Improving the after care for deceased organ donor families and friends, an online peer to peer support network

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List of Abbreviations

AoMRC	Academy of Medical Royal Colleges
CASP	Critical Appraisal Skills Programme
DCD	Donation after circulatory death
DBD	Donation after death diagnosed using neurological criteria
DFAG	Donor Family Advisory Group
DFACS	Donor Family Aftercare Service
ED	Emergency Department
GDPR	General Data Protection Regulation
GMC	General Medical Council
GP	General Practitioner
HLA	Human Leukocyte Antigen
HM	Her Majesty’s
ICU	Intensive Care Unit
MOHAN	Multi Organ Harvesting Aid Network
NHS	National Health Service
NHSBT	National Health Service Blood & Transplant
ODR	Organ Donor Register
OPO	Organ Procurement Organisation
PIS	Participant Information Sheet
REC	Research Ethics Committee
RINTAG	Research Innovation Novel Techniques Advisory Group
SNOD	Specialist Nurse Organ Donation
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

Glossary of Terms

Academy of Medical Royal Colleges	The Academy of Medical Royal Colleges (the Academy) is the coordinating body for the UK and Ireland’s 23 medical Royal Colleges and Faculties.
Critical Appraisal Skills Programme	Critical appraisal skills enable you to systematically assess the trustworthiness, relevance, and results of published papers.
Donation after circulatory death	Donation after Circulatory Death (DCD), previously referred to as donation after cardiac death or non-heart beating organ donation, refers to the retrieval of organs for the purpose of transplantation from patients whose death is diagnosed and confirmed using cardio-respiratory criteria.
Donation following death confirmed using neurological criteria	Donation after Brainstem Death (DBD) is possible from patients whose death has been confirmed using neurological criteria (also known as brain-stem death or brain death).
Facebook	A social media platform which allows people to create a profile, connect with others and form friendships, and engage in conversations with others
Human Leukocyte Antigen	The HLA system is clinically important as transplantation antigens. Molecular HLA allele typing is routinely performed to provide HLA class I and class II allele matching in unrelated donor hematopoietic stem cell transplantation. Prospective lymphocyte crossmatching is critical in solid organ transplantation to prevent allograft rejection.

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Abstract

The thesis explores the use of social media to support bereavement aftercare for families/friends of organ donors following the death of their relative. Existing research appraising the aftercare of families/friends post-deceased donation is limited. The national practice has not progressed, with families/friends receiving limited bereavement support following organ donation.

A closed Facebook group, 'Donor Families Together,' was created for donor family/friends to connect, offering peer support using an online platform. With group participants' consent, a qualitative research study ran consecutively for 12 months. Conversational data from the Facebook group was downloaded, including 1452 posts and the results of 3 polls (short surveys). Six selected participants were also invited to participate in an in-depth one-to-one interview with the researcher, capturing personal experiences from individuals with differing relationships with the deceased. Thematic analysis of group and individual narrative data generated rich integrated findings and new knowledge to inform practice.

The research found that organ donor families who joined the group connected with others living through this unique grief experience, sharing their most intimate feelings with strangers, and offering support any time of the day or night. It has been a welcomed space for organ donor families/friends to unite through their lived experience of death and donation, providing them with a safe environment to share emotions, grief, and questions, offering peer support, and building a special bereavement community. The findings from this unique longitudinal study provided new knowledge related to the aftercare bereavement needs of organ donor families/friends, resulting in the development of a unique grief model for organ donor families/friends.

The study informs best clinical practice and highlights a peer support service developed to improve bereavement recovery post organ donation through real-life peer support. This innovative approach valued the impact of social media in connecting organ donor families, and provided an understanding of the complex aftercare needs of organ donor families/friends.

Chapter 1: Introduction to The Thesis and Topic

Introduction To The Thesis

Working as a specialist nurse in organ donation (SNOD) for over 12 years has placed me in some of the most painful situations when meeting organ donor families/friends. I have seen first-hand and been part of the agonising family experience, observing difficult family decisions. My professional and personal reflections underpin the drive to improve post-donation support and practice, the focus of this research. My nursing career, the families/friends I have met, and my personal life experiences present a strong foundation for the thesis. This chapter sets the scene for the research, presenting the topic of deceased organ donation.

Researcher, Practitioner, And Topic

Organ donation can be an unexpected, devastating issue to raise with a family who faces losing someone they love. Opting to donate your loved one's organs at the time of their death is selfless and the most generous gift anyone can bestow to a stranger. Working as a specialist nurse organ donation (SNOD) for the past eleven years has presented me with some of the most meaningful situations of my life. I have had the privilege of supporting patients and their loved ones at the worst possible time, end of life. The SNOD role is both challenging and rewarding requiring you to assess patients as potential organ donors, supporting families whilst they make end of life decisions and facilitating the process if they consent to organ donation. It has occupied much of my professional career to date, and I have always wanted to ensure that I treat every situation with the respect and admiration it deserves. Taking on the professional doctorate program as a novice researcher encouraged me to personally reflect on my professional career as a nurse, and this reflection has provided me with the passion and motivation to progress this research study. The energising process of critical reflection has been the incentive to improve the aftercare services we, the organ donation organisation, provide to organ donor families. As the student, researcher, and professional nurse, I have had numerous responsibilities within the project; the principal researcher, the lead moderator, the technical specialist, the link to the organ donation organisation, and the transitioning between roles was challenging.

The typical literature on organ donation concentrates significantly on the recipient rather than the organ donor. However, a unique bond is forged between the donor family and the healthcare professional coordinating the donation process (Maloney, 1998). After the paperwork has been signed, the family leaves the hospital, and the donation operation takes place; the focus then inadvertently moves away from the donor and their family and transfers to the recipient and the new life they have received. This process, expressed and described by donor families I have met, is permeated with sadness and a sense of abandonment following organ donation, which I felt motivated to address and, if possible, resolve. Throughout the thesis research findings, the feeling of being abandoned is reinforced and can sometimes be heart-breaking to read. NHSBT strategy, Meeting the Need 2023, recognises the need to increase the visibility of donor families within UK society so that organ donation becomes a societal norm. Donors and their families make the generous decision every day to save and improve the lives and inspire others to donate (NHSBT, 2022).

My professional career has been so rewarding, I have had the pleasure of meeting remarkable families whose noble act has given hope and life to strangers. Supporting families through the sadness that follows the death of a loved one is a crucial part of the organ donation specialist’s role and, more importantly, a responsibility of the organ donation organisation. Seeking to understand better the experiences of organ donor families during this exceptional and unique act inspired me to develop and implement this research. The organ donation field is intense and, at times, overwhelming. Several different clinical experiences while supporting organ donor families provoked and reinforced the need for this study. One encounter with a donor mum, who praised the service and spoke about the positive benefits of organ donation, produced a considerable sense of pride. While she understood the value of organ donation, she also expressed her abandonment and loneliness following the donation, which made me question the lack of aftercare for donor families and friends. Reflecting on the current services we provide as an organ donation organisation, I started a journey to discover ways to improve current services, and as part of this research recognising, we needed to provide improved bereavement support for donor families. My own experiences, values, and beliefs have played a significant part in this research, influencing my motivation and desire to help others has evolved from my nursing values, principles, and compassionate character.

Although the national organisation, NHS Blood & Transplant (NHSBT), operates over a large geographical area, developing local accessible bereavement support groups for our organ donor families was considered impossible to implement, and the practicalities unmanageable and costly. The current practice advises families to gain bereavement follow-up and support within their primary care services or local community. While this seemed a reasonable support strategy, some donor families suggested they wanted to talk to others who could understand their grief and feelings, other donor families. I assumed that connecting organ donor families would be challenging until I met my supervisors and soon realised, they were experienced using social media platforms, having set up supportive information networks using this method. They had created powerful communication networks using social media that allowed patients to share their experiences and information and meet other people, irrespective of geography or where they lived (Vasilica, 2015; 2021). I explored this avenue as a possibility for organ donor families and realised the emergence of social media had transformed the way people communicate and engage with each other (Schneiderman et al., 2011), and it has been used widely to support patients in a healthcare context (Housseh, et al. 2014; Vasilica, 2015; Smailhodzic et al., 2016). Virtual space has also become a place to share experiences, such as bereavement and loss (Nager, de Vrie, 2004). Indeed, the internet bonds grieving people who would never have met (Hollander, 2001). I took the idea to NHSBT and gained organisational support. This seemed an excellent opportunity to create and test out a potential online peer-to-peer support group, discovering if social media could support donor family's post-donation, allowing grieving families to connect, understand each other's grief, and share lived experiences. This would bring people together, hopefully, reduce the feeling of abandonment, and overcome geographical barriers, providing them with an opportunity to grow a community outside traditional methods. This thesis tracks this unique journey, the challenges and encounters of the group itself, documents and reports the stories and experiences of donor families and generates new knowledge and evidence for a novel support strategy using social media.

Thesis Structure

This thesis is presented over seven chapters.

Chapter 1 introduces the thesis and the personal and professional situation of the researcher. The concept of organ donation is explored, providing a background to the study, examining the process of organ donation, and identifying the current provision of support for donor families. The chapter offers a brief overview of the theories of grieving after a bereavement, and the central UK organ donation organisation NHS Blood & Transplant (NHSBT), where the researcher worked for several years.

Chapter 2 critically appraised the current international literature examining strategies to support families after organ donation to inform best practices, identifying gaps in evidence to reinforce the need for developing research. Chapter 3 describes the research study, the methods, recruitment, and the research sample that formed the research investigation to explore the influence of an online peer-to-peer donor family support group. This chapter demonstrates how the group was set up, moderation and online support, the recruitment of organ donor families, and the ethical considerations of researching and supporting people during such a sensitive and emotive time.

Chapter 4 examines the lesson learned throughout this study and the knowledge and insight gained. Chapter 5 draws on the findings following a thematic analysis approach, exploring the influence of building a peer-to-peer support community, analysing the painful group discussions, and capturing families' potential needs during this devastating time. The study explores how people survive post-donation, what support they need, and the impact of building a peer-to-peer support network which may influence how individuals progress through the theoretical stages of the grieving process.

Chapter 6 considers the findings in the context of the literature, identifying what impact these outcomes hold on current practice, including personal reflections on my clinical practice and organisational influence. This chapter discusses the new knowledge uncovered from the findings and how this informs best practices.

Chapter 7 concludes the study and the thesis by summarising critical recommendations for aftercare support for organ donor families and further research.

What Is Organ Donation?

Organ donation can be from living or deceased donors (Neuberger & Keogh, 2013). Only 1 % of the population can become deceased organ donors, dying in a situation allowing them to donate their organs at the time of their death (Ahmad et al., 2019; NHSBT, 2020). There are two types of deceased organ donation, donation after circulatory death (DCD) and donation following diagnosis of death using neurological criteria, formally known as donation after brainstem death (DBD) (Hodgson et al., 2017). Not all deceased patients are suitable for organ donation, and there are many barriers to identifying the correct patients, obtaining consent, and procuring organs to ensure a successful transplant (Hodgson et al., 2017). Most donations come from deceased patients diagnosed using neurological criteria. However, some argue that patients progressing to neurological death has reduced over time due to improved neurosurgical therapy and better patient management (Hodgson et al., 2017; Summers et al., 2010). While most countries depend on DBD donation, organs can be retrieved from patients whose heart has stopped, as in DCD (Bendorf et al., 2013). Another form of donation is living donation, and across the UK, nearly 1,000 people each year donate a kidney or part of their liver while they are still alive to a relative, friend, or someone they do not know (Davis, 2011; NHSBT, 2020). Living donor kidney transplant rates vary across the world and this heterogeneity arises from the different socio-cultural environments and legislative rules in place to encourage the practice. In countries with an established deceased donor infrastructure, living kidney donor programs have complemented the national kidney allocations systems but invariably been championed as the treatment of choice. The success of encouraging living donor kidney transplantation in these countries has led to significant component of overall kidney transplantation activity arising from living kidney donors, although more kidney transplants arise from deceased donors (Kimenai, Minnee, 2022). Living donation will not be considered part of this thesis, and the discussion will concentrate on and apply only to deceased organ donation and bereavement.

UK Organ Donation

NHSBT provides a blood and transplantation service to the NHS, looking after blood donation services in England and transplant services across the UK. This includes managing the donation, storage, and transplantation of blood, organs, tissues, bone marrow, and stem cells and researching new treatments and processes (Harris & McKeown, 2019). Organ donation and transplantation is part of NHSBT, and they manage the NHS Organ Donor Register and the National Transplant Register, which reasonably matches donors to people waiting for transplanted organs. Thanks to the amazing organ donors, 4,532 people have received donated organs from 2,386 donors – living and deceased- in 2022/23. There are currently around 7,000 people waiting for a transplant in the UK, and in 2022/23, 439 people died while waiting for a transplant and a further 732 patients were removed from the transplant list due to deteriorating health and many would have subsequently died (NHSBT, 2023). The UK was placed as one of the lowest-performing countries facilitating organ donation in 2003, forcing the UK government to develop a task force to introduce recommendations to increase organ donation by 50% in 5 years (Neuberger & Keogh, 2013; Hulme et al., 2016). Indeed, since implementing the Organ Donation Taskforce recommendations in 2008, the UK has seen a 98% increase in the total number of deceased organ donors and a massive 81% increase in the number of deceased donors per million per population (Curtis et al., 2021).

International Context Of Organ Donation

Organ donation and transplant rates vary worldwide, and although there is a contrast in rates, the shortage of people donating their organs at the time of their death remains (Gomez et al., 2012). There are around 50 countries that are active regarding transplantation. Countries such as Japan rely heavily on living donors, while countries with developed organ donation programs, such as Spain and the UK, depend on deceased donation (Rudge et al., 2012; Gomez et al., 2014; Tocher et al., 2018).

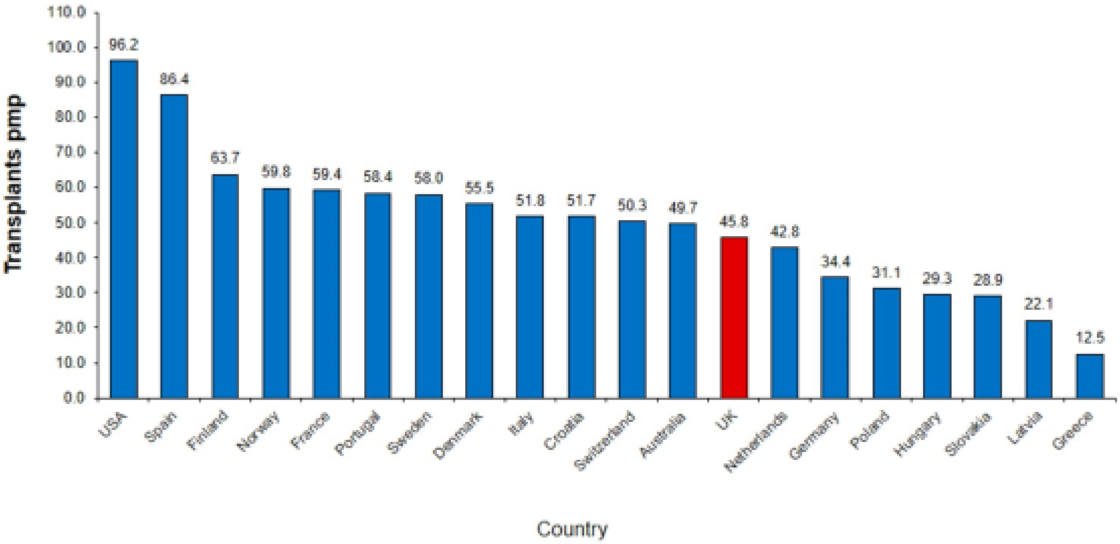


Figure 1: Council of Europe (2020: p27) Deceased donor transplant rates (pmp)

Spain is the world leader in organ donation and transplantation (Rithalia et al., 2009; Ahmad et al., 2019). Since 1992, Spain has maintained the world record for per million per population (pmp) organ donors. In 2019, the rate was 48.9 pmp, totalling 2,302 deceased donations and 5,449 transplanted organs, an average of 6.3 daily deceased donations, and 15 daily transplants (Solanki & Desai, 2021). Several other significant countries have donation rates of 20–30 pmp (including France, Italy, Belgium, and Croatia), whereas, in the UK, the rate is now around 19.8 pmp (Rudge et al., 2012; Solanki & Desai, 2021). Figure 1. illustrates the number of deceased donor transplants rate for Europe, and Australia, compared with the highest number of transplants pmp achieved in the USA during 2020. The UK remains a subordinate and at the lower end of the table, illustrating the need for the organ donation organisation to work hard to ensure all suitable organs are utilised for transplantation and public awareness is increased to better support organ donation.

Opt Out Legislation

In the UK, in May 2020, the new 'Max and Keira's Law' was legislated (Mahenthran, 2021; Jensen et al., 2022). The law now considers all adults to agree to become organ donors when they die unless they have made it known that they do not wish to donate their organs at the time of their death. If you have not recorded an organ donation decision and you are not in one of the excluded groups, it will be considered that you agree to donate your organs when you die.

The excluded groups include:

- Those who are under the age of 18 years
- People who lack the mental capacity to understand the new law and take necessary action
- Visitors to England and those who do not live in England voluntarily
- People who have lived in England for less than 12 months before their death

The opt-out law is called the opt-out system, deemed consent, presumed consent, or Max and Keira's Law (Dimitry & Lee, 2021; Mahenthran, 2021). Max and Keira's Law, passed in May 2020, aimed to help spread organ donation awareness, prompting conversations between families supporting them in making end-of-life decisions.

Under the new legislation, people are assumed to want to donate their organs at their death unless they choose to 'opt-out.' The agreement of the next of kin is still required making this a soft 'opt out' system (Parsons & Moorlock, 2020). The legislation change was introduced to increase consent rates and still offer people the choice to 'opt in' or 'opt out' of the system. The most important message communicated by NHSBT was for people to share their decision with their families (NHSBT, 2020). People's faith, beliefs, and culture will continue to be respected, and the SNODs will always involve the family/friends of the patient in the conversations. If family/friends still do not want to go ahead after being given all the information, then the donation will not proceed, hence the soft 'opt out' decision which still allows families to make final decisions at an emotionally stressful time (Reinders et al., 2018; Hyde et al., 2021).

Global comparisons demonstrate that 'opt-out' consent ideally leads to increased consent rates and the number of organs transplanted (Shepard et al., 2014; Noyes et al., 2019a; Arshad et al., 2019; Mahenthran, 2021). A systematic review by Ahmad et al. (2019) compared the consent rates of opt-out organ donation countries versus opt-in countries. It revealed that the opt-out consent increased the deceased donation rate by 21-76% over 5-14 years, and the deceased transplantation rate increased by 38-83% over 11-13 years. In December 2015, Wales introduced their new 'opt-out' system, which has succeeded in increasing donor consent rates to 80.5%, compared with the rest of the UK at 66.2 % (Mahenthran, 2021). However, the changes in consent laws do not necessarily transform consent rates, as seen in

Brazil, where the presumed consent law was adopted but received such criticism that it was eliminated the following year (English et al., 2019; Etheredge, 2021). Etheredge (2021) argues that there is little difference between an 'opt in' or 'opt out' system, and to increase organ donation rates successfully is complex, requiring a multidimensional approach. Identifying the complexities surrounding organ donation and the varying values and beliefs each family brings into an organ donation conversation, needs further consideration. Challenges in accurately measuring the impact of opt-in versus opt-out systems are diverse across countries, and in some countries, such as Singapore and Austria, a 'hard-opt-out system' has been implemented where the donation will seemingly be followed regardless of the families' wishes (Arshad et al., 2019; Etheredge, 2021; Hyde et al., 2021). In countries like Spain, Wales, and England, families of potential organ donors are always allowed to refuse (English et al., 2019; Parsons & Moorlock, 2021; Hyde et al., 2021).

Moreover, countries with high donor pmp rates combined the opt-out approach with a developed infrastructure and increased funding for transplant programs and staff and public relations campaigns (Etheredge, 2021). The Spanish program has retained its status as a clear leader for organ donation and transplantation for over 20 years (Willis & Quigley, 2014) and the country with the world's highest deceased donation rates. Many countries model their programs, implementing similar strategies in the attempt to increase consent rates (Reinders et al., 2018; Matesanz et al., 2017; Noyes et al., 2017b; Shepard & O'Carroll, 2014). Spain have been the global leader in organ donation and transplantation since 1992. Over the last thirty years, this achievement has become a source of national pride and has bestowed the Organización Nacional de Trasplantes (ONT–National Organization for Transplants) with the confidence to make claims about the integrity of the Spanish people (Herrero Saenz, 2022). This can be seen through their use of media to frame the action as a bond that links the nation highlighting their status as global leaders and part of their identity (Balfour & Quiroga, 2008; Humlebaek, 2015; Herrero Saenz, 2022). This national pride-based publicity may well influence the public's perception and sanction of organ donation. According to Arshad et al, 2019, Spain has no official opt-in register, with family approval always sought, and lessons learnt from Spain emulate their investment in education and infrastructure, as well as using positive reinforcement strategies to improve the consent rates. Countries who are not as successful as Spain have only partially adopted similar strategies resulting in small or transient increases in consent rates (Matesanz et al., 2017). Although Spain is recognised as the leader in organ donation and transplantation, there is uncertainty around their aftercare and bereavement support following organ donation. There is little evidence to suggest that Spain provides an excellent aftercare service, despite the lack of evidence Spain have remained global leaders in organ donation for nearly 30 years.

Impact Of A Global Pandemic On Organ Donation

The last decade has seen a considerable increase in deceased donors and lifesaving or life-transforming transplants (Clarkson & Fahey, 2017; Hodgson et al., 2017; NHSBT, 2021). Until February 2020, NHSBT was confident that the UK would again see a record number of organ donors and transplants. Strategies employed and supported by all four UK nations' governments, NHSBT, professional societies, and patient organisations have delivered a 95% increase in deceased donors and a 58% increase in deceased donor transplants since 2008 (Clarkson & Fahey, 2017). This accounts for 1,580 donors and 3,462 transplants last year (NHSBT, 2023). Then the global COVID-19 pandemic impacted the whole NHS and every aspect of UK society. The COVID-19 pandemic damaged the occupancy of critical care beds in the UK, engulfing NHS hospitals (Plummer et al., 2022). In March 2020, we witnessed a sharp reduction in activity with a decline in deceased donors and the number of transplants. The number of donors fell by 48% during the early pandemic period (Hardman et al., 2020; NHSBT, 2021). This was due to concerns for patient safety and the fact that all the NHS resources were required to deal with the COVID-19 crisis, and organ donation was not considered a priority during the crisis (Moris et al., 2020; Parsons & Moorlock, 2021). The risk of developing COVID-19 infection from infected organ donors is unknown, and so donation is discouraged from donors who have been infected (Moris et al., 2020; Friedman et al., 2020). This impacted on patients waiting for lifesaving transplants and the families of potential organ donors who subsequently missed out on the opportunity to donate their loved one's organs at the time of their death (Parsons & Moorlock, 2021; Ibrahim et al., 2020).

Despite these initial challenges at the start of the pandemic, it is a testament to the strong foundations laid in the UK that we have seen incredible family support for organ donation. In February 2020, there were 125 proceeding donors, matching

February 2019 proceeding donor numbers, and the overall family consent rate remained at 68%, 1% higher than the previous year (NHSBT, 2020; Sharma et al., 2020). Compared with 2019, the number of deceased donors decreased by 66%, and the number of deceased donor transplants decreased by 68%, more significant decreases than estimated (Manara et al., 2020). Even during the worst days of the pandemic, 91 deceased organ donors (March 2020) were still from UK intensive care units (ICU) compared to 120 in March 2019. Impressively, the overall consent/authorisation rate for organ donation has continued to rise over the last year to 68%. During the pandemic, this consent rate was even higher at 74.5% (March, 2020) compared to March 2019, when the consent rate was 68% (Curtis et al., 2021; NHSBT, 2021). With more and more families consenting to organ donation, aftercare for families is essential to ensure support is offered post-donation in recognition of their difficult decision.

UK Specialist Nurse Organ Donation Workforce

In organ donation and transplantation history, the specialised nurse (SNOD) role is relatively new in the UK (Tocher et al., 2018). In many countries with highly evolved organ donation and transplantation systems, such as Spain and USA, communicating with families about organ donation has been the responsibility of specific donation staff rather than the treating clinical staff (Glazier & Mone, 2019; Opdam, Radford, 2021). The role of the SNOD in the UK was introduced following recommendations from the Department of Health Organ Donation Taskforce Report in 2008 (Tocher et al., 2018). Australia shares many comparisons with the UK in respect to donation and transplantation. Traditionally, the donation process depended on intensive care doctors identifying potential donors and communicating with families about organ donation. Like the UK, Australia has transformed its processes, beginning in 2009, which has initiated an increase in donation and transplantation rates (Australian Government Organ and Tissue Authority, 2020). A crucial component has been the introduction of medical and nursing donation specialist roles and the participation of these staff in communicating the donation choices with families of potential donors to ensure that donation is offered to all eligible families in a collaborative way which involves the treating clinicians (Australian Government Organ and Tissue Authority, 2017; Opdam & Radford, 2021).

In the UK, NHSBT employs approximately 260 SNODs to offer and facilitate organ donation to families who’s loved ones are dying in critical care areas. The SNODs are situated within one of the twelve regional organ donation service teams, each covering NHS acute hospital trusts within that region (Tocher et al., 2018; Hulme et al., 2016), embedded within critical care areas in most acute hospital trusts across the UK. They are onsite to identify potential organ donors, support staff, provide education, implement policy, audit, and most importantly, support and offer families the choice of organ donation at the time of their loved one’s death (Walker & Sque, 2016; Hulme et al., 2016). The SNODs are trained in communication and all aspects of the donation process. They work within critical care units and emergency departments, ensuring organ donation is part of an end-of-life choice for suitable patients. Deceased organ donation can only occur when a patient is mechanically ventilated on a life support machine within critical care areas. A small group of patients who die in specific situations within the ICU or Emergency Department (ED) may be eligible to donate organs (Department of Health, 2008; Manara et al., 2012). A fundamental part of the SNOD role is supporting families in their bereavement, and the SNOD’s are provided with appropriate training to ensure that they can support the families they care. Each health professional who works within organ donation also works in the field of bereavement and plays an essential role in helping bereaved persons (Corr & Coolican, 2010).

Donation After Circulatory Death (DCD)

Donation after Circulatory Death (DCD) donation is an end-of-life option for mechanically ventilated patients in a critical care unit or an emergency department (Manara et al., 2012; Lomero et al., 2020). The patient will have an illness or injury in which the medical team caring for the patient has decided that they will not survive, and further treatment is futile. In this situation, treatment will be discontinued, resulting in the patient's death. Following this decision made by the medical team, the patient will be referred to the organ donation team. Donation after circulatory death (DCD) describes the retrieval of organs for transplantation that follows death confirmed using circulatory criteria. This contrasts in many important respects within the modern-day standard model for deceased donation, namely donation after the confirmation of death using neurological criteria and donation after brain death (DBD) (Manara et al., 2012).

An initial assessment will be made based on the patient's condition and medical history. If the patient is considered suitable for organ donation, a SNOD will attend the hospital for a further, more detailed assessment (Figure 2). The SNOD will check the ODR to establish if the patient has already registered a decision to donate or 'opt out'. Working closely with the consultant in charge of patient care, the SNOD ensures that organ donation is discussed with the family at the appropriate time. How and when donation is introduced can vary, the intention is that the family have confidence in the medical decisions and at no point feel that decisions are driven by organ donation (Murphy et al., 2016). Once the family has accepted that their loved one will die, they can begin discussing end-of-life choices. The SNOD will meet with the family and determine the patient's last known decision regarding organ donation. If the family of the patient support organ donation, the SNOD will facilitate this. There are specific tasks that need to be completed before treatment can be stopped; the completion of consent paperwork under the Human Tissue Authority (HTA), virology screening, contact with the patient's General Practitioner (GP), a conversation with His Majesty's (HM) Coroner, and Human Leukocyte Antigen (HLA) blood testing to match the transplant. The assessment of a potential DCD donor can be lengthy due to the offering and allocation process (Siminoff et al., 2001; Murphy et al., 2016).

When all these tasks are completed, and the best recipient match is found, the SNOD will mobilise the dedicated retrieval surgeons. The specialist surgical team travels to the hospital where the patient is being cared for to perform organ retrieval. Once at the hospital and ready to carry out the operation, the critical care doctor in charge of the patient's care will remove mechanical ventilation and stop medications. The medical staff will wait until the patient's heart stops beating. Once this happens, they wait five minutes before confirming death (Figure 2). After verifying death, the patient is transferred to the operating theatre for the organ retrieval operation.

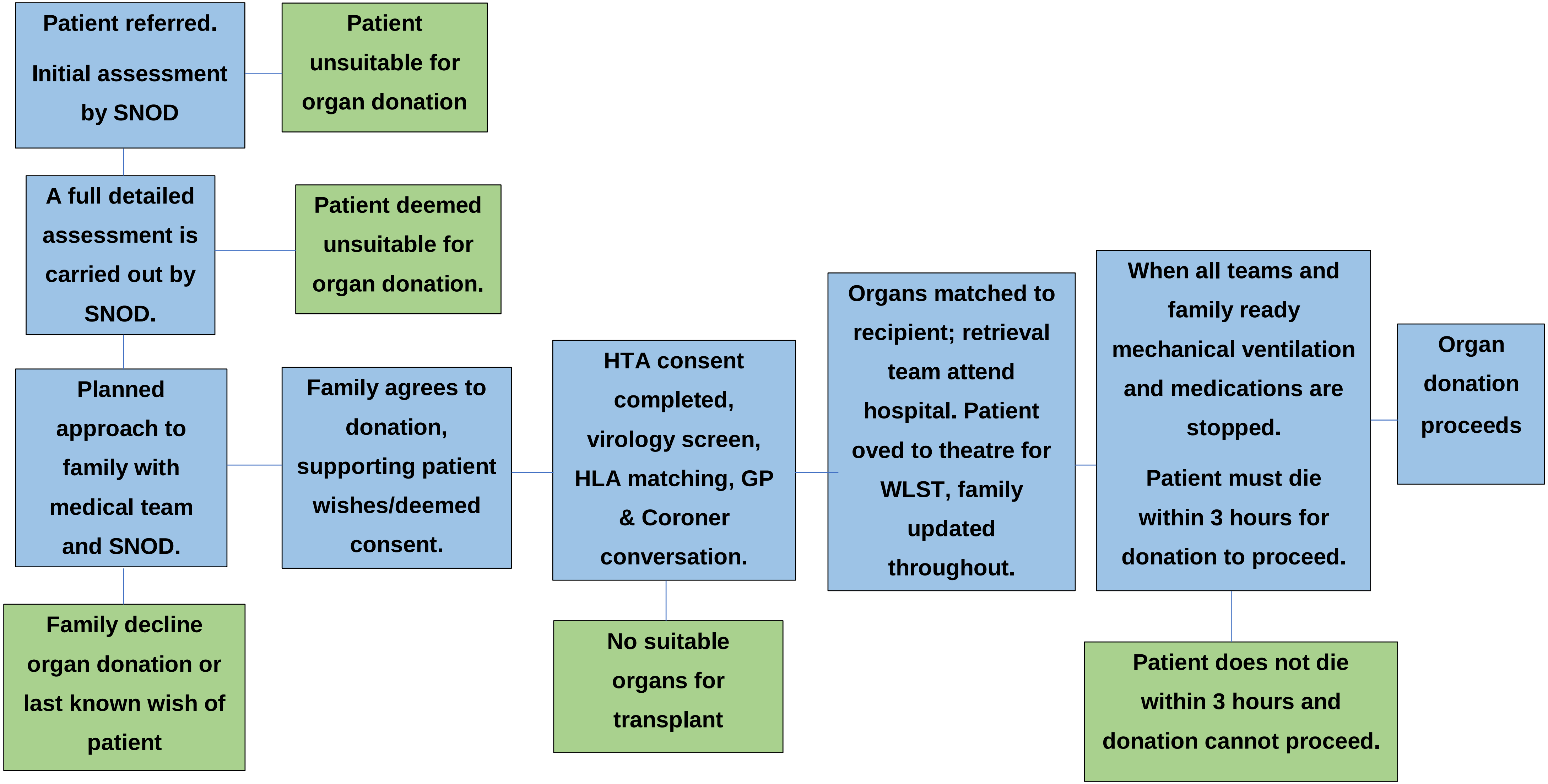


Figure 2: Process of DCD referral and assessment

There are three crucial steps that doctors need to consider when diagnosing a patient’s death following withdrawing life-sustaining treatment for organ donation: identification of asystole, period of observation, diagnosis of death. These steps (Table 1) are pertinent to diagnosing death following the withdrawal of life-sustaining treatment, irrespective of whether organ donation is planned (Murphy et al., 2016; p767), the final step is organ retrieval.

Table 1: Guidance for the diagnosis of death using circulatory criteria following withdrawal of life-sustaining treatments: (Adapted from Murphy et al, 2016; p767)

Setting	Planned withdrawal of life-sustaining critical care treatments. Invasive arterial pressure monitoring, pulse oximetry and continuous surface ECG monitoring likely
Identification of asystole	Asystole is best identified using correctly functioning arterial line or by transthoracic echocardiography. Reliance on an isoelectric ECG may unnecessarily extend warm ischaemic injury but is recommended if invasive pressure monitoring or echocardiography are unavailable. (Digital palpation of a central pulse and plethysmography from a pulse oximeter are unreliable and should be avoided.)
Period of observation	Published recommended observation periods range from 2 to 20 min. There should be no retrieval related intervention during the time recommended for the country/jurisdiction. Any return of circulatory function mandates a further full period of observation on resumption of asystole
Diagnosis of death	Confirmed through absence of consciousness, respiration, and other brain-stem functions after the agreed period of observation
Organ Retrieval	The patient is moved swiftly to the theatre environment for the retrieval of organs

Donation Following Diagnosis Of Death Using Neurological Criteria (DBD)

Organ donation after brain death continues to be the pathway of choice for deceased organ donors (Manara & Thomas, 2020). Brain stem death, as a concept, originated following an Ad Hoc Harvard committee proposed a new definition of death, brain-death, which would apply to ‘comatose individuals who have no discernible central nervous system activity’ (Ad Hoc Committee of the Harvard Medical School, 1968). In 1976 following a Conference of UK Medical Royal Colleges came to the consensus that brain stem death constituted brain death based on specific criteria (which, if met, signified legal death of the person) (AMRC, 2008). This type of donation occurs when patients suffer a devastating brain injury that leads to brain death (Ormrod et al., 2005). Formally known as donation after brain stem death, donation following diagnosis of death using neurological criteria (DBD) is diagnosed using a series of tests on patients when brain death has occurred (Escudero et al., 2015; Manara, Thomas, 2020). Defined as: 'The irreversible cessation of brain-stem function whether induced by intra-cranial events or the result of extra-cranial phenomena, such as hypoxia, will produce this clinical state and therefore irreversible cessation of the integrative function of the brainstem equates with the death of the individual and allows the medical practitioner to diagnose death' (AMRC, 2008;11).

Brain death is diagnosed based on a set of clinical tests carried out with senior clinicians in accordance with international standards (Escudero, 2009; Escudero et al., 2015). There is considerable disparity in how brain death is diagnosed in different countries with opposing legal requirements, and even concerning different geographical areas and hospitals within the same country (Bell et al., 2004; Bernat, 2008). In the UK, two senior doctors, one must be a consultant, and both must have been registered with the General Medical Council (GMC) for more than five years (AMRC, 2008), will carry out a range of tests to determine brain death. Families/friends of the patient are prepared for the tests and can observe if they wish to do so (Pugh et al., 2000; Ormrod et al., 2005), although there needs to be some degree of caution when allowing relatives to observe the brain stem death tests due to the tests appearing cruel (Remijn, 2000). In practice, it is evident that when observing the tests, families begin to understand the gravity of the situation.

There are no precise timeframes between tests, and after confirmation of the first test, this is the time of death that will appear on the patient's death certificate. The patient is left mechanically supported by the ventilator after being declared dead (Ormrod et al., 2005). Families are usually approached for organ donation following the second set of tests, and this is discussed and planned collaboratively with the consultant in charge of the patient's care and the SNOD (Manara & Thomas, 2020). If the family support organ donation, then coordination of the process is similar to DCD donation. The paperwork is completed, virology screening and tissue typing bloods are sent to the regional laboratories, medical notes are accessed, and a discussion occurs with the patient's GP and HM coroner. A matching process occurs; the organs are matched to a recipient, and the national retrieval service is alerted and requested to attend the hospital to perform the operation. In a patient who is donating following diagnosis of death using neurological criteria more organs can be utilised for transplant, and the patient is transferred to the theatre on the mechanical ventilator at the appropriate time (Manara & Thomas, 2020). Having described the process of diagnosis of death by neurological criteria, in reality and practice, the concept is complex. For families and healthcare professionals, inherent anxieties exist when declaring death using this method (Ormrod et al., 2005; Berntzen & Bjork, 2014; Bleakley, 2017).

Family Aftercare Following Organ Donation

Historically, researchers have discussed the need to support families after organ donation, arguing that families experience vulnerability and more research is needed to explore how aftercare can help donor families (Mills, Koulouglioti, 2015; Marck et al., 2016; Dicks et al., 2018). Following organ donation, the next of kin, if agreed, will be contacted by the SNOD directly following the donation operation (Tocher et al., 2018). The donation medical file the SNOD has prepared, containing relevant paperwork such as the Human Tissue Authority consent to donation forms, is posted to NHSBT donor family aftercare service (DFACS) without delay. The DFACS is based in a central office, and administrative staff work to manage donor files and ensure family requests and updated letters are posted at appropriate times. Donor families receive a letter from the DFACS two weeks post-donation, providing a limited update on the recipients who have received their loved one's organs. The information in the letter acknowledges the confidentiality and privacy of the recipient and donor family (Gill & Lowes, 2008).

NHSBT, as an organ donation organisation, is responsible for keeping donor families safe and protecting their identity (NHSBT, 2020).

The aim is to provide families with information regarding recipients, although the information provided is minimal (Sque et al., 2018). Family members having direct contact with recipients is discouraged within the organisation to protect both the donor families and recipients. The World Health Organisation (WHO) recommends that organ donation organisations ensure personal anonymity and privacy to protect donors and recipients. Several donor families and recipients have made contact. Donation aftercare is necessary to ensure that there are no potential untoward consequences to disadvantage the donor family. Despite organisations apprehensions surrounding organ donor family's privacy and anonymity, providing opportunities for donor family members and recipients to communicate with each other provides important support for donor families. A well-established system including process guidelines and resources managed by professional staff is important for the success of a writing program (Larson et al, 2017). Care for the donor family should match care for the recipient, and health authorities have the same responsibility for the welfare of both (WHO, 2010). The Netherlands describes anonymity as a way of preventing both organ donor families and recipients from having unfavourable consequences, feelings of gratitude, emotional concerns, and the potential of disillusionment when expectations are not met (Annema et al., 2013; Dicks et al., 2018). The anonymity protecting the relationships between the donor and the recipient exists by safeguarding the recipient from the potential' mislocations' (Bowlby, 1980: p161). Bowlby's (1980) reference to 'mislocation' is another example that demonstrates a failure to integrate the loss, which encompasses efforts to find their dead loved one somewhere inappropriately. This then stops the acknowledgment of the reality of death (Field, 2006). Bowlby (1980) suggests that maldevelopment of grief occurs when the bereaved, instead of experiencing the dead person somewhere appropriate, such as the grave, will position them within another person. This is significant in organ donation as 'mislocations' may expose damaging effects for the donor family and the recipient, and ideas of personification may be associated with the recipient (Sque & Payne, 1996).

DFACS mediate between the donor families and the transplant recipients, providing families with information when and if they receive it. The aftercare service donor families receive does not reflect the grief loved ones will be experiencing (Ravitsky, 2013; Sque et al., 2018), and although various bereavement resources are signposted to families and friends, there needs to be practical follow-up support for UK families of patients who become organ donors. Relatives receive outcome correspondence from the DFACS two weeks following donation. They are only contacted again if the donor family request contact from the organisation. Approximately one year following the donation, donor families are invited to a recognition awards ceremony hosted by the Order of St John's, a major international humanitarian charity, who joined with NHSBT to work in partnership, initiating these recognition awards for all organ and tissue donor families (Bedendo & Siming, 2019). In 2013, the two organisations introduced The Order of St John Award for Organ Donation in the UK. This nonmonetary award, which takes the form of a pin badge and scroll, is given to the families of deceased solid organ donors as a recognition of the generosity of the donor at public award ceremonies (Stoler et al., 2017; Bedendo & Siming, 2019). Since 2013 over 6000 awards have been presented in the UK to organ and tissue donor families acknowledging their selfless acts of kindness (NHSBT, 2021). The ceremony brings families together, giving them a sense of belonging with others in similar situations (Berntzen & Bjork, 2014; Bedendo & Siming, 2019). During the global pandemic ceremonies stopped, leaving the donor families with no recognition or acknowledgment of their gift and no one to connect with. These services have now resumed, and families are able to attend the Order of St Joh's ceremony in person. Further follow-up with the donor families is limited and they are expected to obtain bereavement support independently post-donation. There is no assistance from the organ donation organisation, although questions have been raised about the integrity of this and whether organ donation organisations have a duty of care to the donor families (Maloney, 1998; Dicks et al., 2018; Walker & Sque, 2019).

