to death, changed their view of dying as the participants expressed they had already experienced it.

"I am not scared of dying."  
"I don't mind. It was pretty quick"  
"It is a good way to go, if you got to go"  
"I am not frightened about dying. Before this I was terrified of dying"

This experience of death as a reality provided the participants' with an awareness that seems to be comforting for them.

**Temporality:** In the re-storying of survival, none of the participants saw themselves as a candidate for a CA. They all lived a life with family, work and leisure. Although some had health issues, the arrest came as a surprise. While the CA happened many years ago, it was still impacting their future. It was a catalyst for change, to promote a healthier lifestyle, to leave an abusive relationship, to write a book, to review career and consider changes. Life moves back to normality but it is a re-storied life; in the beginning with uncertainty before they settle into living with family, work and leisure where the CA is in the background of living, but not forgotten.

**Sociality:** These survivors' narratives highlight the influence and contribution to their re-storied life of survival to people around them. Many did not know much about CA or cardiac illnesses. Support received after the CA from friends and family has been valuable and influenced the re-storying of their social life. Frustration over the often relaxed attitude in society of the health ramifications a poor lifestyle was expressed and attribution of their own survival to being in good condition before the CA.

**Place:** The place where the CA occurs impacted on participants' survival, as did the place for recovery. Participants expressed a need to feel safe and have access to support during the first period after the CA. The current place where they live had a strong influence on and contributes to their re-storied life providing a feeling of security, gratitude and appreciation of life; being alive where they presently are.

**Discussion:** Exploration of seven narratives after CA provides an insight into their long term survival. All participants expressed a positive attitude and although they viewed the CA with disbelief and a hurdle to overcome, after the ordeal they found a new appreciation of life. By narratively describing CA survivors' long term experience, healthcare personnel are given an insight into how the person adapted after their experience and how alterations can be made to accommodate a person centred care approach.

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Clandinin, D.J., & Connelly, F.M. (2000). Narrative Inquiry, experience and story in qualitative research. San Francisco: Jossey-Bass



## **The suitability for Narrative Inquiry in health research.**

*Gunilla Haydon, Pamela Van Der Riet & Jane Maguire,  
University of Newcastle, Australia. Qualitative methods Conference*

*“Qualitative Methods: Better Bounded or Boundless?”*

*April 2015, Melbourne, Australia.*

*Oral presentation*

Narrative inquiry is an emerging methodology in nursing, although commonly used in education and sociology for many years. As an emerging methodology in nursing research there are some differences, both in collection and the presentation of the collected data which hinders the understanding of narrative inquiry and it is often seen as an undependable 'novel'.

We, as human beings, describe our experiences and realities narratively. We explore and comprehend events by telling and listening to stories, we dream narratively, people live narrative lives. Thus, the illness trajectory can be seen as a narrative. A classic narrative has beginning (normal life) - an event (an illness, acute or chronic) and an end (a “new” normal life). Ill people bleed stories and storytelling can support patients in their understating of their illness. This makes narrative inquiry suitable for health research.

Patients storytelling support their understating of their illness and narrative inquiry include the researcher as a participant with a mutual relationship between the researcher and patient. This builds trust and nurtures a deeper mutual understanding, revealing details not accessible in an interview.

The presentation of collected data narratively as collaboration between researcher and patient create a narrative that are informal to read but hold a true and deep understanding of the patients' experience.

Narrative inquiry with its relational data collection and informal presentation may well encourage nursing colleagues to become more engaged in consumption and research participation.

# **Qualitative and Quantitative research in quality of life after surviving a cardiac arrest.**

*Gunilla Haydon, Pamela Van Der Riet & Jane Maguire,  
University of Newcastle, Australia. Qualitative methods Conference  
“Qualitative Methods: Better Bounded or Boundless?”  
April 2015, Melbourne, Australia.  
Oral presentation.*

The impact a cardiac arrest with subsequent cardiopulmonary resuscitation have on the survivor's quality of life is not yet well explored. Although the literature surrounding cardiac arrest and cardiopulmonary resuscitation is plentiful there is less literature exploring the survivors' experience. While the survival rate for cardiac arrest remains low, <10% globally, there is a positive trend indicating that when patients survive to hospital discharge the possibility of long term survival is increasing substantially and steadily. With this in mind not only survival but also quality of life becomes an important factor for what could be classed as a successful resuscitation.