Many studies have focused on factors influencing the organ donation decision (Siminoff et al., 2001; Sque et al., 2006; Manzari et al., 2012; Sque et al., 2018). It is essential that families are supported after organ donation considering the rarity of organ donation and the questions which organ donor families may have post-donation (Merchant et al., 2008; Dicks et al., 2017a; Sque et al., 2018). Limited evidence suggests that a considerable number of donor families suffered complicated grief following the organ donation process (Merchant et al., 2008), measured by the number of people accessing bereavement services for emotional difficulties. Individuals suffering from bereavement will experience emotional difficulties and may need to seek bereavement support services as part of their grief journey (Zilberfein, 1999). Further evidence suggests no differences were observed in the need to seek support after bereavement between families who had consented to organ donation and those who had not, and that the grief experienced was normal (Cleiren &

Van Zoelen, 2002). However, a qualitative study by Jensen (2011) discovered that Danish organ donor families were often left isolated with unhealthy memories and many unanswered questions following the donation, and they needed increased support, which endorsed the need for specialist aftercare. Again, this reinforced earlier calls for the development of specialist services for organ donor families (Sque & Payne, 1996; Maloney, 1998; Dicks et al., 2017a), but the service in the UK has been slow to respond.

In 2021, the UK organ donation organisation eventually introduced recommendations for implementing adequate bereavement support services and aftercare in its strategy. Despite this, adequate bereavement support services and aftercare for organ donor families with, remains limited. NHSBT (an organ and transplant organisation) needs to understand better the evidence of the psychological and emotional trauma families endure after organ donation (Sque et al., 2018). The geographical contact of organ donation services creates difficulties in providing regional support due to the national coverage (Regan & Barnwell, 2000; Noyes et al., 2019a). Face-to-face bereavement support groups would be both resource intensive and unachievable.

Several researchers for several years have suggested that ongoing support for donor families should be the foundation of all organ donation services and this needs to be recognised by NHSBT. There needs to be more consistent aftercare with improved understanding, respect, and reconciliation (Holtkamp & Nuckolls, 1993; Kang et al., 2013; Berntzen & Bjork, 2014; Ashkenazi & Guttman, 2016; Dicks et al., 2017a; Sque et al., 2018).

Current Aftercare Strategies For Deceased Organ Donor Families

A review of current literature examining deceased organ donor family aftercare strategies proved challenging; identifying evidence across the international perspective of successful strategies implemented in practice was difficult, as robust evaluation evidence was lacking. Most of the literature concentrated on the family experiences before donation consent (Hulme et al., 2016; Sque et al., 2018; Ma et al., 2021), not after the donation.

Table 2: Donor family aftercare strategies across international countries

Country	Outcome letters	Memorial Service	Bereavement support groups	Online support groups	Grief Counselling	Follow up Telephone calls	Financial Incentives
United Kingdom (UK)	X	X				X	
United States of America (USA)	X	X	X	X	X	X	
Australia	X	X			X	X	
Netherlands	X	X				X	
India	X	X			X	X	

Examining the literature (Table 2) alongside analysing the International Transplant Societies guidance and websites, produced limited information regarding the aftercare service provided to families (Rudge et al., 2012; Council of Europe, 2020; NHSBT, 2020; Australian Government, 2020). Comprehensive evidence could be extracted for six key countries to provide an overview of aftercare strategies. Most of these followed a similar process: families received an outcome letter, follow-up telephone calls, and an annual memorial service (Corr, 2001; Berntzen & Bjork, 2014; Takaoka et al., 2021).

Current evidence predominantly focuses on organ donation decision-making and the transplant process (Manuel et al., 2010; Makmor et al., 2015; Sque et al., 2018; Kentish-Barnes et al., 2019). An understanding of the complexity of organ donor bereavement is essential for organ donation specialists; more importantly, a more profound knowledge of the experiences of deceased donor families is needed (Dicks et al., 2017a). Sque et al. (2018) explored the experiences of bereaved families and examined their views on how the organ donation experience influenced their decision-making. Findings highlighted inconsistencies in the standard of care delivered by SNODs in the UK and recommended more formal aftercare. Despite this call recommending a more formal approach, minimal improvements have been made to the current aftercare service (Sque et al., 2018; Yeok Kee Yeo et al., 2021). NHSBT does not provide direct bereavement support to grieving families, although evidence suggests that quality family follow-up can offer an improved understanding, recognition, and resolution for many donor families (Maloney, 1998; Dicks et al., 2017a; Sque et al., 2018). The UK donor family aftercare practice is not as developed as other international Organ Procurement Organisations (OPOs), as many recognised organisations encompass support services into their aftercare service (Regan & Barnwell 2000; Corr, 2001; Dicks et al., 2017a, Takaoka et al., 2021).

Much of the literature about current aftercare strategies and bereavement care following organ donation is built on international systems (Holtkamp & Nuckolls, 1993; Maloney, 1998; Regan & Barnwell; Corr, 2001; Vajentic & Calovini, 2001; Dicks et al., 2017; Takaoka et al., 2021). For example, a well-established bereavement program to assist and support donor families is operated by LifeBanc, an OPO in Cleveland, Ohio, USA (Vajentic & Calovini, 2001). LifeBanc OPO has supported tissue and organ donor families during their bereavement since 1991. Their program aims to assist and support donor families through the devastating grief they suffer following the death of their loved ones. They offer all donor families bereavement support for two years after the donation, longer if indicated. Some services provided are similar to those in the UK, such as outcome letters and printed bereavement information resources. In addition, they also provide donor families with face-to-face grief support groups (Vajentic & Calovini, 2001), such services are not offered directly in the UK. However, some primary care GPs could offer general bereavement support. A dedicated national bereavement support group for organ donor families would not successfully operate in the UK due to the geographical distribution of donor families and the national scale of the organisation; this kind of program would be a physical challenge and resource-intensive (Gibson et al., 2020). In Ohio, the bereavement program is facilitated by trained psychotherapists who can provide expert bereavement support. NHSBT does not have access to such a resource, and the SNODs are not qualified or trained to deliver this level of intensive bereavement aftercare. The program appears only to include proceeding organ and tissue donors, excluding consideration for the families who have consented to organ donation but for some reason, it does not proceed (Jensen, 2011).

The Multi Organ Harvesting Aid Network (MOHAN) in India is a non-profit, non-governmental organisation introduced in 1997 to promote organ donation. Their services have increased over time, despite limited evidence of family aftercare (MOHAN, 2020). A study examining the experiences of donor families in a government hospital in Chennai, India, concentrated on the hospital experience and only suggested the need for regular follow-up (Johnson, 2012). Within India, the aftercare strategies often included outcome letters, memorial service follow-up, and grief counselling. The evidence from a small sample from Johnson (2012) needed to have clarified precisely how much aftercare, if any, families received. India offers a DBD program for deceased donors, and although DCD has occurred, it is infrequent in India (OrganIndia.org, 2021). According to Ramesh Pal (2021), only 0.01% of people in India donate their organs at death. The healthcare systems in India and around the world are incredibly different from the unique NHS system in the UK; this needs to be considered when appraising the number of donors elsewhere in the world. The diversity in healthcare systems worldwide influences the interpretation of evidence and, more importantly, the application of different organ donation aftercare programs to the UK context (Tocher et al., 2018).

Donate Life organisation in Australia was contacted and consulted regarding family aftercare programs to gain a deeper understanding of their program, comparable to practices in the UK (Australian Government, 2020). After the donation, all families received a follow-up letter and were invited to a remembrance ceremony. In addition, Regan & Barnwell (2000) developed a teleconferencing group counselling service for organ donor families in New South Wales, Australia. The evaluation examined the group member experiences gathered from three teleconferencing groups. The groups were closed and consisted of up to five participants and two healthcare professionals. User feedback indicated they found it efficient and flexible, providing an inclusive service for donor families regardless of geographical distance (Regan & Barnwell, 2000). The research highlighted the degree of anonymity the group provided, which helped create a sense of protection for the donor family participants. A similar model for donor families allowing them to connect within an anonymous group regardless of their geographical position, could be transferrable to the UK context.

In Norway, Berntzen & Bjork (2014) undertook a qualitative study, interviewing 20 individual donor families from 13 different situations to better understand their experiences after organ donation. They evaluated the effectiveness of aftercare support following organ donation and highlighted similar aftercare practices to the UK model, outcome letter, and commemoration service. It was unclear, however, from the findings how and what bereavement support influenced the donor family's experiences. A small sample size limited the study and, in turn, the depth of the narrative, which restricted the generalisability and applicability of the findings to comprehend the needs of the donor families fully. Deceased donor rates in Norway resemble rates in the UK, although Norway has offered a system of presumed consent longer than the UK, and there is no organ donor register. Norway has high public approval for organ donation, and they have both a

DBD and DCD program (English et al., 2019). The practice in Norway is very similar to that of the UK, with families being asked for permission for organ donation despite the presumed consent legislation.

The country offering the most comprehensive donor family aftercare is the USA, where there is a combination of; outcome letters, memorial services, bereavement support groups, online groups, grief counselling, and follow-up calls, used in practice to support grieving families in different ways, based on their need and preference (Table 2). Compared to the UK and my clinical experience, only an outcome letter, memorial service, and follow-up calls are offered. This option has not yet been available in the UK, although it could be a simple and cost-effective solution. Online support groups need to be approached with caution since there are many concerns from professionals about the ability of online support groups to maintain privacy and confidentiality concerns, lack of provider knowledge about such practices, as well as challenges to participants' use of technology (Gibson & Anderson, 2008; Lubas & De Leo, 2014, Gibson et al, 2020). However, with advancing technology and the continued evolution of online practice, more organizations and individual providers are considering development and facilitation of online grief support (Gibson et al, 2020). I communicated directly with these organisations, and several offered further information on the model used to develop a Facebook support group. The composition of support groups in the USA was made up primarily of females aged between 40 and 60. Supporting previous research that white females frequently use online support groups (Van der Houwen et al., 2010; Tolstikova & Chartier, 2010; Fearon, 2011). However, there was no robust evaluation from the OPOs which could provide evidence of the impact and effectiveness of the online support groups for organ donor families. Whilst verbally group managers reported positive anecdotal results, a formal evaluation had not been implemented. A comprehensive search for empirical evidence revealed the need for wider robust research appraising the effectiveness and potential benefits of developing Facebook support groups. It was unclear whether support groups positively or negatively impacted the donor family's bereavement journey, their experiences, or whether and/or how peer support helped them through the grieving process. These conversations shaped my research focus: I decided to set up the first UK online organ donor family Facebook support group and examine if and how an online support group influenced bereavement experiences, determining if this was a viable aftercare support strategy in the UK. An online micro-community with expert bereavement support could provide a space to connect donor families and enable them to share their experiences, discuss organ donation, and grieve together (DeGroot, 2012; Moyer & Enck, 2018; Gibson et al., 2020). This strategy would expand the current provision of support for organ donor families in the UK, recognising that the online approach is only one support platform, and other forms of support may need to be implemented to provide an inclusive service. A deeper understanding of the concepts of grief, mourning, and bereavement was needed to understand the influence of aftercare strategies on bereavement.

Grief, Mourning and Bereavement

The terms grief, mourning, and bereavement are generally used interchangeably when considering death, although they all denote different meanings (Buglass, 2010). Grief is a personal response to a loss that leaves the individual with emotional, spiritual, physical, and behavioural changes (Greenstreet, 2004). The academic study of grief is a relatively modern-day occurrence and has been studied by psychologists since the beginning of the 20th Century (Freud, 1917; Klein, 1940; Lindermann, 1944; Bowlby, 1980; Worden, 1983; Parkes, 1985; Stroebe & Stroebe, 1991; Holtkamp, 2000; Neimeyer et al., 2002; Buglass, 2010; Corr & Coolican, 2010; Kubler-Ross & Kessler, 2014). Early grief work was commenced by Freud's comparison of mourning and melancholia (Freud, 1917), identifying that grief was mourning and could manifest and present itself as clinical depression (melancholia). As Freud developed his thinking, he described mourning as a common reaction to the loss of a loved one, which can, in some people, produce melancholia as an alternative to mourning, and this can consequently lead to suspicions of a pathological disposition (Freud, 1922). His early paper 'Mourning and Melancholia,' published in 1917, was regarded as benchmark writing on the topic of bereavement, suggesting the emotional commitment of grief was to remove all emotional energy from the dead, becoming disconnected from the loved one. Freud believed that the bereaved must work through the grief, which he saw as an emotional reaction to loss, revisiting memories of the deceased. Through this process, painful as it is, the bereaved could attain detachment from their loved one, and the bonds with the dead diminish (Klein, 1940; Field, 2006; Mallon, 2008). Wortman & Silver (1989; p351) argued that this position's suggestive grounds were *considered unconvincing*. The work of Freud was too early to consider organ donation as an aspect of the bereavement model, as organ donation programs did not start in the UK until 1965. Many organ donors die in sudden and tragic circumstances, which may affect this process, particularly when the event is traumatic, the bereaved person's world may be wholly devastated (Neimeyer, 2007; Mallon, 2008). Organ donation also adds an element of uncertainty regarding the location of the donated organ, hypothetically affecting Freud's theory of attaining detachment from the loved one. Klein (1940) progressed Freud's views on mourning and melancholia to recognise that mourning is an experience of losing one's internal 'good' objects relating to the primary caregiver, usually the mother. Experiences of loss and mourning in adult years reawaken the tasks of early development that expose deficits that remain from childhood (Klein, 1940; Zilberfein, 1999; Mallon, 2008). Klein's rationalisation in mourning early childhood tasks aligns with Bowlby's (1979) later attachment theory, highlighting the significance of the bonds and attachments we develop during childhood (Buglass, 2010; Doyle & Cicchetti, 2017). According to Bowlby (1980, 1982: p208), *'from the cradle to the grave,'* attachment to others is a core human goal associated with resistance to separation and significant disruption when a loss occurs. Our relationships position us for further development throughout our lifetime. These fundamental relationships include our parents, early care and education providers, peers, and romantic partners (Doyle & Cicchetti, 2017). Parkes (1972) described bereavement as an experience that drives the person who has lost to give up the world as they knew it and to construct a new existence. Grief theorists such as Parkes (1972) and Bowlby (1979) examined how loss can disrupt the bereaved person’s life and wellbeing. Their work justified the creation of a stage model of grief. The stage model of grief quickly became accepted in bereavement research. It provided a tool for researchers and healthcare practitioners to identify the bereaved and their journey along a linear process, recognising deviations.

The stage model of grief recognised that many factors affect bereavement, including the bereaved individual's emotional character and previous life experiences. Bowlby and Parkes (1970: p8) proposed four linear stages to the grief process of losing an attachment figure:

- Shock and numbness with a sense of denial and unreality
- Yearning and searching encompassing physiological symptoms such as anxiety, tension, sobbing, loss of appetite, lack of concentration
- Despair and disorganisation lead to low mood
- Reorganisation and recovery, which involves letting go of the person and looking toward the future

John Bowlby's work on attachment and loss emphasised the strong need for maintaining those connections with the loved one. Within organ donation, the constant desire for information about the donor organs' recipients will support the attachment theory, from the family perspective feeling that their loved one is living. Drawing on the work of Bowlby (1980), Neimeyer (2007) recognised that one of the central goals of mourning was understanding the meaning of the loss one had experienced. The stage model of grief resonated with emerging models, such as the Five Stages of Dying (Kubler-Ross, 1970). As a result, Kubler-Ross expanded Bowlby and Parkes's (1970) theory of the stages of grief to illustrate five stages of dying (Figure 3) based on her work with patients who had a terminal illness (Stouder et al., 2009). The five stages were not considered linear, and people may experience all stages, miss stages, and move from stage to stage at different times (Kubler-Ross, 1970; Mallon, 2008). The five stages of dying were not proposed as a theory of after-death bereavement, even though they are frequently adopted to explain and rationalise bereavement behaviour (Corr & Coolican 2010). Neimeyer (2012) argued that Kubler-Ross's work should be used more effectively as it applies to the dying, not the bereaved; it asserts its authority without meaningful qualitative or quantitative evidence.

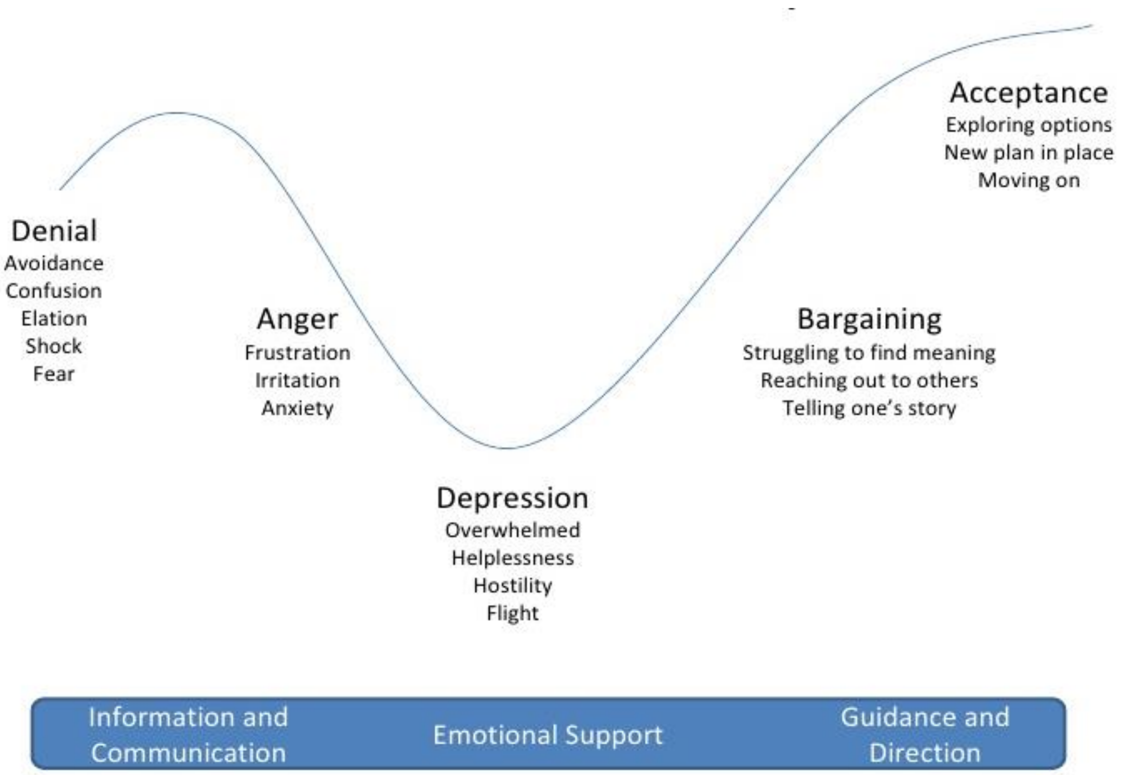


Figure 3: Kubler-Ross Grief Model (1970: p216)

Kubler-Ross (1970) staged theories of dying and grief could offer some way of viewing and interpreting the needs of bereaved families after organ donation (Figure 3), although the model has been challenged by researcher as there was not sufficient evidence to support her concepts (Spiegel & Yalom, 1978; Stroebe & Schut, 1999; Corr, 2007; Friedman & James, 2008; McVean, 2019). Despite the criticism for a lack of evidence, educators, authors, and healthcare professionals still return to the original grief model created for terminally ill, not the bereaved (Corr, 2019). Kubler-Ross (1970) proposed a stage of acceptance that possibly would be realised by the terminally ill. However, it is possible for the bereaved to accept the death of their loved ones, or do they adjust their lives without them (Worden, 1983).

Worden's Four Tasks of Mourning (Worden, 1983; 1996) provided a framework to help support the understanding of a person's journey through grief. Continuing Freud's idea of grief being a task to work through, he suggested four' tasks associated with mourning that an individual must undertake. (Worden, 1996):

- Task 1 - Accepting the reality of the loss
- Task 2 - To process the pain of grief
- Task 3 - To adjust to a world without the deceased
- Task 4 - To find a continuing connection with the deceased while embarking on a new life without them

Worden's theory moved away from stages and concentrated on the practicalities of mourning (Klass, 1988; Mallon, 2008; Worden, 2009). Finding a continuing connection (task 4) with the deceased could be valid for organ donor families who may feel a deep personal association with the recipient. However, this connection may impede the healing and prevent them from moving forward. These grief models (Bowlby & Parkes, 1970; Kubler-Ross, 1970; Worden, 1983) are created to understand better the difficulties of grief reactions rather than presenting a process for the bereaved. Despite this, the concepts of moving through rigid stages have been taken up and accepted by professionals as a way to recommend clear goals, allowing the bereaved to return to everyday life (Bowlby, Parkes 1970; Kubler-Ross, 1970).

These models often guide the development of aftercare support. However, it should not be overlooked that death affects not only the person left behind but also the work, school, religious beliefs, communities, and society in general (Strouder et al., 2009; Corr & Coolican, 2010; Dicks et al., 2018). Many of the bereavement models should have referenced the broader cultural and religious beliefs which may impact the grieving process, preventing the bereaved from engaging in the stage models (Stroebe & Schut 1999; Deeken, 2004; Mallon, 2008). There is a need to consider and encompass grief responses in different cultures to acknowledge bereavement care in the twentieth century (Parkes et al., 1996; Mallon, 2008). This is important when applying grief and bereavement theories in the diverse cultural context of the UK, where families who agree to organ donation originate from diverse backgrounds. Parkes et al. (1996, p232) discovered different cultural needs between and within groups. The dangers of stereotyping are as severe as entrenched ethnocentrism. Practitioners must constantly be vigilant about imposing their assumptions about what is 'right,' 'best,' 'normal,' 'healthy,' or 'appropriate', mainly when the individual's or family's wishes are not obvious or forthcoming. Every individual and every family are different and will all have different needs. How the loss is experienced depends on many critical variables such as how the person dies (traumatic, sudden, unexpected), the relationship the donor/patient has with their loved one, the previous loss experiences and coping strategies, as well as the support provided to them at the time of the loss and in subsequent months following the loss (Neimeyer, 2007; Corr & Coolican, 2010; Dicks et al., 2017a).

Several studies have focused on the organ donation experiences of family’s intra-hospital, concentrating on events impacting the family's grief and the decision to consent to organ donation (Holtkamp, 2000; Falomir-Pichastor et al., 2013; De Groot et al., 2012). Dissatisfaction with hospital care impacted decision-making and grief symptoms (Cleiren, Van Zoelen, 2002; Sque et al., 2006; Berntzen & Bjork, 2014; Fernandes et al., 2015). Studies also focused on the concept of brain stem death and the families understanding of this mode of diagnosis (Sque et al., 2006). Indeed, families communicated that not having a good understanding of death certified by neurological criteria impacted their experiences when considering organ donation (Sque et al., 2006). Poor communication leads to a poor understanding and acceptance of brain stem death, resulting in upsetting experiences and the potential refusal to organ donation (Franz et al., 1997; Long et al., 2008; Fernandes et al., 2015).

Conversely, clear communication could facilitate organ donation consent (Ghorbani, 2011; Fernandes et al., 2015; Mills & Koulougliotti, 2016). The effectiveness of communication will impact not only organ donation but the first stages of grieving for the donor family, which begins at the hospital and can have a lasting impact on the bereavement experience (Dicks et al., 2017b). Dicks et al. (2017b) identified that the organ donor family and the critical care staff are responsible for the outcomes. However, they recognised that the family experience of hospital events needs to be better understood since each family dynamic is unique. Despite evidence of the importance of bereavement support (Maloney, 1998; Sque et al., 2006; Fernandes et al., 2015; Sque et al., 2018), there remains a paucity of evidence on what aftercare deceased organ donor families receive to support them through the weeks and months to follow (Maloney, 1998; Strouder et al., 2009; Corr & Coolican 2010; Dicks et al., 2017a; Sque et al., 2018). Parkes (2002) emphasised the need for specialist bereavement services, which are more effective if personalised and integrated with healthcare professionals. Without confirmation about what is categorised as normal and complicated grief, interventions can be offered for those who are bereaved and coping independently. The aftercare strategy of grief counselling is provided in some countries. However, the general literature suggests that early intervention with grief counselling is often unnecessary and can occasionally impede rather than assist the grief process (Jordan & Neimeyer, 2003; Shear & Shair, 2005). Traditional models of grief have more recently been challenged (Maciejewski et al., 2007; Holland & Neimeyer, 2010; Stroebe & Schut, 2010; Dicks et al., 2017a), arguing that each bereaved individual will have different needs and that bereavement support should be adapted to the needs of the bereaved. This is essential when considering organ donor families and their adaptation to the loss and the organ donation procedure. Stoebe & Schut (2010) offered a new grief model taking into consideration challenges and criticisms surrounding the stage models of grief, the inaccuracies, the failure to signify a dynamic formula characteristic of grieving, lack of empirical evidence and authentication across different cultures and eras, and the lack of focus on intrapersonal processes and health outcomes. The Dual Process Model (2010) offers more of a focus on how an individual should cope with the bereavement, identifying types of stressors, loss and restoration, oriented, and a dynamic, controlled coping method of fluctuation, whereby the grieving individual at times faces the loss at other times avoids the loss (figure 4). This model offered the individual an adaptive way of coping by confrontation avoidance of loss and restoration stressors, highlighting the complexities of dealing with the loss of a relative.

Figure 4: Dual Process Grief Model (Stroebe & Schut, 1999; p213)

There has been no grief model formed which focuses on bereavement after organ donation. Sque & Payne, (1996), offered a model of donor relatives experiences during their work on dissonant loss (figure 5). After interviewing 16 organ donor families they found 11 areas which conceptualised the experiences of organ donor families.

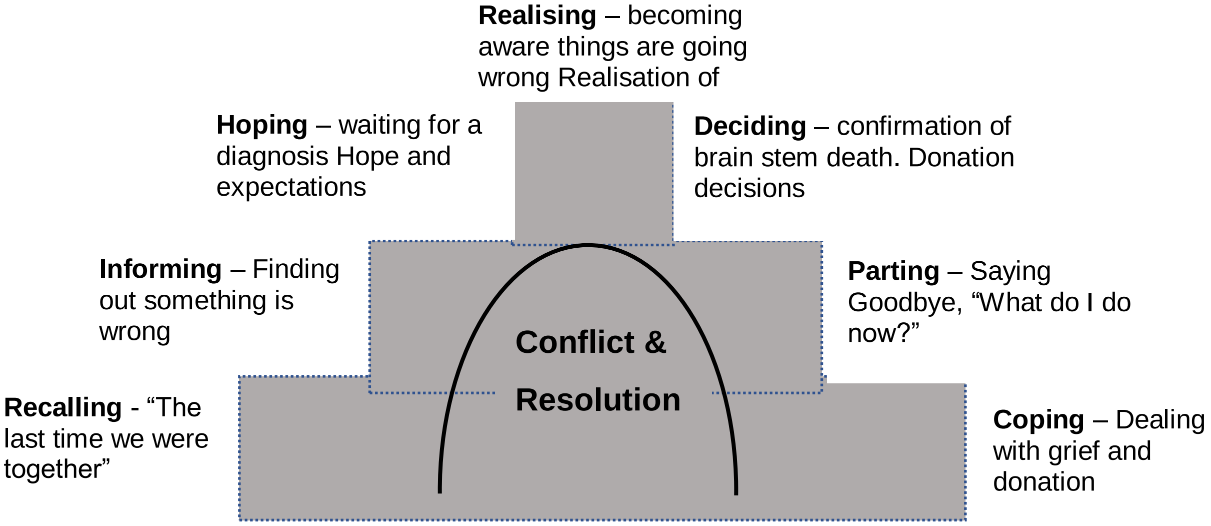


Figure 5: A model of donor relatives experience (Sque & Payne, 1996; p1361)

This small sample study contributed to the theoretical perspective supporting organ donor families' experiences, providing a framework that could help make sense of the organ donation process. There is limited evidence regarding bereavement support for organ donor families and the concept that bereavement is a profoundly personal experience that strangers should not approach, which has previously discouraged researchers (Shear & Shair, 2005). The different theoretical grief models, the tasks, and stages of grief experienced during organ donor family bereavement need further consideration to examine the gaps in theory and generate an evidence base of what aftercare strategies work for whom, when, and how.

Use Of Social Media In Healthcare

The application and use of social media in healthcare has increased, with healthcare providers using social media platforms to offer social support, empowering patients while improving health outcomes (Prescott et al., 2020; Farsi, 2021). Social media started in the early 2000s and has become a useful source of social support for patients. Social media can assist in the connection between social relationships, well-being, and health. Virtual communities connected through healthcare use social media to access information about their medical condition and, more importantly, to share with others the daily emotional aspects of their life (Lin & Kishore, 2021; Khan & Loh, 2022). Social media is being utilised by healthcare professional as a way of offering social support, as a result, improving the health needs, as well as meeting the fundamental needs of an individual for companionship, understanding, creating the feeling of belonging, and self-respect (Khan & Loh, 2022). Today, many healthcare organisations, patients, and community support groups provide numerous social support strategies for patients (Zhang et al., 2021). Prior to utilising online peer support groups to deliver aftercare support for organ donor families, a deeper understanding of social media concepts in healthcare as a communication tool is essential. Social media is now integrated into our everyday lives. As of January 2023, there were five billion internet users worldwide (Statista, 2023). Almost all adults aged 16 to 44 years in the UK were recent internet users (99%), compared with 54% of adults aged 75 years and over, which could impact the study participants, excluding donor families who may not access the internet. While there was only an increase in daily use since 2018, it has risen by 32% in the last decade, and the UK is amongst the highest internet users in Europe (Office of National Statistics, 2020) (Figure 6).

The term social media is broad and constantly evolving. The internet-based tool lets individuals and groups communicate, sharing ideas, experiences, messages, and content in real-time (Ventola, 2014). Social media has been defined over time in many different ways, and some focus on the technical characteristics of social media while others concentrate on the communication aspect of social media (Kaplan & Haenlein, 2010; Chen & Wang, 2021). Social media sites provide a variety of features that serve different purposes for the individual user, such as blogs or social networking (Childs & Martin, 2012: p2045):

- Social networking (Facebook, MySpace, Google Plus, Twitter)
- Professional networking (LinkedIn)
- Media sharing (YouTube, Flickr)
- Content production (blogs [Tumblr, Blogger] and microblogs [Twitter])
- Knowledge/information aggregation (Wikipedia)
- Virtual reality and gaming environments (Second Life)

Social media as an online environment is often where the users provide the content, emphasising that the content is usually created for users by users (McGowan et al., 2012).

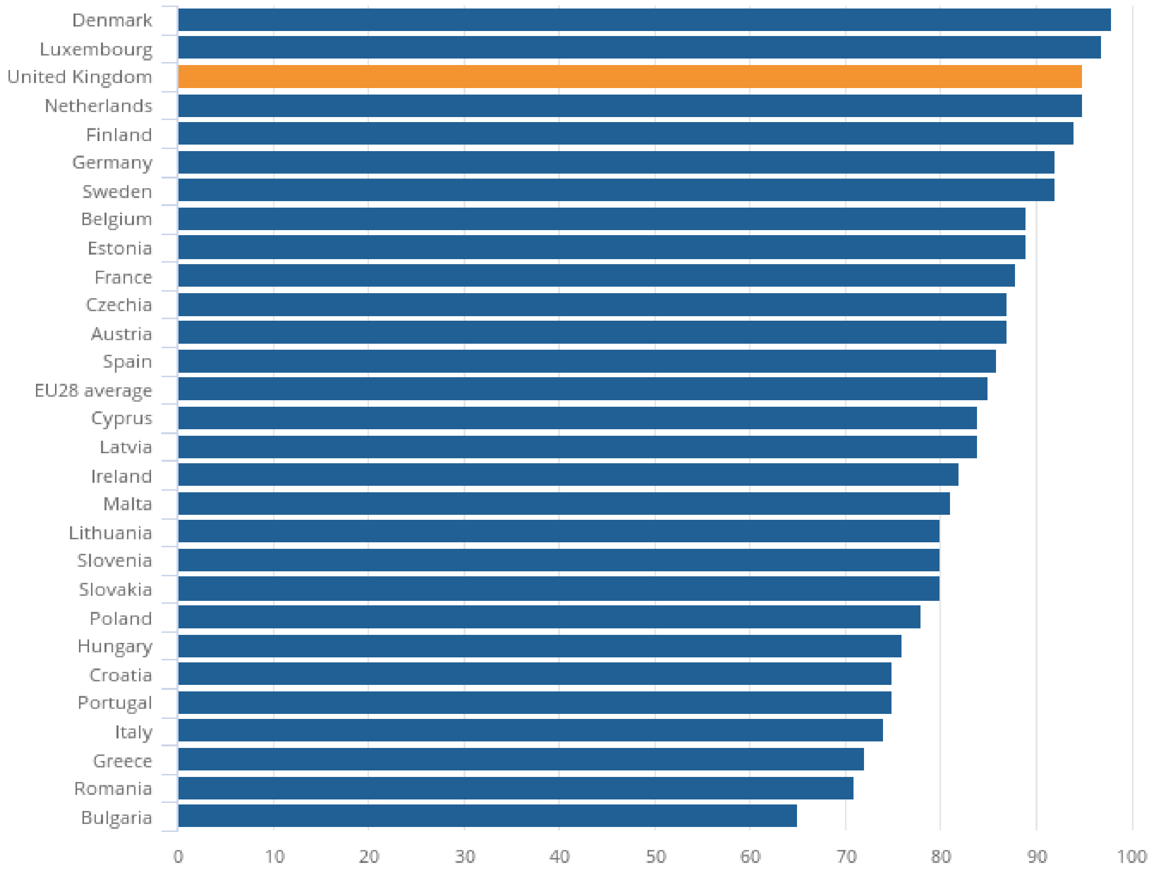


Figure 6: Office for National Statistics Internet Users in Europe, (2018)

Currently, the most influential social media platforms comprise of Facebook, YouTube, Instagram, Linkedin, and Twitter (Statista.com, 2023). Facebook is the most extensive social media network worldwide (Statista.com, 2022) with roughly 2.9 billion monthly active users. Instagram had around 28.81 million users in the UK alone in July 2021 (Statista.com, 2022). There are 192 million daily active users on Twitter. Facebook was founded in 2004 and is open to students enrolled at Harvard University. In 2006, Facebook became open to anyone with an email address and revolutionised how people interact (Moyer & Enck, 2020). As of 2022, the United Kingdom was one of the largest markets for Facebook in Europe, with over 46 million users, which is expected to grow to 50 million by 2027 (Statista, 2023). Blogs are described as online journals (Petko et al., 2015), the term ‘blog’ formed by truncation of ‘web’ and ‘blog’ and is the oldest and most recognised form of social media, used in the medical field since 2004 (Grajales et al., 2014). The arrival of social media revolutionised how people communicate and engage (Eckler et al., 2010; Schneiderman et al., 2011), providing a new way for people to share and transfer information, including personal stories, thoughts, and feelings, in many different forms (Kamel Boulos et al., 2010).

The growth of social media has increased health communication between patients and healthcare specialists, supporting patients to become more engaged in their health (Qualman, 2011; Vasilica, 2015). Patients participate in social media if they have a definite purpose, such as accessing information and peer support (Vasilica, 2015; Vasilica et al., 2020; Vasilica et al., 2021). The UK government intends to embed digital technology into public service delivery, making services accessible wherever people live and whenever needed (Gov.UK, 2017; Topol, 2019; NHS Long Term Plan, 2019). The Topol review (2019), recommended transforming digital services provided by the NHS and including patient service users in the co-design of any digital projects, strengthening this research study in which the organ donor families are at the heart, informing new knowledge through their lived experiences. This study directly responds to the Topol review recommendations by introducing online aftercare services to expand access to peer support for NHSBT organ donor families. It is anticipated that online peer support will empower organ donor families to take more control, extending access to information, enabling better choices, and ultimately an improved bereavement journey (Honeyman et al., 2016; NHSBT, 2020). The extensive influence of social media delivers an opportunity to focus on the needs of grieving individuals, providing them with information, resources, and education, as well as connecting them with peer and clinical support in a convenient and accessible way (Ferguson & Frydman, 2004; Varga & Paulus, 2014; Gibson et al., 2020). Since we have experienced a global pandemic, the world has been forced to adapt everyday practices, and life has turned into a digital sphere. Workplaces, schooling, meeting friends, and even healthcare have turned to applying digital procedures (Heeok et al., 2021; Lampa et al., 2021). Given the widespread use of social media, and the positive connection between social support dimensions, empowerment, and peer support, the idea that social media can create online social support for organ donor families is strengthened (Khan et al., 2022).

The number of bereaved people using the Internet to assist with their bereavement experience is rapidly growing (Nager, de Vries, 2004; Strobe et al., 2008; Tolstikova & Chartier, 2010). At one time, grief and mourning were experienced at a distance. With the growing use of social media, grieving can now be shared via these mediums, which facilitate sharing of grief that, in turn, helps to relieve the pain (Falconer et al., 2011; Rossetto et al., 2015; Buxton, 2019). In addition, it allows people to connect at any given time of the day (Falconer et al., 2011).

Social, emotional, and physical isolation is a familiar experience for bereaved people. For many reasons, they may experience greater isolation, leading to social segregation and loneliness (Hollander, 2001; Tolstikova & Chartier 2010). The recent global pandemic has also highlighted the importance of offering bereavement care, and bereaved people have felt isolated and unable to access the benefits of social support, which further strengthened the need to adapt how bereaved people are supported (Pearce et al., 2021). Online resources offer alternatives to support people during bereavement, especially when social distancing was in place. However, these options may present challenges, particularly for certain groups, such as the frail or people with cognitive/sensory impairment, which needs consideration (Moore et al., 2020).

Table 3: Positive and negative factors of social media in bereavement (Tolstikova & Chartier 2010: p330)

Positive Factors	**Negative Factors**
Large geographical population access Time/Cost effective Around the clock access	Difficult to control the study environment Unmonitored participants Generalisability of the results is in question

Non-Intrusive Greater anonymity Access to individuals who may be isolated Allows automatic information entry Dynamic and interactive	Technologically/educationally biased population Impersonal quality of the relationships Self-selected participants Limited assessment/diagnostic tools Insecurity of transmissions

Using social media to connect with others who have had similar experiences, such as in organ donation, could support this. It would also allow individuals to connect without having to meet face to face, protecting anonymity and helping certain groups who may find it difficult to ask for help or talk about feelings (Falconer et al., 2011). Researchers have argued that the bereaved, by posting a range of content material, benefit themselves and others who are also bereaved, although they also may experience harm (Klass et al., 1996; De Groot, 2012; Rossetto et al., 2015). Tolstikova & Chartier (2010) highlights the positive and negative aspects of using the Internet to support bereavement (Table 3). This study presents novel ways of generating evidence to understand the influence and use of online groups for bereaved deceased donor families.

Definition Of Peer Support

Peer support is a system of giving and receiving help founded on fundamental principles of respect, shared responsibility, and mutual agreement on what is helpful (Mead et al., 2001; Ali et al., 2015;). Peer support is not based on psychiatric models and diagnostic criteria, and it is about understanding another's situation empathically through the shared experience of emotional and psychological pain. When people find affiliation with others, they feel "like" them; they feel a connection (Horgan et al., 2013; Hall et al., 2015; Prescott et al., 2020). Much of the evidence found related to peer support centred around mental health. Berger et al (2005), suggested that online social networking represents a primary form of communication in many people's lives. For individuals with stigmatised illnesses, such as severe mental illness, social media may make it possible to connect with others who share similar health conditions, providing the ability to and seek or disclose health information without revealing one's identity. This could also relate to organ donor families, who share similar experiences and are acutely bereaved.

This connection, or affiliation, is a deep, holistic understanding based on mutual experience where people can 'be' with each other without the constraints of traditional (expert/patient) relationships (Mead et al., 2001). A systematic review evaluating the evidence regarding the benefits of peer support services for bereaved survivors found that the studies reviewed suggested that online peer support approaches used for the bereaved are relatively new but encouraging, displaying evidence of value as well as having some functional advantages such as the 24/7 accessibility (Bartone et al., 2017). The ability to use technology may cause some anxiety (Prescott et al., 2020; Chen & Wang, 2021). Anonymity can also be a drawback, and some Internet support group participants expressed a desire for face-to-face contact with a peer (Gibson et al., 2020). Bartone et al. (2017) suggest that research is needed to appreciate which Internet peer support methods may be most beneficial for bereaved individuals. This study responds to this recommendation by examining the data to inform future technology support methods for organ donor families. Peer support is recognised as a specific kind of social support, and some people are ready to provide individuals with emotional, practical support and advice, helping them to process and understand events that have taken place. There is encouraging evidence to suggest that peer support is helpful for the bereaved (Barlow et al., 2010; Aho et al., 2011; Bartone et al., 2019), and it can facilitate adjustment to the loss. Bartone & Dooley (2021) suggested that there are crucial elements to achieving a successful peer support program which includes confidentiality, easy access, providing participants with a safe space to disclose, as well as matching the bereaved, the more similarities between each other the more they will create a connection of trust and openness. Naslund et al. (2016) highlighted the emerging risks associated with online peer support groups, warning of the danger of not knowing the reliability of the information provided by peers. For this study the Facebook group was moderated by me and other healthcare professionals, which guaranteed participants an element of expertise and specialist advice, connecting them with individuals with similar experiences.