In a literature review, exploring papers published between 2000 and 2014, the quality of life for survivors of cardiopulmonary resuscitation was investigated. Of the final twenty-eight papers included, five were qualitative research. There was a marked difference between the qualitative and quantitative findings. The complexity of survival and cultural differences was evident in the qualitative findings compared to the quantitative literature. In quantitative research quality of life is commonly explored with questionnaires. More than 50 different questionnaires were used to evaluate quality of life of the survivors, making it challenging to compare the quantitative findings.

This presentation will highlight the differences and argue the need and importance of further qualitative research to explore the personal experience of a cardiac arrest, cardiopulmonary resuscitation and a new altered living situation.

## **Narrative Inquiry: a suitable method in health research.**

*Gunilla Haydon, Pamela Van Der Riet & Jane Maguire,*

*University of Newcastle, Australia. Nordic Conference in Nursing Research*

*“Methods and Networks for the future.”*

*June 2016, Stockholm, Sweden.*

*Oral presentation*

Narrative inquiry has been accepted in education and sociology research for many years, although not yet commonly used in nursing research. The differences, both in collection and presentation of the collected data often hampers the acceptance of narrative inquiry and it is frequently seen as an undependable 'novel'.

In reality, we describe events and experiences in stories. We explore and understand actions by telling and listening to stories, we dream in stories, we use stories continuously- it is part of who we are. Hence, when the experience of illness is expressed in a story, it can be studied and findings presented through the lens of temporality (time-past, present, future), spatiality (where the story takes place and also where the story is told) and sociality (people and social norms influencing the story teller).

‘Ill people bleed stories’ this makes narrative inquiry appropriate for nursing research, as well, it can support patients’ in their understanding and experience of their illness

The relational aspect of narrative inquiry, where researcher and participant enter a shared relationship during the research period, creates trust and deeper shared understanding, revealing details not accessible in a single in depth interview.

With fewer participants and a longer period of data collection, the presentation of findings narratively as collaboration between researcher and participant creates a longer story that is informal to read but hold a true and deeper understanding of the participants' experience. This informal presentation may well encourage nursing colleagues to become more engaged in research consumption and participation.

## **Narrative inquiry, a relational research methodology**

*Gunilla Haydon, Jane Maguire and Pamela van der Riet,*

*University of Newcastle, Australia. Asia Pacific International Conference on Qualitative Research in Nursing Midwifery and Health.*

*October 2014. Poster presentation.*

Qualitative research endeavour to investigate individuals' perspective of events and experiences. Narrative Inquiry as a methodology gives participants an opportunity to tell their stories and place participant, researcher and event in relation to each other.

A narrative researcher will analyse stories told in relation to their own experience and must therefore first ground themselves in relation to the theme of the narrative. During data collection relational ethics have a strong influence of how the narrative is received. There is a focus on subjectivity and development of relational ethical space that includes an effort to explore and honour individuals' values and experiences.

People use stories to explain and make sense of experiences, it is a logic method for individuals to categorise and create an understanding of events. To live through any illness is an event worthy of a narrative and Narrative Inquiry gives participants an opportunity to tell their stories with an emphasis on what is important to them.

All narratives told are in relation to spatiality (where), sociality (why) and temporality (when). Where the story is placed and where it is voiced will influence how it is presented. The social influences of the audience and how these social influences changes with time will also have an impact on the stories. Stories contain past or present events, or possibly a plan for the future drawn from past experiences.