Using Facebook

Using Facebook to communicate will allow individuals to share feelings and experiences, whatever the time of day (Tolstikova & Chartier 2010; Rossetto et al., 2014). Creating a social networking site, such as a Facebook support group, will empower the organ donor families to connect and support each other using a social media platform accessible 24 hours a day, seven days a week. The benefit of social media is that it connects grieving people who would not typically have met (Hollander, 2001). The internet can be accessed at any time of the day or night, allowing people to share their grief with individuals in a similar position who have experienced organ donation (Tolstikova & Chartier, 2010). Since the global pandemic, how we interact with each other has changed (Heo et al.,2021), so there is no better time to develop online innovations to ensure organ donor families can connect, find support, and build a community. Investigation into the best support and aftercare strategies for UK donor families has remained stagnant for the last 20 years. This research explored social media as a method to connect donor families, providing them with continual peer support and adding to the evidence base to improve the development of new aftercare strategies and knowledge in the UK. Facebook offers an easily accessible, inexpensive way to support bereaved individuals. It has the means of creating a closed private group offering restricted access (Avizohar et al., 2022), which may appeal to the vulnerable who seek support but want to remain unseen. There are many reasons why people prefer to access bereavement support online. Time and schedule limitations may prevent them from attending a face-to-face meeting; online groups can also help reduce the nervousness of pursuing emotional support (Feigelman et al., 2008; Gibson et al., 2020). In addition, geographic and social seclusion, reduced support networks, and access to transport could prevent accessing any form of face-to-face support (Gibson et al., 2020). It must be acknowledged that this research study will only benefit some organ donor families; some will have additional needs which need to be addressed through this support platform, and culture may inhibit the use of some or digital technology literacy (Ji et al., 2010). Facebook will not appeal to every organ donor family, and this will need thought and consideration when analysing the findings and recommending the future practice.

Rationale For The Study

Organ donation and transplantation saves lives (Sque & Payne, 1996; Corr & Coolican, 2010; NHSBT, 2020). Successful transplant operations often allow patients to return to work and undertake a more productive life, reducing hospital visits (Sque et al., 2006; NHS Blood & Transplant, 2015; Sharif, 2012). The UK has one of the lowest rates of consent for deceased organ donation in Europe (Tocher et al., 2018). NHSBT UK's strategy, 'Taking Organ Donation to 2020,' set a target to increase organ donation consent rates from 57%

to 80% by 2020 to match the best countries in the world (NHSBT, 2015). This target figure was not attained, although significant progress has been made, and the current consent rate is around 65% (NHSBT, 2023). NHSBT has recently published its latest strategy, 'Organ Donation and Transplantation 2030: Meeting the Need,' in which it describes several challenges which impact consent rates, including the inequalities which exist in terms of age, gender, and ethnicity. As highlighted earlier, only a limited number of people die in circumstances in which they can donate their organs for transplant (Manara & Thomas, 2020), suggesting that an organ donation is an infrequent event, limiting the understanding that we have of families who choose to donate their loved one's organs.

NHSBT has invested resources to ensure that all patients who could become organ donors are identified appropriately to maximise organ donation opportunities, increasing consent rates (NHSBT, 2015; Sque et al., 2018). During this time, sensitive aftercare and bereavement support are crucial to ensure that the organ donor's family/friends' experiences are as positive as they can be in this devastating situation. There is very little evidence analysing the aftercare of families who consent to organ donation, or the effect organ donation may have on a bereavement journey (Walker & Sque, 2016; Dicks et al., 2017a; Sque et al., 2018). Indeed, evidence suggests the urgent need to consider family members' aftercare following organ donation due to a gap in our current knowledge and understanding of the bereavement response (Jensen, 2011; Berntzen & Bjork, 2014).

This original longitudinal study investigates the influence of an online peer-to-peer support group and the development of a micro-community for families and relatives of deceased organ donors on their grieving process. The community benefits from peer and professional support mechanisms to identify and address families'/friends' questions and concerns after the donation process.

In many circumstances, confusion and unanswered questions about the whole process, and anxieties could emerge weeks and months after the event indicating the need for follow-up care (Corr, 2001; Berntzen & Bjork, 2014). Research recommends that healthcare professionals provide follow-up to donor families after the donation process, ensuring they are presented with a better understanding, recognition, and a feeling of reconciliation (Sque & Payne, 1996; Corr, 2001; Dicks et al., 2017a). Family experiences of donating their relative's organs in the UK are not fully understood, and there is a need to interrogate their journey further to develop supportive aftercare support (Walker et al., 2013). The organ donation experience can have many critical variables that impact families' bereavement following deceased donation, which can be life-altering (Walker et al., 2013). There is significant work surrounding anticipatory grief and grief when someone dies in natural circumstances (Bowlby, 1980; Stroebe & Stroebe, 1993; Cassidy & Shaver, 1999; Zilberfein, 1999; Sque, 2000; Parkes, 2002; Stroebe et al., 2008; Corr & Coolican, 2010; Kubler-Ross & Kessler, 2014; Sque et al., 2014; Dicks et al., 2017a). Parkes' (1985) early work suggested that the care given to families before bereavement can influence subsequent adjustments. Limited evidence exists on how grief manifests following unexpected loss, trauma, or violent death as part of an organ donor family's experiences (Strouder et al., 2009; Walker et al., 2013). Indeed, many families who agree to organ donation have experienced a traumatic end to their loved one's life, which may have lasting effects on their emotional health and bereavement journey (Manzari et al., 2012). There is also the issue of donating a loved one's organs to a stranger and the impact this will have on bereaved relatives (Holtkamp & Nuckolls, 1991, 1993; Martin & Mehakovic, 2017).

There is a significant lack of understanding around bereavement in organ donor families, and individuals have different grieving styles influenced by varying cultural, religious, personal, and social beliefs (Shear & Shair, 2005; Corr & Coolican, 2010). This thesis creates an evidence base to understand the use of an online support platform. If effective, the proposal to NHSBT would be to implement this or similar as an aftercare strategy to improve aftercare services for this group. As a SNOD, knowing there was some form of aftercare support available would be reassuring, recognising the need to provide continuous support following organ donation. Positive experiences of an aftercare online support group could also enhance the reputation of NHSBT, influencing more families to come forward and donate, increasing potential donations in the future. Many families experience intense pain from the death of their loved one but also joy from the continued life they have been gifted (Maloney, 1998).

Recommendations from many years ago are still relevant today (Walker & Sque,2015; Dicks et al., 2017a; Sque et al., 2018;), highlighting a need to do more and help reduce a family's sense of isolation, helplessness, and uniqueness that some families feel after this exceptional phenomenon (Maloney, 1998; Horgan et al., 2013). Families are essential to the organ donation process to provide consent, although their voices are often absent (Robertson-Malt, 1998). This unique research study provides a forum for the voices of organ donor families, who rarely regret organ donation but often have several unanswered questions following the process, to be heard. Over 25 years ago Robertson-Malt, (1998) promoted the idea of creating an informative, valued space for organ donor families to communicate to shape policy and support each other. This online peer support group would provide such a space. It is time to respond to the need for support and develop appropriate aftercare support mechanisms for organ donor families. Current research reinforces that the relatives of organ donors need to be provided with social and emotional support following the donation process (Rossetto et al., 2014; Fernandes et al., 2015). This research seeks to understand if online support groups are helpful, for whom, when, and how. The influence of offering organ donor families a way of communicating and connecting with other bereaved families/friends, the chance to build a community for those who have experienced this rare, complexed phenomenon that is organ donation. In addition, examining organ donor family experiences will enable the research to explore the bereavement journey, contribute new knowledge, and generate an evidence base to inform this underdeveloped and neglected area of organ donation practice.

Summary

This chapter has provided the background to the complexity of organ donation, the rationale for the study, and the reasoning and motivation for developing a Facebook bereavement support group to transform the aftercare provided to relatives of organ donors. Despite years of academic research studies highlighting the need to support organ donor families better, little has changed in practice. There is an ethical, moral, and professional need to ensure that organ donor families are adequately cared for and supported during their bereavement. However, it is evident that the aftercare support organ donor families receive is inconsistent. Organ donation is a complex process that involves supporting some of the most vulnerable individuals; by offering them support, aftercare and recognition may well influence their bereavement. Aftercare support will help to acknowledge the years of academic evidence that reported a need to provide social and emotional support to families following organ donation. Now is the time to develop and implement organisational structures to guarantee that organ donor family aftercare becomes a priority, not an omission in practice.

Chapter 2: Review of Organ Donor Family Aftercare

Introduction

Before embarking on the research, it was essential to critically examine what we already know surrounding the experiences of organ donor families, the bereavement and aftercare journey, and moving past the point of the donation process. This chapter draws together current evidence to expose family experiences of the donation process and the influence of current support during their bereavement as a way of understanding the concepts and challenges surrounding organ donation to inform the research. A comprehensive search strategy, applied across different resources and databases, identified relevant papers pertinent to the study topic. The retrieved papers were appraised, and the findings were themed to discuss the research to date, identify gaps in knowledge and current practice, and expose evidence to support family aftercare strategies adopted.

The aim of the literature search was twofold:

- To critically appraise existing literature related to the aftercare of organ donor families to identify an evidence base to support current strategies
- Explore the use and evaluation of social media in bereavement aftercare

Reviewing previously published literature is essential to the research process (Coughlan et al., 2013; Bernard & Ryan, 2010). Making sense of a body of research and presenting a breakdown enables a researcher to understand what is already known (Aveyard, 2014; Ferrari, 2015). From the outset developing a search strategy for this review presented a challenge, narrowing down and sifting through the copious amounts of literature on organ donation to find articles only related to the bereavement aftercare of organ donor families. The literature review process was enriched by the researcher’s own experiences, interpretations, existing theories, and philosophical perspectives as a SNOD and the senior organ donation lead for NHSBT (Charmaz, 2006; Jones, 2004). The review was important to develop a deeper understanding of grief experiences families endure following organ donation, to demonstrate which support strategies are effective, for whom, and to map the strategies used by different organ donation organisations.

Conducting The Literature Review

The literature review aimed to identify the evidence related to the aftercare and support of organ donor families while also considering using social media to support the bereaved. The search included assessing electronic databases and organ donation organisational websites. The initial search strategy yielded numerous sources of unwanted evidence, many articles focusing on the hospital process and decision-making leading up to organ donation (Manuel et al., 2010; De Groot et al., 2015; Hulme et al., 2016; Poppe et al., 2019). To filter these articles, an Inclusion/exclusion criterion was created (table 4). Each study was critically and analytically appraised to examine the value and merit of the research (Moule & Goodman, 2014) using a structured critical appraisal tool to aid the screening process (Critical Appraisal Skills Programme, CASP, 2019; Hannes & Macaitis, 2012; Dalton et al., 2017; Long et al., 2020)

Inclusion And Exclusion Criteria

The literature review inclusion and exclusion criteria are purposely broad (Table 4), with English language-only sources obtained, with no date range applied. Papers that focused on transplants and recipients were excluded, as well as articles that referred to tissue and living donation, decision-making regarding organ donation, education, critical care nurses, and the organ donation process within the critical care environment.

Table 4: Inclusion/Exclusion criteria for literature search

Inclusion	**Exclusion**
• Peer review journal and publications • International papers • English language studies • Studies that focus on post donation bereavement experiences rather than decision making • Focus on Organ donation family experiences, Family aftercare, grief & bereavement & social media in bereavement • No date range • Grey literature	• Studies focusing on Transplant recipients • Studies that focused only on death & dying, not related to organ donation • Studies focusing on Education of organ donation • Studies focusing on living donation and tissue donation • Studies focusing on organ donation within the critical care environment, decision making, critical care nurses • Non-English language studies

The search strategy also captured several sources that were clearly out of the scope of this research, such as medically focused transplant research, and these were excluded. The review focused on the aftercare of organ donor families, grief and bereavement, and social media, and no sources were excluded based on factors such as study type or methods.

The initial scoping exercise emphasised the need for more literature on the use of social media for organ donor families and failed to uncover any evidence that linked the two. As a result, the search terms were applied separately to increase the scope of the search and engage a more comprehensive understanding of the impact of using social media on bereavement and grief recovery. Peer-reviewed research papers were included, and where the full text could be retrieved.

Search Strategy

A comprehensive search strategy was undertaken using three research databases, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medical Literature Online (Medline), and OVID. All databases were access via Salford University Library website. Professional websites and grey material relating to organ donation were also explored to identify additional professional evidence. A series of keywords were created using a combination of truncations and quotations to capture the search term (Table 5). Applying Boolean search operators developed and redefined the search.

Table 5: Key Search Terms

1st search on the topic of Aftercare organ donation families
‘*Organ donation*’, ‘*organ donors’, ‘deceased donors’, ‘cadaveric donation’, ‘organ procurement’, ‘family’, ‘next of kin’, ‘relative’, ‘friend’, ‘loved one’ ‘bereavement’, ‘grief’, ‘mourning’, ‘death & dying*’, ‘*family aftercare’, ‘bereavement support’*
2nd search on the topic of use of social media in bereavement
‘*Social media in bereavement*’, ‘*building online communities’, ‘online bereavement support’, ‘Facebook support groups’*

Two separate searches were carried, since finding relevant literature was a challenge:

1. The first search focused on organ donation and the aftercare family support. A simple search using the term ‘*organ donation’* generated 6670 articles on CINAHL, 18,801 on Medline, and 13,681 on OVID.

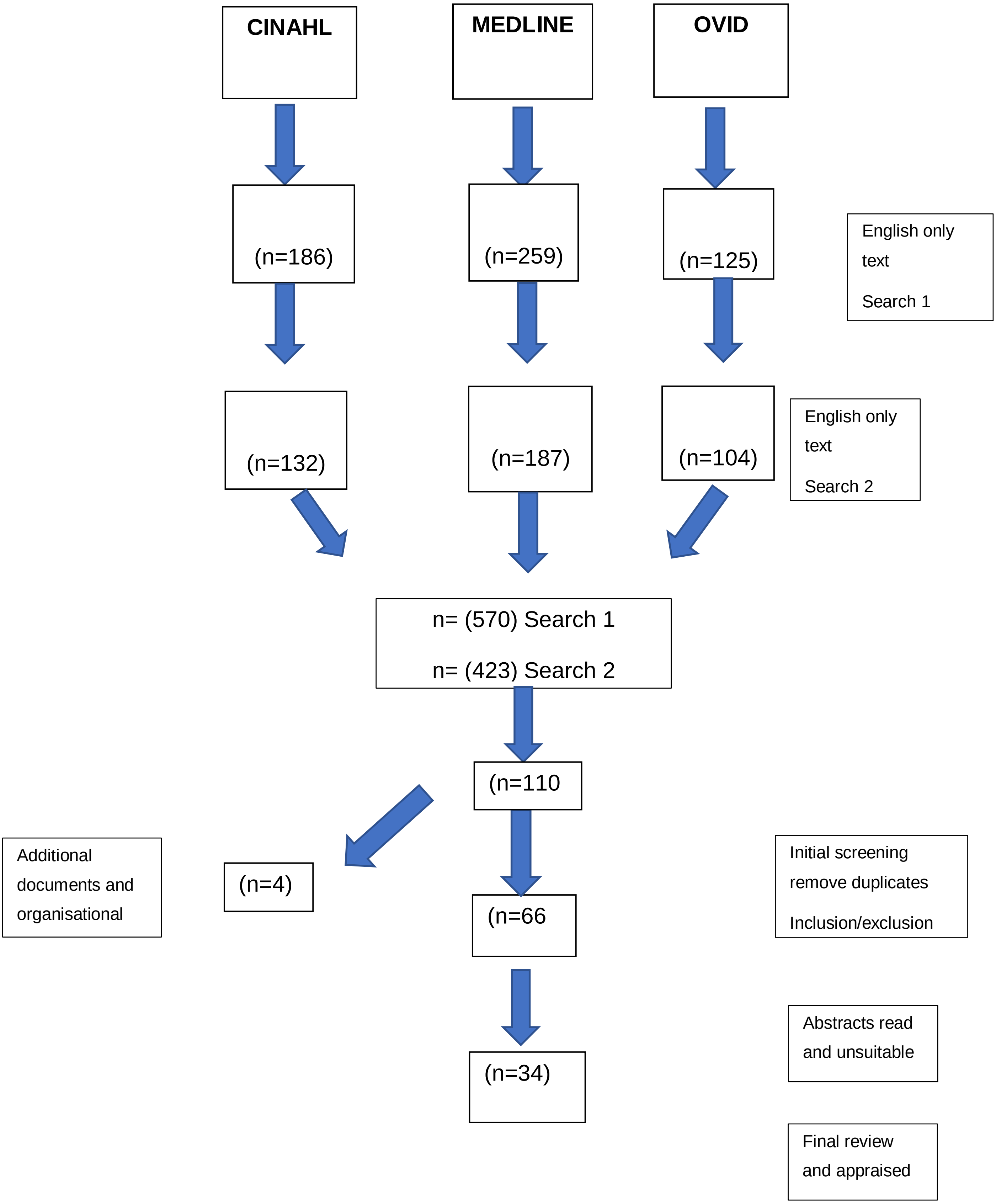
2. The second search concentrated on the use of social media in bereavement. An initial search using '*social media support*' generated 483 on CINAHL, 646 on Medline, and 274 on OVID.

Search Results

The original literature search was conducted in April 2020 and updated in February 2023, with no new relevant research papers identified. 993 articles were initially identified in total from the combined database search. 570 articles from search 1 and 423 from search 2, and four additional reports were gathered from professional websites: these included policy documents and organisational reports. On Initial screening, all articles deemed unequivocally unrelated were removed. The duplicates were removed, leaving 110 articles. Abstracts of the 110 papers were read, and a further 44 articles were deemed unsuitable. The full text of the remaining 66 articles were read, and a further 32 articles were removed from the final selection. 34 papers were included in the final review as they were considered to match the study focus (Figure 7). The literature search identified studies that had employed a variety of different designs and approaches, including, qualitative, quantitative, systematic review of literature, and narrative reviews and, therefore, different approaches to data analysis and interpretation, as a result of the variation in the chosen studies, specific quality appraisal tools were required. The Critical Appraisal Skills Programme (CASP) tool was selected to review the strengths and weaknesses of all the presented publications identified in the literature review (Critical Appraisal Skills Programme, 2019), allowing for a systematic review of the chosen studies. Using the CASP tool identified (Critical Appraisal Skills Programme, 2019), research papers were appraised, and an assessment was made of their quality. Studies appraised and included in this review are listed (Table 6), presenting an overview of the different types of methods, sample size, demographics, and summary of key findings.

The literature review reinforced the lack of evidence supporting bereavement aftercare for organ donor families. Only four papers specifically reviewed organ donor family aftercare; three were from the USA, and one was from Australia (Coolican & Politoski, 1994; Regan & Barnwell, 2000; Vajentic & Calovini, 2001; Corr, 2001). All four papers were published over 20 years ago, descriptive in nature, informing the reader of the aftercare services that they had developed to support organ donor families after donation. None of the four papers evaluated the impact of the described specific aftercare strategy on organ donor families. The papers described the benefits to the organisational, highlighting the lack of research into the aftercare of organ donor families.

Figure 7: Combined searches 1 and 2 results



Of the remaining 34 papers, 20 were research studies, one was a service development project, six were descriptive accounts of family experiences and bereavement aftercare projects, and seven literature reviews. The studies included different designs and approaches, and this was due to the lack of empirical evidence focused on organ donor family aftercare. Eighteen papers originated from the USA; six in the UK; one in Denmark; two in Australia; one in New Zealand; three in Canada, one in Iran; one in Norway; and one Netherlands.

The research studies were critically appraised applying the Critical Appraisal Skills Programme checklist for qualitative research (Ferrari, 2015). It was explicit from the papers that the family experiences had been considered throughout, although the context in which the experiences were described varied. Three of the studies (Pearson et al., 1995; Ormrod et al., 2005; Manzari et al., 2012) focused on family experience of organ donation after brain death (diagnosis of death using neurological criteria, as it's now known). Three studies explored social media as a form of communication for the bereaved, investigating the popularity and access to online support tools to support the bereaved. One study considered the challenges and implications of setting up an online bereavement support group, acknowledging the ethical, legal, and confidentiality issues and the need to reach diverse groups. Two studies (Sque et al., 2006; Sque et al., 2018) considered the organ donation process and how their intra-hospital experiences before their loved one's death had impacted the family's final organ donation decision. The remaining eleven studies examined family experiences, revealing the emotional effects of bereavement and organ donation, the support needed, and their overall involvement with the organ donation process. Within all the studies, the evidence base evaluating the aftercare services for organ donor families was lacking.

Table 6: Summary of papers included in the literature review

Author		Type of Study/ paper	Method	Sample (why and N=)	Limitations/Challenges	Key findings (See further detail table 8) Most important
1.	Berntzen, & Bjork (2014)	Qualitative study	20 Interviews, 13 different situations	Organ donor families	Timeframe following donation until the one-to-one interview was significantly long, may have impacted on the participants recollection of events	Highlighted the need for clear comprehensive communication. Time spent with the patient was a central finding and some families left straight after diagnosis of death
2.	Bolt, Witjes, Van Den Ende (2018)	Qualitative study	19 In depth Interviews	Organ donor families	Limited number of families interviewed with a large variation in the time between death and the interview. The longest being 27 years and the shortest 6 months which could impact on the findings	This paper highlights how organ donor families expect to receive gratitude in exchange for the gift of their relative's organ and that by not receiving this gratitude they are left with restless feelings
3.	Cleiren & Van Zoelen (2002)	Quantitative cross-sectional study	Interviews with 95 bereaved relative	Bereaved relatives	Large sample of bereaved relatives interviewed over a 6-month period. Structured interviews containing precoding answering categories	Dr in charge of the patients' care approached for donation which impacted on the family decision/conflict of interest
4.	Corr & Coolican (2010)	Comparative analysis	3 donor family case studies	Bereaved	Number of papers included in the review is not clear	Overview of grief, bereavement and mourning which is related to organ donation in parts
5.	Corr (2001)	Descriptive review of aftercare services	Unknown	Organ/tissue donor families, National Donor Family Council USA, National Kidney Foundation	Explanation of services offered to organ donor families but no evidence from families evaluating the services	Description of the services provided to the organ donor families
6.	Dicks et al (2017a)	Systematic review	Narrative synthesis 120 sources included	Bereaved relatives of organ donors	More focus on DBD donation than DCD and consented only donors	Exploration of the families intra hospital relationships and experience. Organ donation aftercare is discussed in some details as well as linking the donation process to grief theory
7.	Dicks et al (2017b)	Systematic review	Grounded theory review method using 7 full text reviews	Organ donor families	Limited number of full text reviews eligible	Focused on understanding the families' experiences in hospital and how their experiences may affect their decision-making process's when thinking about organ donation
8.	Falconer et al (2011)	Descriptive synthesis	Review of online grief tools	Internet grief tools	No clear evidence of how the tools were selected and why. Unclear of how many tools had been reviewed	Focuses on grief and the different models of grief, linking this to the use of online sources and providing an understanding of how clinicians can support relatives by offering online support options

9.	Gibson et al (2020)	Narrative review	26 papers reviewed. Literature spanned over 10 years	Mental Health Facebook groups	No clear strategy regarding the number of studies reviewed and the inclusion, exclusion criteria	This review highlights the challenges and benefits of using online bereavement groups providing rational as to why online support should be recognised
10.	Hollander (2011)	Narrative review	Ethnographic Study joining a suicide support group to engage with members. One to one Interviews with 25 participants	Relatives of suicide/Internet support groups	Narrative and personal count	Although focusing on suicide, this paper offered evidence on building a bereavement community
11.	Holtkamp & Nuckolls (1993)	Qualitative study	131 participants included in cross sectional survey, with 91 respondents	Family members of organ/tissue donor	Survey used, challenge when researching the bereaved is acknowledged. Study carried out over 20 years ago	The study provided evidence that supports the bereavement services provided by the Tennessee Donor Services, although it recommends focusing on gender responses
12.	Jensen (2011)	Ethnographic study	Ethnographic fieldwork, involving 4 months in the Donor Family Aftercare Department New York Donor Network	Donor family aftercare staff at OPO/Organ donor families	Methodology is not clear, no clear recruitment strategy identified	Descriptive account of organ donation experiences in New York & Denmark. The study shows the doubts and questions families have regarding brain death. It also highlights how organ donation is recognised in both countries and societal perceptions of organ donation
13.	Kentish-Barnes et al (2019)	Narrative review	15 papers reviewed following intensive literature search	Family members approached for organ donation	Much of the data used in this review came from USA, Canada and Australia. Some of the sample sizes in the reviews were small and the strength of the evidence weak	The review highlights the absence of bereavement support and how many organ donor families live with unanswered questions which may impact on their grieving process
14.	Maloney (1998)	Comparative analysis	Two Case Studies with donor families	Organ Donor Families	No clear evidence of how the selected data was collected including any inclusion/exclusion criteria. This paper is outdated but remains relevant due to family experience. Very small sample with only two case studies	Poignant narrative regarding the experiences and feelings of organ donor families, highlighting the need to provide a more adequate aftercare service
15.	Manuel, Solberg, MacDonald (2010)	Qualitative Study	5 Unstructured Interviews	Wives of organ donors	Small sample	Aimed to provide nurses with some understanding of what organ donor families experience to enable them to personalise their care and support following organ donation

16.	Manzari et al (2012)	Content analysis	38 Unstructured Interviews	Relatives of consented donors/relative who declined donation	The use of unstructured interviews may have limited the conversations	14 families consented to organ donation and 12 had declined organ donation. The study suggests that families struggle with the concept of brain death and need added aftercare support following organ donation
17.	Marck et al (2016)	Qualitative study	49 Semi Structured Interviews	Donor families	No English-speaking families were not included in the study due to lack of funding	This study suggested that the need for clear communication is helpful in the grieving process and that organ donor families would benefit from follow up and/or aftercare support
18.	Merchant et al (2008)	Bivariate Analysis	73 completed mailed surveys	Donor Families	The sample was mainly white Christians and so not diverse or multicultural in response	There was suggestion that donor families felt confused regarding the concept of brain death The study demonstrated an overall positive reflection of organ donation
19.	Moyer & Enck (2018)	Qualitative study	91 completed Online questionnaire	Facebook users	The study acknowledges the need for a more diverse participant population. It was a cross-sectional study design only capturing a small section	The study revealed the benefits of using social media to bring people together and share their lived experiences with similar people.
20.	Ormrod et al (2005)	Qualitative study	27 Structured interviews	Relative of patients who had brain stem death tests in ICU	The structured interviews may not have allowed for a more open discuss regarding this emotive and distressing topic	This study found that relatives who witness brain stem death testing experience further distress, although all participants did not regret their organ donation decision
21.	Pearson et al, (1995)	Qualitative study	Survey 69 families	Relatives of patients with brain death	Included families who had been asked and consented/not consented as well as families who had not been asked	The study highlights that organ donation is helpful, although goes on show that families experienced unresolved grief, bad memories, and expressions of regret. There is also some discuss around communication and the lack of understanding regarding brain death
22.	Prescott, Rathbone, Brown (2020)	Systematic review	14 UK posts & 11 US posts acquired over 3-month period	Mental Health Facebook groups	Small study over a short time frames No demographic information was obtained about the participants	This study highlights the positive impact of sharing similar lived experience arguing the need to see mental health in a more positive light and not negatively
23.	Regan & Barnwell (2000)	Service evaluation	Discussion regarding the counselling services provided to donor families	Donor families	No comparisons made to any other similar services. No clear evidence or evaluation provided	Clear explanations of the counselling service provided as a part of the organ donation aftercare service in their area

24.	Rossetto, Lannutti, Strauman (2014)	Qualitative study	Online survey of 265 participants with 454 units analysed	Facebook users who had experienced death	More diversity needed in the participants as mainly female	This study explored the benefits to using social media and how it is helpful in bringing together and growing a community of people who shared experiences
25.	Sque & Payne (1996)	Qualitative study	Narrative Interviews carried out with 24 relatives	Bereaved relatives	Outdated study, although still relevant Participants recruited from only 3 regional centres	The study suggests that brain death may complicate grief due to the no traditional nature of the death. The complexities of organ donation needing further understanding
26.	Sque, Payne, Macleod Clark (2006)	Comparison study	Data review of 3 studies	Organ Donor Families	Small sample of studies reviewed	Discussions around the decisions made by organ donor families and the complexity of organ donation being a 'Gift of life' or a sacrifice
27.	Sque et al (2018)	Qualitative study	Interviews 43 participants of 31 donor families	Organ donor families	No families who declined organ donation were included in this study	The study focused on the intra hospital experience of both DBD/DCD organ donors. The participants all had a positive organ donation experience, highlighting the need for clear communication
28.	Strouder et al (2009)	Qualitative study	Written survey to all organ/tissue donor families in San Diego and Imperial County 945 surveys emailed to families with 18% (N=170) response rate	Organ & tissue donor families	Small sample survey may limit the response rate	Spiritual and cultural needs of families is extremely important, and this study addressed this issue. The study found that many organ donor families found that support from family and friends helped with their grief
29.	Takaoka et al (2020)	Qualitative study	26 Interviews and 2 focus groups	Bereaved families who had been offered organ donation/clinicians/organ donation coordinators	Participants are made up of donor families and clinicians/organ donor coordinators which could be challenging as they all have different roles which will make the experiences very different. The study acknowledged the variation in end-of-life practices across regions/cultures	Evaluated a pilot project which focused on personalised end of life care. Identified that organ donation is complexed, and organ donor families require extra care.
30.	Tolstikova & Chartier (2009)	Comparison Study	Online Survey 262 participants 84 participants mailed questionnaire	Bereaved individuals	Not equal number of participants for each comparison. Recruitment for each of the samples were recruited in different ways	Accessibility of online support for bereaved individuals and the need to share experiences and open to strangers without being seen

31.	Vajentic & Calovini (2001)	Narrative/ Descriptive	Service review 18 families (19 adults, 6 children over 18 years of age and 14 children ages 51⁄2-17).	Donor Families/OPO	No comparisons to similar services	Review of the aftercare services provided, highlighting alternative and flexible design to aftercare services. The use of Music therapy helped to inspire emotion. They used a Family Night to bring families together to share their grief and receive support as one.
32.	Walker & Sque (2016)	Qualitative inquiry	Semi Structured Interviews with 43 participants from 31 donor families	Organ Donor Families	Acknowledge challenges surrounding the recruitment of bereaved participants and the methodological and ethical challenges	The study highlights the meaning of organ donation and the positive experiences some families had. It also recognises the need to understand the support required by organ donor families
33.	Walker & Sque (2019)	Case Analysis	One Individual case study	Organ donor family who experienced DCD	Only concentrated on DCD donation with only one family experience	The use of education and training to adequately support organ donor families will help to ensure compassionate end of life care
34.	Yeok et al (2021)	Service improvement evaluation	Semi Structures telephone interviews with 201 families	All relatives who's relative died on ICU	Exclusion criteria included decisions based on the intensivist discretion. The interviews were not audio recorded	The enrolment of participants was successful and included a wide range of families from diverse cultures providing learning. The use of bereavement follow up phone calls assisted with providing comprehensive end of life care

Overview Of The Review Themes

The final 34 articles selected were critically appraised, an iterative process was initiated to identify key themes and links between each source (Critical Appraisal Skills Programme, 2019). The evidence base examining the aftercare strategies was limited, so the review was widened to include articles that provided a more explicit context of the research and service development in this topic area, in particular elements that may impact the aftercare and bereavement journey of the family. Five critical themes were identified (Table 7):

- Understanding the concept of Neurological Death
- The meaning of organ donation
- The need to connect with transplant recipients
- Bereavement support and aftercare
- Use of social media as a bereavement resource

The interrogation of these core themes generated an interest to explore the experiences of organ donor families further. It was evident from the literature and my own practice, that organ donation created emotional anxieties, which left the family with doubts and questions. It was also clear that providing additional support into the bereavement phase would help to address these uncertainties that organ donor families are left with following this unique phenomenon. The findings from the literature review authenticated the motivation for this study, providing assurance that we need to provide more support to organ donor families following the death of their loved one and organ donation.

Table 7: Summary of key thematic finding

Key themes	**Key Findings extracted from papers**
Neurological Death	Recognition that brain stem death is a complex process and can confuse relatives making them question the validity of their relative’s death (Berntzen, & Bjork, 2014). Highlights the stress families are going through and their ability to process the information regarding brain stem death at such a traumatic time (Cleiren & Van Zoelen, 2002). Explored the need for quality communication to ensure families understand brain stem death, showing that not understand the concept of brain stem death can contribute to the increased risk of complicated grief (Kentish-Barnes et al., 2019). Described the participants struggling to understand the concept of brain stem death and the need to identify some sign that their relative was alive (Manuel, Solberg, MacDonald, 2010). Families needed support after they had made the organ donation decision and that they needed to understand that brain stem death means death with no hope of survival before they can be approached for organ donation (Manzari et al., 2012) The language used when discussing the prognosis with families, can be confusing and leave family members with hope despite their loved one being brain dead (Marck et al., 2016). Need to improve communication so that families were not left confused about the concept of organ donation. Suggesting that healthcare professional could help this by educating families about brain stem death (Merchant et al., 2008). Ambiguity amongst bereaved relatives regarding the understanding and accepting of brain stem death, with families left with unanswered questions sometime after the donation (Ormrod et al., 2005). People found that brain stem death was a difficult concept to understand and despite being able to rationalise the concept emotionally there remained some degree of hope (Pearson et al., 1995) People found it difficult to recognise their relative was dead after confirmation of brain death as they remained on a ventilator, pink and warm. When organ donation was agreed it was still conflicting as their relative looked alive (Sque &, Payne, 1996) Most people were satisfied with the understanding got the situation when their relative was diagnosed with brain stem death, although some participants found it difficult to associate the way their relative looked, pink, warm, with death (Sque et al., 2018). Inconsistent with some of the other studies, 95% of the respondents in the study understood that their loved one had died (Strouder et al., 2009).

The meaning of organ donation	Several people found the experience brought meaning to the death of their loved on, although some people found they could never find a meaning to the death but there was a search for some understanding (Berntzen, & Bjork, 2014). Families who consented to organ donation believed that this would bring them some sense of meaning, finding a positive outcome to a devasting situation (Dicks et al., 2017a) Highlighted the ongoing need for organ donor families to be provided with follow up information about the recipients, wanting to know about their wellbeing (Holtkamp & Nuckolls, 1993) Need for organ donors to been seen in a positive light in the USA allowed families to gain comfort even if the nature of the death was traumatic (Jensen, 2011) A common theme was related to the living memory of the organ donor and the hope that a piece of them lives on in the recipient (Manuel, Solberg, MacDonald, 2010) Families found consolation in the knowledge that their loved one had been an organ donor, with no families regretting their decision. Some of the families who declined organ donation did regret that decision following the death of their loved one (Marck et al., 2016) The basic idea of providing the gift of life by donating organs is questioned when the recipient does not receive recognition questioning if organ donation is a ‘gift of life’ or a ‘sacrifice’ (Sque, Payne, Macleod Clark, 2006) Participants saw donation as a way of promoting organ donation to the public and the societal recognition for what their loved one had done in donating their organs (Sque et al., 2018) Highlighted the motivation for donating relatives’ organs and the perceived benefit if saving another life, but the pain suffered from losing your loved one (Walker & Sque, 2016)
The need to connect with transplant recipients	Suggested that the connection with the recipient allows the donor family to remain connected with the dead relative. It also explores the need for recipients to accept that the donor did not die for them (Corr & Coolican, 2010) The need to share the organ donor families with recipients could help to keep the narrative open and the donor families’ stories heard. It may also help the organ donor families and their grief having the connection with the recipients, being able to share the stories of their loved one (Maloney, 1998)
Bereavement support and family aftercare	Before the introduction of the support resources discussed in the paper, families found themselves becoming disenfranchised grievers, identified a need for more aftercare and support (Corr, 2001) The review found that families had many unanswered questions in the months after donation which needed support. It also suggested that organ donation brings a new aspect to the grieving of families (Dicks et al., 2017a) A model is offered to enhance the support families are provided with and this should begin in hospital and continue following organ donation (Dicks et al., 2017b) The need to support families with an aftercare programme was seen as a necessity as they are left with unanswered questions (Jensen, 2011)

	Showed that the absence of bereavement support means that families are left with unanswered questions and that further research is needed to better understand family's needs (Kentish-Barnes et al., 2019) Support needed for families after organ donation, questioning the aftercare that is provided to families who agree to such a unique process and the responsibility to provide to the families who have given so much (Maloney, 1998) The family need support through and after the organ donation process and recommended that organisations focus more on the human factors rather than the safe removal of organs. The healthcare professional need to ensure they are truthful, open, and supportive to families (Manzari et al., 2012) Suggests the need to provide ongoing support for families who may experience complicated grief following organ donation (Merchant et al., 2008) Telephone counselling service evaluated showed the benefits to providing a service which was not just face to face, as it provided a safe space for donor families to open about their feelings whilst remaining anonymous (Regan & Barnwell, 2000) People found that it was important to talk to someone who had been through similar experiences. They had used other bereavement services but felt they had not help as they did not understand organ donation and at times passed personal judgement (Sque & Payne, 1996) Suggested that by providing the organ donor families with an adequate aftercare service could help with the understanding, recognition and acknowledgment (Sque et al., 2018) Questions the act of organ donation and whether it eases the grief process, recommending more research be done to understand the role of organ donation in complicated grief (Strouder et al., 2009) The importance of organ donation aftercare support was emphasised, and it was suggested that some families whose relatives cannot donate may also need supporting due to the disappointment of not being a donor (Takaoka et al., 2020) The aftercare service reviewed highlighted the support that bereaved groups provide to each other. They share that similar experience having no hesitation to offer each other support (Vajentic & Calovini, 2001) Providing education and training to healthcare professional regarding organ donation and how best to support families after donation can help to provide them with quality support and aftercare which can be personalised to their needs (Walker & Sque 2019) Providing a structured end of life support programme for families who's relative died ion critical care promoted the consents for organ donation. The bereavement programme was run in collaboration with critical care and the organ donation coordinators (Yeok Kee Yeo et al., 2021)

Use of social media as a bereavement resource	With the increased use of social media, it is suggested that the development of online tools which will support grieving process can be helpful. It is also suggested that clinicians have some awareness and understanding of the online tools to support relatives (Falconer et al., 2011) Recognises the opportunities online support groups can provide for the bereaved whilst highlighting the challenges and anxieties that online support can bring. It recommends that organisations embrace the use of technology to provide a rounded support package (Gibson et al., 2020) Found that sharing the experience with others who have been involved in similar situations is helpful and being able to do this online helps (Hollander, 2011) There are therapeutic qualities from engaging with social media to express grief and is a way of bringing people together to share their own experiences (Moyer & Enck 2018) A positive aspect of using online support groups is the peer support that can be obtained, and participants found emotional support which helped them feel less lonely and empowered to gain support from others experiencing similar feelings (Prescott, Rathbone, Brown 2020) Discusses both the positive and negative aspects for using social media for bereavement support. It highlights the easy instant accessibility, providing autonomy to users whilst allowing them to grieve in an open safe space (Rossetto, Lannutti, Strauman 2014) Revealed the benefits of online bereavement support and how it has grown to become a space to share the loss with people who have experienced similar trauma, building a community which can be accessed at any time. The virtual space can provide those who feel vulnerable with a platform to be open and less isolated (Tolstikova & Chartier 2009)

Understanding The Concept Of Brain Death, The Impact On Bereavement

A common theme exposed in the literature review was a relative's lack of understanding of brain death and the lasting emotional effects neurological death can have on relatives (Sque et al., 2018; Marck et al., 2016; Berntzen & Bjork, 2014; Merchant et al., 2008; Sque & Payne, 1996; Pearson et al., 1995). The experience of organ donation is complex, and donation after brain death (as it was previously known) can be a difficult concept to manage. Many families found brain death difficult to understand as their relative remained pink in colour, and warm to the touch. Their chest was rising and falling, albeit driven from the mechanical ventilator. The monitors surrounding them in the critical care unit show blood pressure and heart rate, creating questions regarding the legitimacy of death (Berntzen & Bjork, 2014; Manuel et al., 2010). This can have long-lasting consequences for the family, especially if their relative is taken to the theatre for organ donation, still looking pink, warm, and with a pulse (Kentish-Barnes et al., 2019). There was sometimes conflict between understanding the concept of brain death and accepting that this was happening to their relative, uncovered through a phenomenological study of five women following their relative's donation (Manuel et al., 2010). Although a small sample of only five female participants, the findings highlighted significant differences between adult and paediatric donation. This suggests that further research was needed better to understand the family's perception of brain death, especially when the relationship to the deceased is a child. Furthermore, Manuel et al. (2010) study included only female participants, which is constricting; it should be considered that male participants may have contrasting experiences, seeing it through a different lens. Effective communication is crucial, and the information given to donor families to confirm the death of their relative does not always reassure them that death is death (Kentish-Barnes et al., 2019; Marck et al., 2016; Berntzen, Bjork, 2014; Merchant et al., 2008; Sque & Payne, 1996; Pearson et al., 1995). Death confirmed using neurological criteria is challenging as medical professionals ask loved ones to accept the non-traditional death of their relatives. This can cause anxiety about when to leave their relative and if the organ donation process has caused suffering (Pearson et al., 1995). Relatives were left questioning the legitimacy of the death, which could complicate their grief (Berntzen & Bjork 2014; Pearson et al., 1995). At least two-thirds of the families surveyed (69 out of 211) admitted that while they appeared to have accepted the death of their relative, they still felt they were alive, and some had doubts regarding their relative being 'really dead' (Pearson et al, 1995). This challenges the evidence and questions if the families had in fact accepted the death. The Australian study included 69 families of brain-dead patients; 32 were from donor families, 21 had not agreed to organ donation, and 16 were from next of kin who had not been asked about organ donation. It was carried out in a large tertiary hospital in Australia. Although the sample size was small, not all responses came from families who had consented to organ donation, making their experiences different from consenting organ donor families. This study could be perceived as dated, and clinical practice has progressed significantly over the past 20 years, although recent evidence also suggests that families continue to experience similar thoughts (Merchant et al., 2008; Marck et al., 2016; Sque et al., 2018). With regards to the aftercare of donor families, Pearson et al. (1995) found that most participants would have liked follow-up information to be sent on regarding brain death and suggested a solution would be offering further information and support through family providing donor family aftercare. Nearly 30 years ago, aftercare was an identified need for donor families, but practice and support have not progressed over this time. Bereavement aftercare strategies would allow donor families to reconnect with the organ donation organisation, receive further support gain responses to unanswered questions and anxieties (Kentish-Barnes et al., 2019). In current practice, and through my years of clinical experience, families appear to accept their relative's death when informed by the clinician, although at times this is a bewildering acceptance due to the nature of the bereavement. Little consideration is given to the potential aftershock and the need for clarity. Many families value the idea of helping others through donation, although uncertainties about the diagnosis of death manifest, with some experiencing feelings of mistrust and anxiety; others believe that it's god's decision and it should be respected (Dicks et al. 2017a; Sanner, 1994). Experience and observations in practice reinforce first-hand that families from certain faiths or ethnic backgrounds wrestle with this apprehension of death which influences their decision to decline organ donation (Stouder et al., 2009). Appreciation of different faith and beliefs across ethnic communities must be considered when developing inclusive online research. The review of evidence strongly indicated the need for healthcare professionals to communicate neurological death effectively and concisely, with reference to providing families with written information (Marck et al., 2016; Pearson et al., 1995). Neurological death can be considered a non-traditional, western death. For relatives not to witness the heart-stopping before their relative is taken to an operating theatre for organ donation may gravely impact their grieving. Potential organ donors may not look dead and often have no external indications of injury; they look unscathed, resting, warn, and florid, their chest moving as if breathing (Sque, 2000). Certain factors contribute to poor bereavement outcomes, including feelings of blame and untimely, painful, or mismanaged death (Parkes, 1985), which could occur be associated with a neurological death, disturbing the grieving process.

The Meaning Of Organ Donation

Organ donation has advanced significantly over the past 15 years; now accepted as part of normal end-of-life care, organ donation offers families of patients dying in critical care a chance to gain something positive out of the tragedy (NHSBT, 2021). Historically, the emphasis has focused on the need to save lives and its effects on transplant recipients. Little evidence draws on organ donor families' experiences, and their reasons for allowing their relatives to donate, and practice has not developed to care for families of organ donors (Dicks et al., 2017a; Sque et al., 2018). SNODS, including myself, often used the phrase 'gift of life' to 'help others' to recognise the enormity of organ donation for families, although evidence from years earlier warned against using such coercive phrases (Pearson et al., 1995). More recently, there has been the introduction of advanced training and education surrounding the conversations SNODs have with potential organ donor families have developed, taking an open and sincere tone (NHSBT, 2021). However, many families agreed that organ donation was a positive consequence and helpful in the grief process (Sque et al., 2018). Other than the training that is provided to the SNODs, there is not enough emphasis placed on supporting families after organ donation, despite their generous gift and the bereavement journeys they face. This synthesis of evidence exposes that aftercare has not improved over time or responded to evidence that has emerged (Pearson et al., 1995; Corr et al., 2011; Hogan et al., 2013; Berntzen & Bjork, 2014; Sque et al., 2018). Donation does not change the requirement to grieve, but it does emphasise the relative's death being part of an achievement, a socially accepted belief that the act of kindness lives on in others (Sque & Payne, 1996; Jensen, 2011). In an anthropological study comparing donor families' experiences from Denmark and the USA (New York), three themes emerged: 'brain death,' living on', and 'hero or good citizen' (Jensen, 2011). Interviews took place with donor family's months and sometimes years after organ donation, which certainly could have impacted the authenticity of the results. The analysis revealed how families were left with bad memories and unanswered questions, deprived of sharing their experience or even being recognised for their selfless act, as this was not a priority for the organ donation organisation. Within the UK, we are unaware if the current experiences of donor families are similar to those families who participated in the study by Jensen (2011), and there needs to be evidence to validate this, so improved aftercare may be necessary to uncover and resolve these issues. The study also recognised the differences in culture, infrastructure, and organisational contexts between both countries. Despite differences in the construction of understanding and position, experiences from both countries' values regarding life and death equated to the same meaning (Jenson, 2011).

Nearly 30 years ago, Sque & Payne (1996), in a narrative study of 24 organ donor families, emphasised the importance relatives place on the fact that their relative lives on. The findings identified the need for recognition, value, and for organ donors never to be forgotten. Indeed, others argue that the gift of organ donation interactions should be appreciated through religious and nonspiritual terms of sacrifice (Mongoven, 2003). As time goes by, the effects of organ donation are preserved in the yearning to receive information regarding the recipient of their relatives' organs. As organ donation organisations seek to ensure donation is routine practice, donors and their families must be aware of the reality regarding their sacrifice (Mongoven, 2003). The dated findings still harmonise with conversations I have had in clinical practice with donor families during the last ten years working as a SNOD, underpinning the motivation and requirement for this research. The organ donation professionals working in the bereavement arena are responsible for supporting donor families, not leaving them forgotten or unrecognisable (Sque et al., 2006).

While studies identify that families consent to organ donation to give some meaning to their relative's life and death (Jensen, 2010; Berntzen & Bjork, 2014; Walker & Sque, 2016). Families can also experience feelings of disappointment and deflation of non-proceeding DCD donation, where the distress of supporting organ donation results in negativity as their relative did not die in the timeframe, and grief is recharged (Corr et al., 2011; Sque et al., 2018). When families cannot make sense of death, and when organ donation does not proceed, it can leave the family feeling that they did not honour their wishes, and this impairs the ability to make sense of the situation (Dicks et al., 2017a; Sque et al., 2018). For some, just the offer of donation, even if not successful, is sufficient (Marck et al., 2016). This is important in practice, as all relatives of non-proceeding DCD donation offered donation may expect a positive outcome, but sometimes, they are left with nothing. Aftercare support in practice for these families is not readily available to access, and the families need to express their need for additional support to be signposted to external organisations offering bereavement support that is not specific to individuals who have experienced organ donation. As an organ donation organisation, we want to support families beyond donation and into their bereavement, leaving them feeling valued and proud of their loved ones; we do not want to leave them feeling forgotten. As a SNOD, you can form a special bond with families during the organ donor process (Maloney, 1998). This relationship often stops straight after the donation when the SNOD moves on to the next family requiring support and facilitating organ donation, and my clinical practice supported this concept, I felt that you were moving on before the family was ready to detach from the organisation and the experience of organ donation. Many of the studies generated evidence based on a small qualitative sample (Maloney, 1998), again some could be considered outdated. Yet, the experience in practice appears to reflect these findings, suggesting they are still pertinent today. Although NHSBT is attempting to improve the aftercare services for organ donor families, much more still needs to be done.

Culture and community values influence experiences; for example, Danish families who took part in the narrative study by Jensen, (2011) revealed that they did not need to reframe or reinterpret their donation experiences, as the social meaning was self-evident (Jensen, 2011). Framing the donation action as part of 'being Danish' can form a profound outcome and give families peace of mind. NHSBT consent data illustrates that this is not replicated in the UK, and the current UK consent rate sits around 62%, with 1130 people saying no to organ donation in 2022/23 (NHSBT, 2023). As a society, we do not perceive organ donation as a devoted nationalistic offering as emphasised in Denmark. In comparison, organ donor families in the USA are public facing, using public speaking to construct their stories, relive their experiences, and present their relatives as having performed an act of heroism (Jensen, 2011). Like the UK, some donor families see public recognition as promoting organ donation (Sque et al., 2018). Seeking public recognition and talking about their relatives and how proud they are of them could act as a way of coping with the bereavement and helping them heal (Dicks et al., 2017a; Sque et al., 2006).

The Need To Connect With Transplant Recipients

Families agree to organ donation with the knowledge that their relative is saving the lives of a stranger. Many find peace in knowing that their relative impacted the lives of others, contributing to their family narrative (Manuel et al., 2010). Extensive research has shown for many years that families of deceased organ donation desire correspondence from the recipient of their relative’s organs to confirm their correct decision (Sque et al., 2018; Azuri et al., 2013; Sque et al., 2006; Maloney, 1998). Organ donation can significantly affect families and relatives for the rest of their lives. A fundamental aspect of donation centred around the need for organ donor families to acquire information about the recipients of the organs (Sque & Payne, 1996). The bereaved frequently track this goal in part by reforming the relationship with the person who died to preserve a continuous bond, usually forming an idea of that particular person who received the organ transplant (Corr et al., 2011). There have been several studies contesting the belief that organ donor families discovering too much information about the recipients can complicate the grief process (Dicks et al., 2017b; Holtkamp,1997; La Spina et al., 1993). For some years, NHSBT has moderated the information provided to donor families, restricting the individual components, and making the relationship between the donor family and the recipient anonymous and depersonalised. There are benefits and disadvantages of contact concerning donor families and transplant recipients, which include uncomfortable feelings about being alive while the donor family’s relative is dead; fears of reliving painful memories; and worries that the donor family might want some involvement in the recipients’ life (Azuri et al., 2013; Corr et al., 1994). There are also ideas that recipients need to say, ‘thank you,’ and that donor families want to make contact with their relative through their recipient (Bolt et al., 2018; Azuri et al., 2013; Politoski et al., 1996; Corr et al., 1994).

The anonymity and privacy of donors and recipients have initiated significant discussions over time. Bolt et al. (2018) explored why donor families seek direct contact with recipients of their loved one’s organs and struggle with enduring feelings of restlessness. The study examined the views of death and dying with 25 families who had consented to organ donation in the Netherlands to expose the diversity of the Dutch population. The findings identified that donation families are left with unfulfilled, unfinished, and unsatisfied feelings, and gaining more information or access to recipients would help to resolve these feelings. These findings are consistent with a study in the UK by Sque & Payne (1996), where donor families appreciated the initial information regarding recipients but desired further communication, and this desire did not lessen over time. The complexity surrounding organ donation family responses while grieving is evident, reinforcing the need for improved aftercare services (Bolt et al., 2018; Sque & Payne, 1996). A fundamental goal in mourning is to find ways to comprehend the meaning of the loss one has experienced. Bereaved persons frequently follow this aspiration by reforming the relationship with the deceased person to preserve a continuing bond or special connection (Corr et al., 2011). Adult mourners do not cautiously ‘detach’ from the lost person but instead reposition their ideas of self and lost figures to make a permanent bond and change to real circumstances possible (Bowlby, 1982). In practice, families often desire to connect with the future recipients of their relatives’ organs, which could be an influencing factor to consent.

The Need For Bereavement Support And Aftercare

There is uncertainty regarding donor family experiences and their journey towards healing following organ donation. There needs to be more research on what aftercare strategies work for whom when is exposed in this search for evidence. Instead, research has concentrated on the decision-making, the events leading up to the death of their loved one, and the source of comfort it brings, and little attention has been paid to the continuing support needed by donor families (Dicks et al., 2017a; Walker et al., 2013; Holtkamp & Nuckolls, 1993). Some believe organ donation can bring comfort and meaning to donor families (Sque & Payne, 1996; Jensen, 2011). Indeed, evidence suggests that organ donation has no impact or influence on the grieving process (Cleiren, Van Zoelen, 2002; Sque et al., 2018). Others oppose this position claiming that the process of organ donation can compromise the emotional state of donor families, causing added stress which may hinder the grieving process, affirming the need for organ donation organisations to provide appropriate aftercare and support (Maloney, 1998; Warren, 2002; Sque et al., 2006; Sque et al., 2018). Whilst working in the UK organ donation organisation, I was mindful of the nominal aftercare and bereavement support provided to families. This was the primary justification for focusing the search and exploring positive and negative explanations on which to develop ideas for a support group. The nature of the bereavement and the act of organ donation requires experts to tailor support, provide recognition, and ongoing bereavement assistance to ensure that the grief process is supported and not amplified (Dicks et al., 2017b). This requires specialised support from the NHS organ donation organisations, and they have a duty of care to provide this (Holtkamp & Nuckolls,1993; Vajentic & Calovini, 2001; Berntzen & Bjork, 2014; Dicks et al. 2017b). A systematic review suggested that allowing organ donor families to present a narrative of their bereavement journey will provide organ donation organisations with guidance on how best to offer aftercare support (Dicks et al., 2017b). Donor family experiences are varied, recognising that many families who agree to organ donation have ongoing bereavement needs, such as further information, acknowledgment and recognition of their act, assurance, and bereavement support (Dicks et al., 2017b). The responsibility to provide this information and support remains with the organ donation organisation and not the hospital that provided the patient care due to the complexity of the support needed (Sque et al., 2006; Ralph et al., 2014; Maloney, 1998). Parkes (1993), over 20 years ago, suggested that specialist bereavement services were more efficient if they were built into the services provided by healthcare professionals. Despite bereavement support initiatives being introduced into the aftercare support for families/friends, such as the St John Awards, the capacity of psychological bereavement support appears limited, with constant reference to a lack of resources. Ten years ago, the research identified that the evidence related to the bereavement support and aftercare of organ donor families was insufficient, despite the requirement to improve the quality of bereavement care for organ donor families (Berntzen & Bjork, 2014). The lack of empirical evidence may be why aftercare has not progressed. However, it is unclear why organ donor organisations have not customised or encouraged research to fill the gaps in knowledge to inform and improve organ donor family care. Calls suggested it was time to involve families in developing organ donation services instead of hypothesising the family’s needs (Jensen, 2011; Dicks et al., 2017b). Despite many recommendations spanning over 20 years, little has advanced within the aftercare services, and communication post-donation for UK families is often inconsistent, suggesting that if families receive quality aftercare, this can provide better understanding, recognition, and bereavement outcomes (Maloney, 1998; Sque et al., 2018; Berntzen & Bjork, 2014).

Using Social Media As A Bereavement Resource

Social media access has transformed how people communicate and connect (Shneiderman et al., 2011; Househ et al., 2014; Khan & Loh, 2022). The use of social media for personal and health purposes is on the rise. Social media can provide a platform for patients to gather information, explore options, and share experiences (Househ et al., 2014). Researchers have started identifying the benefits of using social media within a health context (Househ et al., 2014; Vasilica, 2015; Smailhodzic et al., 2016). This includes using social media to support bereaved people, as the virtual space becomes a place to share the experience of a loss (Jones, 2004; Nager & de Vries, 2004). It has been suggested that social media can provide bereaved individuals access various resources to help them cope with their grief (Stroebe et al., 2008).

Moreover, the internet and social media Apps such as Facebook, Twitter, TikTok, Instagram, and Reddit can help connect people who otherwise would never have met (Hollander, 2001; Centola, 2013; Moore et al., 2019). It also allows them to disclose their feelings and share their experiences with people in similar situations. However, there is little evidence regarding online bereavement support groups (Lenferink et al., 2020). For survivors of relatives who had committed suicide, online platforms are a place to share their narratives and are valuable in connecting with unseen others who have experienced similar suffering (Feigelman et al., 2008; Honeycutt & Praeorius, 2016). This could be similar for bereaved organ donor families, allowing them a space to express concerns and anxieties to be addressed and discussed. It could provide people with an opportunity to grieve aloud, a safe place to unload thoughts or feelings, an online group could offer support 24 hours a day. There has been increased internet use in bereavement, and bereaved communities' access online support (Tolstikova & Chartier, 2010). An online group could provide professionals with an opportunity to deliver information and distribute knowledge while learning about the grief of these families. Healthcare providers are seeking alternative ways of communicating with patients due to traditional methods, such as leaflets, becoming archaic (Househ et al., 2014).

Despite the proposed benefits to the bereaved, expressing their grief and sharing their stories can be distressing. Alternatively, sharing thoughts and emotions rather than internalising them can be a positive coping mechanism (Robinson & Pond, 2019). Rossetto et al. (2014) revealed various challenges to privacy, ownership, and control during the bereavement journey, which can enhance the loss-orientated stress to the existing grief. Their analysis, however, supported the hypothesis that despite its challenges, Facebook remains a valuable aid during the grieving process. It enables the bereaved to connect with others irrespective of location or time, giving them a space to share experiences, support each other, and build relationships. Geographical isolation, social isolation, and transport limitations can impact an individual accessing in-person support services (Gibson et al., 2020). A review by Gibson et al. (2020) highlighted the opportunities and challenges of providing online bereavement support services, reinforcing the potential for organ donor families. Findings revealed that technology presents a new approach to reaching extensive audiences enabling them to access essential services and information. However, the findings emphasise the need to consider diverse communities and groups who resist technology. The need to evaluate the influence of an online group, particularly in bereavement, strengthens the justification for the proposed study and the gap in the literature.

Summary

In summary, this chapter exposed the shortage of research on organ donor family aftercare. The evidence from the literature review reinforced that neurological death is a difficult concept to understand for both healthcare professionals and, more importantly, the families of the patient, leaving them with questions and concerns regarding the process and uncertainties regarding the death of their relative. Organ donation is a selfless act of kindness that can comfort many donor families. Despite the positive outcomes, it can also leave families with unanswered questions. The literature reveals the motivation for agreeing to organ donation but also highlights the importance of providing ongoing support and recognition to these generous families. What emerges clearly from the existing literature is the need to provide ongoing support and aftercare to organ donor families. Having explored the literature, it is clear there is a gap in the evaluation of bereavement services following organ donation, as this complex process provides multifaceted issues which require personalised care and support; this is supported by bereavement theories (Freud, 1957; Kubler-Ross, 1969; Bowlby, 1980; Stroebe & Schut, 1999; Worden, 2009). There is a growing demand for the use of social media for health care purposes. The

Box 1: Key Findings and Gaps in Evidence

What we know:

- Neurological death is a difficult concept for families to understand, which leads to uncertainties and questions regarding the death of a loved one in the days that follow organ donation
- Organ donation is a selfless act of kindness which can bring comfort to many donor families but can also leave donor families with unanswered questions
- Recognition that families require ongoing support post donation
- Organ donor families need to acquire information about the recipients of organs, seeking acknowledgement
- There is a gap in aftercare services for donor families - currently outcome letters and St John Award, 12 months post donation, is the only aftercare people receive
- There is limited evidence appraising aftercare support for organ donor families
- We don't really know what donor families want/need following organ donation we have never ask them

What we don't know:

- Limited evidence that supports the use of social media as a bereavement resource
- No empirical evidence of using social media to support organ donor families
- Limited evidence showing that current aftercare support methods work
- It is unknown if donor families ever move forward in their grief
- It is unclear clear what support strategies would help support donor families
- Uncertainty around the impact organ donation has on the grieving process
- No evidence to strengthen the need for organ donor families to provide peer support

literature revealed the benefits of information sharing and apparent self-efficiency, especially in the current global pandemic (Aarts et al., 2021; Househ et al., 2014; Gibson et al., 2020). The 34 articles reviewed provided little evidence regarding using social media as a bereavement resource to support organ donor families' aftercare. Although we have narrative evidence that this model of support is a success in the USA, it has not been critically appraised. Box 1 outlines the key findings from the review and areas for development.

In conclusion, the key findings from the literature review suggest that organ donor families are left isolated with minimal support post-donation despite having continuing questions, anxieties regarding the process, and a need to know about the recipients, and the organs of their loved ones, in addition to their grief.

Chapter 3: Research Methods and Setting Up the Group

Introduction

The background to organ donation and the context of the study was presented, introducing evidence regarding organ donation's meanings on a family, emphasising the need for support and aftercare. The literature review exposed a lack of empirical evidence grounded in family aftercare, despite there being an accumulation of research advocating that additional aftercare was vital in supporting organ donor families (Holtkamp & Nuckolls, 1993; Walker et al., 2013; Dicks et al., 2017a; Sque et al., 2018).This chapter clarifies the epistemological position I have applied, considering my reflexive positioning and relationship to the research as a healthcare professional working in organ donation. It also introduces the research study, methods, recruiting participants, and setting up the Facebook support group. Ethical issues associated with interviewing acutely bereaved relatives and more wide-ranging confidentiality and anonymity concerns are considered. The aims and objectives of this study seek to address the gaps in the evidence base to create innovative and new knowledge to inform aftercare strategies for organ donor families.

Questions, Aims and Objectives

The study's primary aim was to examine the influence of an online community providing peer-to-peer support to families of deceased organ donors following organ donation. The group provided a natural and safe forum to converse about their feelings and experiences with someone who had experienced a similar loss, supported, moderated, and guided by professionals. The study explored the influence of such an aftercare strategy on supporting the needs and grieving pathway of organ donor families. Three key objectives were identified:

- To explore the lived experiences of the families who donate their loved one’s organs at the time of death and understand the bereavement and grieving process post donation.
- To evaluate the use and influence of a Facebook closed group in providing peer to peer support group for organ donor families post donation and during their bereavement.

- To identify aftercare strategies that heroic donor families, need to support them through the grieving period post organ donation, informing the development of a new strategic aftercare plan for NHSBT that will develop and improve practice and the care of organ donor families.

Philosophical Stance and Methodology

Exploring values, views, and perceptions is the domain of qualitative inquiry, with rich, meaningful subjective data instead of acting as the goal (Creswell, 2008; Birks & Mills, 2011). Current evidence informing this study supports a qualitative approach to ensure that the views and experiences of donor families are central to the study, which is important to me as a practitioner. This research acknowledges the need for multiple realities directed by individual experiences (Lincoln & Guba, 2000; Rehg & SmithBattle, 2015; Bleakley, 2018). These lived experiences may vary from family to family but are essentially individual understanding. Four different scientific paradigms supporting philosophical assumptions comprise positivism, realism, constructivism, and critical theory (Sobh & Perry, 2006). The constructivism interpretation has been applied by health care professionals over time, predominantly in psychology, as it is believed that the emphasis is on the person or patient involved in the research. Accepting this assumption, people create their views of reality and knowledge from the human experience. Constructivism is a theory of knowledge (epistemology) to argue that humans generate meaning and knowledge from their experiences (Olohan, 2017). Social constructivism supported the study research question, as this paradigm maintains that people's experiences construct the world, and these interpretations of the world will strengthen their realities (Guba & Lincoln, 1994). The meaning of constructivism varies according to perceptions and position, defining the opportunities and boundaries of life's beliefs in the realisation of humanity (Ultanir, 2012). Social constructivism addresses the ontological–epistemological questions of constructivism in describing the bodies of knowledge developed over human history as social constructs that do not reflect an objective external world. Everything we know has been determined by the intersection of politics, values, ideologies, religious beliefs, language, and so on (Given, 2008). Social constructivism is a relevant philosophical opinion in studying social phenomena within social science. By social phenomena, we mean human experience, attitude, relationships, feelings, culture, etc. (Barbosa de Silva, 2008). A constructivism paradigm offers multiple realities which are subjective, and which can also be influenced by others' narratives and behaviours. The goal of the research is to rely as much as possible on the participants' views of the situation being studied, in this case, the certainty and complexity of bereavement. Questions are broad and general so that the participants can construct the meaning of a situation, typically forged in discussions or interactions with other persons (Creswell, 2008). Within the concept of organ donation, all families will grieve differently depending on their views of the world, constructed realities, relationship with the deceased, and previous grief experience. Constructivism is concerned with explaining how individuals define, explain, and account for the world around them, including themselves (Gergen,1995). Sobh & Perry (2006) stated that in the theory of constructivism, reality is perception, so simplifying one research finding about a person's perception to another person's belief about reality cannot be done. This could be similar for bereaved families; everyone experiences grief and bereavement differently, and their views, culture, and beliefs will impact their constructed realities (Sobh & Perry, 2006; Guba & Lincoln, 1994). Epistemologically, I the researcher will take a subjective and transactional approach to examine the phenomena under research. This involves interaction between me and the participants to create the findings accurately. Unlike the positivist and post-positivist paradigms, ontology and epistemology are interwoven as within constructivism, the belief is that it is impossible to consider one without the other (Sobh & Perry, 2006). In this study, I the researcher interact with donor families, accessing multiple views of reality that existed through their own lived experiences (Appleton & King, 1997). The constructivism approach allowed me to ask questions and discuss any issues with the participants, generating a candid narrative, informing the research, and providing the donor family community with a voice to make a change. I gained a deeper understanding of the phenomenon to recreate the perceived social reality through the lived experiences of donor families (Thomas et al., 2014). The philosophical foundations, thoughts, and perspectives of the researcher form an important element that will help to inform any decision and choice of methodology (Denicolo et al., 2016). The methodology for this study takes a qualitative approach (Berntzen & Bjork, 2014; Dicks et al., 2017; Sque et al., 2018), building on what has been used effectively before to draw out the voice of the donor families, their realities, and experience which is central to the study, allowing me to act as an advocate, driving the experiences of the participants forward to make a positive impact on future aftercare. My personal and professional experiences influence the methodological framework and supporting philosophy. My nursing background and career are underpinned by a philosophy of caring and listening to interrelated beliefs about the world and how individuals understand them. I frequently evaluate what this represents and how I can positively help (Reay et al., 2016).

Reflexivity

Considering this approach to the research, there needs to be some requirement of accountability and responsibility for the decisions and actions made throughout the study. Reflexivity is a process of self-analysis exposing who we are as a person but also as a researcher, whilst also accepting how our personal biases may influence the research process (Creswell, 2014; Berger, 2015). Willig (2013) notes that the researcher influences and shapes the research process personally and as a theorist/thinker. These ideas of personal reflexivity (the person) and epistemological reflexivity (theorist/thinker) present the opportunity to recognise the researcher's identity, preconceptions, and epistemological and theoretical positions linked to the research process and its findings. This also signifies both my values and beliefs and the validation of any assumptions that may impact the co-production of the data and its analysis (Cromby & Nightingale, 1999). It is acknowledged that within this reflexive research the families experience is situated and inescapably, shaped by the process and practices of I the researcher. Indeed, the researcher subjectivity, and the aligned practice of reflexivity, is seen as key to successful thematic analysis (Braun & Clarke, 2022).

My views on organ donation have been constantly positive, which could influence and shape the research and knowledge produced. Recognising that my position, values, and beliefs possibly affected how I interpreted the data being collected and the questions I sought to answer, I became aware of several factors that may have influenced the analysis. I was aware that I had worked as a healthcare professional, supporting bereaved families for over 12 years. I strongly advocated organ donation, believing it was a positively selfless act. My personal experiences of bereavement have been limited to losing grandparents and extended family members only. This changed during the research period when I suffered the sudden bereavement of my dear father. My personal experience provided me with more profound empathy, although I found the raw narrative challenging to read at times early in my bereavement journey. I was mindful of my professional position and the personal suffering I had experienced during the research process, which was a challenge. Acknowledging my personal experience, I maintained a professional approach, having supported families through bereavement for many years while being aware of my ideas and beliefs in relation to death and grief. I continued to collect data from the group, ensuring that I paused for reflection and self-care. However, acknowledging it is not always possible for researchers to set aside things about which they are not aware" (Ahern, 1999).

Furthermore, I supported my thinking using a research journal in which I recorded my thoughts and reflections, recognising they informed the analysis process and were consequently highly useful when incorporating reflexivity considerations. Through the analysis process, I have also interrogated my own personal beliefs concerning organ donation, having been immersed in the emotional narrative, which at times demonstrated elements of pessimism, producing questions regarding my position and the value of organ donation. I have always considered organ donation a positive end to a person's life. Although throughout the study there were times when I was uncertain about my beliefs, observing how organ donation intensified the grief of organ donor families, causing additional anguish and pain. This additional sorrow caused by the process of organ donation forced me to reflect on my own position.

Research Strategy

Online bereavement support as a virtual space has quickly become a place to share the loss experience (Jones, 2004; Nager & Vries 2004). Employing a qualitative approach enabled the analysis of individual organ donor family experiences while collectively examining the data to establish patterns drawing on the disclosed themes, establishing how services may improve within the healthcare setting (Broom & Willis 2007). Organ donation was such a unique experience (Sque, 2000; Dicks et al., 2017b), and a distinctive phenomenon explored through the narrative data collected from the Facebook support group, as well as through interviewing individuals about their lived experiences. This is the first research study to evaluate the use of an online social media support group allowing organ donor families nationally the opportunity to connect and support each other through the bereavement journey. The group offered peer support, responded to each other’s questions, shared their lived experiences in the weeks and months following the donation and the death of their loved one. The study provides an exciting opportunity to develop new knowledge, informing the bereavement support, which is essential for organ donor families and for NHSBT to ensure the development of organisational policy and aftercare. It also considers the use of social media in connecting bereaved families. With the unprecedented constraints set by the global COVID pandemic, individuals were left feeling isolated, and this research study assisted in ensuring that families could connect and feel less disengaged with society at such a difficult time. The world as we know it has transformed, relying on technology increasingly. The use of social media in bringing people together continues to magnify and evolve, becoming part of our everyday lives (Akram & Kumar, 2017).

Benefits And Challenges Of Using Facebook

There are many positive and practical reasons for electing to use a social media platform to connect organ donor families and support their aftercare. Sanderson & Cheong (2010) suggest that social media use can enable meaningful grieving habits, promote the connection between bereaved individuals, and facilitate community-building practices for people across different geographic locations, ethnicities, and religions. This confirms the value of the support as it is offered nationally, impacting families nationwide. These benefits of online networks are cost-effective, accessible, and anonymous, providing instant and unrestricted access to others, allowing organ donor families to express grief, vanquish distance to form an online community that provides and also offers support to other organ donor families (Carroll & Landry, 2010; Smartwood et al., 2011). Professionals have raised concerns (Cronquist & Spector, 2011; Lubas & De Leo, 2014) regarding the ability to maintain privacy and discretion, lack of contributor professional knowledge, and participants' use of technology. Initially, I offered practical support to anyone who needed more confidence in using Facebook, although none of the participants accessed this support. In addition, using Facebook removes the personal element, not having physical contact that some may desire (Rossetto et al., 2014).

Approval And Agreement From NHS Blood & Transplant

Within NHSBT, several internal stakeholders were consulted about the proposed research study. NHSBT supports and encourages new research, and the establishment of the Research, Innovation, and Novel Technologies Advisory Group

(RINTAG) has provided a route for understanding current innovations, supporting the implementation of appropriately approved and funded research, innovations, and service development in organ donation and transplantation (NHSBT, 2020). A full risk assessment was completed per the guidance set by information & governance and the quality & assurance department within NHSBT. The risk assessment highlighted any potential risks to the study and the impact factor on the donor families and organisation. The study proposal was also approved and sanctioned by NHSBT's internal Research, Innovation and Novel Technologies Advisory Group (RINTAG) (appendix 1) prior to starting the research study.

Setting Up The Peer Support Group - ‘Donor Families Together’

The development of the first UK social media bereavement support groups, specific for families/friends of deceased organ donors, is based on the theoretical authentication gathered from the literature review, affirming the need to continue support and care for families who have consented to donate the organs of their loved one at the time of their death. Facebook was chosen as a platform to connect donor families due to its popularity, simplicity, and cost (Prescott et al., 2020). The Facebook support group acquired features similar to the Facebook support pages developed by OPOs in the USA. Participants could join a closed, confidential group on Facebook using secret group features and settings. Secret groups offer a cloak of invisibility for participants (Tolstikova & Chartier, 2010). No one can search for secret groups or request to join them. Although, even the closed or private group settings that Facebook implements only serve as a control method and do not ensure exclusivity (Hoondert & Van der Beek, 2019). This was an important consideration when developing the group and a worry for NHSBT as a professional organisation. The only way to access the group would be through a formal invitation and this would prevent non-donor families from accessing the group. Everything shared within a secret group is visible only to its members and I retain access control, so this issue was removed. The practical development of the group was challenging as a relatively novice social media user. The initial construction occurred cautiously, and all elements were considered before being implemented due to the complexity of the members and the topic of discussion:

- Deceased donor families were identified via DFACS

- Invitation (appendix 2) to join the group was posted following proceeding organ donation
- Invitations were included in the donation correspondence letter, providing families with information about the group and the researcher's email address
- Family members could join the group at any point
- If the family choose to join, then they contacted me as the lead researcher, who sent them a Participant Information Sheet (PIS) (appendix 3), consent form (appendix 4), netiquette (appendix 5), and group description (appendix 6)
- A link to the Facebook group was then forwarded to the family member once I received the completed consent form
- A database containing a list of all participants was and kept on a password-protected computer, accessed only by me as lead researcher
- Each family member was given a pseudonym to protect their identity

Online Security And Site Moderation

Online security is an essential aspect of this research (Gulotta et al., 2016; Gibson et al., 2020). NHSBT carried out a full risk assessment to ensure the donor families and NHSBT status was kept safe throughout the study. Donor families were given permission to join once their identity was verified by me as lead researcher. The Facebook site was established to be secure and private, and involvement from NHSBT's social media department was obtained throughout the project. The group was developed as a closed secret group, providing an element of protection to the participants. Open groups can be detected by regular Internet searches. However, search engines do not index closed and secret groups, consequently these Facebook groups cannot be found by search outside Facebook (i.e., by using Google). Only secret groups offer a complete “members only” environment. Although, it requires additional work to create, and new members have to be personally invited by the administrator (Miron & Ravid, 2015). Donor family members were provided with netiquette guidance prior to joining the group, along with the consent form and group description. The netiquette guidance outlined the research project, expected behaviour, confidentiality, anonymity, and expectations for joining the group. At times tone can be misunderstood in written communications allowing interactions to become hostile (Beltran-Ponce et al., 2022). Although this was assumed to be unlikely, the netiquette guide established appropriate boundaries. The Facebook group was regulated and moderated by me, the researcher, a member of the NHSBT communication team, donor family advisory group, and a chaplain who is a trained counsellor. Embedded in the team were also experienced peers who can help support health/emotional/spiritual questions posed within the group. The moderation team, all work for NHSBT, and were trained in supporting acutely bereaved families, and so it was agreed that no further training was needed. Advice and management of the Facebook group were required from NHSBT social media communication department, who have experience in social media monitoring. Following the development of the group, the social media communication team had little input, this is due to the group not requiring input or guidance. The professionals were brought together as allies to support the me the lead researcher throughout the project, offering expert advice and assistance. I delivered a multi-professional information session to give the moderation team information about the study and the expectations of their role. I presented the aims and objectives, recruitment process, their role in supporting the group, and what to do if they had any concerns or worries, provided them with additional signposting information. Any moderation team need to be aware of the Facebook group communications preferences, they also need to provide education, signposting, and reminders of the privacy settings to the wider group members (Partridge et al., 2018). The moderation team were familiar with the process and information that all Donor families who requested to join the group are issued a PIS, group description, and netiquette guidance on expected behaviour and fully understood the extent of their role. The NHSBT information governance department approved all the relevant documents to ensure they meet NHSBT organisational guidelines.

Confidentiality And Anonymity

When using online platforms, there is always the possibility of a confidentiality breach, so participants should always be aware of the potential risks (Gibson et al., 2020). Data protection was an important focus throughout the study. NHSBT demonstrated an element of apprehension during the development stages of the study. Assurance was needed before NHSBT granted permission to continue. All data collected was kept in a locked cabinet or secured password-protected devices. The data has been kept for the duration of the study, and all personal details will be destroyed as per General Data Protection Regulations (GDPR). The Netiquette guidance outlined the need to keep the discussion on the Facebook page as confidential as possible, limiting identification, although it evident that some of the participants wanted to make direct contact, and this possibility was addressed in the netiquette guidance issued to all participants prior to joining the group. If names were used, then a pseudonym was given in exchange for the individuals personal identity. Fundamental to me as a nurse is the Nursing and Midwifery Code (NMC) code of conduct, which states, we must respect people's right to privacy and confidentiality. As a nurse, midwife, or nursing associate, you owe a duty of confidentiality to all those who are receiving care. This includes ensuring they are informed about their care and that information about them is shared appropriately. Making sure that people are informed about how and why information is used and shared by those who will be providing care and respecting that a person's right to privacy and confidentiality continues after death (NMC 2018). Even though this is a research study, these standards continue to be an essential aspect embedded throughout.

A written introduction to the research was given to all interested participants, describing the study, data collection methods, analysis, and dissemination.

Donor Family Advisory Group (DFAG)

A donor family advisory group (DFAG) was initially established to support me (the researcher and NHSBT lead for organ donation) and other moderation team members. The DFAG comprised of past donor families who played a crucial role in sustaining and developing the group discussions. In the context of this study, the DFAG had an essential role in supporting the moderation by bringing their lived experiences and knowledge necessary to relate with donor families. They all received moderation training and support from myself and my supervisor, who is a social media expert.

With their individual lived experiences, the group provided awareness of the donor families' knowledge and encouragement. Bi-monthly meetings and further communication via email and telephone were initially provided during the development of the Facebook support group. Once the group became established, the DFAG had minimal participation, occasionally commenting on a participant's statement or welcoming new members to the group. On reflection, the DFAG group did not engage as expected; however, their input into the initial development was essential, advising, supporting, and endorsing decisions throughout. The lack of engagement could relate to the nature of the conversations which took place between the bereaved relatives. These painful accounts may have been upsetting to hear, revisiting their own grief. It may have been that my own initial expectations were set to high, wanting constant interaction which was evidently not needed.

Target Population/ Sample

The study intended to engage as many donor families as possible, offering them a means of connecting with other donor families in similar situations. NHSBT provide a national service, 2021 saw 1574 families donating their loved one's organs at the time of death. This figure is small compared to the annual number of deaths in the UK, which is around 600,000 (NHSBT, 2019). Several researchers have identified problems accessing bereaved participants (Pelletier, 1993; Sque, 2000; Shaw, 2011). Pelletier (1993) reported only a 29% recruitment rate from an exploratory study undertaken in Canada, which may have impacted the outcomes. Parkes (1995) highlighted problems in acquiring contact with bereaved individuals. He indicated that 'gatekeepers' need to be wary in authenticating the researcher and the candidness of the research; they are inclined to deprive the bereaved of the opportunity to support research, consequently impacting the research sample. I was in a unique and privileged position, having direct contact with the bereaved organ donor families and positively influencing the direction of the study through my role as a SNOD.

Tolstikova & Chartier (2010) found that online bereavement communities help to offer a connection to people who have had similar experiences or a place they can talk about their grief and loss. Expressing their feelings allows them to make sense of what they have experienced. Social media is the central feature of this study. However, it may be an obstacle for some donor families, for instance, families from diverse communities who may not access social media, English not being their first language, or individuals who do not engage with social media (Prescott et al., 2020). This essential element will need consideration when reviewing the participants who took part in the study, and some thought on how the organisation can become more inclusive when supporting donor families must be considered. Only some people have access to social media (Falconer et al., 2011; Smailhodzic et al., 2016; Gibson et al., 2020), and further research will be needed to address complementary bereavement resources for these underrepresented groups.

Recruitment

Following organ donation, all donor families receive a letter informing them of the outcome of the donation unless they explicitly decline this service. At this point, the invitation to join the Facebook support group was forwarded to all proceeding donor families; this invitation was not sent to families where organ donation did not proceed. This letter was sent by the Donor Family Aftercare Service (DFACS) administration staff. The DFACS staff were informed about the study and provided with specific guidance regarding the recruitment process. With organisational management agreement, I worked in collaboration with DFACS, identifying all proceeding donors, ensuring that an invitation to join the group was sent alongside the donation outcome letter. The time DFACS sent the letter was carefully considered at the start of the process. Initially, the plan was to send the invitation three months post-donation, allowing time for the family to process the death of their loved one. Following discussion and consultation with the donor family advisory group (DFAG) it was apparent that the invitation should be sent with the follow-up letter two weeks after the donation. Concerns regarding the sensitivity of researching the bereaved can potentially governor some research because of the assumed stress bereaved people will generally experience (Sque, 2000). The DFAG, based on their experiences, felt that it would have been useful to have this support immediately after the donation. Donor families were not restricted and could join the support group anytime, see the process of recruitment of organ donor families (Figure 8).

Figure 8: Recruitment process

1. Deceased Donor Families are invited to join
    - Invitation to join Donors Together Facebook group
    - Invitation sent with the 1st correspondence after donation by DRD
2. Participants express interest to join
    - Contact the researcher via email or telephone
    - Any questions answered
3. Researcher sends study pack and responds to queries
    - Patient Information Sheet, netiquette, group description and consent form
    - Questions answered
4. Sign consent and provide email address
    - Return the consent form via email or post to the reseracher
    - A link to join the group is sent to participants
5. Participants are welcomed to Facebook group
    - A moderator will welcome participants
    - Participants are reminded te group communation and behaviour rules (netiquette)

Informed Consent

The study objectives, group description, and all documents relevant to the study were embedded in the Facebook group description facility. In addition, this information was shared directly with participants when they initially contacted me as lead researcher. Participants were allowed to ask questions before they consented to join the group. Family members selected to participate in supplementary interviews were also sent an additional consent form to sign before the interview. All participants were made aware that the narrative from the site will be used to form part of the researcher's thesis and support the development of the NHSBT organ donation aftercare service.

There were two initial stages to the consent process:

- Initial letter inviting them to join. They then contacted me as lead researcher, who forwarded a consent form, PIS, netiquette, group description, and link to join the Facebook group. The completed consent form was returned to the me.
- Written informed consent was sought from individuals who agreed to take part in the one-to-one Interviews. The participant was provided with additional consent (appendix 7) once the sample had been selected and the interview agreed.

Qualitative Methods: Data Collection

This section will explore the use of narratives produced as posts on the Facebook group, polls, blogs, and interviews, exploring the significance related to each one of these methods. Informative or authentic approaches are often adopted to extract the information requirement and draw out individuals' perspectives, so the value is in the qualitative data used (Ormandy, 2008). The methods used draw out the information needed on a personal level, providing a more individual account of the genuine bereavement experience. The user-generated content generated on social media platforms is acknowledged as a readily available and ubiquitous data set. It includes 'ordinary actors' behaviours, attitudes, and beliefs (Kennedy et al., 2015). Data retrieved from platforms were used to inform health surveillance (Sharpe et al., 2016; Barros et al., 2020) and explore the unmet needs of patients with long-term conditions (Vasilica et al., 2021).