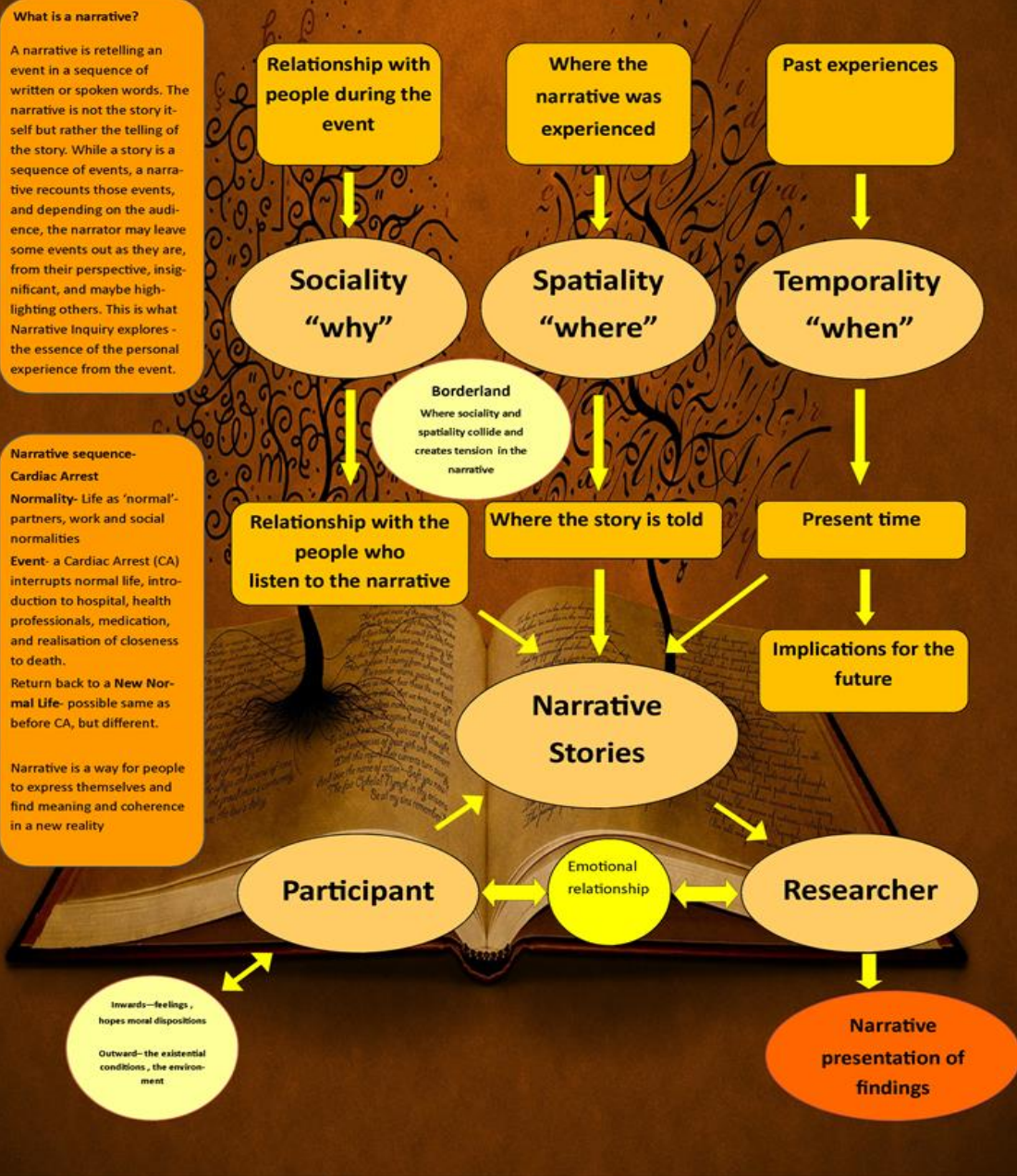
This poster will visualise the relational research used in Narrative inquiry and how this methodology supports the patients' narratives of their illness.

# Poster 2014 Narrative inquiry, a relational research methodology



Gunilla Haydon<sup>1</sup> Jane Maguire<sup>1</sup> Pamela van der Riet<sup>1</sup>  
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## Narrative Inquiry: a relational methodology Clandinin & Connelly



## Appendix 2 Acknowledgment of Authorship

### ACKNOWLEDGMENT OF AUTHORSHIP

I hereby certify that the work embodied in this thesis contains published paper/s/scholarly work of which I am a joint author. I have included as part of the thesis a written declaration endorsed in writing by my supervisor, attesting to my contribution to the joint publications.