Digital methods offer a methodological approach to collect, manage, and analyse digital social data (Rogers, 2017). The methods are born within the platforms and combine qualitative and quantitative methods to gain an in-depth understanding of a topic. However, digital methods approaches are more than just neutral, presenting, amongst other issues, privacy challenges (Kennedy et al., 2015). The Association of Internet Research (AoIR) (2019), over the years, have created guidance on how to address privacy and confidentiality when using large datasets without users' content. This study used Facebook as an internet platform to create this unique group for organ donor families.

Posts And Comments Data Set

The data generated via Facebook provided in-depth evaluation of the support group and the potential benefits to organ donor families. The Facebook site acted as a micro-community platform for organ donor families to discuss their experiences, ask questions, and communicate with individuals who have had a similar experience. Online bereavement communities may perhaps offer the chance to connect with people who have had similar experiences and can endure sharing their feelings in relation to grief and loss, allowing for grief to be expressed and sense made from the experience (Tolstikova, Chartier, 2010; Gibson et al., 2020). The Facebook group narrative was extracted at different intervals throughout duration of the study, ensuring that the lived experiences of donor families were captured. The data focused on their bereavement journey providing a rich and authentic narrative.

The intention was to scrape (download) data from the Facebook page, adapting the principles validated by Vasilica et al. (2021). During the study Facebook altered its permissions, impacting the ability to scrape anonymised data. As a result, all group conversations were manually extracted for analysis, which took a considerable amount of time and effort. All the participants were allocated a pseudonym when joining the group, and this ensures that their identity is protected. The poignant discourse extracted from the Facebook group has been analysed to create new knowledge.

Facebook Poll/Question

A Facebook poll is a question feature that is presented to the group. A Facebook poll was initiated every month to gain an understanding of how the group was working (Parsons, 2013). Polls support a real-time response process, which allows instant analysis and the introduction of different methods (Rossetton et al., 2014). The intention was to regularly explore the usage, benefits, and challenges via polls and use the poll as a conversation starter. On Facebook groups, polls can be administered differently – using the integrated poll function or as a post. I initially opted to post questions instead of polls to allow members to comment. This was a less structured method, yet the data was more comprehensive and detailed through this feature, giving the opportunity for opinion and comment. The reasoning was also due to my inexperience and lack of expertise in managing a Facebook group. It took time to develop skills and understanding regarding the tool's functionality.

Blogs And Information Sharing Platforms

The prevalence of social media has stimulated interest in using blogs as a research method. Blogs have been successfully utilised in the context of health, being perceived as therapeutic (Ressier et al., 2012; Vasilica, 2015; Paterson et al., 2015). In health research, blogs have been used as part of a suite of methods to collate information about participants' experiences and perceptions (Wilson et al., 2015). In the context of this study, blogs would have provided donor families with an opportunity to share their personal stories and experiences beyond the Facebook group. A study website was initially set up to enable donor families to share lived experiences via blogs. Research has shown that sharing stories expressively, writing (Pennebaker & Chung 2011) and blogging about distressing experiences can help the healing process (Rossetto et al., 2014). Although part of the preliminary research proposal, it became apparent from the start that blogs would not benefit this grieving community at this stage. This was due to the sensitivity and intensity of the donor family situation. It would have been intrusive and callous to consider approaching donor families in the group at this time. However, it may be a helpful tool for organ donor families who are more advanced in their grief journey and want to support NHSBT in promoting organ donation. Sharing experiences for some organ donor families can be therapeutic (Sque, 2000) and in the future this may be an option.

Interviews

To strengthen the data findings, it was estimated that ten donor families would be selected using a stratified sampling method and asked to participate in one-to-one interviews. Interviews are often geared towards understanding the how and what of people's lives (Denzin & Lincoln, 2000). The interviews add depth to the existing data, recognising individual beliefs, opinions, and perspectives in the context of organ donation. However, interviews are not without limitation, as information is often collected not in the natural setting of the participant and reported only through their perspective, which is likely to be biased or influenced by the researcher's presence (Creswell, 2014). A total of six participants were interviewed in total. The data collected during the six interviews was plentiful and therefore a decision was made to pause at six interviews and not complete the 10 as initially planned. The interviews took place via Microsoft Teams. The interviews assisted in determining the motivations to join the group at such a challenging time, perceptions regarding aftercare, use of social media as a bereavement tool, and to gain a greater understanding of the circumstance. It is essential to understand the identification, the purpose and meaning to an individual in the context of their lives, values, and personal perspectives (Julien & Michels, 2004). The aim was to compose semi-structured interviews, which would take place over the telephone or via Microsoft Teams, depending on the participant's preference. All interviews were carried out by me, the lead researcher, via Microsoft Teams platform. I have significant experience supporting acutely bereaved families in my role as a SNOD; therefore, I felt comfortable carrying out the interviews and adeptly supporting the participants during the interview process. There are distinct considerations that affect the researcher involved in bereavement studies. The work's sad nature necessitates experienced people to carry out the study (Sque, 2000).

A stratified sampling method was employed to ensure that the diverse composition of the group was captured. Stratified sampling observes the underlying principles of random selection; however, it presents an element of researcher guidance in the selection process. Stratified sampling sections the research population into different subgroups. Introducing this selection process ensures the necessary participant population is represented (Denscombe, 2014). The one-to-one interviews helped when evaluating the use of the Facebook group and also captured the experiences of the donor families at individual level. An Interview guide was developed with 14 questions (Table 8), examining the use of the Facebook group and the organ donation process, and exploring suggestions for improving the services provided to organ donor families. The intention was to encourage donor families to communicate their meaning and understanding of the situation; therefore, semi-structured questions were designed, providing an element of digression.

Semi-structured questions enable more in-depth answers, and two-way communication, allowing respondents time to open up about sensitive issues while permitting inductive probing (Guest et al., 2012). The interview guide was developed using a combination of study objectives, evidence from the literature review, and the narrative from the Facebook group. The initial questions were centred around the donor families loved ones, offering a chance for them to speak openly about their relative and share happy memories. It is advised that early interview questions be easy to answer and constructed to help relax the participant, such as factual data such as name (Moule & Goodman, 2014; Denscombe, 2014). The initial questions allowed the participants time to speak about their loved ones allocating time to listen and connect. The interview guide was designed to be flexible, allowing for probing of questions if needed, seeking to discover the donor family's experiences of organ donation and the Facebook support group. Semi-structured interviews provide the interviewer with a clear list of subjects that need to be addressed.

Table 8: Interview Guide

Question 1: Are you able to tell me about (donor's name) and what happened?
Question 2: Did you already know if (name of donor) wanted to be a donor?
Question 3: Do you think social media/Facebook support group is a good way of supporting families?
Question 4: Do you feel that you were invited to the group at the right time?
Question 5: Did you find the online Facebook support group useful to you?
Question 6: Did you find it helpful to connect with other donor families?
Question 7: Did you find the resources on the page useful?
Question 8: What could I have done differently?
Question 9: How often did you use/look at the support group?
Question 10: What other support do you think you needed; we could provide?
Question 11: How do you feel about the organ donation process?
Question12: Do you think you needed extra support following organ donation?
Question 13: Have you any suggestions, recommendations for NHSBT?

Nonetheless, there was a willingness to be flexible in terms of direction and, perhaps more significantly, to enable the interviewee to create ideas and speak more freely on the issues raised by the interviewer (Denscombe, 2014). One of the intentions was to understand how social media facilitated bringing families together. However, this was not a primary consideration for the family members at this time of discussion, as they focussed on their relative and their grief experience during the conversations, which I accepted. A study by Dyregrov (2004) emphasised that 100% of the parents experienced participation as "positive" or "very positive," and none regretted participating. They linked the positive experiences to being allowed to tell their complete story, the format of the interview, and the hope that they might help others. Processes of meaning reconstruction and increased awareness of the bereavement process were facilitated by the interviews. Brought to my attention by a donor family who spoke about the comfort they got talking about their loved one.

> *"I love to talk about them; it feels comforting and helps with the grief."* (Helena, mother of donor).

The value of the interviews may have been perceived as a form of support by NHSBT, which may have influenced the candidness of the conversations. However, Sque (2000) suggests that other therapeutic results may provide a platform for participants to share the suffering they have experienced. As they have been part of the incident period leading up to the death, sharing this may clarify specific questions, helping them make some sense of their experience.

The main aim of the interview was to determine the value of the Facebook group, establish if the support it had brought to organ donor families was useful, timely and valued, and explore the need for aftercare support. The nature and topics discussed in the interviews were sensitive, emotive, and sometimes distressing (Sque et al., 2014). I confirmed the consent with the participant prior to starting the discussion, informing them that the interview may be tiring and emotional and that we could stop at any time. I also discussed the opportunity that post-interview support was available, prior to commencing the interview. None of the participants interviewed accepted any further post-interview support. There may be an element of selection bias due to the members of the group comprising of mainly females which is not representative of the organ donor family population. In addition to this the support group was online which may automatically exclude organ donor families who do not access the internet. Selection bias is ‘a systematic tendency to exclude one kind of unit or another from the sample’ (Freedman, 2004).

Stratified Sampling

Stratified sampling adheres to the underlying principle of random selection, although it does present an amount of researcher influence in the selection process. Stratified sampling segments the participant population into subcategories (Denscombe, 2014). By applying stratified sampling to the one-to-one interview selection, I aimed to target donor families with different experiences of bereavement due to their age, relationship to the deceased, gender, location, and donation experience (Table 9). I attempted to ensure that the group's diversity was captured and that different family members' views were invited. There were only two male participants in the support group, and I reached out to each one regarding one-to-one interviews; but neither of them responded. The stigma associated with asking for help especially for males, may discourage the bereaved from seeking personal help (Clarke et al., 2004). Evidence suggests (Zinner, 2000; Versalle & McDowell, 2004; Shepard, 2016;) that grief responses between men and women differ which may explain the lack of engagement from the male participants. Both the male participants rarely posted comments and although they actively read other participants comments and posts they both remained silent within the group.

Table 9: Target Interview sample

Sample characteristic (Based on loss)	**Families Interviewed**	**Scheduled**	**Completed Interviews**
Parent	1	Oct 2021	Oct 2021
Partner	1	Jan 2022	Jan 2022
Sibling	1	May 2022	No Response, not interviewed
Child/positive about donation	1	May 2022	Nov 2021
Male	1	May 2022	No Response, not interviewed
Different stages of grief	1	Nov 2021	Nov 2021
Does not interact with the group	1	Dec 2021	Dec 2021
Negative comments about donation	1	Jan 2021	Jan 2021

Face To Face Interviews

In the current climate and during the recovery from a global pandemic, it was not possible to undertake face-to-face interviews. If it had been possible to complete face-to-face interviews, they would occur in a location agreed by the researcher and the participant. There are benefits of face-to-face interaction, although the benefit of reaching a wider participant population due to the flexibility of Microsoft Teams meant I could interview donor families from a wider geographical area.

Telephone Or Online Interviews

Telephone or online interviews using a virtual platform such as Microsoft Team was a simple and more accessible way to perform interviews during this time, whilst recovering from a global pandemic. Given the geographical spread of donor families, it also reduced the requirement to travel to participants' homes. All participants had the opportunity to ask questions before deciding to participate in additional one-to-one interviews. The consent form to take part was shared and explained over the screen whilst being recorded. The participant responses were documented on the consent form whilst observed over the screen. The participant was made aware when the recording device started. The chosen sample of donor families were interviewed at various points throughout the study to understand their experiences. Six interviews were completed in total, two participants approached but did not respond as mentioned above. There was a delay in commencing the interviews due to the need for the group to become established, with a small number of family members joining initially the group needed time to develop, to ensure I could gain a deeper understanding of the group demographics before selecting participants to interview.

The first interview took place on the 18th of October 2022, with a mother who had lost her child, the interview took place over Microsoft Teams, and this was mutually agreed by me and the donor mother. The interview was recorded, and the transcription downloaded for analysis. All further interviews took place via Microsoft Teams.

Exit Poll

Anyone who expressed a wish to leave or disengage from the group was asked to complete a voluntary exit poll (appendix 8). The poll intended to capture information regarding the reasons for withdrawing from the group. The short questions include:

- What is the main reason why you stopped participating?
- Has the group been of any benefit to you on your bereavement journey?
- What are the challenges you have experienced?
- What could we have done differently?
- How can NHSBT improve our services for donor families after the donation process?

Only one participant left the group during the 12 months study, and they completed the exit poll.

Ethical Considerations

This research study required special consideration due to the sensitivity and complexity of the topic presented, and gaining approval was both challenging and time-consuming. Research ethics principles are intended to protect human participants' rights through consent procedures and independent review, as well as ensure the safety of researchers and participants and the safe collection, storage, and use of information gathered during the research process (Shaw, 2011). This research study needed ethical approval from several organisations, including, The University of Salford (appendix 9), the NHS Research Ethics Committee (REC) (appendix 10), and the NHSBT ethics committee (RINGTAG). Each ethics committee required explicit standards requiring various questions which emerged from each application, enabling me to ensure that the study was refined. The concerns raised throughout the ethics process related to researching the acutely bereaved, although I was able to satisfy all committees that the safety and wellbeing of the participants were paramount and adequate support was in place to support the participants. This was anticipated, as bereavement is considered an emotionally tense period for participants taking part in research since they lost someone they loved. As such, the understanding of bereavement makes it even more important that participants who take part in research are supported and their well-being considered paramount (Cook, 1995; Sque et al., 2014; Park et al., 2022).

Table 10: Practical strategies to ethical considerations

Ethical Considerations	**Practical Strategies**
Access	Formally identification deceased organ donor families
Respect/Compassion	Consider the participants situation and personalise the interaction and information giving
Informed choice	Provide them with written clear information about the study and the researchers details in the event of queries
Non-coercion	Allow participants to join at any time when they feel ready
Choice & respect	Agree the interview method/date/time avoiding dates that coincide with significant events
Safety & support	Lone working policy in place if researcher is conducting interview alone. Ensuring researcher has experience of supporting the bereaved
Choice	Providing participant with various interview methods to suit their needs

Informed consent	Providing an overview of the study and information for the participants to keep as well as a copy of the consent form
Support	When carrying out interviews researcher to observe for signs of distress and act appropriately
Confidentiality & anonymity	Ensure all transcripts, recordings, downloaded data are secure and stored on a password protected computer or locked in a secure cabinet. Protect anonymity using pseudonyms
Support following interview	Arrange for appropriate experts to support study and participants if necessary. Offer signposting to relevant professional if needed. Offer the chance for participants to reflect/evaluate and ask any questions
Appreciation	Send a personal thank you letter to all participants of the interviews
Involvement	Provide all participants the opportunity to evaluate their experience and offer information regarding the outcomes of the study
Support	Determine support for the researcher to debrief, if necessary, with an appropriate individual whom they feel comfortable with

A framework for ethical decision-making (Table 10) for the study was constructed based on essential ethical principles, supporting research governance (Sque et al., 2014). Furthermore, the privacy and confidentially widely discussed in digital methods were addressed through obtaining informed consent.

Wellbeing

The emotional well-being of the participants and the researcher was considered throughout this study, recognising the subject can be sensitive and emotive. “Interviewing victims of social disadvantage, personal tragedy, and family strife and so on, clearly seeks to elicit data that has huge potential to provoke distress, grief and all manner of emotional reaction” (Long & Johnson, 2007). By allowing for the well-being of the participants, I the lead researcher applied rigour and trustworthiness to the study signifying transparency and integrity, which provides the study with authenticity. The narrative from the group was moderated throughout the study primarily by me, the lead researcher, the DFAG (donor family advisory group), the NHSBT communications department, and a qualified counsellor who had sight on the group narrative. Any concerning comments were monitored and dealt with immediately; family members showing signs of extreme distress were contacted directly and offered further support by the supporting counsellor and signposted to external organisations which can support them if necessary. Such strategies were implemented to safeguard donor families involved in the research study. The trained counsellor was part of the moderation team but also supported the group ensuring that the donor family members are cared for and directed to further services if identified as vulnerable. The need to provide extra support from the counsellor was only required on one occasion. The family member expressed signs of distress, and I contacted the counsellor, who provided a one-to-one session with the donor family member. A group online session was also arranged and offered to all group members. The trained counsellor met with the group to provide more generic support, offering coping methods to the donor families.

Thematic Analysis

A methodology is an approach adopted to generate the knowledge required to answer a research question. Creswell (2009) claims that when determining a research design, a key consideration should be in relation to what the actual research problem is. Noble & Smith (2014) describe qualitative research as an approach to understanding the meaning within a situation, which can be either interpretative or explanatory, as well as exploring how people feel about a situation to enable practitioners to develop their practice (Lee, 2006; Ryan et al., 2007). Having reviewed and considered the different approaches to qualitative research, the qualitative methodology selected to conduct the study sits within the thematic analysis domain. Thematic analysis was chosen for my study as it is an adaptable and robust method for me to apply to this qualitative study. Qualitative research is positioned in an activity that places the researcher in that world (Denzin & Lincoln, 2005). It is a valid analysis where there is paucity of current evidence to support the theory (Broom & Willis 2007). The fundamental aim of qualitative research is to gain a better understanding of a phenomenon through the experiences of those who have directly experienced the phenomenon, acknowledging the value of the participant's unique viewpoints that can only be fully understood within the context of their experience and worldview (Castleberry & Nolen, 2018). Thematic analysis has been applied to classify the data's primary themes and core concepts. Applying a thematic analysis approach fosters transparency and reflexivity and is not restricted by any theoretical limits that may affect the study's scope. This approach provides the researcher flexibility and freedom and supports the constructivist position (Braun & Clark 2006). Thematic analysis has been poorly recognised as a primary method and is rarely appreciated in the same way as other methodologies such as grounded theory, ethnography, or phenomenology (Braun & Clarke, 2006). Research suggests that thematic analysis is similar to that of grounded theory (Kellehear, 1993), although grounded theory goes beyond thematic analysis (Ezzy, 2002; Tuckett, 2005). Often it is embedded within other approaches as a data analysis tool rather than a standalone approach. Thematic analysis varies from other analytic methods such as IPA and grounded theory. Both IPA and grounded theory search for patterns in the data which are academically confined (Smith et al., 1999; Smith & Osborn, 2003). Using thematic analysis is less restricted allowing for more autonomy. Thematic analysis, as in grounded theory, demands researcher contribution and explanation, focusing on identifying and describing implicit and explicit concepts which can be identified from the data (Guest et al., 2012). This qualitative study primary aim was to evaluate the use of a peer-to-peer online bereavement support group while understanding the lived experiences of deceased organ donor families. The group offered a safe place to discuss their experiences, supporting each other through the bereavement journey after donating a loved one's organs. The findings can be used to influence future aftercare practice that NHSBT offers to organ donor families, which may help support the development of future marketing campaigns and service development strategies. Braun & Clark (2006), six stages of analysis was applied to identify, analyse, and report patterns that emerge from the data. Qualitative approaches are incredibly diverse, complex, and nuanced (Holloway & Todres, 2003), and have been used in education, sociology, and anthropology for many years. The use of qualitative research is starting to be adopted in health research but remains underutilised (Castleberry & Nolen, 2018). Maguire & Delahunt (2017) support the use of thematic analysis describing the process as a foundational and flexible method for qualitative analysis, offering a hypothetically flexible approach to this research that is not distinguished by any explicit framework. Guest et al. (2012) argue that thematic analysis is still the most advantageous form of analysis, which captures the complexities of meaning within textual data sets and is the most used method of analysis in qualitative research. The thematic analysis provides a versatile and practical research tool through its inductive approach and theoretical freedom, advantages and disadvantages summarised in Table 11 (Braun & Clarke, 2006: p97).

Table 11: Advantages and disadvantages of thematic analysis

Advantages of Thematic Analysis	Disadvantages of Thematic Analysis
• Flexibility • Relatively easy and quick method to learn, and do • Accessible to researchers with little or no experience of qualitative research • Results are generally accessible to educated general public • Useful method for working within participatory research paradigm, with participants as collaborators • Can usefully summarise key features of a large body of data, and/or offer a 'thick description' of the data set • Can highlight similarities and differences across the data set • Can generate unanticipated insights • Allows for social as well as psychological interpretation of data • Can be useful for producing qualitative analysis suited to informing policy development	• Is a poorly 'branded' method, as in it does not appear to exist as a named 'analysis' tool, no kudos • The flexibility of the method allows for a wide range of analytic options which can mean that the potential range of things to be said about the data could be broad • It can make developing specific guidelines for higher-phase analysis difficult • Limited interpretive power beyond description if not used within existing theoretical framework • Unable to retain a sense of continuity and contradiction • Simple thematic analysis does not allow the researcher to make claims about language use, or the fine-grained functionality of talk

The data analysis commenced when donor families began to post conversations on the Facebook group. The sensitive yet intuitive data has been constantly analysed throughout the data collection phase. To support this data, the semi-structured one-to-one interviews were also analysed and coded using the six staged analytic processes (Braun & Clarke, 2006). Initially, a manual approach to coding was employed as I was familiar with this and immersed in the data from day one of the study. This has been enhanced using computer-assisted qualitative data analysis software, NVivo, registered with the University of Salford. Managing NVivo was challenging, I am unfamiliar with the software, and my preference leaned towards the manual coding process, which was the preferred approach I adopted as it was familiar. The one-to-one interviews with donor families offer depth and strength to support the research. At the same time, the narrative from the Facebook group assists with evaluating the support group while supporting the richness of the data (Figure 9).

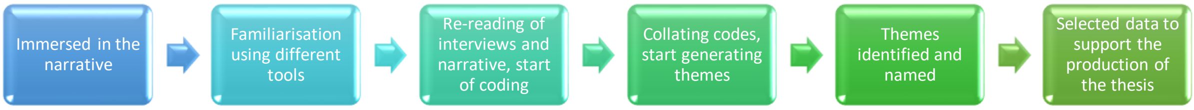


Figure 9: Six staged analytical process adapted from (Braun, Clarke, 2006: p35)

The six-staged analytical approach allowed me to familiarise and immerse myself in the data, using familiarisation doodles to identify initial codes before generating themes informed by the narrative, constructing clearly defined concepts related to the research question (Campbell et al., 2021). Following a systematic analytic process increases the rigour of the findings and the quality of the research (Nowell et al., 2017). Consideration has been given to the donor families engaged in the group. The gender, age, relationship to the donor, the time elapsed following donation, and considerations surrounding the circumstances of death, have also been examined and measured throughout the study. The recommendations will also consider how we can extend support to families who did not join the support group. Thematic analysis has offered an accessible and practical data analysis method. It is acknowledged that qualitative data analysis presents deeper complexities than quantitative data analysis processes, primarily because analysing qualitative data relies on individual conclusions and interpretations of the researcher (Silverman, 2019; Moule & Goodman, 2014; Bryant & Charmaz, 2007; Grbich, 1999). There are significant challenges facing the researcher when analysing qualitative data, including the effort required in the analysis of a lengthy interview narrative and how the data can be translated into meaning and value (Polit, Beck, 2012). I certainly experienced these challenges due to the considerable amount of narrative generated from the group discussion and the one-to-one interviews.

Summary

Adopting a thematic analysis approach to analyse the data facilitated a deepened understanding of the phenomena in a personal context and a distinctive analysis of the actual bereavement journey as it happens. Analysing the data from the Facebook support group conversations and one-to-one interviews has strengthened the study, generating evidence from bereaved families in real time. The data analysis allows links between the initial research objective and the emerging material, permitting the development of the initial research inquiry and evolution of new theory to develop and improve service delivery, improving the experiences of future organ donor families.

Rich data has been extracted from multiple sources:

- Narrative data (posts and comments) produced on the Facebook group (Facebook data sets)
- Facebook polls/questions
- Semi-structured one-to-one Interview
- Exit questionnaire

The need to further enhance the family aftercare service will be determined and is informed by the study findings, outcomes, and recommendations.

Chapter 4: Observations and Insight

Introduction

Fundamental to this thesis is identifying the support needs of families following organ donation and evaluating the use of an online platform in bringing these bereaved families together. The narrative data downloaded from the Facebook group has provided the study with in-depth emotional real-time discussion. The conversations have been challenging to read at times, providing a complete representation of grief as it transpires. Early in this process, my initial hopes and expectations remained optimistic, and I anticipated considerable interest from organ donor families. The reality proved otherwise, and initially, the number of organ donor families joining the group appeared small, not requiring the breadth of support I had initially expected. On reflection, various elements I incorporated into the preparation are now deemed unnecessary. This chapter will consider my learning from this process and offer a model to construct future online network support groups.

Facebook Polls

Despite my technological challenges, the ongoing monitoring and downloading of the narrative data allowed me to identify active users and posts that generated broader engagement. As a novice Facebook administrator, the polls generated were more illustrative of well-being questions. The study intended to generate discussion through the polls, although this was not evident from the narrative. On reflection, the polls could have been posted more frequently and the questions broader to help generate further discussion. Initially, I did not employ the Facebook poll function, posting questions rather than actual polls. I learned over time how to make use of the functions Facebook offer, gaining new knowledge throughout the process, enabling me to operate the many more functionalities.

Blogs

At the start of this research study, I anticipated donor families would find writing a blog therapeutic (Vasilica, 2015). Through this study, I realised that the pain of losing a loved one is so distressing that often, even posting a simple comment on the Facebook group was difficult. Families experience organ donation when their grief is all-encompassing (Sque, 2000), and to invite them to write a blog at such a difficult time would be intrusive. During this study, it became evident that while blogs can generate new, rich data which could support the development of future services, it was an inappropriate time to approach acutely bereaved relatives to write about an experience that has devastated their lives. Despite being a positive initiative of previous research studies (Vasilica, 2015; Wilson et al., 2015), it has proved to be ineffectual for this study, although in the future, donor family members who are further into their grief journey, may consider contributing to a blog.

Moderation Team

The initial development of the moderation team, which Vasilica (2015) informed, involved creating a group of professional's rich in experience, consisting of a broad range of the organisational team, SNODs, communications experts, and the donor family aftercare lead nurse. I also involved previous donor families who worked closely with NHSBT to promote organ donation. Previous donor families I felt, would benefit the group, and their involvement would be hugely significant. I also gained support from a hospital chaplain and a trained counsellor, who agreed to help support the group if needed. The training was provided to the moderation team prior to the launch of the support group. A netiquette guide was created and approved by the moderation team. The guidance helped ensure that participants' behaviour was appropriate and respectful, providing the moderation team with support and direction on mitigating any issues within the group. The support required was minimal, although all the group remained visible and on hand to the group in a monitoring capacity rather than an active capacity. The donor families welcomed new members into the group but stood back from the personal discussions. On reflection, it may have been due to the emotional nature of the conversations, producing painful memories of their own experiences. This was addressed with some members of the donor family advisory group to gain an appreciation of their involvement and insight into the whole process and they assured me that it was due to the group not needing the support as anticipated. This adds to the new knowledge about involving existing donor families in peer support and co-designing aftercare services for newly bereaved organ donor families. My expectations may also have needed to be more explicit, flawed by my need to create a positive environment for organ donor families in such stressful circumstances. The support provided by NHSBT operational team was helpful, although the moderation team members rarely engaging in discussion or feedback with me, the researcher. Over time, some team members departed due to role changes and restructure within the organisation.

Characteristics Of The Participants

All proceeding organ donor families were invited to join this group. At the end of the data collection period, 45 individuals had consented to join the group. Only two participants in the group are from the same family.

Table 12: Characteristics of sample

Participant	Relationship to donor	Gender	Participant	Relationship to donor	Gender
P1	Daughter	Female	**P24**	Partner	Female
P2	Brother	Male	**P25**	Partner	Female
P3	Mother	Female	**P26**	Mother	Female
P4	Partner	Female	**P27**	Daughter	Female
P5	Mother	Female	**P28**	Partner	Female
P6	Mother	Female	**P29**	Daughter	Female
P7	Partner	Female	**P30**	Mother	Female
P8	Partner	Female	**P31**	Daughter	Female
P9	Mother	Female	**P32**	Mother	Female
P10	Mother	Female	**P33**	Mother	Female
P11	Auntie	Female	**P34**	Partner	Female
P12	Partner	Female	**P35**	Daughter	Female
P13	Partner	Female	**P36**	Partner	Female
P14	Partner	Female	**P37**	Sister	Female
P15	Daughter	Female	**P38**	Daughter	Female
P16	Sister	Female	**P39**	Partner	Female
P17	Daughter	Female	**P40**	Mother	Female
P18	Mother	Female	**P41**	Mother	Female
P20	Brother	Male	**P42**	Partner	Female
P21	Daughter	Female	**P43**	Mother	Female
P22	Daughter	Female	**P44**	Partner	Female
P23	Daughter	Female	**P45**	Mother	Female

There were two males and 43 females who are part of this community. The age range of the participants was unknown, as I have never met them in person, and this question was not integrated into the consent process. The time following the donation was also unknown although most of the participants had joined the group following the invitation received post donation. The relationship composition was made up of eleven participants whose parents died, fourteen mothers of organ donors, fifteen partners, two brothers, two sisters, and one auntie. From the 45 participants, only one withdrew and left the group after completing an exit questionnaire. Most participants were female, supported by Duggan & Brenner, (2013), who recognised that Facebook especially appeals to adult women. Tolstikova & Chartier, (2010) observed internet bereavement forums as unique and poorly researched. The need for exploration of participants, demographics, social and personal characteristics, clinical characteristics, and coping methods could strengthen the opportunity for growth within the virtual community.

Characteristics Of Interview Participants

The aim was to interview individual participants to explore their experiences and understand the value of the conversations that took place in the group. In total, eight people were approached, two people did not respond, so six participants were interviewed throughout the course of the study. It was a sensitive situation trying to judge when best to approach people who were openly grieving, the group discussion guided my decision observing people’s engagement, as to when might be the right time to invite people to interview. After generating rich data from the first six interviews alongside the copious group discussion data and receiving two non-responses to invitations I decided to stop recruiting, already aware I had sufficient new knowledge and data to confidently answer the research aims. A range of participants with varying relationships with the deceased were approached to take part; these included two parents of organ donors, one of whom had lost their child over two years ago and so further on in their grief experience, one participant who posted positively throughout the study, one participant who does not interact with the group, one participant who posted was particularly active, sharing both positive and negative opinions, and one participant who lost their partner. The data was transcribed and recorded at the time of the interview. The interview data complemented, supported and generated a deeper understanding of the large narrative data set downloaded from the group discussion, offering further in-depth examples of individual lived experiences of organ donor families.

Participant Withdrawing From The Group

Only one participant withdrew from the study. Suzie (pseudonym) was invited to join as her relative was a proceeding organ donor, although no solid organs were transplanted at that point. Unfortunately, the organs were subsequently deemed unsuitable for transplantation during closer inspection at the transplant centre. This can occasionally happen, and although the patient proceeded to organ donation, the outcome was not successful. Suzie joined but then sent me a private message via the group, explaining that due to the circumstances of the donation, they found the narrative within the group was adding to the disappointment of not donating any organs. This experience impacted on Suzie’s support group involvement, creating a negative impact of their overall engagement. I offered support via the DFACS and apologised to Suzie for adding additional stress to her grief. As a result, I changed my view on the recruitment to the group, reinforcing the need to separate proceeding and non-proceeding donors (Dicks et al., 2017b). Suzie agreed to complete the exit questionnaire and was appreciative of the support and reflection we provided. Following this example, I was approached by a family in a similar situation, and organ donation had not been successful. I offered support, explaining the positive nature of the discussion in the group. I was able to share my experiences with Suzie, informing them of the potential distress joining may cause. This allowed for some consideration, and I was able to provide this family with information regarding local support groups. This was welcomed, and the family member decided not to join the Facebook support group.

Allow The Community To Grow Organically

Building a safe online community to enhance the experiences of organ donor families was one of the key drivers of the study. Organ donation organisations must begin considering their approaches to creating and facilitating grief support (Gibson et al., 2020). The initial concern was the potential need for more interaction in the group. The researcher’s role as a moderator, trainer, and influencer could influence the study results (Vasilica, 2015). The first few months demonstrated difficulties in engaging and managing the conversation. One of the main challenges throughout this study has been minimising any researcher bias while being immersed in the group and wanting to encourage reflective conversations between the group members. The group initially had four participants offering minimal discussion and interaction. This caused apprehension and, on reflection, unnecessary concern. The apathy of the group steered me to begin posting comments and attempting to initiate conversations. As the conversations in the group developed and more families joined, I recognised the need for me to retract, allowing them to support each other since this was a peer-to-peer support group. This was challenging because of my professional need to ensure these donor families were supported. On average, 3-4 families joined the group each month. In the initial two months, I developed bereavement support information, which I stored on the page, providing resources and ensuring the group had ongoing support outside the group if needed. This process has provided continuous reflection, allowing me to develop several supportive approaches.

Box 2: Key strategies to inform moderation of organ donation groups

- Inform and support: In my moderator role, I posted comments and information pertinent to the group. I was able to provide the group with various resources and live online sessions. I asked the group what they needed and acted on their responses, inviting the counsellor to provide an online session, recommending coping strategies to the group, an online session with the Family Aftercare lead nurse, who provided advise and information regarding contacting recipients. One participant asked for coping strategies to be posted on the group weekly. Some of the discussions involved clinical questions about the organ donation process. Initially I was able to answer these questions directly.
- Listen
- Step back: Initially I would post comments, questions, attempting to initiate conversation and engagement. As time went by, I recognised my participation was not needed, as the aim of the group was for peer-to-peer support
- At the start I was emersed in the discussion which at times was extremely upsetting. I recognised, after discussion with the other moderators and my supervisors that I needed to step back and allow the group to grow organically. This would help me to detach myself from participant’s evident grief.
- I recognised the tensions faced by the moderators in the groups, including emotional …. It is therefore advisable to have a moderation rota to allow disconnection from the group in addition to an advisory group to seek advice

Engagement Within The Group

Central to this thesis was determining the experiences of how social media engages organ donor families during their grief, sharing their lived experiences, and peer-to-peer support each other at the most vulnerable time in their lives. The levels of engagement differed considerably throughout the study. Participants’ levels of engagement varied; some offered a more expressed narrative, while others remained in the background without posting or commenting (Table 13).

Table 13: Levels of engagement, adapted from Vasilica, (2015; p145)

Engagement Level	Activity	Examples of responses
Influencer	- Initiates conversation, - Shares opinions - Asks Questions - Offer peer support - Shares resources - Regular poster	*Just got letter to say that Order of St John for Organ Donation ceremonies are (cancelled again this year until 2022. I don't think I will attend. Has anyone else got this letter? (*Mary, mother of donor)
Conversationalist	- Answers questions - Shares personal experiences - Peer supports	*So sorry for your loss. You know that your son tried to help another and without conditions attached (Ruth, wife of donor)*
Silent Reader	- Reads other posts - Finds comfort - Passive consumer of information only	*I've been very quiet within this group, but my beautiful sister died about 15 months ago. I feel her loss every day. That her organs made a difference is a source of huge pride. I hope this is the same for you too (although the grief is terrible). I will love her forever* (Paul, brother of donor) *Thank you all. I'm struggling today as it's a month since I lost my husband. But I'll put an introduction on when I can xx* (Joyce, wife of donor)
Confidential Communicators	- Contact was made directly to the researcher via online messenger to ask questions	*Could you please advise me on writing to recipients* (Amy, daughter of donor) *Hi, I saw on a post that you are able to find out how the recipients are doing, would you be able to do this for me* (Maggie, mother of donor) *Hi, I know I haven't commented at any point on the group, but I have read the posts. I just haven't felt ready to post yet* (June, mother of donor)

In a study of kidney patients within a social media information network, Vasilica (2015) identified three main categories of engagement: Influencer, Conversationalist, and Browser. I recognised three similar levels of engagement within the Facebook group and an additional level of engagement - the confidential communicator (Table 13).

The initial engagement was slow, during which time I engaged in the discussions with participants and initiated conversation. As some got more used to the group, more comfortable with the people talking, they felt able to share their own personal content, starting conversation, asking questions to the group, and offering support to others but demonstrating understanding. Other participants took longer to interact while refraining from posting; some found some comfort in reading the comments of others and not sharing themselves. Some members messaged me directly via online messenger to ask private questions, clarify comments, and request information regarding the recipients of their loved one's organs.

Influencer

Throughout the process, certain individuals could be identified as influencers within the group: Initially, as the researcher I was the influencer, but as time evolved certain participants have been more candid, posting comments, asking questions, and sharing feelings/emotions consistently. The role of influencer was important in generating discussion and initiating conversation, seeking to support the other group members, intending to develop the group. My role as an influencer changed over time. As the group developed and more participants joined, I was able to step back, allowing the active group members to guide the conversation and take over as primary influencers, although initially my intention was to stimulate conversation.

> *"Morning everyone I'm sure it is going to be difficult for you all over the festive break. How is everyone feeling? Please don't forget to chat to each other if you need any support x".*

> *"Hi, I just thought I would share the link for The Donor Family Network in case any of you haven't heard of them. There is a charity set up by donor families. There is lots of information on their website".*

Mary, who joined the group near the start, has been a consistent influencer, asking questions, sharing feelings, information, and supporting others. It constantly influenced and guided conversations. Contributions ranged from sharing information to moral support.

> *"Not sure if any of the group like to read. I read a couple of books (fiction) that touch on Organ Donation. One is called 'One Minute Later' by Susan Lewis, and the other is 'The Donor' by Clare McIntosh. The second is a quick read and both books deal with the subject in completely different ways. Some may have already read them and maybe some wouldn't like to read them but just thought I would share" (Mary, mother of donor)*

Mary was a reassuring support for many participants throughout the study. Creating a virtual space where organ donor families can share feelings and ask questions, such as ‘does this sound stupid’ is unique. It offers participants a safe platform to seek clarity and emotional care from individuals in similar situations. Mary offers support and understanding to the other participants in a responsive and approachable way.

> *“Maggie it’s not stupid at all and this page is here for us to be honest”. (Mary, mother of donor)*

Samantha was also a recognised support for the other members, openly sharing her thoughts and feelings with the other group members.

> *“Today is my beautiful Mum’s funeral. Her death was unexpected- she was not ill. The intensity that surrounded her death, the donation process and the pressure of having to organise a funeral to make her proud by myself alone has been massively overwhelming. Today, in my advent calendar, for the first time, an angel was there. I don’t know what I believe, but I like to think that this is a sign from my Mum. Feeling very scared about the hardest day of my life which lays ahead, but I aim to do my best. This is the last thing I can control*”. (Samantha, daughter of donor).

Conversationalist

Many of the participants have been active conversationalist throughout, willingly posting comments, sharing feelings, asking questions, whilst providing a caring, gracious, responsive support to the other participants.

> *‘They say time heals but does anyone else feel worse as time goes by and the reality kicks in that you’re not going to see them again?’ (Amanda, mother of donor).*

Many of the participants developed strong bonds with each other despite being complete strangers. Stacey responds to a post written by Debbie explaining it was the funeral of her husband.

> ‘*Debbie, I read that its going be a very tough day for you and your family... you’re in my thoughts today. Be kind to yourself and be very proud of your amazing husband. You will be in my thoughts’.* (Stacey, mother of donor)

Silent Reader

Some participants did not engage with the group and remained silent throughout the process. Although dormant in conversation it became evident that some participants benefited from just being part of the group without the need to post comments. Most comments posted were read by all group members, each time, demonstrating that all engaged despite not actively commenting or posting. Some of the possible explanations behind silent reader behaviour may possibly be that certain group members believe that writing a posting takes up too much time, have concerns about privacy or safety issues, feel awkward using Facebook, or still can feel a strong sense of community just from reading others' postings without writing anything (Nonnecke & Preece, 1999; Hoybye et al., 2009). The grief some members of the group experienced inevitable prevented them from commenting, for example, it took several months for one of the group members to open up to the group, although they had not been actively commenting or supporting others, the person had been reading the comments of other participants. The person shared an element of guilt for not being a support to other, admitting it had been too painful to actively be involved.

> *'Thank you all. I'm struggling today as it's a month since I lost my husband Sam. But I'll put an introduction on when I can xx'.* (Joyce, wife of donor)

Paul was one of the first family members to join the group, taking the length of the study (nearly 12 months) before feeling comfortable enough to post a comment. This comment presents an additional level to the use of the group, providing support for participants who I'd assumed had left the group, or found it unhelpful.

> '*I've been very quiet within this group, but my beautiful sister died 15 months ago. I feel her loss every day. That her organs made such a difference is a source of pride. I hope this is the same for you too (although the grief is terrible). I have seen your posts over the months, and I have been in too much pain to acknowledge. I'm sorry'.* (Paul, brother of donor).

There was evidence that many of the participants in the groups read the posts without comment. When a comment is posted, the number of group members who viewed the posts was visible, a Facebook feature for smaller groups. It was evident from the number of participants reading the posts that several of the members were 'Silent Readers', reading other comments.

Confidential Communicator

Several of the participants directly contacted me via Facebook messaging service throughout the process. The general reasons for the participants contacting me direct was to ask for updates or advice on contacting recipients.

> *"I saw on a post that you're able to find out how the recipients are doing, would you be able to do so for me too, also, would you be able to find out if they definitely got the letter, I emailed to the donor support address I was given, many thanks x".* (Maggie, mother of donor)

> *"Hi ang how do I start this letter to the recipients? X".* Barbara, mother of donor)

I did receive a message at the end of the study from a participant who was uncertain about her involvement in the group.

> '*I would like to continue with the new page, but if I don't feel its beneficial, I would come off in the future if that's okay? Hope this doesn't come across as negative, I just want support from people that understand, but don't make you feel worse when you read comments.'* (June, mother of donor)

Interestingly, this participant remains part of the group to date, although these comments suggest that the some of the comments may have been overwhelming, impacting on their own grief. What this signalled was the importance of accessing and providing multiple bereavement support opportunities (not just a peer support group), to better suit all the bereavement needs of the individuals within organ donor families.