By signing below, we, Pamela van der Riet and Jane Maguire, confirm that Gunilla Haydon contributed substantially to the concept, design, data collection, data management, data analysis, interpretation of findings and writing of the publication entitled

Haydon, G., van der Riet, P., & Maguire, J. (2017). Survivors' quality of life after cardiopulmonary resuscitation: an integrative review of the literature. *Scandinavian Journal of Caring Sciences*, 31(1), 6-26. doi: 10.1111/scs.12323. Epub 2016 Jul 21.

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Haydon, G., van der Riet, P., & Inder, K. (2017). Survivors' quality of life after cardiopulmonary resuscitation: an integrative review of the literature. *Scandinavian Journal of Caring Sciences*, 31, 6-26. Doi: 10.1111/scs.12323

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## Appendix 4 Acknowledgment of authorship

### ACKNOWLEDGMENT OF AUTHORSHIP

We hereby certify that the work embodied in this thesis contains published paper/s/scholarly work of which I am a joint author. I have included as part of the thesis a written declaration endorsed in writing by my supervisor, attesting to my contribution to the joint publications.

By signing below, we, Pamela van der Riet and Kerry Inder, confirm that Gunilla Haydon contributed substantially to the concept, design, data collection, data management, data analysis, interpretation of findings and writing of the publications entitled

Haydon, G., van der Riet, P., & Inder, K. (2020). A narrative inquiry of survivors' experiences of the time just before and after a cardiac arrest. *Collegian*. Published on line 14 September 2020.  
doi:10.1016/j.colegn.2020.06.008

Haydon, G., van der Riet, P., & Inder K. (2020). The experience of returning home after surviving cardiac arrest: a narrative inquiry. *Nordic Journal of Nursing Research*, published online June 24, 2020.  
doi:10.1177/2057158520932348

Haydon, G., van der Riet, P., & Inder, K. (2019). Long-term survivors of cardiac arrest: A narrative inquiry. *European Journal of Cardiovascular Nursing*, 18(6), 458-464. doi:10.1177/1474515119844717

Haydon, G., van der Riet, P., & Inder, K. (2017). A systematic review and meta-synthesis of the qualitative literature exploring the experiences and quality of life of survivors of a cardiac arrest. *European Journal of Cardiovascular Nursing*, 16(6), 475– 483. doi: 10.1177/1474515117705486.

#### Author List

Associate Professor Pamela van der Riet. University of Newcastle.

Signature: \_\_\_\_\_ Date: 26/11/2020

Associate Professor Kerry Inder. University of Newcastle.

Signature: \_\_\_\_\_ Date: 25/11/2020

Faculty of Health and Medicine Assistant Dean Research Training,

Associate Professor Lesley MacDonald Wicks. University of Newcastle.

Signature: \_\_\_\_\_ Date: 2/12/2020

## Appendix 5 Human Research Ethical approval

### HUMAN RESEARCH ETHICS COMMITTEE



#### Notification of Expedited Approval

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|                                              |                                                                      |
|----------------------------------------------|----------------------------------------------------------------------|
| To Chief Investigator or Project Supervisor: | <b>Associate Professor Pamela Van Der Riet</b>                       |
| Cc Co-investigators / Research Students:     | <b>Mrs Gunilla Haydon</b><br><b>Associate Professor Jane Maguire</b> |
| Re Protocol:                                 | <b>What is the experience of surviving CPR?</b>                      |
| Date:                                        | <b>10-Jun-2015</b>                                                   |
| Reference No:                                | <b>H-2015-0132</b>                                                   |
| Date of Initial Approval:                    | <b>09-Jun-2015</b>                                                   |

---

Thank you for your **Response to Conditional Approval** submission to the Human Research Ethics Committee (HREC)

seeking approval in relation to the above protocol.

Your submission was considered under **Expedited** review by the Chair/Deputy Chair.

I am pleased to advise that the decision on your submission is **Approved** effective **09-Jun-2015**.

In approving this protocol, the Human Research Ethics Committee (HREC) is of the opinion that the project complies with the provisions contained in the National Statement on Ethical Conduct in Human Research 2007, and the requirements within this University relating to human research.

Approval will remain valid subject to the submission, and satisfactory assessment, of annual progress reports. *If the approval of an External HREC has been "noted" the approval period is as determined by that HREC*

The full Committee will be asked to ratify this decision at its next scheduled meeting. A formal *Certificate*

Approval will be available upon request. Your approval number is **H-2015-0132**.

**If the research requires the use of an Information Statement, ensure this number is inserted at the relevant point in the Complaints paragraph prior to distribution to potential participants** You may then proceed with the research.

### Conditions of Approval

This approval has been granted subject to you complying with the requirements for *Monitoring of Progress*, *Reporting of Adverse Events*, and *Variations to the Approved Protocol* as detailed below.

#### PLEASE NOTE:

In the case where the HREC has "noted" the approval of an External HREC, progress reports and reports of adverse events are to be submitted to the External HREC only. In the case of Variations to the approved protocol, or a Renewal of approval, you will apply to the External HREC for approval in the first instance and then Register that approval with the University's HREC.

- ***Monitoring of Progress***

Other than above, the University is obliged to monitor the progress of research projects involving human participants to ensure that they are conducted according to the protocol as approved by the HREC. A progress report is required on an annual basis. Continuation of your HREC approval for this project is conditional upon receipt, and satisfactory assessment, of annual progress reports. You will be advised when a report is due.

- ***Reporting of Adverse Events***

1. It is the responsibility of the person **first named on this Approval Advice** to report adverse events.
2. Adverse events, however minor, must be recorded by the investigator as observed by the investigator or as volunteered by a participant in the research. Full details are to be documented, whether or not the investigator, or his/her deputies, consider the event to be related to the research substance or procedure.
3. Serious or unforeseen adverse events that occur during the research or within six (6) months of
4. completion of the research, must be reported by the person first named on the Approval Advice
5. to the (HREC) by way of the Adverse Event Report form (via RIMS at <https://rims.newcastle.edu.au/login.asp>) within 72 hours of the occurrence of the event or the investigator receiving advice of the event.
6. Serious adverse events are defined as:
  - Causing death, life threatening or serious disability.
  - Causing or prolonging hospitalisation.

- Overdoses, cancers, congenital abnormalities, tissue damage, whether or not they are judged to be caused by the investigational agent or procedure.
- Causing psycho-social and/or financial harm. This covers everything from perceived invasion of privacy, breach of confidentiality, or the diminution of social reputation, to the creation of psychological fears and trauma.
- Any other event which might affect the continued ethical acceptability of the project.

7. Reports of adverse events must include:

- Participant's study identification number;
- date of birth;
- date of entry into the study;
- treatment arm (if applicable);
- date of event;
- details of event;
- the investigator's opinion as to whether the event is related to the research procedures; and
- action taken in response to the event.

8. Adverse events which do not fall within the definition of serious or unexpected, including those reported from other sites involved in the research, are to be reported in detail at the time of the annual progress report to the HREC.

• ***Variations to approved protocol***

If you wish to change, or deviate from, the approved protocol, you will need to submit an *Application for Variation to Approved Human Research* (via RIMS at <https://rims.newcastle.edu.au/login.asp>). Variations may include, but are not limited to, changes or additions to investigators, study design, study population, number of participants, methods of recruitment, or participant information/consent documentation.

**Variations must be approved by the (HREC) before they are implemented** except when Registering an approval of a variation from an external HREC which has been designated the lead HREC, in which case you may proceed as soon as you receive an acknowledgement of your Registration.

### Linkage of ethics approval to a new Grant

HREC approvals cannot be assigned to a new grant or award (ie those that were not identified on the application for ethics approval) without confirmation of the approval from the Human Research Ethics Officer on behalf of the HREC.

Best wishes for a successful project.

Professor Allyson Holbrook

**Chair, Human Research Ethics Committee**

*For communications and enquiries:*

**Human Research Ethics Administration**

Research Services

Research Integrity Unit

The Chancellery

The University of Newcastle

Callaghan NSW 2308

T +61 2 492 17894

F +61 2 492 17164

[Human-Ethics@newcastle.edu.au](mailto:Human-Ethics@newcastle.edu.au)

RIMS website - <https://RIMS.newcastle.edu.au/login.asp>

## Appendix 6 Recruitment Poster

Associate Professor Pamela van der Riet  
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# HAVE YOU SURVIVED A CARDIAC ARREST?

If you have, this will give you an opportunity to participate in a research project studying survivors' experience of the event.