Informing The Future

Several learning opportunities have arisen through this process. Reflecting on the study and the development of the Facebook group, I feel a sense of pride and appreciation toward the organ donor families who have participated. Developing an online bereavement support group can be helpful for individual groups of people, providing them with emotional distance and a secure space to share more openly (Gibson et al., 2020). We need to be open to the concept that people access information and support in many different forms. The internet will provide some individuals with opportunities to connect with others, grieve together, access information, building a community that will support them in a convenient and accessible way (Tolstikova & Chartier, 2010; Varga & Paulus, 2015; Gibson et al., 2020). Having insight into the development of the group and the learning taken from supporting acutely bereaved individuals has informed the proposed model. The proposed model considers how an effective recruitment process is fundamental to the progression and growth of the group. Setting out clear expectations from the inception will ensure the group's needs are met. Accepting that the group will grow organically will prevent concern and permit authenticity. Engagement, listening, and support will build trust and integrity, creating a safe and open space. Providing adequate support will strengthen the engagement and commitment of the participants. Once all these phases have been implemented, the community should grow and thrive with minimal involvement and intervention (Figure 10) as ‘Donor Families Together has don and continues to do.

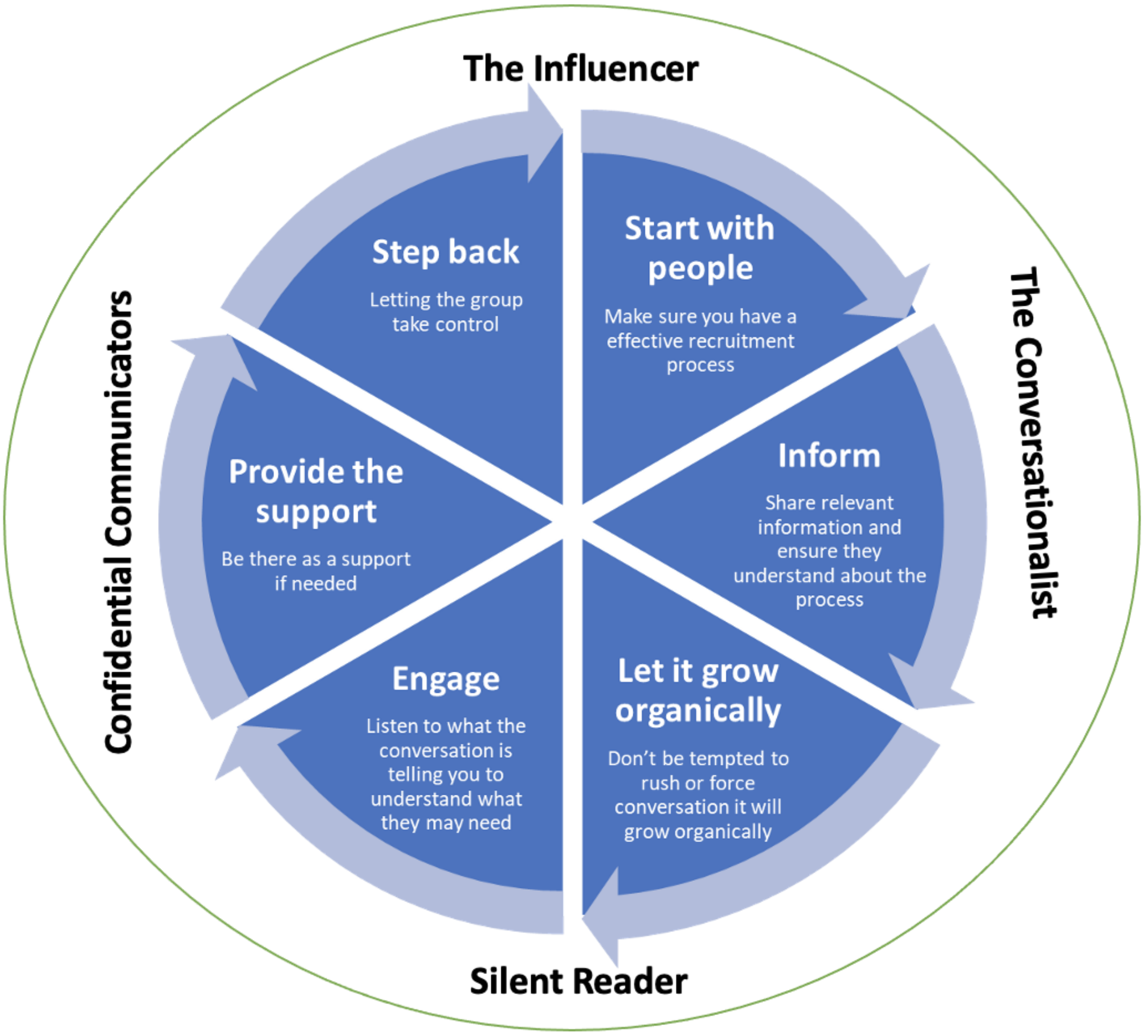


Figure 10: Setting up online group, growing a community

Summary

These past few years have been both energising and thought-provoking. I have identified elements of the process that could have been managed differently to enhance this research experience, such as allowing the group to grow organically instead of forcing the engagement, allowing for authenticity.

This research examined the impact of a virtual peer support group but simultaneously created a growing community of organ donor families to provide support at the darkest of days when managing the grieving process. The peer support group approach was valuable, and the findings generated present what works and why, but also further improvements that could be introduced to meet the needs of this group. This chapter has identified the best methods of setting up and establishing a group and the operational considerations when supporting people through a period of bereavement.

The study findings provide a unique insight into the grieving process for organ donor families, extending grief theory to generate a deeper understanding of the needs of bereaved families following organ donation. The critical study findings are presented in Chapter 5, drawn from an extensive data set. For this thesis and the aims of the study, the focus remains on the grieving process, and Chapter 6 presents a new theoretical model of bereavement that will inform the aftercare of families. There is updated and new knowledge gleaned from families' experiences of organ donation and new evidence exposed on how best to improve organ donation family aftercare practice, regarding the need for supplementary methods to be considered, when developing future services and recommendations.

Chapter 5: Building Social Capital: A Community for The Bereaved

Introduction

The study aimed to explore the influence of an online peer-to-peer support network for families of organ donors, the use of peer support underpinning the central themes from the findings generated from the six staged analytic processes described in chapter three. The concept of peer support is presented, providing new evidence that authenticates using a social media platform to help acutely bereaved individuals and families of organ donors. The meaningful narrative regarding how and why bereaved families used the social media platform to gain support after organ donation is exposed through the conversations the donor families have with each other within the Facebook group and reinforced within the one-to-one interviews. The longitudinal study generated an extensive dataset, which allowed me to become immersed in the real-time grief of organ donor families, witnessing their pain and heartache each day following the death of their loved ones. Painful as it was to observe such anguish, it was also a privilege to be part of building a community in which individuals formed genuine human connections to grieve as a community (Walter et al., 2011). The purpose of this chapter is to present the key emergent themes identified during analysis to draw out what is important from the compassionate data. Using a constructivist thematic approach (Braun & Clarke, 2022), several themes of interest emerged. I focused the data analysis on connections to the central theme of peer support, observing patterns of articulation related to the donor families providing support. The rich data on grief and the grieving process for these families was synonymous to the peer support themes, which is addressed further in Chapter 6. This chapter brings together the analysis of group support through the worse time, despite the participants being strangers. Following the initial coding, I re-reviewed the entire data set to confirm and construct critical themes that emphasised conversations relating to peer support. I was able to continue to grow a deeper conceptual analysis surrounding peer support to construct the following core five themes (5.3-5.8).

- Sharing lived experiences: connection through death
- Sharing and supporting the pain of grief’
- Sharing and supporting with information and resources

- Acknowledgment of the ‘Gift of Life”
- Aftercare: What do families need or want

The underpinning theme of this findings chapter is the observed building of social capital, embedded within the themes, between the group participants. Extrinsic bridges, weak and strong ties among people who had donated their family members' organs (Alder & Kwon, 2002), built within the peer support group. While social capital has been observed in other peer support groups (Putnam, 2001; Williams, 2006; Ellison et al., 2007) and indeed formed the premise of why this type of group was set up in the first place, it has not been evidenced in this context. This is the first study to capture organ donor families showing help through giving information and demonstrating the provision of emotional support to each other through peer support.

Analysis Process

The Facebook group offered a safe space for organ donor families to express multiple responses and ask the unanswered questions left in the days following donation (Regan & Barnwell, 2000; Berntzen & Bjork, 2014; Kentish-Barnes et al., 2019). Donor family experiences were varied. The findings reinforced existing research that many families who agree to organ donation have ongoing bereavement needs, such as further information, acknowledgment and recognition of their act, assurance, and bereavement support (Dicks et al., 2017a). This became evident as the group organ donor families expressed the need for information relating to various issues.

The six-stepped analytical process (Braun & Clarke, 2006) involved moving forward and backward between the data to illuminate key similarities and variances. To achieve this, I used electronic and paper copies of the data throughout my analysis, which helped provoke different ideas, thoughts, and perceptions. My aim was to discover relevant themes that responded to the research question and represented the nature of the participants' lived experiences. Thematic analysis works well to reflect participant's experience and authenticity, in addition to revealing reality (Lincoln & Guba, 2000; Tuckett, 2005).

The initial phase of data familiarisation post-data collection started with great anticipation, after all, I had spent every week for 12 months moderating the group, reading every comment posted, providing me with a deep understanding (analytical step one), invested, and embedded in the data during the data collection phase (Charmaz, 2014; Moule & Goodman, 2014). The conversations among donor families produced sensitive, poignant accounts of their personal experiences, which were sometimes challenging to analyse, particularly to draw out meaning and value (Polit & Beck, 2010). Developing a meaningful appreciation was enhanced because of my extensive practice experience and knowledge (supporting my role as a researcher). Immersing myself in the data was also easy after being part of the group, and I wrote notes (figure 11) and examined contradictory data to develop a critical understanding (analytical steps two and three). Familiarisation notes don't have to just consist of textual notes; visual notes might also facilitate grasping the data (Braun & Clarke, 2022).

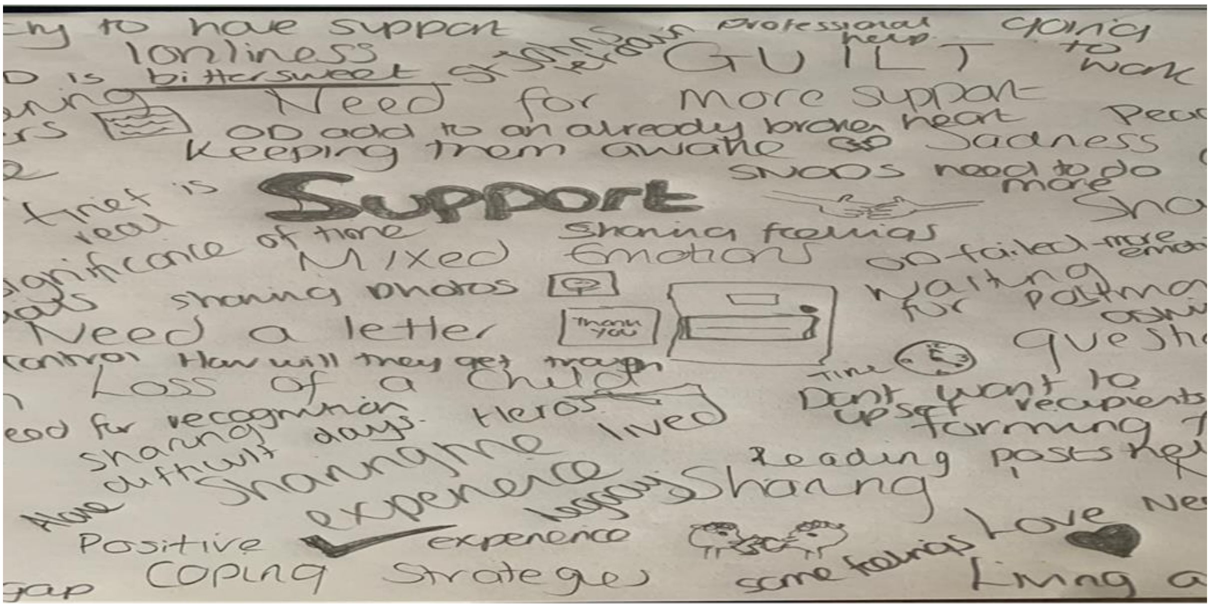


Figure 11: Familiarisation note

The analytical codes were generated from the expressed meaning captured from the discussion in the group. This deductive process generated codes that were participant-driven; initially semantic codes were generated, rather than latent codes, on a more conceptual level. Codes were consistent with the focus of the study to explore lived experiences, examine the use of the peer support group, and identify aftercare strategies, but not restricted to these areas. Indeed, refinement of the participants ’comments exposed more personal assumptions and social theories uncovering more latent meanings, the more exact meaning of what people are saying

(Braun & Clarke, 2022). Much of the data was sensitive and distressing, triggering a strong emotional reaction. I recognised my professional position and strong views towards organ donation as a potential influence in the data interpretation (Buetow & Zawaly, 2022). As the process continued, the narrative accounts of the donor families' experiences became highly emotional, requiring compassion and, at times, intervention to help shape the analysis; without this, I was unable to interpret meaning subjectively and emotively. Having a trained counsellor as part of the moderation group helped me to support certain families on a more personal level. I gained advice and professional support from the counsellor, using time and resources better to support families. As I moved into the final steps of the analytical process, I was able to generate initial themes positioned around the overarching theme of 'peer support' (step four), and I named the themes before beginning to write up the analysis presented in this thesis (step five and six).

Sharing The Lived Experience: Connection Through Death

There was an overwhelming need for peer support combined with sharing the lived experience of the phenomenon with others in a similar situation. Peer support permits the participants to draw on their shared experiences and life events to provide others with compassionate understanding, information sharing, and advice to those they are supporting (Bartone et al., 2018). Meeting other donor family members in similar situations, asking questions and finding answers about donation, and sharing knowledge and uncertainty about what has become of the organs is important (Sque et al., 2003; Thomas et al., 2009; Berntzen & Bjork, 2014). Some group members were reluctant to initiate conversation and used their 'story' to start the discussion. Sharing their personal experience leading up to the death of their loved one was a frequent way of introducing themselves to the other group members and a way of 'breaking the ice'. These discussions usually led to other group members coming forward to share their experiences, recalling the events leading up to the death of their loved ones.

For example, some participants had lost their husbands due to cardiac arrest, leaving them on life support machines with no hope of survival.

> *'Hi, my husband was 45, he had a cardiac arrest 15 days ago, and he spent 7 days in a coma before we had to turn off his ventilator. He kept breathing for himself for 2 and a half hours before passing, so he was only able to donate*

> *his kidneys. They have also taken his eyes, I hope. Today is the first time I've been home alone for an hour; I've worked out how to turn on his record player and have been searching through so many photos of him and our 2 children (2 and 5) for the perfect one for his funeral service sheet. I just can't stop crying these last 2 days, I may have been in shock before that, I guess. I can't believe he was here making pancakes for us, and now he's just gone. How is that even possible? My best friend, their daddy, just not here anymore.'* (Debbie, wife of donor, Facebook comment)

Sharing this personal account of the death-initiated others in the group to share similar experiences. This generated peer support from others within the group, allowing them to relive emotional events, seeking support and comfort from others in similar situations. The opportunity for individuals to share their thoughts and experiences with others going through similar sadness is one of the main benefits for the participants of bereavement communities (Moss, 2004).

> *'I'm so sorry to hear this - heart breaking! I'm in tears reading your story so hard to understand. My husband dropped dead 5 weeks ago, he was fit and healthy only 46 and we have 3 kids - 11, 9 and 7. An aneurysm burst in his brain, and he died. It's really tough. Just want you to know I'm here very hard to understand and come to terms with but your husband and you did an amazing thing to donate his kidneys and eyes XX'* (Lisa, wife of donor, Facebook comment)

The group members offered support to each other, connecting them in a virtual space while at their most vulnerable, regardless of being strangers. Over time, the group became a place where the bereaved could connect to share their grief with others they would never have usually met (Hollander, 2001). Social capital involves bringing individuals together who share similar experiences and bonds. These heart-breaking accounts posted by three wives and mothers who had lost their partners guided them to share their grief, exposing themselves, making new connections (social capital) in a safe space, and gaining support from strangers who had been affected by very similar stories (Hofmeyer & Marck, 2008).

> *'So sorry to hear about the loss of your husband Debbie and your husband Lisa. It's so heart-breaking to hear your stories x My partner had a cardiac*

> *arrest 15 weeks ago. My daughter and I gave him CPR and he was in intensive care for 4 days before he passed. I think I'm still trying to process it now and it hit really hard last week that he's not coming back to us.'* (Jodie, wife of donor, Facebook comment)
>
> *'So sorry to hear your story. It's absolutely heart breaking - it just doesn't feel real, does it? I found the having to give CPR very traumatic and hard to get order I still have nightmares about it. You and your daughter were so brave to do that.*
>
> *I keep checking his office (he worked from home) as I expect to see him there - it's so hard to process. Thinking about you and your family as you try to process things Xxx'* (Lisa, wife of donor, Facebook comment)
>
> *'I don't think I've processed the CPR bit yet, but I feel so so guilty that as I was ringing 999, I had to go for a wee. What if that 30 second made the difference in his brain function? I haven't been able to say that out loud before.*
>
> *The kids are downstairs with my parents, and I can't bring myself to leave our bed. I miss him so much.'* (Debbie, wife of donor, Facebook comment)
>
> *'Debbie getting out of bed in the worst! 'I'm still trying to get up this morning. We feel guilt over everything but try not to. I know that is so much easier said than done as I feel the same - all the what ifs go round and round me head. I can't make it any better for you but please feel you are not alone with how you feel. All I want is a massive hug from him to tell me it will be ok. Glad you have your parents to help you out, my parents have been fab too, but it doesn't make it any easier   sending my love Xx'.* (Lisa, wife of donor, Facebook comment)

There was an apparent reference to the participants' guilt and the regret of not doing more to save their loved ones. This was shared by others in the group, providing them with the realisation that their emotions and feelings were not unique and that others experienced comparable thoughts following death and organ donation.

> *'Sorry to hear your pain, Debbie. I too feel the guilt as I didn't realise, he was having a cardiac arrest and hesitated in starting CPR. He was a type 1 diabetic and I thought he was having a hypo in which he usually fell out of bed unconscious before coming round a bit. I did soon realise this wasn't the case*

> *but it’s very difficult not to feel guilty’.* (Jodie, wife of donor, Facebook comment)
>
> *‘So, I think initially the group felt a little bit more supportive, but as it's grown it's felt more like somewhere to get information. I mean, I think I identified more with people who perhaps lost a partner or husband for me. I kind of feel more of a connection on that basis rather than it being to do with the fact we've all you know, got the organ donation in common’.* (Jodie, wife of donor, taken from interview)

The online community for the bereaved organ donor families offered a connection to people who had similar experiences or can endure talking about grief and loss so that the grief can be communicated, and sense can be made from the experience (Tolstikova & Chartier, 2010). The similarities across the accounts were visible, at comparable stages in life, loss of their partners, similar age of the deceased, similar cause of death, and children at similar ages. Allowing them to share their situation in a safe space with people who may understand confirmed that their thoughts and feelings were a normal response. Evidence shows that support group members can benefit from sharing experiences with others who have experienced similar bereavement and will regain hope for their futures as they see others surviving (Vajentic & Calovini, 2001). This was a positive outcome observed across the donor families over time, and the support group created an informal support network that was readily available. Like other support groups, there was a need post organ donation for the family (or significant other) to share experiences with others in similar situations (Regan & Barnwell, 2000). Families need the opportunity to share their experiences with others and have the chance to revisit unique issues which may remain unrequited and are related to the process of organ donation. Like others on the internet, this organ donor family community nurtured social capital and social support (Drentea & Moren-Cross, 2005); this was evident when group members supported each other through the painful grief.

Sharing And Supporting The Pain Of Grief

Throughout the study, there was an overwhelming sense of grief emanating from the participants' profound statements. The discussions at times, left me feeling hopeless, wanting to do more to take away the pain. When offered organ donation, individuals are in the midst of that family's grief, and grief therapy is not enough for organ donor families due to the questions they have that are not limited to grief (Maloney, 1998). Accessing the group and other families who have experienced loss and grief provided additional support and a platform to ask questions and get them answered post-donation. Even if the group was not sustained, SNODs and NHSBT need to recognise that families require follow-up and answers to questions to facilitate closure or acceptance of their family members' death, an integral part of the grieving process. Many participants could share feelings, disclose raw emotions on difficult days, and instigate peer support.

> *‘It was 4 weeks ago today that my Keith took his last breath. How can it have been 4 weeks? It's getting worse, the missing him. Everyday life with him feels so long ago and is blurring already. I've walked around the house calling his name, asking where he is, if he's OK. I'm not OK, this is not OK. I want my life back, with him and our little ones, like we had. I don’t want this’.* (Debbie, wife of donor, Facebook comment)
>
> *‘Debbie it’s awful. I never imagined pain like it. So sorry you are feeling like this. It is heart-breaking x’.* (Julie, mother of donor, Facebook comment)
>
> *‘Bad week as it should be Luke’s 18th birthday on Saturday, forever 16. Wish he was here so much xx’.’* (Francis, mother of donor, Facebook comment)
>
> *‘It’s still very painful, so many triggers and the feeling like I don’t want to let go and move on yet as I don’t want to forget Lee. I try to get out for walks with friends which helps a bit but don’t feel like I can keep on talking about what has happened although I probably need to. I also feel like I’ve got to be strong for my kids’.* (Jodie, wife of donor, Facebook comment)
>
> *‘I’m struggling today. Little things setting me off. It’s 7 weeks since Neil had the bleed. The ambulance service sent an update on the investigation and that got to me. And I just feel so exhausted. Not sure why I’m posting, I just feel like I can here rather than my personal profile 😢💔’.* (Joyce, wife of donor, Facebook comment)

The participants disclosed profound feelings of heartbreak, offering support and comfort to one another. They reassured each other that they were not alone, sharing stories of their loved ones, offering encouragement to use the group to impart their feelings and seek support, and almost offering authorisation to speak openly in a safe community, creating a place for strong bonds and close connections in closed networks (Thomson et al., 2015).

> *'You are posting because it's a comfortable likeminded group to post to*
>
> *It's difficult and I've found Easter an absolute nightmare to deal with. Emotions running high and grief taking over. Feeling for you and hoping you are ok 🙏.'* (Pat, partner of donor, Facebook comment)
>
> *'I'm struggling so much, can't stop crying my daughter died in January I've spent the whole weekend crying. I'm so numb and empty. I miss her with my whole soul. Can't see how I will ever recover from this I'm a mess. Sorry, but again just feel I can't do this anywhere else. 💕'.* (Julie, mother of donor, Facebook comment)
>
> *'Hi Julie - I am sure we I speak for all of us when I say no need to apologies at all. I am so sorry for the loss of your daughter. I lost my son five years ago. I think we all feel totally overwhelmed and the pain can be almost unbearable. Keep talking to us, much love'.* (Donor Family Advisory Group Member, father of donor, Facebook Comment)
>
> *'Hi Julie, my daughter died in car crash and had to give permission for life support to be turned off, so I know were u coming from 7 yrs before her on 29 Sept lost my son so everyday battle and struggle this group best thing as we all have lost people, life so cruel we all hear for u xxx'.* (Laura, mother of donor, Facebook comment)

The Facebook group was a place to share painful emotions and grief. Realising that other group members experience similar feelings brings comfort and affirmation that they have all lost someone they love, accentuating the pain that brings to each one of the participants. One participant used the group to discuss the challenging time they were experiencing, which generated support from other group members, despite the fact they were also broken-hearted and strangers. The caring bond developed among the group members is vital. It emphasises the capability of building social capital, bringing strangers together to support each other at the worst possible time, and supporting and growing friendships with like-minded individuals.

> *‘Not sure what life has left to throw at me & my sister. Mum taken so suddenly from us in November and now we have just found out our dad has months to live. Not really even sure why I am putting this here really - the one person I needed to speak to was mum’. (*Charlotte, daughter of donor, Facebook comment)

> *‘It’s so hard to deal with our lovely people going and leaving us here to cope with them not being here. Be strong they wouldn’t want you to be sad’.* (Julie, mother of donor, Facebook comment)

> *‘Lost my son and daughter son 2013 daughter oct 2020 so I know what like to lose such a lot xxxx’.* (Laura, mother of donor, Facebook comment)

Participants continued the support, checking with Charlotte to make sure she was feeling ok, offering that ongoing friendship and care in the weeks that followed.

> *‘I was thinking about you and your situation today so just wanted to check in with you. Xx’* (Lisa, wife of donor, Facebook comment)

> *‘Hi Lisa Thank you for asking. My dad died on 25th February, I’ve been busy with sorting things, and I think that's been distracting me really. Not too sure it's really sunk in yet to be honest. I think maybe my brain is also blocking a lot. 33 years old and both parents gone within 4 months... you couldn't make this stuff up! Xx’* (Charlotte, daughter of donor, Facebook comment)

> *‘Oh, my goodness - I’m heart breaks for you. Please know I am thinking about you’. (*Lisa wife of donor, Facebook comment)

Regardless of being strangers’ some participants used the group as a safe space to relate their sorrow to others, reinforcing the effectiveness of the Facebook group. These painful conversations between participants demonstrated opportunities to connect individuals with comparable grief, providing them with emotional support, friendship, affection, and a connection with another person who understands.

Working in organ donation, which encompasses bereavement, requires professionals to develop trust and provide support at the time of death and into bereavement. We have a duty of care and a responsibility to provide accurate information, opportunities for accessible communication, and offer appropriate aftercare to donor families. Organ donor families will present with different needs, and we as an organisation need to respond to these aftercare needs; this does not happen in current practice.

Providing them with a space to connect, such as the Facebook group, imparts organisational integrity, strengthening our support post-donation. Listening can make people feel cared for and safe and allow them to express their honest emotions (Zilberfein, 1999). This unique Facebook group has provided organ donor families with a safe space, allowing them to express themselves.

The evidence of sharing grief in the group led to the considerations of grief theories (described earlier); the narrative highlights that organ donation adds an increased intensity to this painful experience. Previous grief work suggests that the emotional process the bereaved go through, coping with the loss of their loved ones, requires them to become detached, adapting to a new situation in which the deceased is not part of (Lindeman, 1944; Parkes, 1972; Bowlby, 1980). However, the reality of a stranger living with an organ donated to them by a deceased family member proposes the concept that a part of the bereaved family member lives on. This prevents them from completely detaching themselves, continually imagining the organ recipient and their life, including a part of their loved one. These thoughts and feelings cannot be assumed for all organ donor families, although the comments and discussion suggest that such feelings can Influence the direction of bereavement.

> *'I received a letter today from the man who received my husband's liver. I'm so so glad he wrote, and I will treasure it but I'm a complete mess about it too.*
>
> *So proud of him for donating his organs, so pleased that two little kids have their dad because of the transplant. But also bitter, resentful, jealous, angry! All those emotions and more hitting me from all angles.*
>
> *Feel so bad for having these feelings - anyone else have mixed feeling after receiving a letter? Xxx'.* (Lisa, wife of donor, Facebook comment)
>
> *'Hello fellow donor families. I take comfort that my husband was able to donate his kidneys. One to a recipient and the other to research. So sorry that we have all lost loved ones.'* (Ruth, wife of donor, Facebook comment)
>
> *'Kept awake last night by recurring thoughts. The gentleman that was gifted Luke's lungs sadly passed away shortly after transplant. I keep thinking about where he is buried or where his ashes are as part of him was Luke and I would like to know where that part of Luke is now. Is this as weird as it sounds? Xx* (Francis, mother of donor, Facebook comment)

Although the positive element of organ donation is recognised and the donor's pride displayed by the family member, there remain elements of unease, leaving the donor families with speculative thoughts that may never leave them.

The grief model offered by Kubler Ross (1970) describes five different stages of grief. This model claims to be a non-linear process allowing the bereaved to experience these aspects of grief at different times and not in any particular order. As discussed in Chapter, Kubler Ross’s five stages of grief has been criticised over time by researchers for the lack of evidence verifying her theory. Despite the lack of supporting evidence endorsing this theory the presented narrative from the group clearly displayed the identified stages presented by Kubler Ross. Although the stages appeared evident the data suggests that organ donation adds a different dimension to an individual's grief, potentially preventing them from moving into the acceptance stage. At least for those observed during the 12-month study, but also reinforced by families joining the group several years post-organ donation and their comments suggesting acceptance were absent. Table 14 identifies comments made by the participants during the study which relate to Kubler-Ross five stages of grief, although I have adapted this grief model to incorporate the themes identified throughout the study, demonstrating the lack of acceptance observed throughout the study. It could be that the data collection timeframe did not allow the bereaved to experience any feelings of acceptance. The evidence from this study suggests that many organ donor families constantly question the whereabouts of their loved one's organs, which may interfere with moving to the acceptance stage compared to others going through a 'normal' grieving process.

The organ donation element adds a layer of complexity, suggesting that families who have opted to donate their loved ones organs face a differing berevement experience and one that they may never accept.

Table 14: Grief Model, adapted from Kubler Ross (1970; p216)

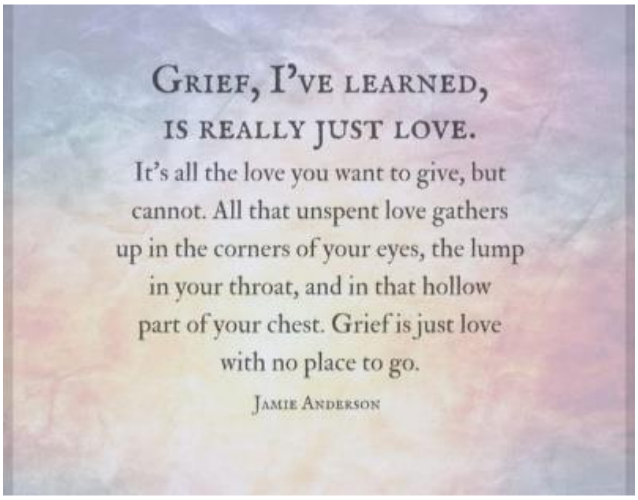
Stage of grief	**Examples and participant comments**
Denial	*'Am really struggling coming to terms…Just can't do life without him it's so hard'.* **(Barbara, mother of donor)** *'I just can't stop crying these last 2 days, I may have been in shock before that, I guess. I can't believe he was here making pancakes for us, and now he's just gone. How is that even possible. My best friend, their daddy, just not here anymore'.* (**Debbie, wife of donor)** '*Heart breaking! I'm in tears so hard to understand I keep checking his office (he worked from home) as I expect to see him there - it's so hard to process'.* (**Lisa, wife of donor)** *'So many triggers and the feeling like I don't want to let go and move on yet as I don't want to forget him'.* **(Jodie, wife of donor)**
Anger	*'They would have heard of me right away soon as I was fit. I would have said thank you so much for thinking of others in your hour of need am sorry that you had to make that decision. Nothing sometimes I regret it x'* (**Barbara, mother of donor)** *'I'm not OK, this is not OK. I want my life back, with him and our little ones, like we had. I don't want this'* (**Lisa, wife of donor).** *'haven't had anything from the recipients which I do get angry about. I got a letter 2 weeks after with brief details on who had got which organ donated and then after 18 months, I emailed the donor team for an update which I got but still nothing from the family's xx'.* (**Francis, mother of donor)** *'My daughter was 17 killed by her bf in car crash she passed away oct after intensive care for 3 day she saved 6 lives my son passed away at age of 25 in 2013 so had worst years believe me no one loses people close are ever ok or same people again they once were. I cut my self-off from lots of people as I can't take posing anyone else. My partner is so amazing even when am angry upset he just takes it on chin hugs me when need it gives space when needed I would be lost without him. My world is empty without my kids they were my world and my life xxxx'.* **(Laura, mother of donor)**

Bargaining	*‘Yes true... I only wanted to feel his heartbeat again x’.* **(Barbara, mother of donor)** *‘I keep hearing the word bittersweet, and I think it does describe a little how it can feel with organ donation. I wish I didn't feel resentment towards his recipients, but I do. Why did my lovely husband die, and they get to live’***. (Lisa, wife of donor)** *‘I barely remember the first month or so after my husband died. Shock, disbelief, longing for his return, so many emotions. Sending you love at this painful time* 💚’. **(Ruth, wife of donor)** *‘Massive Christmas Eve meltdown. I just want my brother back* 😢😢😢*’.* **(Donna, sister of donor)**
Depression	*‘Just need to express my emotions.* *Having a really bad few days constantly crying over my beautiful son I lost 6wks ago to a massive stroke* 😭*’.* **(Barbara, mother of donor)** *‘My heart hurts. People tell me 6 months is such early days, but it feels like forever. Xx’* **(Debbie, wife of donor)** *‘My heart is absolutely broken especially when my little boy is saying granny daily. I just thank myself daily that I have him and my baby girl on the way to keep me going. It’s still feels like I’m in a bad dream’.* **(Charlotte, daughter of donor)** *‘Mine is truly broken and will never mend. They’ve got a brand-new heart and can’t even say thank you… sorry again - not having a good day and can’t say this out loud xx’.* **(Julie, mother of donor)**
Living through others	*‘My first time posting - we received my daughters award and pin through the post. So very overwhelming for myself and my son* 💔*we are very proud of Sue and her decision to become an organ donor she has saved 3 men’s lives. We just miss her so so much* 😢*xx’.* **(Helena, mother of donor)** *‘Receiving this news made us all feel extremely proud and emotional. He had actually strangely expressed to his mum just a few days before his death that he would like to be an organ donor, so this was his choice. The idea of his organs living on with someone else makes part of his death somewhat more bearable, but I would love to know more information about the recipients and have been considering writing to them but do not want to upset them’.* **(Elaine, auntie of donor)** *‘It doesn't take our pain, but I get such a comfort to know that Rick saved 3 lives, 3 families will not have to feel the pain and heart break that we feel.* *I miss him so so much, but I am also so so proud of him for being able to be an organ donor and saving other lives* 💙*’.* **(Tracey, partner of donor)**

	'I've been very quiet within this group, but my beautiful sister died about 15 months ago. I feel her loss every day. That her organs made a difference is a source of huge pride. I hope this is the same for you too (although the grief is terrible). I will love her forever. X'. **(Paul, brother of donor)**
Acceptance	**There were no posts that suggest acceptance, although this could be due to the timing of the study in relation to the bereavement journey, although some families in the group were several years into their grief and still showed no signs of acceptance**

Sharing And Supporting With Information And Resources

The Facebook page became a dependable space to share not only grief and painful lived experiences but also empathetic information that could benefit the grief journey. Some participants shared specific grief quotes and poems that they had used to help them make sense of their grief, expressing how they related to the words and how they would like to share with others in the hope that it may comfort them somehow. Sharing such representational material typically occurred around significant celebrations, such as holidays or birthdays. Sharing such poignant texts was welcomed by some of the group participants.



GRIEF, I'VE LEARNED,
IS REALLY JUST LOVE.
It's all the love you want to give, but
cannot. All that unspent love gathers
up in the corners of your eyes, the lump
in your throat, and in that hollow
part of your chest. Grief is just love
with no place to go.
JAMIE ANDERSON

'This resonated with me, that constant lump in my throat and the gaping hole I feel inside me. I think it's really lovely so wanted to share with you guys ❤️'. (Charlotte, daughter of donor)

"My hubby put this up on his page earlier. It sums up exactly how we feel today. This is our first Christmas without our daughter, and I've never felt less Christmassy than I do today 😭". (Maggie, mother of donor)

It's Christmas Day, but it's not Christmas;

There's no Christmas spirit (you had more than the rest of us put together)

It's Christmas Day, but it's not Christmas;

You weren't here to wake us up at 5am to open presents

It's Christmas Day, but it's not Christmas;

You weren't here to get as excited about opening your 8th DVD as you were your 1st

It's Christmas Day, but it's not Christmas;

You weren't here to say "wow" "oh, my god" or "that's great"

It's Christmas Day, but it's not Christmas;

You weren't here

And it's shit:

It's Christmas day, but it's not Christmas

(Poem shared - Maggie, mother of donor)

People used quotes and poems to search for meaning or to make sense of what has happened to them, to offer comfort to others. Sharing with the group assisted them in supporting others, giving them hope that it would alleviate some of the sorrow for another individual experiencing similar painful feelings.

The group also discussed the need to write to recipients, and this is explored in detail later in the chapter. The participants did share the difficult task of writing a letter to a recipient. One participant shared the cathartic process of contacting the stranger who had received their loved one's organs. This conversation prompted others to seek guidance and peer support from Esther.

> 'Yes *I did a generic letter so it was suitable for any of the recipients….I can send it to you if you'd like see if it can help you?….you can watch videos on YouTube that help you to write a letter that you'd be happy with…it's such a*

> *difficult thing to do and the videos are quite helpful xx'.* (Esther, daughter of donor)
>
> *'Esther, I would really appreciate it if you could send it to me. As I have said in previous posts, I did write to the family of the young girl who received my daughter's heart, but she sadly passed away. I never got a reply, so I am thinking I didn't word it right. So hard'.* (Mary, mother of donor)
>
> *'Esther I could do with that too. Such a flipping hard time of year. Xx'.* (Debbie, wife of donor)
>
> *'Hi Esther, I would be grateful if you share the letter template with me. It's a wonderful idea to send a letter first. Thank you kindly'.* (Caroline, daughter of donor)

Esther decided to donate her mother's organs after she suddenly became unwell and was taken to the critical care unit, where she was treated but could not be saved. Esther has been a positive influence within the group and has supported many others during the study. I interviewed Esther in May 2022. Throughout the one-to-one interview with Esther, it was evident that the organ donation experience had been positive. She needed to foster friendships with others in the group, offering them a compassionate, supportive relationship. This need to support others was part of the grieving process, and Esther found it therapeutic to her bereavement recovery, resulting in reduced symptoms of grief due to the feelings of inclusion and belonging, as well as an increase in personal growth and well-being (Bartone et al., 2018). Esther needed to provide the group with care and understanding, and during the study she undertook a bereavement counselling course. She shared this with the group, and her role within the group transformed from being a conversationalist to more of an influencer. This training built her confidence and placed her in a position where she could advise the group on a professional, qualified level and a personal, experienced level. She often supported other participants, and within the individual interview, Esther talked about building strong bonds and friendships. Here she talks about how she found the group had great support and she started friendships with others in the group while supporting them to write letters to the recipients of their loved one's organs.

> ‘*And I think that's why I found talking to the other people in the group because of actually like being.... There’s a certain few ladies in the group that I've actually been private messaging and we've kind of got like a we've been chatting back and forward because they've been finding it difficult writing a letter’.* (Esther, daughter of donor)

Nearly one year since her mother’s death and Esther finds it nice to chat to others who share similar experiences. She has enjoyed supporting others in the group, sharing the letter she wrote to her mother’s recipients with others in the group who were struggling to know what words to write.

> *‘But it's been like it's been nice to chat to other people that have gone through the same. You know whether it be their mom, their dad, their brother, their sister, you know, heartbreakingly some of them, have lost children, and I always put myself in a situation for me I did not think it's Loss is loss at the end of the day. But I kind of put myself in a situation. Part would be your child that you've lost. Doesn't appear in one of the ladies on the group I've been chatting back and forth here quite regularly cause she's struggling to write a letter, so I've been trying to sort of help her. That's been a great part of the group meeting other people that. We've gone through the same as me’.* (Esther, daughter of donor)

Esther was extremely positive about organ donation and had a huge amount of pride for her mother. She was thankful for joining the group to help others.

> *‘I'm glad I I'm glad I joined a group. I'm glad I think I've got some I. I'd like to think I've been able to help some of them’.* (Esther, daughter of donor)

Throughout the study, participants have shared information, whether that be, help books, organ donation related documentaries, and even memorials of their loved ones.

> *‘I was just reading about the UK’’s oldest transplant patient, who is 90 years old, on the BBC news website. He said about the donor; ‘I think about them almost every single day, even now. Especially now. You can't ever put into words how kind, generous and unselfish he and his family are for donating his heart to somebody he doesn't know’. I just thought that was lovely to hear,*

> *especially as a lot of us don’t know much about the recipient’.* (Esther, daughter of donor)

> *‘Not sure if any of the group like to read. I read a couple of books (fiction) that touch on Organ Donation. One is called ’One Minute Later’ by Susan Lewis and the other is ‘The Donor’ by Clare McIntosh. The second is a quick read and both books deal with the subject in completely different ways. Some may have already read them and maybe some wouldn’t like to read them but just thought I would share’.* (Mary, mother of donor)

> *‘Went to visit the donor memorial today for my mum’s birthday. It was beautiful to see it. I love her and miss here beyond words.* 🦋*’.* (Samantha, daughter of donor)

In addition to the resources and sharing of coping strategies, the group also looked to NHSBT for guidance and support. The knowledge that the moderation team was from the organ donation organisation added an element of safety and reassurance. Several of the participants needed clarification and questions answered regarding the donation process. Having healthcare professionals on hand to respond to these uncertainties was valuable. Here one of the participants responds to the moderator after requesting information about the process while also asking the opinion of the other group members.

> *‘Thanks to moderator for today for her help. I took a notion into my head that I had said I didn’t want any feedback from recipients, but I didn’t. So much of*

> *the process is still a blur for me. What does anybody else think?'.* (Mary, mother of donor)

At times the posts appeared to be exceptionally sorrowful, and the pain experienced by the participants was overwhelmingly profound. Having the experience and knowledge of supporting bereaved individuals from the NHSBT moderators was invaluable. Here the moderator, a SNOD with extensive bereavement support experience, responds to a post by one of the participants, asking about the need to seek professional counselling. Julie also responds to the answer posted by the moderator. The participants' vulnerability was a prime concern throughout the study. Being able to support the group adequately is part of our professional integrity and ethical responsibility. By having the bereavement experience and training, the SNODs supplemented the care provided to the group members.

> *'Six weeks is just the beginning of your grief journey; I have no doubt you are still in shock. You have clearly recognised what helps for you - continuing to function/distraction through work but please be aware that feelings not dealt with will likely come back to the surface later. I also suspect work would much rather you reached out so that they can offer you some support with your grief'.* (Group moderator)

> *'Thank you for this - I was battling today, and this helped xx the hurt in my heart is so painful* 😟'. (Julie, mother of donor)

> *'Let that pain come - meet a friend and get rid of some, cry/talk/rant - it's like tipping some water from your psychological bucket that is spilling over with grief. In theory you should feel a little lighter for it* 👍*'.* (Group moderator).

Allowing NHSBT healthcare professionals to be part of the group facilitated the contribution of professional support and guidance. This provided group members with direct access to the experts, who could offer instant answers to queries about the organ donation process while supporting their bereavement needs. Before this group, many families lived with unanswered questions with limited access to bereavement support (Ralph et al., 2014; Sarti et al., 2018)

> *'Thanks to NHSBT today for her help. I took a notion into my head that I had said I didn't want any feedback from recipients, but I didn't. So much of the process is still a blur for me. What does anybody else think?'.* (Mary, mother of donor, Facebook comment)

Mary asks many questions to other participants and also to the moderators using the group as a way of gaining clarification and responses.

> *'Maybe a long post but would appreciate other people's opinions. I recently received an update on the recipients of my beautiful daughters' organs. Sadly, one of the recipients has passed away. My first thought was to write to send my condolences, but I have been thinking.*
>
> *What if the family don't know that I know?*
>
> *What if they don't want me to know?*
>
> *What if they don't accept the letter and will I know if they do?*
>
> *What if they don't reply?'.* (Mary, mother of donor, Facebook comment)

> *'It's a difficult one, my initial thoughts earlier were to write letters but now I'm not sure.im asking myself the same questions xxx'.* (Francis, mother of donor, Facebook comment)

Some of the questions asked to the group referred to the clinical situation and without these questions being answered may have left the donor families in a state of constant curiosity.

> *'A question. We left the hospital a few hours after Luke was pronounced brain stem dead, but he didn't go to theatre for another 24 hours. Would he have stayed on life support until organ donation was completed? I never asked at the time but always wondered'.* (Francis, mother of donor, Facebook comment)
>
> *'My husband suffered a cardiac arrest at home. My son gave him chest compressions until the ambulance crew arrived and restarted his heart. The A and E doctors said my husband was clinically dead at home, but he was transferred to ICU because there was still a chance of recovery. He never*

> *woke up and after they removed life support (briefly) he clearly had brain damage including the brain stem. There was no hope, but I was asked if I wanted to be there when he "officially died" prior to organ donation the next day. I declined as I had said my goodbyes. So, his date of death is the date of organ donation. I guess it's when the heart stops beating?'.* (Ruth, wife of donor, Facebook comment)

Being part of the group NHSBT professionals were able to respond to the clinical questions directly, providing a prompt response and reassurance to the families.

> *''Yes, you're right, however there are two ways in which donation can happen so some of you may have had different experiences - I'll try and explain in simple terms:*
>
> *1) After Brain Stem death occurs (or neurological death). In this situation the heart stops in theatre at the time of the donation operation. The time of death on the certificate is the time the Doctors carried out the first set of neurological death tests.*
>
> *2)Donation after cardiac death - this is when brain stem death hasn't happened, but a decision has been made to remove life support and the patient isn't expected to survive. In this situation we have donation teams ready in the hospital, withdraw treatment & the patient would have to die in a timeframe (approx. 3 hours) to be able to donate, if they go beyond then donation can't happen due to organ damage. If they do die in the timeframe, then the donation operation happens after cardiac death has been verified - usually around 5-10 mins after.*
>
> *I Hope that offers some clarity for you all'.* (NHSBT SNOD, Facebook comment)

The group discussion offers essential information which could inform NHSBT regarding the experiences of organ donor families, having instant access to their thoughts and feelings, enabling them to develop more robust aftercare services which meet the needs of some families. The peer support strategy allows access to a hidden group of bereaved organ donor families who could readily contribute to the planning and development of responsive aftercare services to meet their needs (Sque et al., 2014). The new knowledge gained from this unique study allows the voice of the organ donor families to be heard, providing NHSBT with instant access to respond to queries and provide needed support where required while also gathering compelling contributions which could positively inform service development.

Acknowledgement of the ‘Gift of Life’

Organ donation is a selfless act that the family makes without expecting recognition (Maloney, 1998; Jensen, 2011; Sque et al., 2017a; Walker & Sque, 2019). However, there is compelling evidence generated from the narrative and supported by the interviews with organ donor families that families are not happy with the lack of acknowledgment from recipients. The constant longing, at times painful to read, was a solid recurring theme throughout the analysis and group conversations. Participants yearned to hear from the recipients, wondering where the stranger was, how they were living their lives, and most importantly, with a part of their loved one’s organs will remain with them forever, questioning the grief journey they will encounter, and if the impact of the connected emotions on the ability to eventually repositioning their grief recovery. This novel group provided a safe space for organ donor families to discuss their thoughts and feelings about the organ donation process, allowing them the freedom to release thoughts and emotions that only other organ donor families will understand.

> *‘I find it hard to think of my loved one’s organs being donated in the first place and so it helps to hear somebody’s heartfelt appreciation. I understand it’s completely up to the recipient to decide whether to write or not, but I think for me personally, I would feel hurt not to hear. I know it might be hard to know what to say but a simple thank you is enough for me’.* (Mary, mother of donor)

Mary appears to reveal an element of uncertainty concerning the organ donation decision in this discussion, stating that ‘*it’s hard to think of my loved one’s organs being donated in the first place’,* suggesting that there are multiple anxieties linked to organ donation.

> *‘I get angry that recipients haven’t made contact, it’s not that I want thanks, maybe just acknowledgement. I get upset when I hear that donors have received correspondence, almost jealous. Then I tell myself it’s not a*

> *competition. I haven’t had anything from the recipients which I do get angry about. I got a letter 2 weeks after with brief details on who had got which organ donated and then 18 months, I emailed the donor team for an update which I got but still nothing from the family’.* (Jodie, wife of donor, Facebook comment)

Others receiving correspondence from recipients stimulated for some feelings of anger and jealousy which indicated belonging to the Facebook group could generate additional pressure. However, it has provided a platform to share feelings openly with others who understand those feelings. The painful conversations of the donor families construct a negative representation of organ donation, questioning the idea that it is a positive phenomenon. These anguished discussions require some reflection, questioning organ donation and the possibility that it causes added harm. Kentish-Barnes et al. (2019) proposed that donor families consolidate the organ donation decision, understanding that the lives of many other individuals will be saved, and this can be a motivating factor for consent as the family intends to turn a tragic situation into something positive. This may be the original understanding; however, the narrative demonstrates how eager the donor families are to receive information from the recipients, and through disappointment, leaves them questioning the donation decision.

> *‘I haven’t heard anything yet, not sure if it’s too soon or not but it’s just coming up 6 months. A simple thank-you to my mum is all I need. I was always taught by her to be well mannered and to thank people so it would hurt me if she didn’t get a thanks for this biggest gift that one person could possible give another’.* (Charlotte, daughter of donor, Facebook comment)

The suggestion that not receiving a ‘*simple thank you’* from recipients is discourteous, given that they have received an organ from their loved one, ‘*biggest gift that one person could possible give another’.*

> ‘*Today marks 8 weeks since my son gained his angel wings. He helped 5 people live on an I truly hope in my heart that they contact us to say thank you 💔because as a person that made that decision, I would like to think they would be grateful that their families aren't going through what we are as a family 😭thank you* ***…’.*** (Barbara, mother of donor, Facebook comment)

> *'I sometimes think it's selfish that recipients don't get in touch xx'.* (Jodie, wife of donor, Facebook comment)

The conversations occasionally provide some balance and reasoning to situations, offering an alternative opinion which could potentially offer some comfort. Debbie acknowledged the loss of Barbara's son, proposing that organ donation was a selfless act that may not need recognition. Comments such as these strengthen the position of peer support. There is some acceptance from a few members of the group that recipients may also struggle with emotions leading to the lack of recognition. Francis's comments below offer some explanation as to why there is no contact and expresses the need to respect recipients and take comfort in the donation process alone.

> **'***So sorry for your loss. You know that your son tried to help another and without conditions attached'.* (Debbie, wife of donor, Facebook comment)

> '*It must be difficult for the recipients as well and I expect that they will be going through a lot of emotions and feelings at their end. So, if I put myself in their short it's as personal as grief and each step takes time. They I'm sure will get in touch when they are ready and for some that might be never for whatever reasons. If that's the case, I suppose it's something we have to respect and hopefully find some solace in the fact that our loved ones could help. It's a difficult situation.💔'.* (Francis, mother of donor, Facebook comment)

Some comments offered a balanced view and presented participants with support and alternative opinions. This approach will encourage organ donor families, providing an element of choice. Without this accessible support from the group, they may spend time deliberating their thoughts, not having access to alternative views, which could potentially cause more stress and anxiety. One advantage of the group was that it offers a space where organ donor families can be honest and open and share these thoughts and feelings with others who hold some understanding. When other group members received letters from recipients and shared them with the group, it provided others with the hope that they may receive a letter one day. In addition, the discussion refocused on the quantity of contact needed from the recipients, with several participants maintaining that all they need is a thank you and would not wish for any personal contact.

> *'I haven't heard a peep from any of the donors and I don't know if I'd want to actually meet them or not, I know it's silly and it's none of my business what the recipients do, but if we didn't get on or they were doing or saying things that I know would've upset or angered my beautiful girl, I'd be quite annoyed yes, I know it's stupid, but I'm just being honest'* (Maggie, mother of donor, Facebook comment)
>
> *'Maggie it's not stupid at all and this page is here for us to be honest. You read stories about families meeting up and I am not sure if I would want to x'.* (Mary, mother of donor, Facebook comment)
>
> *'Although I said I'm happy to receive a letter from the recipient/s if they wish to make contact, I'm not sure I could meet them in person. For me that might be one step too far if that makes sense. I really feel for those here who've had no correspondence from recipients of their loved one's donated organs. It's early days for me (two weeks) but I do hope they make contact even if it's only once. Surely, it's the least they can do. I know it's something I would do if the roles were reversed'*. (Donna, sister of donor, Facebook comment)

Despite suffering immense grief following the death of their mother, Louise offers peer support combined with an open-minded assessment of what the recipient must experience, providing the other participants with an alternative perspective that may assist their discouraging reflections.

> *'Not sure I would want physical contact; it's only been 6 months (for me) and still I struggle with PTSD (post-traumatic stress disorder) I think I opted for written contact but I honestly think from the recipient's perspective how daunting and probably never being able to convey the full gratitude that is probably expected in written form is quite a big ask to send to an almost strangers family????.....'.* (Louise, daughter of donor, Facebook comment)

A paper over 30 years ago reported that organ donor families feel that the gift of life can be considered undervalued and, therefore, not appreciated if they are not provided with information and updates regarding the recipients (Pelletier, 1993). This remains an important longstanding issue still relevant today, with similar feelings exposed by families in the Facebook group. In practice, nothing has progressed to ensure people feel informed post-donation writing encouraged by NHSBT, but it cannot be mandated. There is a balance to be found between providing an update for those who desire and encroaching on the life of the organ recipient. The recognition of the continuing effects of organ donation on families and longing for information about the recipients suggests even now that general bereavement counsellors are unaware of what is needed to support better-bereaved individuals who have experienced organ donation (Sque & Payne, 1996). It was clear from the many conversations and discussions on the group that the insecurity and lack of information regarding the recipients, for some obstructed and others, influenced how organ donor families managed their grief. This was not unique to all organ donor families, and some comments suggested that certain participants did not share these feelings or need further information.

> *‘We didn't donate to receive thanks we did it as it seemed the right thing to do but it would be nice to receive a thank you. Don’t beat yourself up for feeling this way xxx’.* (Francis, mother of donor, Facebook comment)
>
> *‘Although it's a horrendous situation I felt the team made an unbearable situation more bearable. I have been informed how Mike's donations have helped but not directly from the recipients, but it's very early days. It must be difficult for the recipients as well and I expect that they will be going through a lot of emotions and feelings at their end. So, if I put myself in their short it's as personal as grief and each step takes time. They I'm sure will get in touch when they are ready and for some that might be never for whatever reasons. If that's the case, I suppose it's something we must respect and hopefully find some solace in the fact that our loved ones could help. It's a difficult situation 💔’.* (Pat, wife of donor, Facebook comment)

Indeed, in clinical practice, at the time of organ donation, some families openly choose not to accept any further contact from NHSBT, or organ recipients, and felt that the organ donation was enough, wanting no additional contact.

The Use Of Social Media To Connect The Bereaved: ‘Value Of The Group’

Humans are instinctively social creatures; therefore, socialising using the internet has become the norm for people worldwide, empowering them to share information and connect regardless of location (Whiting, Williams 2013). One of the most common grief experiences is isolation, manifesting as social, emotional, and physical seclusion. Individuals may feel detached from the world for many reasons, such as the nature of the death may place the bereaved outside of societal norms or because people may deem that what is a standard time/intensity of grieving is abnormal (Hollander, 2002). Therefore, bereaved people may remove themselves from social interactions, leading to further isolation and loneliness (Clark et al., 2004; Tolstikova & Chartier, 2010). For some people using the internet to connect with others who have had a similar experience, people who may understand and appreciate the need to openly grieve in that space can benefit their mental health and well-being. This was supported by Helena, whom I interviewed in May 2022, whose narrative demonstrates the benefits of the Facebook support group and the positive effect it has had in supporting her and her son through their grief.

Helena lost her 24-year-old daughter after she took her own life, having been in an abusive relationship. Here Helena talks about how she knew organ donation was her daughter's wish, but despite this, she still grapples with a mix of raw emotion for her baby girl. She expressed how she wished the recipient no harm, but organ donation was still difficult. She finds that being part of the group helps her rationalise her feelings.

> *‘I know this sounds awful that I just wish that there was something I could have done to save my baby girl. And so, it's mixed emotions. But knowing that knowing that this because we have only heard from one, that this person doing really, really well is what my daughter…. And that's why. That's why she ticked the box to being a donor, cause that's what she would have wanted. It’s just like the because part of me thinks that maybe shouldn't feel like this, but on your page seeing other people experience similar feelings and you know that that's alright to feel like that because I don't, for one minute wish them any harm. I wish them all the best they've got part of my wee girl there, so*

> *yeah'.*
>
> *'It's just difficult, and as a parent in to know that their wiping her away and taking these organs and they can't save your child so. This is absurd. Lola wanted to do so as a mother I probably wouldn't have done it in for the simple reason. Is taking pieces of my child away in and given them in other people. It's just the thought of that'.* (Helena, mother of donor, taken from interview)

Helena openly shares her anxieties about the organ donation process and her guilt for doubting her decision. She explicitly affirms the value of the group, being able to share openly with others in similar situations and gaining confirmation from others that it is ok to experience such feelings. Ease of accessibility, anonymity, privacy, and the non-confrontational nature of utilising a bereavement community can and does offer great benefits (Tolstikova & Chartier, 2010; Clark et al., 2017).

The group provided comfort to Helena at night-time when she couldn't sleep, she would turn to the group. However, there appears to be an element of guilt and possibly regret in allowing her '*little girl'* to become an organ donor, although throughout the interview Helena reiterated how it was her daughter's decision. Helena also refers to the fact that she wouldn't want harm to come of the recipients but her feelings where to protect her daughter. At one point she refers to the organ donation process as '*wiping her away to take her organs'*. It's clear from the interview that Helena experienced mixed emotions regarding the organ donation decision, knowing she had honoured her daughter's decision, but also as a mother allowing this to happen was painful and deplorable.

I asked Helena if she thought using social media was a good way of supporting families after organ donation. She explained how she thought it was a helpful way of providing support and how the instant accessibility was her main reason for joining the group. She wanted instant access at any time of the day or night.

> '*I'm not a very good sleeper anyway. But not afterwards and my daughter I just don't sleep. But the group pages active all the time, so if I if I was feeling really, really badly, which is nearly every day, and I couldn't sleep I would go on your page and would read everybody else's comments. And there's some comments that I can relate to and that they've got different ways of dealing with things, and so you can take on. There's quite a lot that page does. When*

> *you're going through all these different emotions and because it’s out 24 hours a day’*
>
> *‘If there’s anything you want to ask there’s always somebody that would come back and say something. Uh, so Its be good it’s really good’.*
>
> ‘I*t's not it's not easy to be able to phone up somebody or make an appointment to come and speak to somebody. That is your feeling how you're feeling at the time*
> *you can go on and they are also you can go on and there's always somebody cause they're obviously probably not sleeping the same as me and everybody else. Whereas if you’re waiting for some other support. You have to wait till you're in a in a queue for an appointment or a phone call that page it's just there when you need it’ When your page is there and is active there's always somebody or I don't always comment on things, but I'm always active on it and I always see. And then when other people come in here, you can't help but feel their pain because you know what they're going through and it's just like it's. It's just a nice page to have and be part of um because I've never had to deal with this in donor, but I don't know how to deal with this as well as my loss. Talking to other people and seeing other people, it helps. That think your page being on social media. That's where everybody is now. But the difference with your page and speaking is something like I've said before. It's. It's a 24-hour page*. *You can't get any more support than that and it's everybody that is going through the exact same, and so I think having that as it's been a massive help to me and I think we don't know what other comments is, it's definitely the best thing’.* (Helena, mother of donor, taken from interview)

Here, Helena disclosed the positive effect the group has had on her bereavement; despite not being an active participant, she describes the comfort it creates and knowing that there is always someone in the group. She also affirms how she feels the other participant’s pain, as she is suffering similarly. Helena also expressed the sentiment of dealing with the organ donation process and the painful loss. Knowing others were experiencing the same positively impacted her grief. She was a ‘Silent Reader’ gaining solace from the knowledge that others are in similar situations, reading comments from other participants, and having a sense of belonging, knowing she is not alone in this lonely world of grief, validating the concept that the bereaved can feel isolated from society.

Throughout the interview Helena was particularly encouraging when relating to the value of the group. When asked about other support mechanisms and if she had considered accessing counselling, she spoke about the Facebook group as being all she needed at this time. She felt that the group was providing her with adequate support and care at this stage and she did not want to see anyone face to face or in a bereavement group setting. Helena felt the group removed the pressure of being in a social situation, providing support without having a physical presence.

> *'Yeah.so you're just constantly on it. So, you would have thought like if it was a support group. I'm not sure how I would feel about attending that. I can attend this page without being physically seen, if you do get upset, you're reading it. It doesn't matter because nobody can see that, so it takes a bit of pressure off a lot of things, so as well as getting support and answers when we even haven't posted anything yourself. You don't want to, but it's giving you lots and lots of abilities to cope, its open to get information. We don't even have to say anything'.* (Helena, mother of donor, taken from interview)

Some evidence exposed negative feelings toward using Facebook support groups, suggesting that Facebook provides a lack of face-to-face interaction and loneliness, creating further isolation and disconnect (Bartone et al., 2018; Prescott et al., 2020).

Jodie found it difficult using a social media platform to engage with others. During our interview she exposed her discomfort of using Facebook.

> *'It's just I don't really like Facebook, I'm not a big Facebook fan, or joining any forums online. I didn't really kind of like writing things very much because I don't know how it's going to be interpreted by others. it's much easier when you talk to people because you get a sense of their body language and how they're responding to what you're saying and'.* (Jodie, wife of donor, taken from interview)

Helena offered a different opinion and discovered that accessing remote support through social media was a preferred option, and she would have struggled with in-person support. Some people, however, may prefer face-to-face, and the need for different support options is important (Bartone et al., 2018).

Throughout the study, discussions have inferred the value of ‘Donor Families Together’; participants express their gratitude and gratitude for being invited to join the Facebook group.

> *“Hi there to my new group of friends. I'm Stacey and feel so pleased to be added to such an amazing support group’.* (Stacey, mother of donor, Facebook comment)

> ‘*It is so hard but it’s better to talk and that’s exactly what this group is for - sending strength and support xx’.* (Julie, mother of donor, Facebook comment)

Stacey joined the group after the SNOD, who supported her after donating her son's organs after his sudden and unexpected death, suggested it may help her grief. Stacey lost her son ten months earlier and expressed to the group how she would have joined sooner. May also joined several months following her daughter's death, expressing similar feelings. The participants were invited to join this group in the days that followed the donation, and I questioned this initially, thoughtfully considering the right time to invite donor families. There was acknowledgment from some of the participants that joined later into their grief journey that they would have welcomed an invitation sooner, supporting my decision to invite them immediately after the donation. These comments also highlight the benefits of the group, with donor families still searching for comfort and support several months after the death of their relative.

During the interview, I asked Jodie, if she felt she was invited to join the group at the right time.

> *‘Yes, I think it was the right time. Because I think I might have been sort of processing other things if it had been left longer and maybe I wouldn't actually notice the invitation to join’* (Jodie, wife of donor, taken from interview)

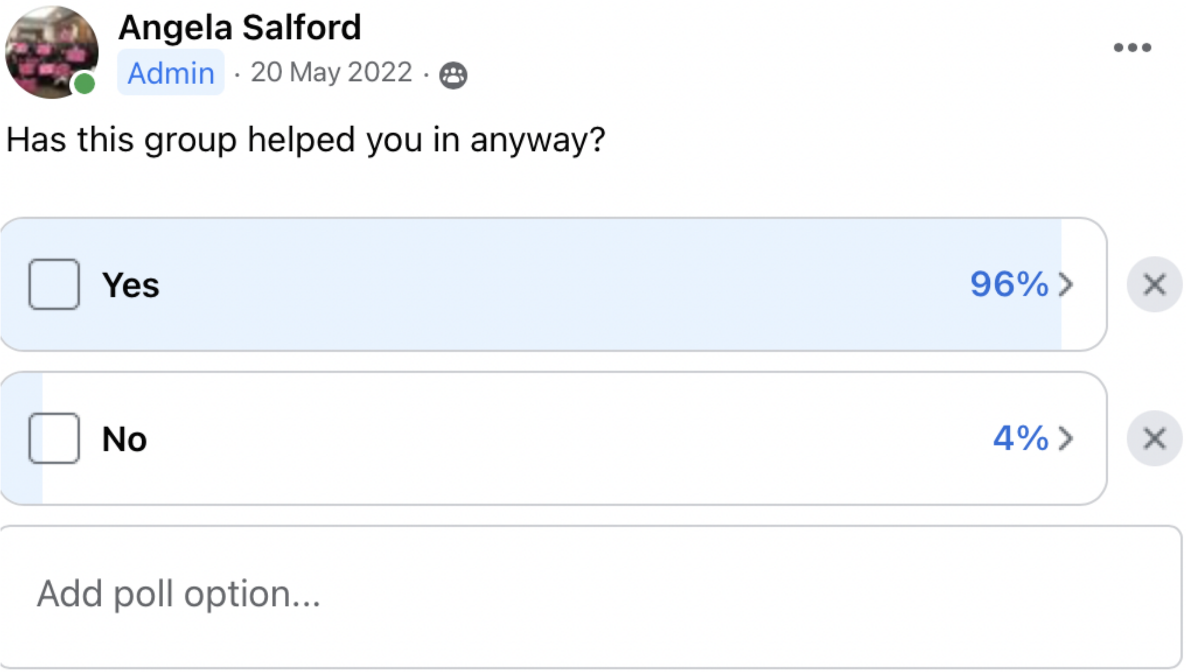
> *‘So* g*lad you’ve asked me, and I’ve joined. I'm 10 months on from losing my son. I would have definitely joined earlier if I'd have known xxx’.* (Stacey, mother of donor, Facebook comments)

> *'I would have loved to have been invited to this group during the earlier days. It can be a lonely place and I desperately wanted to make contact with others in the same position'.* (Mary, mother of donor, Facebook comment)

There was a strong unity in relation to the page being a safe space to share personal emotions and opinions with each other. The group members encouraged sincerity, supporting, and encouraging other group members to share their grief. The unreserved connections formed between these strangers was emotional yet heart-warming.

> *'Thank you for this support I was battling today, and this helped xx the hurt in my heart is so painful 😢'.* (Julie, mother of donor, Facebook comment)
>
> *'Hi everyone, first off a big thank you for allowing me to be part of this group'.* (Esther, daughter of donor, Facebook comment)
>
> *'This page is here for us to be honest'* (Barbara, mother of donor, Facebook comment)
>
> *'Love reading your other posts, again I am really sorry we are here'.* (John, father of donor, Facebook Comment)

There is a real sense of the group coming together to support each other and using the group as a protected space to be their genuine selves. At the end of the data collection phase I posted a poll to obtain feedback from the participants regarding the value of the group (Figure 12).


Angela Salford

Admin · 20 May 2022 ·

Has this group helped you in anyway?

☐ Yes 96%

☐ No 4%

Figure 12: Example of Facebook Poll

Although only 51% of participants responded to the poll, the results remain positive, with only one participant who felt that the group had not benefited them. In general, the results revealed the Facebook group's positive impact on the participants.

Aftercare: What Do Families Need Or Want

The 'Donor Families Together' Facebook group is a real place of honesty and openness. The donor family discussion amplified certain areas of practice that may need to be improved, intending to enhance the aftercare experiences of the organ donor families. It was not until the group had become more established that participants started to open up regarding the expectations of support from NHSBT.

> *'Sometimes I think I should have said No but then I realise it was the right thing. I am just having one of those days and getting cross about lack of follow up care. What do these specialist nurses do? It would have been nice if the hospital had thought to let the donor families know. No aftercare from the specialist nurses.* (Mary, mother of donor, Facebook comment)

There is some discussion within the group regarding the scarcity of communication from NHSBT. Several participants mentioned the importance of acquiring information after donation and the tardiness of receiving a response from NHSBT. Allowing them to express their feelings and objections as an alternative to repressing their feelings demonstrates the importance of the group. They can also converse with each other, confirming that they are not alone, and other group members have had similar experiences.

> *‘I sent a generic email to the donor team and asked them to forward it on to the various recipients, I didn’t hear anything so a few weeks later I called to confirm it had been received and was told it had arrived, but the donor team hadn’t processed it yet. Not heard anything since’.* (Maggie, mother of donor, Facebook comment)
>
> *‘I didn't want to be a bother, so I never asked again - and I never got a letter or any communication from NHSBT at all from 2018 until last week.*
>
> *I brought this up the other day with one of the nurses, saying I felt it was (is) important for the donor families to hear how recipients are doing, even if there is no direct communication. This January I did not get an update from NHSBT either - but a couple of days ago I did get a letter in the post, letting me know that the two living recipients are doing well. I believe it may have been due to the conversation I had with the nurse.*
>
> *I'm not sure that I would want to hear from the recipients directly, but I think it is important for us to hear how they're doing, even if the news isn't good. It does seem to be rather hit-or-miss, though, in terms of reports and updates. I think NHSBT should take this on board as one of their priorities. I'm not saying they aren't busy, but "after care" is important, too. I feel sad about not knowing, but worse about pleading for information. All I can do is wish them well. They don't owe me anything. I simply wanted some assurance that they were helped’.* (Christine, wife of donor, Facebook comment)

Christine lost her partner several years ago, and her bereavement could be considered less acute than some of the other participants. However, the comments suggest that this pain of not knowing about the recipients continues even over time. Donor families with no contact experience disappointment and distress, feeling that the donation did not provide closure (Azuri et al., 2013). By understanding the feelings articulated by organ donor families, NHSBT may well consider the impact on organ donor families, regulating communication and responding to the needs of families. Some participants commented on their experiences and how positive they had found donation, although the aftercare disappointed them.

> *'Luckily ours was a positive experience. That sounds wrong based on the circumstances but what I mean is that we weren't bullied into making a decision and were supported all the way through the process. I just wish that support continued afterwards. Don't the relatives of the deceased donor deserve as much, if not more support than the recipient? Their gain means we have lost someone very precious to us. They get to live because someone we love is dead. It makes me feel a bit bitter at times. Sorry if that sounds harsh. Xx'.* (Donna, Sister of donor, Facebook comment)

> *'I completely agree with you that there should be support for the donor families and this is seriously lacking. I found the feedback form awful. To me it was like a comment form after doing a training course. I never returned it. Also 'around the first anniversary' I received a generic card, but the postage hadn't been paid. Like you I don't mean to sound harsh, but I think there is something lacking x'.* (Mary, mother of donor, Facebook comment)

> *'I completely agree with you Mary. I didn't get a feedback form, nor did I receive the promised follow up phone after a fortnight. I also had to make contact to see if Paul's kidneys had been successfully transplanted when it should have been them contacting me. The email I sent over a week ago asking if his corneas have now been used has been ignored. They're all over us like a rash during the actual process but afterwards it's like we don't matter anymore. Xx'.* (Donna, sister of donor, Facebook comments)

The conversation between Mary and Donna continued with other participants joining in and commenting. Even though some of the comments expose the stark reality of certain donor families' experiences, Mary continues to commend the Facebook group as a space to speak freely.

> *'I think we all find a sense of pride that our loved one's organs made a difference, and we will always love them forever. But I truly understand why families may say No when it actually comes to signing the form. In my opinion more aftercare for donor families would be invaluable. I think NHSBT set up*

> *this group to try to increase the incidences of organ donation. Everyone in this group has had different experiences and it’s great that it’s a private group where members can speak freely x’.* (Mary, mother of donor, Facebook comment)
>
> *Of course, Mary, and your experience is your experience obviously. I will not defend a bad experience. We should strive for better. How do we make the donor family experience better? I ask that question of the owners of this group.* (Paul, brother of donor, Facebook comment)
>
> *‘I am not saying that my experience was bad but with hindsight it could have been better. It is my understanding that this group has been set up to find out how the donor experience could be made better and hopefully it will help x’.* Mary, mother of donor, Facebook comment)

NHSBT could learn from the candid lived experiences of the donor families, informing the development of the aftercare services with new knowledge acquired from the real-time narrative of bereaved organ donor families. The participants have honestly interpreted their most intimate feelings regarding the aftercare services provided, encouraging NHSBT to respond.

> *‘Then I found out one of the recipients had died, but the other two were doing well. I didn't want to be a bother, so I never asked again - and I never got a letter or any communication from NHSBT at all from 2018 until last week. I brought this up the other day with one of the nurses, saying I felt it was (is) important for the donor families to hear how recipients are doing, even if there is no direct communication. This January I did not get an update from NHSBT either - but a couple of days ago I did get a letter in the post, letting me know that the two living recipients are doing well. I believe it may have been due to the conversation I had with the nurse. I'm not sure that I would want to hear from the recipients directly, but I think it is important for us to hear how they're doing, even if the news isn't good. It does seem to be rather hit-or-miss, though, in terms of reports and updates. I think NHSBT should take this on board as one of their priorities. I'm not saying they aren't busy, but "after care" is important, too’.* (Christine, wife of donor, Facebook comments)

> *‘I sent a generic email to the donor team and asked them to forward it on to the various recipients, I didn’t hear anything so a few weeks later I called to confirm it had been received and was told it had arrived, but the donor team hadn’t processed it yet. Not heard anything since. I suppose it was fairly quick, but I really wanted to hear that she had made a difference to others, I don’t know if the email was even forwarded on to the donors though, the communication from the office that arranged the donors is sadly lacking and I’ve not had any reply from anyone’.* (Maggie, mother of donor, Facebook comment)

> *Maybe a bit harsh but it's just how I am feeling today. As for the Order of St Johns Award that other members have mentioned, that has been just another huge let down! There seems to be no support for donor families on the ground. I saw a photo of my local hospital that has made a heart shaped flowerbed in honour of donors and thought 'wouldn’t it have been nice to be told about it?'* (Mary, Mother of donor, Facebook comment)

Despite some comments appearing hostile, they provide NHSBT with real-time productive feedback and tangible reflections in a safe space. This new authentic knowledge can help improve the aftercare services that NHSBT provides to organ donor families. The comments provided may support the learning and embedded work carried out by the SNODs in the acute care setting, strengthening the intra-hospital experience and informing the hospital staff about the lived experiences of organ donor families.

Summary

This chapter draws out key findings and new knowledge to identify how social media peer support improved and influenced the bereavement journey of donor families, offering aftercare and a way to get answers to questions that help grieving. Clearly, the group found comfort, friendship, and support in a safe environment where they could share their most private feelings. The primary outcome alongside positive peer support included sharing their lived experiences, sharing information, sharing their grief, and sharing thoughts and feelings regarding the acknowledgment of the precious gift their family member had presented to strangers. The group also expressed truthful opinions about the process and the aftercare, providing NHSBT with feedback and lived experience. The presence of NHSBT healthcare professionals was evidently welcomed, providing instant access to professional support, and gaining answers to unanswered questions. These findings and subsequent narrative offer NHSBT new knowledge of organ donor families' experiences which they may not have every uncovered.

Box 3: Summary of key findings

- The group contributed to building social capital, growing a community of individuals bonded by death and organ donation.
- The levels of engagement varied, although it was clear that most members accessed the group reading the comments if not contributing.
- The discussions on the 'Donor Families Together' Facebook page encompassed the raw grief that each family member was experiencing, sharing their loss and supporting each other through their lived experiences.
- The recipients lack acknowledgement of their selfless gift of life was impacted on their grief.
- There was a need to have the professional support from NHSBT.
- The sharing component was immeasurable and through the peer support the group shared feels, experiences, emotions, grief, information, wisdom etc which was a significant part of the framework.
- The group improves and provides support when needed, helping families through the grieving process

The key themes emerging from this chapter will be further discussed in chapter 6, within the context of the wider bereavement literature to expose the new knowledge generated by the study and extend theory.

Chapter 6: Discussion

Introduction

This study explored whether a peer-to-peer online support group improved or influenced the bereavement journey for organ donor families in the UK. The focus was on the lack of aftercare and bereavement support provided for organ donor families after the organ donation process, in addition to understanding their lived experiences and how we can improve the support provided following organ donation. Social media provided a virtual space to bring organ donor families together, which has never happened before in the UK, to share lived experiences, get answers to questions, listen to others, and provide support. The findings from this study are enlightening and provide a deeper insight into the different and challenging grieving journey's bereaved organ donor family's experience. These original findings extend knowledge on the organ donor grieving journey, challenging existing theoretical grieving models and demonstrate how using social media as part of aftercare can improve and alleviate anguish and conflict, addressing some of the grieving hurdles faced. However, others, such as longing and curiosity, remain unresolved. The findings directly inform best practices for organ donor family aftercare; what is missing, what is needed, and why.

The chapter will focus on three key themes:

- Lived experience
- Social media aftercare to meet the needs of donor families
- Grief theory

The findings emphasised peer support as a primary source of help, bringing together a community with similar experiences. The peer support encompassed several aspects: sharing the pain of grief and the lived experience, information/asking and answering questions, and acknowledging the significance of organ donation and the lack of resolution. The value of the group was evident throughout the study, bringing individuals together in a protected space to open up and express raw emotions, thoughts, and heartache. A vast amount of the discussion was directed towards the recipient of their loved one's organs and the acknowledgment of the 'gift of life' (Rapport & Maggs, 2002), which had been donated to them. It was clear that the participants shared a special connection and understanding. Their thoughts and feelings regarding the organ donation experience could be openly shared and understood with others bonded by grief and organ donation.

This chapter draws together and discusses the main conclusions from the research in an attempt to understand the role that social media can play in bringing together a group of bereaved relatives who made a courageous decision to donate their loved one's organs at the time of their death, demonstrating the need to offer additional bereavement support to organ donor families. The purpose of this chapter is to present the findings using the new knowledge collected from this novel study. The themes which emerged from the data related to the aim of the study, creating a positive impact and therefore necessitating discussion:

Lived Experience: Connection Through Death

Participants who joined the Facebook group had something in common; they had all donated their relatives' organs to a stranger. The strong bonds developed amongst the group were distinctive and unique. Berntzen & Bjork (2014) suggested that to understand the process of organ donation fully, further research is needed to explore the sharing and comparing of emotional strain with other relatives who had experienced similar situations, which would be of interest. A considerable amount of the discussion on the 'Donor Families Together' Facebook page occupied the participants lived experiences and the painful death of their loved one. Many shared the distressing stories of how their mothers, brothers, sisters, partners, fathers, and children came to be in a situation that ended in death and organ donation. Although heart-breaking to read, it appeared to bring the group together, as they shared this common purpose, strongly bonding them through grief. Maloney (1998) proposed some years ago that organ donation organisations need to find a way to empower families to come together and unite, suggesting that we need to moderate the sense of isolation and peculiarity that some families may feel by bringing them together to share this unique experience. Through conversations, families can recreate the post-death character and memoir of their loved one, fostering an emotional bond and intimate narrative about that person. However, many families of organ donors are spread out geographically and have no opportunity to grieve together (Dicks et al., 2018; Bolt et al., 2020). 'Donor Families Together' has provided a platform of togetherness, allowing families to share their real-life experiences of grief as it happens. Families have reported that providing this support will increase hope and resilience (Bonanno,2004; Jensen, 2011). The reality of grief was intense and undoubtedly visible through the heart-breaking conversations from the 'Donor Families Together' Facebook group. Participants shared various coping methods and resources throughout the study, developed strong bonds, and created personal friendships. Some of the painful narratives exposed their vulnerability. However, this has occurred in a safe space, surrounded by others who identify with the raw emotions and need to disclose honest feelings (Gibson et al., 2020; Prescott et al., 2020). They used the confines of the group to question their responses to the grief and their experience of death and donation, questions about the organ donation process, and to share resources and coping strategies. For many families, uncertainty and questions about the process of organ donation do not occur until weeks or even months later, suggesting the need to provide appropriate aftercare (Swartwood et al., 2011; Berntzen & Bjork, 2014; Dicks et al., 2017a; Bolt et al., 2020). The group used each other to create meaningful conversations, questioning the events that had occurred weeks and months before. Some families had been left with uncertainties surrounding the organ donation process and looked to other group members to explain. Establishing 'Donor Families Together' offers some families a necessary form of support for aftercare following this perplexing phenomenon. Some of the participants acquired confirmation regarding certain feelings they were enduring, affirming normality and providing them with a piece of mind that the feelings were a usual response to the grief experienced by others (Swartwood et al., 2011; Robinson & Pond, 2019). Zilberfein, (1999) suggested that following the death of someone you love, it is essential to understand that certain emotions are part of the grieving process, and you may need reassurance that such feelings and emotions are a typical response to normalise your grief. Although this may be a true reflection of specific individual bereavement, the findings suggest that organ donor families' grief is undoubtedly not normalised. In addition, some participants used the group to share personal keepsakes of their loved ones, memorials, and even gravestones, demonstrating the strength of the relationships formed with strangers who understand and can provide reassurance. The group would offer acknowledgment and virtual salutations, such as virtual hugs, to create an environment of acceptance and understanding, encouraging each other to share anything.

Several of the conversations in the group centred around the need for the donation to be acknowledged by the recipients, and the lack of communication from recipients produced pain and anxiety. The narrative provided consistent evidence of the emotional torment faced by organ donor families associated with recognition. Without information about the organs and well-being of the recipient, 'the gift of life' looked unappreciated (Pelletier, 1993), with many comments suggesting that recipients were thankless. Professional experience informs me that this is not the reality; many recipients are genuinely grateful for the donation and a second chance at life. Despite this, I could appreciate the desperate need for acknowledgment. Several discussions led to the organ donor families discussing their feelings and expressing the need for recipients to say,' Thank you.' Several conversations occurred regarding the decision to donate was not taken to gain reward or gratitude; they wanted recognition of their loved one's gift. This painful discourse undoubtedly disrupts bereavement, producing anger, pain, and a lack of resolution. The findings from this study may offer the transplant recipient community a deeper understanding of the impact that no contact has on organ donor families. Using the narrative to provide education may encourage more transplant recipients to write to their donor families. An alternative solution maybe providing the organ donor families with a generic ‘thank you’ letter following organ donation. Although, this could be considered uncaring and depersonalised. With organ donation being perceived as a positive and selfless legacy, many families may not consider the aftermath of donation prior to consent. 'Donor Families Together' has allowed families to share these painful thoughts and feelings, providing each other with support and the knowledge that they are not alone in relating their experiences. It has also provided families a space to share their joy of receiving such acknowledgment from recipients, offering hope to others who may not have heard. This unique study and future peer support platform may help encourage more organ recipients to communicate with their organ donor families. Revealing the emotional and compassionate significance of such a simple statement could improve organ donor family experiences, benefiting future aftercare and the reputation of organ donation. Educating the medical teams and the transplant community could have a positive impact on how recipients correspond to donor families.

Social Media: Aftercare To Meet The Needs Of Donor Families

The building of this unique community has been invaluable in allowing me to witness the intensity of grief experienced by organ donor families as it occurs. It has also been an easily accessible way for families who have experienced organ donation to connect. ‘Donor Families Together’ has successfully involved this bereaved community in active research, which could influence future family aftercare services (Sque et al., 2014). It has also been a platform to empower organ donor families to unite (Gibson et al., 2020; Prescott et al., 2020) by providing them with information and resources and an accessible way to connect with others. The best person to offer organ donor families support, comfort, and assistance is an individual who has the same lived experience and has been in their shoes (Maloney, 1998; McKenna & Bargh, 1998; Lenferink et al., 2020). This observation has been evident throughout the study, offering families the opportunity to build a community with many social benefits, among which friendship, trust, affection, and social support have guided them through the most challenging time in their lives. The use of social media has brought together individuals who would never have met. The findings exposed the strong bonds created amongst the group participants, several of whom found the group valuable, helping them through their grief journey.