How will it be investigated?

Participate in a face to face conversation with Gunilla Haydon RN

When?

Interviews will be held during 2016-2017

Where?

At a place selected by you and the researcher that is suitable for a conversation.

Why?

To increase the knowledge of survivors' experience of cardiac arrest in order to provide better care for survivors

How do you get involved?

Located at the reception desk at this GP surgery are information packs containing further material on how to get involved in the research and what you do as a participant.

# RESEARCH STUDY

[www.newcastle.edu.au](http://www.newcastle.edu.au)

### *Complaints about this research*

This project has been approved by the University's Human Research Ethics Committee, Approval No. H- 2015-0132. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, telephone (02) 49216333, email [Human-Ethics@newcastle.edu.au](mailto:Human-Ethics@newcastle.edu.au).

## Appendix 7 Participation information statement



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M+61421052552  
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### Information statement for the research project: **What is the experience of surviving CPR?**

**Assoc. Prof Pamela van der Riet, Assoc. Prof Kerry Inder, Gunilla Haydon BN(Honours) RN**

Document Version 3 dated 05/06/2015

You are invited to participate in the research project identified above which is being conducted by Associate Professor Pamela van der Riet, Associate Professor Kerry Inder and doctoral student Gunilla Haydon RN from the School of Nursing and Midwifery at the University of Newcastle.

#### ***Why is the research being done?***

Cardiac arrest is a leading cause of death, with an estimated 15,000 people suffering a cardiac arrest in Australia every year. Between 6% and 13% of cardiac arrest victims in Australia will survive more than one year past the event. The fundamentals of early recognition and activation, early CPR, early defibrillation, and early access to emergency medical care have saved many lives. Survivors of CPR can also expect to live longer after the event. This means that not only survival but also quality of life becomes an important measurement of a successful resuscitation.

This research will give insight in what survivors find to be the most important elements needed to provide optimal care and rehabilitation after surviving CPR.

#### ***Who can participate in the research?***

If you have survived CPR, are older than 18 and living independently in the community you are eligible to participate.

***What would you be asked to do?***

If you agree to participate you will be invited to take part in recorded interviews to discuss your experiences following CPR.

***What do you need to do to participate?***

Please read this information statement and be sure you understand its contents before you consent to participate.

If you decide to participate, fill in the forms and put them in the envelope provided in this information pack and post it. After receiving your information, Gunilla Haydon, a Doctoral student and Registered Nurse, will contact you to find a suitable time and place for these conversations to take place. This could be in your home or in another quiet safe location.

There will be a minimum of two conversations and there is no stipulated time limit for these. It is your choice to decide the time for the next meeting, preferably within a month. In these conversations there will be no stipulated questions to answer –only conversation starters. If you feel uncomfortable during the conversation it will stop and you have the right to withdraw from the project at any time during the research period.

***What are the risk and benefits of participating?***

To have a conversation and talk about the experience of CPR can support an understanding of your situation. It is often considered therapeutic to have the opportunity to recount experiences and express thoughts of events.

*Although, to talk about the experience might also awake memories and emotions that are not pleasant. If you feel that the conversation is too much for you, you can stop at any moment without having to explain or excuse yourself.*

*Included in this information pack is a brochure from Lifeline, together with contact numbers from other counselling services, if you would like to talk to a counsellor.*

***What choice do you have?***

Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you.

If you do decide to participate, you may withdraw from the project at any time without giving a reason and have the option of withdrawing any data you have provided. After conclusion of meetings and agreement of transcript, the data you have provided will be un-retrievable and part of the final results.

***How will your privacy be protected?***

Participants will not be named within the research outcomes. Any information collected by the researcher which might identify you will be stored securely and only accessed by the researcher unless you consent otherwise, except as required by law. Data will be retained for at least 5 years at the University of Newcastle. On completion of the data collection all data will be kept in a secure password protected directory for five years. After which, all identifying information and data will be destroyed following University of Newcastle procedures for shredding of sensitive documents.

***How will the information collected be used?***

The face to face meetings involves starting a conversation over your experience of surviving CPR and these conversation will be recorded. These recordings will be transcribed and common themes and trends between different recordings will be investigated by Gunilla Haydon. The collected data will be part of a Doctoral Thesis and presented in journal articles. There will be opportunities for you as a participant to review your transcribed recording and amendments will be done to your satisfaction. These transcribed conversations will not include any names and your identity will be protected. During the research all data will be burnt on a CD and password protected, hard copy material will be stored in a locked filing cabinet and destroyed after 5 years as per university protocol.

These conversations allow the participant to tell of their experiences as they have occurred over time. Themes and trends will be summarized and the findings from this project will be presented as publications in peer reviewed nursing journals. Conference presentations will also be part of the distribution of gained knowledge.

As a participant you will have the opportunity to receive a project summary at the end of the project.

Non-identifiable data may be also be shared with other parties to encourage scientific scrutiny, and to contribute to further research and public knowledge, or as required by law.

### ***Conversation starters***

Tell me about your experience of waking up after CPR?

What has changed the most since waking up after CPR compared to your life before the cardiac arrest?

What has been the largest obstacle to overcome? Such as mobility restrictions or being alone.

Have your personal relationships between your loved ones changed after the cardiac arrest?

### ***Further information***

Your participation will be greatly appreciated and if you need any further information, please do not hesitate to contact Gunilla on 02 6581 6357 during office hours.

*Kind regards,*

*Associate Professor Pamela van der Riet*

*Gunilla Haydon, RN*

### ***Complaints about this research***

*This project has been approved by the University's Human Research Ethics Committee, Approval No. H-2015-0132. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, telephone (02) 49216333, email Human-Ethics@newcastle.edu.au.*

## Appendix 8 Consent form



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[Pamela.vanderRiet@newcastle.edu.au](mailto:Pamela.vanderRiet@newcastle.edu.au)

### Consent Form for the Research Project:

## What is the experience of surviving CPR?

Assoc. Prof Pamela van der Riet, Assoc. Prof Kerry Inder, Gunilla Haydon RN

Document Version 1 dated 20/03/2015

I agree to participate in the above research project and give my consent freely.

I understand that the project will be conducted as described in the Information Statement, a copy of which I have retained.

I understand I can withdraw from the project at any time and do not have to give any reason for withdrawing.

I consent to

- participating in an interview and having it recorded;
- the recording to be transcribed

I understand that my personal information will remain confidential to the researchers

I have had the opportunity to have questions answered to my satisfaction.

**Print Name:** \_\_\_\_\_

**Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

Please indicate in the box below if you require a summary of this research and where you would like it sent.

**Insert X in box**

|     |  |
|-----|--|
| Yes |  |
|-----|--|

|    |  |
|----|--|
| No |  |
|----|--|

My contact details and summary to be sent to:

Home address:

.....  
.....Or email address  
.....  
.....

## Appendix 9 Personal data collection form



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Statement for the research project:

### **What is the experience of surviving CPR?**

Assoc. Prof Pamela van der Riet, Assoc. Prof Kerry Inder, Gunilla Haydon RN

Name: \_\_\_\_\_

Born: \_\_\_\_\_

Place of cardiac arrest: \_\_\_\_\_

Time of cardiac arrest: \_\_\_\_\_

People present: \_\_\_\_\_

CPR given by: \_\_\_\_\_

Time in hospital: \_\_\_\_\_

Other Information: \_\_\_\_\_

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## Appendix 10 Acknowledgment of authorship

### ACKNOWLEDGMENT OF AUTHORSHIP

We hereby certify that the work embodied in this thesis contains published paper/s/scholarly work of which I am a joint author. I have included as part of the thesis a written declaration endorsed in writing by my supervisor, attesting to my contribution to the joint publications.

By signing below, we, Graeme Browne and Pamela van der Riet, confirm that Gunilla Haydon contributed substantially to the concept, design, data collection, data management, data analysis, interpretation of findings and writing of the publication entitled

Haydon, G., Browne, G., & van der Riet, P. (2017). Narrative inquiry as a research methodology, exploring person centred care in nursing. *Collegian*, 25(1), 125–129.  
doi:10.1016/j.collegn.2017.03.001

Author List

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Faculty of Health and Medicine Assistant Dean Research Training,

Associate Professor Lesley MacDonald Wicks. University of Newcastle.

Signature:  Date: 2/12/2020