Online bereavement care may help support an area requiring more support services (Lenferink et al., 2020). Offering an online service to support bereavement care, compared with face-to-face, may provide individuals with a space to feel less vulnerable or ashamed and might be less afraid of being judged when disclosing painful thoughts or emotions (Lenferink et al., 2020; Tolstikova & Chartier, 2010), there are also many benefits including, instant accessibility, providing support at any time of day. Furthermore, for those with difficulties finding support, because of limited availability of bereavement services in their area, or because of timing difficulties, online peer support could offer the opportunity to participate in bereavement support from home (or another place where they feel comfortable and safe) at any time of the day or night (Swartwood et al., 2011; Li et al., 2013). This was supported by the study's findings, connecting organ donor families from different parts of the country.

Although this is an easily accessible means to support the bereaved, thought must also be given to individuals who may not have the resources ways or disposition to access social media. Therefore, alternative support strategies need to be considered.

The use of open expressions of grief and loss on social media can aid in the grieving process and help people to process death in a different but meaningful way (Moyer & Enck, 2020). This is strengthened by the findings with participants expressing their feelings to the group, stating that the group is one place to be open, exposing their vulnerability. Using social media to support organ donor families has also helped build a robust online community connected through experience, able to endure talking about grief and loss, letting the grief be expressed and sense made of the situation (Tolstikova & Chariter, 2010). It has also brought people together who are geographically stretched, offering support to organ donor families regardless of their location (Sanderson & Cheong, 2010). Some participants in the group shared their location, offering to meet with others in person. Some participants have also contacted each other more personally, growing friendships and developing solid emotional bonds outside of the group.

Some evidence suggests that social media use can be deemed isolating due to the lack of in-person social interaction (Rossetto et al., 2014; Prescott et al., 2020). Although, these findings revealed that some individuals would not appreciate face-to-face support, finding comfort in reading the posts rather than participating. This was demonstrated in the explanation of the levels of engagement and the description of the silent reader. During the one-to-one interview, participant Helena expressed her need for the group to be online as she was not ready to participate in any discussion or meet people face to face. Helena disclosed how she had found comfort and support from reading the posts unobtrusively in the background. Supporting this theory is the number of participants who viewed posts within the group. Despite some posts generating minimal discussion, they continuously generate views from most group participants affirming the existence of the silent reader (as described in Chapter 4).

This form of social media provides the SNODs with an accessible resource they can easily pass on to donor families, helping them contribute to the aftercare post-donation. It can reassure the healthcare professional that the families are being supported in a protected environment by individuals who have shared a similar lived experience and can understand the nuances of organ donation.

How the group reveal their Grief

The compelling grief witnessed during the study indicates the need to modify the bereavement care services we offer to organ donor families, considering the situation's complexity. Organ donation is believed to add questioning to the direction of bereavement and is not part of the 'normal grieving' process (Pitman, 1985; Holtkamp, 2002; Sque et al., 2003). Society has advanced the customs and rituals that enable grief support over time, which vary between cultures, religions, and communities. These practices present ways for individuals to gain support as they work through the tasks of mourning without needing professional help (Falconer et al., 2011). Many grief theories have been discussed earlier in this thesis and they focused on the standard task models of bereavement, such as Kubler-Ross's (1970) 'Five Stages of Grief' and Worden's (1991) task orientation model. These models of bereavement set out steps aimed at working through grief and towards accepting the reality of the loss, adjusting to a new environment without the person they loved being part of that environment. The study demonstrated that organ donation offers additional layers to the grief, which could potentially modify or disrupt the bereavement pathway. The findings uncovered feelings of unrest and uncertainty, with many of the participants longing for recipient contact and needing information about their relatives' organs. This added layer of complexity, which continued to impact the participants' grief throughout the study, highlighted that there was a continual curiosity regarding the recipient, that could be detrimental to the grieving process, preventing the move to the stage of acceptance. The experiential qualitative approach engaged throughout the study focused on the participants' experiences, emphasising participant language when communicating with each other and trying to make sense of their devasting experience. The constant yearning for recipient information and acknowledgment observed throughout the study was palpable. This may not be the case for all organ donor families. However, it was evident from the 'Donor Families Together' Facebook group that organ donation may have complicated the grieving process.

Considering the previously discussed grief theories, it was clear from the findings that the participants experienced reactions associated with several of the grief models considered in Chapter 1. Freud, Mourning, and Melancholia (1917) described two responses to losing a person or thing. Mourning is a state bereaved individuals need to work through, which is an emotional reaction to the death of their relative. By working through the loss, the bereaved can detach from the emotional union, a process he called decathexis (Corr & Coolican, 2010), moving into a stage of resolve and recovery, reinvesting in life. The participants in the study show no signs of resolve and recovery, having an infinite connection with a stranger who has received their relative's organs. Freud's work also described Melancholia as a state of profound painful dejection, the reaction to the loss of someone who is loved (Freud, 1917), causing depression which can be a symptom of blocked mourning. Organ donation may well contribute to block mourning, although it is difficult to predict if any participants experienced this.

Bowlby's (1979) concept of 'mislocations' described in chapter one is evident from the findings. Many participants longed to know how the recipients' lives had been changed because of their relative's gift of an organ. They constantly sought information, aching to receive correspondence from them. Bowlby (1979) described 'mislocations' as a form of unfavourable development that occurs when the bereaved, instead of experiencing the dead person as a companion, locates them within another person, which can, if persistent, easily lead to behaviours that are not in the best interest of the bereaved. Evidence from the findings highlights the pain that organ donor relatives experience when they do not receive any form of communication from the organ recipients, suggesting that although organ donation is a gift of life to another, it may cause added pain to the donor families, which is not in their best interest. Bowlby's (1979) suggestion of 'mislocation' not being in the best interest of the bereaved could place uncertainties in the benefit of organ donation, or at the least the aftercare support provided to relatives, as they are left discontented (Bolt et al., 2019).

There was evidence that the participants moved through stages of grief. Bowlby & Parkes's (1972) four stages of grief model was evident in the painful discussions had by participants, although the final stage, re-organisation, involving letting go of the attachment and investing in the future, was never apparent. The ability for organ donor families to ever let go appears impossible due to the realisation that someone somewhere has an organ of their dead relative. The stage-based models offer some form of structure to a painful experience, although they appear wide-ranging and general. Consideration needs to be given to people's life experiences, culture, relationships, and end-of-life encounters with the deceased (Parkes, 1985; Stroebe & Stroebe, 1995; Corr & Coolican, 2010). Some aspects of Kubler- Ross's (1970) grief model and Worden's (1992) four tasks of mourning again were observed throughout the study, and participants experienced certain stages of these proposed models without showing evidence of reaching the final stages of acceptance and adjustment. Worden's four tasks of mourning suggest that, eventually, the bereaved find a continuing connection with the deceased while embarking on a new life without them. This would appear to be a reasonable representation of organ donation, knowing there is still a connection with the recipients. In reality, the study exposed continuous suffering and longing for information about how organ donation changed recipients' lives. This yearning for information appears to prevent organ donor families from moving forward and can be problematic as there is also the possibility that the organ is rejected, or the recipient dies, causing the organ donor families to experience the loss all over again (Corr et al., 2011; Bolt et al., 2020)

Sque, Payne (1996) offered a model of donor relatives' experiences in their work on dissonant loss. Dissonant loss is a bereavement or loss characterised by a sense of uncertainty and psychological inconsistency (Sque & Payne, 2007). This relatively small sample study of organ donor families interviewed concentrated on the donation experience, focussing on the donation process while acknowledging the psychological effects that organ donation can have on relatives. This limited study identified the ongoing needs of donor relatives, suggesting that even as time goes by, the effects of organ donation are prolonged. Despite this, Sque &, Payne (1996) condensed their dissonant loss theory to the grief experienced only at the point of organ donation. The dissonant loss theory proposes that individuals hold conflicting or incompatible beliefs and are likely to experience dissonance and distress during organ donation. The conflicting/resolution idea explains the decision-making families experience during organ donation. Participants in the study expressed issues that resulted in resolutions to the conflicts they were experiencing during the organ donation process (Sque & Payne, 1996). Sque & Payne (1996) suggested that relatives dealing with grief and donation focused on the realisation that some good had come from their relative's death and that the donation is recognised, valued, and not forgotten. Opposing this view are the findings from this study, as it is evident from the narrative that organ donor families do not necessarily focus on the good, and the donation for many has not been recognised, valued, and appears forgotten. Bolt et al. (2020), agreed with Sque & Payne (1996), suggesting that organ donor relatives experience conflicting issues leading to restless feelings, which can be resolved by direct contact or access to more information. Bolt et al. (2020) maintain that if the relative receives confirmation of a successful donation, answers questions about the recipient, responds to the donor's story, or recognizes the organ donation gift, this will resolve their restless feelings. The findings from this study show that this is not always the case. Many families are left with unanswered questions (Ahmadian et al., 2019), no acknowledgment or gratitude for the gift of organ donation, rejecting both Bolt et al. (2020) and Sque & Payne (1996) theories that organ donor relatives can find some form of peace and resolution. However, Bolt et al. (2020) have acknowledged the strain organ donation can put on relatives, recommending that bereavement guidelines reflect these difficulties. The findings from the study have provided evidence to suggest that the support relatives need after organ donation is ongoing and that there is no resolution for some, as some do not cope or deal with the grief of organ donation.

This study has provided a deeper understanding of the issues faced by organ donor families during and, more importantly, after this complex experience. Many grief theories and frameworks offer explanations and theories to understand grief and bereavement better. However, none focus on the aftercare needs of organ donor relatives, and the exclusive findings from this study expose the requirement for better aftercare and bereavement support. The analysis from this study has revealed new knowledge which has led me to the develop a unique new model of bereavement exclusively for organ donor families which enabled me to map the grief observed throughout the study. This unique model has been adapted using Kubler-Ross's (1970) Grief Cycle with the understanding (Figure 13). This contemporary model of bereavement offers clarity and transparency regarding the blend of emotions experienced as part of the organ donation process. The intended grief model aims to illustrate the intricacy that organ donation presents to families who live through the organ donation experience. It will provide healthcare professionals with a deeper understanding surrounding the complexities of grief following organ donation, exposing the responses and emotions organ donor families go through. This progressive new grief model identifies five responses to the poignant discourse identified within the 'Donor Families Together' discussions. Every aspect of the organ donor family grief model relates to using a social media peer support group. Using social media as a method to support organ donor families offers a unique, straightforward, and cost-effective way of connecting organ donor families.

The five emotional responses identified are categorised:

- Anguish
- Conflicting emotions
- Longing
- Pride
- Constant Curiosity

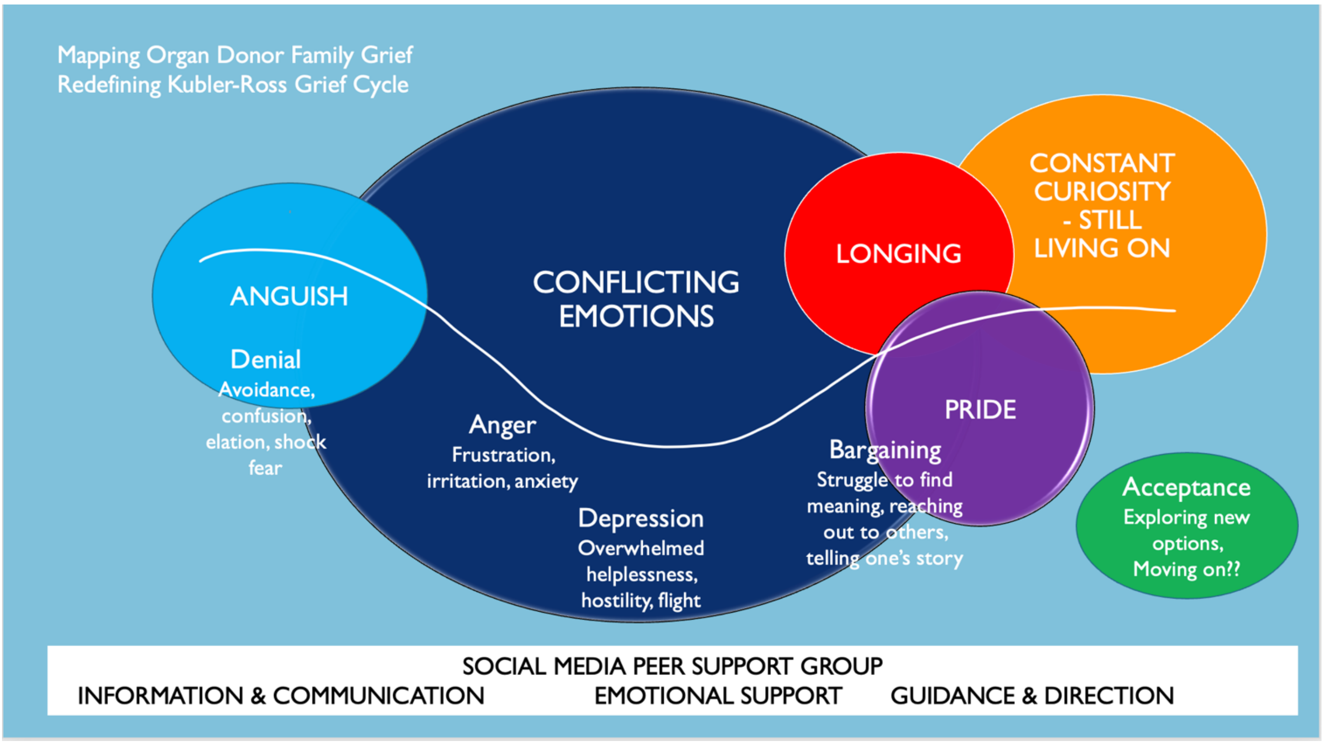


Figure 13: Mapping Organ Donor Family Grief, redefining Kubler-Ross Grief Cycle (1970)

Anguish

There was an evident sense of anguish discussed within the group. Many participants shared their utter disbelief and pain. This could be associated with any bereavement, not unique to organ donation. It is a recognised stage that bereaved individuals experience, identified in many of the proposed grief models (Kubler-Ross, 1970; Worden, 2009). The understandable anguish was observed throughout the study with constant posts about the extreme pain organ donor families was experiencing. These grief reactions are normal and will include the typical responses described in other grief models, such as shock, anger, sadness, and guilt, to name a few (Corr et al., 2011). These feelings are not related to the organ donation process but to the mourning of the dead loved one. Although, consideration needs to be given to the experience of organ donor families, with many of the deaths being sudden and unexpected. The shock of losing a loved one suddenly adds another layer to a complex and heart-breaking experience.

Conflicting emotions

Many discussions exposed that grief reactions to loss, whether experienced privately or publicly, are usually a natural response to grief. However, our reactions are unique to each loss and bereaved person (Corr & Coolican, 2010). The model recognises that the natural path of bereavement will occur alongside many other emotions and stages unique to organ donation. The array of emotions experienced by a bereaved person are well informed, with numerous theoretical frameworks accessible which support the bereavement process (Stroebe & Schut, 1999; Worden, 2009; Neimeyer et al., 2014). Many families reveal that the primary purpose for donating their loved one's organs was for them to need a positive outcome from their loss, and they hoped that by donating the organs, a stranger might have a better quality of life (Stouder et al., 2009). This has been my experience, working in clinical practice as a specialist nurse, with many families wanting to pursue a positive ending. Despite this heartening offer of generosity, the raw pain of loss remains, and many families have described organ donation and the emotions that follow to be 'bittersweet'. The idea that organ donation can help the grief journey that families experience could be questioned. Sque et al. (2006) suggested that although the 'gift of life' is simplistic, it may add unexpected effects and emotions. Dicks et al. (2017a) discovered that families of organ donors endeavour to give meaning to an otherwise meaningless death, wanting to find something positive in a devastating event. The proposed model acknowledges that organ donor families will experience conflicting emotions, which may intensify anxiety, which can be disconcerting. Having a safe space to share these emotions with other families united by death provides comfort and support. When composing the story of their loved one's death, organ donor families alternate between preserving hope while seeking meaning and feeling hopeless as they lack a sense of meaning (Walker & Sque, 2016; Frid et al., 2007). Following the death, many families face fears and uncertainties, which adds to the turmoil and distress which families must endure.

Longing

The contextual comments reinforce an evident sense of longing, emphasising the desire to have more information regarding the location of their loved one's internal organs. Although this is notably related to gaining information about the organ recipient, there are also many questions and feelings of uncertainty related to organ donation. Confusion and questions about the process do not arise until weeks and months following the organ donation (Berntzen & Bjork, 2014). This was observed throughout the study, with many participants asking questions of their peers. In a study by Jensen (2011), donor families reported being left alone with bad memories and unanswered questions, which is clear from the analysed data, leaving them unable to construct a meaningful representation of the phenomenon that has occurred.

Pride

Organ donation presents families with an enormous sense of pride, with motivation to donate their loved one's organs influenced by the knowledge that donation will benefit others, their loved ones will 'live on,' and a feeling that the death is not in vain. Jensen (2011) found that many organ donor families adopt a sense of pride associated with the reality that their loved one's organs live on.' The enormous sense of pride that organ donation created was unmistakable throughout the Facebook group discussion and positively influenced decision-making (Holtkamp, 2002; Sque et al., 2003). Many participants share this feeling of pride, allowing them to create a narrative regarding the person they were and the satisfaction that organ donation has brought them at such a painful time. This sense of pride described throughout the narrative links to the conflicting emotions, bestowing a positive and honourable emotion amid anguish and pain.

Constant curiosity

Organ donation imparts a lack of closure, making stories challenging to finish since the end of the donors' organs remains unknown. When organ donor families do not know where the body parts of their loved ones are, it is hard to construct a momentous aftermath, and their death will never reach that definitive end (Jensen, 2011). Sque et al. (2006) recognised that organ donation is a precious gift, even though it has occurred in tragic circumstances and can be an intense hindrance to the family. The narrative provided an appreciation of how organ donor families feel after donation, through constant emotional struggles of wanting to help others but then being left with the sacrifice being unrecognised and the constant desire to hear from the organ recipients. This desire remained with the organ donor families, irrespective of time, the discourse revealed that this constant curiosity regarding the donated organs would remain, suggesting that organ donor families need ongoing emotional support in the months and possibly years that follow organ donation. Bowlby (1980) suggested that the bereaved can intensely desire to continue their relationship with the deceased. Sque & Payne (1996) recognised that this need might be exhibited in organ donor families through the longing to identify with the organ recipient, searching for information, and valuing the realisation that their loved one lives on in the organ recipient.

To provide accuracy and transparency to the proposed grief model, I invited five active participants to appraise the content and concept, encouraging them to provide open and honest feedback. Their response was overwhelmingly positive, affirming that their bereavement is distinctive. One of the participants commented on how she found the model relevant; The proposed model offers an exclusive framework that will benefit both organ donor families and healthcare professionals caring for this community. The suggesting that this selfless act adds additional nuisances to the grief and bereavement of organ donor relatives, acknowledging the importance of preceding grief models (Kubler-Ross, 1970; Parkes, 1972; Bowlby, 1980; Worden, 1991), whilst introducing the deeper layers which are created through organ donation.

> *"It is very interesting and relevant. Sums up how I feel".* (Beverley, wife of donor)
>
> *"It is really good, particularly about donor families needing ongoing support".* (Chrisitne, wife of donor).

All the participants who reviewed the model agreed that it was a true reflection of their feelings and experiences. One participant commented on their struggle with losing their partner so suddenly, making the situation perplexing, and agreeing to organ donation. This needs further exploration as it's clear from the earlier narrative that most deaths are unexpected and even traumatic, and some family members have witnessed or been involved in the event. This validates the need to provide a more supported family-centred aftercare programme. Obtaining this feedback provides the model with authentication and rigour, demonstrating accuracy in the analytic process. The study has provided a 12-month exploration of organ donor family grief; therefore, consideration must be given to further developing this proposed grief model. The model will inform the future aftercare of organ donor families, recognising their individual needs associated with organ donation. It will provide medical professionals with a new understanding of the complexities of organ donation and its aftereffects.

The proposed grief model acknowledges different reactions unique to organ donor experiences, it does not assume that the donor family members transfer from one emotion to another, nor does it imply that they do not actively work through further task-orientated models of grief. It justifies encouraging thoughtful, tailored bereavement support following organ donation. This model does not imply that organ donor families will not, in time, accept the death, adjusting their lives without their loved ones, merely offering an appreciation of the complexity of organ donation identified throughout this study.

Summary

The focus of this chapter was to bring together the findings from this study, drawing on the evidence presented in the literature review. This study has shown that organ donor families require additional bereavement support and aftercare following organ donation. It presents a strong justification for using social media to connect families and grow a robust peer-to-peer support network supporting their grief. The study has highlighted that organ donor families experience complex emotions which can manifest over time. Having a group of individuals who have experienced similar emotions can help alleviate the pain by sharing feelings, grief, memories, futures, resources, and friendships. The emerging new grief model highlights the many emotions that organ donor family's experience, distinct to this phenomenon. This new knowledge acquired from the observed grief of the organ donor families can help to improve the way we care and support future families, in addition to providing healthcare professionals with new concepts related to the situation, allowing them to tailor the care to their individual needs.

Furthermore, the unembellished narrative related to the organ recipients could act as an educational tool, providing evidence to the transplant recipient communities of the distress organ donor families experience without knowledge of the recipient's wellbeing. Alternatively, working with the transplant community may help to provide the donor families with explanation and clarity as to why some transplant recipients do not make contact, offering them awareness of the journey they have made, and the complexities transplantation can bring. Empowering health professionals to feel comfortable when offering information and support to organ donor families will ensure that they can respond to the needs of the individual's grief (Hogan et al., 2013). In addition, this may provide clarity and approval to organ recipients, encouraging them to write a simple yet powerful 'Thank You' to the families who imparted a life-changing gift.

Chapter 7 Conclusion and Recommendations

Introduction

The final chapter draws together the observations and last comments on the contribution of this unique study, highlighting the influence that social media has had on growing a community that has supported strangers who experienced similar heartbreak. The goal of the thesis was to contribute new knowledge, strengthen the evidence to support the development of aftercare for organ donor families and authenticate the use of social media as a channel to connect and support organ donor families. The future direction of ‘Donor Families Together’ and recommendations are provided on how this new knowledge could be used to educate and influence clinical practice and improve communication between organ donor families and the transplant recipients. Finally, the limitations of the study are acknowledged.

‘Donor Families Together’ Research

The central aim of this study was to develop a social media facilitation platform that would enable organ donor families to come together to share their grief, offering support to each other in the process. Directed by a constructivist methodology, the aim was to explore the influence that building an online community would have, offering aftercare support following organ donation. It was evident from the literature review that there was a gap when considering the aftercare support following organ donation. In relation to existing academic knowledge, the evidence suggested the need to strengthen donor family aftercare (Maloney, 1998; Sque et al., 2006; Jensen, 2011; Dicks et al., 2017a; Sque et al., 2018,) reinforcing the need for this unique study. The research provides new concepts which can be adopted and developed in clinical practice. A new grief model has been developed to support healthcare professionals who are caring for organ donor families. It is proposed that the grief model will help to assist in providing donor families with effective, compassionate, and exclusive bereavement aftercare.

Organ Donor Family Aftercare Strategies

The study has also identified strategies in which to enhance the support offered organ donor families.

- At least one letter from recipients to acknowledge their gift
- Social media peer support group – with professional support to answer post organ donation questions which never get addressed
- Improved communication with the organ donation organisation, NHSBT
- Yearly updates on the progress of the recipients
- More personalised aftercare, providing donor families with a sense of worth

The identification of new findings emphasis the benefits of undertaking this valuable study and it is hoped that they will be used to influence the development of the aftercare support offered to organ donor families.

Professional Strategies

This study has identified new ways in which healthcare professional involved in end-of-life care and organ donation can support families. This new evidence could help to encourage improved collaboration with the transplant community. It offers a deeper understanding of the emotions and perceptual restlessness that some organ donor families experience during the grief period and beyond. The study has identified strategies which may assist the healthcare professionals in providing person-centred aftercare.

- SNODS need increased supportive strategies to offer families of organ donors including access to a virtual support group. This support may be provided in collaboration with external stakeholders such as The Donor Family Network or other such organisations to ensure that families are adequately supported.
- Transplant nurses could reassure the recipient that a letter to say thank you to the donor families would be enough
- All healthcare professional involved in the organ donation process should have a deeper understanding of the emotional impact organ donation has on families in the weeks and months after
- Aftercare support should be tailored to ensure that donor families are psychologically supported in the weeks and months after donation

The results of the findings are significant to the future learning of healthcare professionals, particularly SNODs. The compelling evidence produced from this study highlights the positive emotional and social benefits of connecting organ donor families for peer-to-peer support. The evidence generated will provide the SNODs with a deeper understanding of the lived experience of families following organ donation. Once organ donation is complete, the SNODs rarely interact with the donor families. This new evidence will present them with an empathetic appreciation of what organ donor families feel in the following days and months.

Strengths And Limitations

The strength of this unique study has instigated a deeper understanding of grief, offering new in-depth knowledge on how social media can support acutely bereaved relatives following organ donation. It has demonstrated that an online group can connect and build a peer support community regardless of location and loss. The study has exposed the unremarkable journey that organ donor families take daily, revealing their raw grief and emotion. The management of the group for the past year has proved challenging yet motivating, and it has been a privilege to be part of each one of the participants' lives in some way. There is a clear indication that online support is needed, and the engagement and factual discourse told by the organ donor families validate the evidence suggesting more aftercare and support are needed for organ donor families. The experience and knowledge I gained throughout this process, alongside using a thematic methodology, caused me to take on an experiential orientation to the research, creating new knowledge in which to develop existing theories. Thematic analysis encourages an active role in the knowledge production from the researcher (Byrne, 2021). Being so actively immersed in the knowledge may produce bias and to help minimise any bias, I acknowledged my position through reflexivity, while it must be recognised that it may not always be possible to avoid bias from influencing my analysis. Although the quotes included in the findings section are honest and clear with minimal scope for misinterpretation due to the raw grief being expressed.

The challenges of growing such a passionate group have been both exhilarating and saddening; walking alongside a donor family amid grief has been a struggle at times. These challenges have been softened with input and support from my supervisors and growing knowledge that 'Donor Families Together' was helping to comfort these remarkable individuals.

“Donor Families Together” The Future

During the study there became an unanticipated absence of engagement by NHSBT The current financial crisis facing the NHS impacted the available resources NHSBT could provide to support the continuation of the Facebook group. There was also a considerable amount of organisational restructuring, which has led to a change in service provision. This restructuring initially impacted 'Donor Families Together' participants and future organ donor families. NHSBT made the decision to remove themselves from the group, no longer wanting to take ownership. Despite their disengagement from the group, NHSBT was crucial in ensuring that the members were provided with safe, secure, and accurately informed. The participants found NHSBT's support invaluable, benefiting from having the healthcare experts to hand, answering questions, and offering professional guidance. Regardless of having peer support, without the professional relationship from NHSBT, organ donor families felt they have lost the personal link with the organisation that was part of their loved one's death. When I informed the participants of NHSBT’s departure, they unanimously felt a sense of disappointment, but all agreed they wanted it to continue. The decision was made to hand over ownership of the group to a selection of donor families who offered to take on the role of moderators. Since taking ownership of 'Donor Families Together,' the moderators have actively supported the group. They have developed in their role as moderators and are passionate and enthusiastic, wanting to preserve the group. My supervisors from Salford University have also supported the emerging moderators, offering continued support without assistance from NHSBT. Other group members have commented on their appreciation for the new moderators for taking on this role and keeping the Facebook support group open, revealing the clear need for such a support group. I continue to support group ensuring they have encouragement and assistance, although I am no longer working at NHSBT and have no link to the organisation. Not having the organ donation organisation part of the group has taken away the accessibility of professional support. Even though the group thrives, having instant access to healthcare experts to provide accurate information was undoubtedly advantageous.

Dissemination

The findings from the study will be compiled into a summary report and communicated to the research participants via the Facebook group and there is no question that the organ donor families who have taken part in the study are eager to discover the study's findings, providing them with evidence and support that aftercare support is needed. Communication with NHSBT and other healthcare professionals working in organ donation and transplantation, will provide a better understanding of organ donor families' experiences, presenting them with new knowledge. The evidence produced from the study offers a foundation to build on existing support frameworks, developing further specialised training and enabling healthcare professionals to better support organ donor families following this complex, unique phenomenon.

It will also help to educate the transplant community of the desperate need to encourage communication following transplantation. The study's findings will give transplant recipients a deeper understanding of the emotional burden caused by not receiving any communication from them.

Recommendations For Further Research

The study findings have provided evidence that organ donor families require specific bereavement support following organ donation. Social media has been an accepted form of support for the participants and a cost-effective way of connecting this grieving community. Despite the positive outcomes, it must be recognised that this form of communication does not appeal to all families, and it was evident from the participant's characteristics that it appealed to specific individuals. Further exploration of certain areas would assist in enhancing and developing the existing body of knowledge. The recommendations are for further research to:

- Consider inclusivity of all families, the diversity of the organ donation family population, and how NHSBT can inclusively provide access to support and information.
- Further exploration into the aftercare support provided by the organ donation organisation, identifying additional support methods.
- Explore the type of loss experienced and the aftereffects on the family.
- Develop research strategies to discover secondary factors, such as understanding the relationships to the deceased and how these may impact on grief and organ donation.
- Measure the effectiveness, and growth of 'Donor Families Together' as the donor families continue to develop the group.

- Discover how organ donor families lived experiences can positively contribute to the education and learning of the transplant community.

Concluding Remarks

The intentions of this study have been completed. The constructivist methodology brought together evidence that supported the rationale of the study. Immersed in the participants' language allows them to construct their own reality by sharing their experiences with other families. Being part of their grief has enabled me to understand the complexities they face when undertaking the path of organ donation. This selfless unique experience also brings many other unfavourable emotions. Using social media as a way of communicating provided challenges however, it also allowed families to connect, building strong bonds and friendships in a safe space.

This research study has also changed how I view death and grief. As an experienced senior nurse, I have great empathy, the skills, and compassion to support bereaved families appropriately. During the initial few months of the project, I questioned my professional abilities, feeling overwhelmed by the grief and sadness experienced by the participants. Despite mistrusting my ability to complete the study, my academic capability, and my reason for undertaking this research, I am thankful for this process. If this study has positively impacted one family, then this will have exceeded my expectations, and I will have fulfilled my commitments and responsibilities. Organ donation is a fascinating occurrence that can positively impact so many people. However, I firmly believe that the selfless families who go on to donate their loved one's organs need to be provided with additional aftercare. This study has revealed the mixed emotions experienced by organ donor families, highlighting the lack of consideration given to this incredible community following organ donation. There is so much more that could be done, to provide a healthier experience which could positively impact on this amazing life changing choice.

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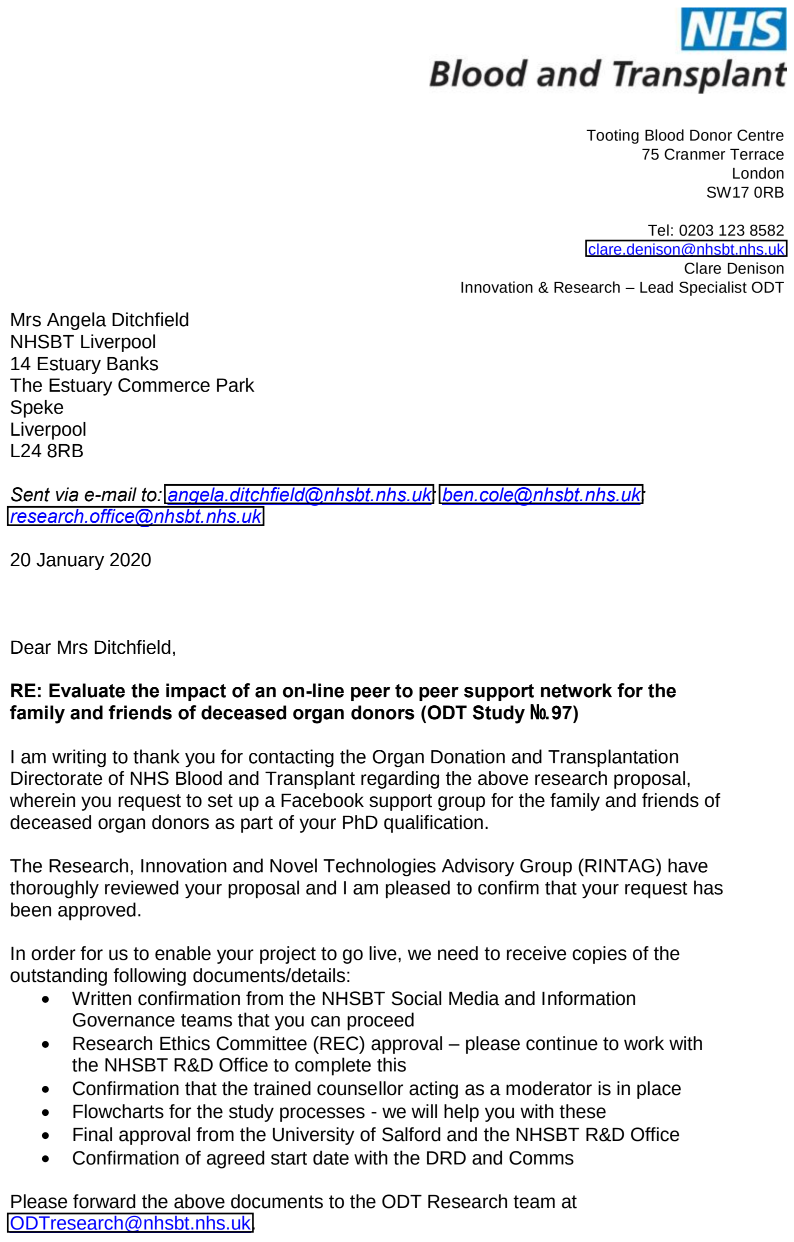
Appendix 1 - NHSBT Research and Innovation of Novel Techniques Advisory Group Approval



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Sent via e-mail to: angela.ditchfield@nhsbt.nhs.uk; ben.cole@nhsbt.nhs.uk; research.office@nhsbt.nhs.uk

20 January 2020

Dear Mrs Ditchfield,

RE: Evaluate the impact of an on-line peer to peer support network for the family and friends of deceased organ donors (ODT Study №.97)

I am writing to thank you for contacting the Organ Donation and Transplantation Directorate of NHS Blood and Transplant regarding the above research proposal, wherein you request to set up a Facebook support group for the family and friends of deceased organ donors as part of your PhD qualification.

The Research, Innovation and Novel Technologies Advisory Group (RINTAG) have thoroughly reviewed your proposal and I am pleased to confirm that your request has been approved.

In order for us to enable your project to go live, we need to receive copies of the outstanding following documents/details:

- Written confirmation from the NHSBT Social Media and Information Governance teams that you can proceed
- Research Ethics Committee (REC) approval – please continue to work with the NHSBT R&D Office to complete this
- Confirmation that the trained counsellor acting as a moderator is in place
- Flowcharts for the study processes - we will help you with these
- Final approval from the University of Salford and the NHSBT R&D Office
- Confirmation of agreed start date with the DRD and Comms

Please forward the above documents to the ODT Research team at ODTresearch@nhsbt.nhs.uk.

Appendix 2 - Participants Invitation to join the group

IRAS ID: 277370

Invitation to Join Facebook Peer to Peer Support Group

The Donor Family Aftercare service & Salford University have created a confidential and secure Facebook group as part of a research study. The purpose of the Facebook group is to provide a forum where donor family members can connect with and support one another along their grief journey. The group will be moderated during week-day business hours only by Donor Family Aftercare Specialists and the research team. However, members can participate 24 hours a day 7 days a week. The Facebook group is part of an ongoing research project aimed at evaluating the donor family experience. If you would like more information about the how to join the research study Facebook group and discover how you could be part of shaping the organ donation aftercare service, then please contact:

Angela Ditchfield

Mobile: 07764280741

Appendix 3 - Participants Information Sheet

IRAS ID: 277370 **PARTICIPANT INFORMATION SHEET**

Title of study: Improving the after care of deceased organ donor families and friends, an online peer to peer support network.

1. Introduction

We would like to invite you to join in a small research project to examine the use of Facebook to help support families & friends following organ donation. The secure, private Facebook group will be a forum for donor families & Friends to connect and support each other following organ donation. You can only join the Facebook group if you agree to be part of this research study.

The Facebook group is open to any family members or friend who's loved one has donated their organs at the time of their death. It will be a secure, private group (a private group where your friends or family cannot see that you are a member) and you will need to get permission to join the group from Angela Ditchfield Specialist Nurse Organ Donation lead researcher, her details are below. The group will allow you to communicate, connect with other donor families nationally who have experienced organ donation.

Being part of the group will mean that you will give us permission to use the information that you share on the group so we can evaluate the use of the group and to learn more about your experiences so that we can develop the aftercare services NHSBT provide. A Donor Family Advisory Group will help to assist with the moderation and running of the group. The research is being run by Angela Ditchfield who is a Specialist Nurse Organ Donation. Angela will work alongside colleagues within NHSBT & also Salford University who are the sponsor for the research study. Also helping to support the group is a trained bereavement nurse and a trained counsellor who will support the group as needed.

Before deciding if you would like to participate in this social media study, please take time to read this information sheet and, if you wish to discuss taking part use the contact details provided to ask any questions to the research team.

2. Why have I been invited to take part?

You have been invited to join an online confidential group to provide you with support following your bereavement. It will allow you to connect with other donor families & friends who have experienced organ donation. We hope that the group gives families & friends who are in similar situations the opportunity to chat to each other and help support each other in the difficult weeks and months ahead.

Being part of this research will allow you to share your experiences, support each other and help to enhance the future experiences of organ donor families & friends. By sharing your experiences, you will participate in the possible development of the aftercare services NHSBT provide and the continuation of a Facebook group for future donor families & friends. Training will be offered to participants who may not feel confident with online groups. If you wish to receive any training prior to joining the group let the researcher know and this will be carried out over the telephone by the researcher, Angela Ditchfield.

3. Do I have to take part?

No, you do not have to take part. If you decide that this is not for you it will not affect any future communication with NHSBT

4. What will happen to me if I take part?

If you agree to participate in this study after reading this information sheet, the netiquette (guidelines for online behaviour) and having time to ask questions you can **use the email address:** **angela.ditchfield@nhsbt.nhs.uk**

See the steps below of what to expect:

- Any family member or friend of the donor can join the group following agreement from next of Kin

- You’ll be asked to read this information sheet, guidelines for online behaviour (netiquette) and provide consent for the study.
- You’ll need to email to angela.ditchfield@nhsbt.nhs.uk
- You’ll receive a confirmation email with the consent form and points to agree.
- After confirmation, you must provide the email address linked to your own Facebook profile.
- You’ll receive an invitation from the group moderator/researcher to join the private group.
- Once you’re in the group please refer always to the netiquette that sets up the group rules (i.e., you must be nice to others, respectful and considerate).
- I understand that any disclosure of criminal activity or other disclosures requiring action will have to be reported to the appropriate authorities.
- If any information is disclosed in which you need further communication regarding the hospital admission prior to organ donation, then the researcher will ensure that you are directed to the relevant department.
- If you leave the study at any time is your responsibility to leave the Facebook group and to inform the researcher.
- If you leave the group, you will be asked to complete an exit poll to gain information about why you left, although completing the exit poll is not compulsory.
- You may be asked to participate in a one-to-one interview with the researcher which will be separate to the online group. This is to gain additional information about your donation experience. If you are asked to participate in these interviews, then you will be asked to sign a separate consent form. The one-to-one interviews will last up to 1 hour and can be face to face or telephone/Skype interviews. The conversations will be audio recorded at this time by the researcher who will be the only person transcribing the interview data.

The research part of the project involves:

- Contributing to the group as much as you want or need.
- Participate in the bi-monthly group poll, exit poll.

5. What will the researcher do with the information (data) from the group?

The University of Salford is the sponsor for this study based in the United Kingdom. We will be using information from you (data) in order to undertake this study and will act as the data controller for this study. The data from the Facebook group discussions, chats, email conversations will be downloaded to a secure University server where we will analyse this to examine the Facebook group assessing if it has provided support following a bereavement it will also give us evidence about the organ donation process and aftercare services NHSBT provide, potentially helping to develop the services further. This means that we are responsible for looking after your information and using it properly.

We will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded and to oversee the quality of the study. Individuals from the University of Salford and regulatory organisations may look at your research records to check the accuracy of the research study. The University of Salford site will pass these details along with the information collected from you. The only people who **will** have access to information that identifies you will be people who need to contact you to ask questions related to the research or audit the data collection process. By taking part:

- The discussions you may have on the Facebook page will be analysed and the data used as part of the research study.
- All conversation data used will be anonymized and a research code given which will only be known by the researcher.
- All participants who consent to take part will be recorded on a password protected database accessed only by the researcher.
- All paper and audio taped data will be uploaded onto a password protected database only accessed only by the researcher. Any paper texts will be stored in a locked cabinet accessed only by the researcher.
- The data collected will be anaylsed and will form part of the researcher’s thesis. The information will help to provide NHSBT develop the future aftercare of donor families and the evaluation of the Facebook page will determine the need to introduce this as an ongoing bereavement support.
- All donor families will be invited to join the Facebook group when they are routinely contacted as part of the aftercare service following organ donation.

- The data collected will be used to inform practice and develop services and may be used as part of publication. It will be annonymised and if names are used, they will be given a pseudonym which you will be asked to check.
- All data will be kept for 3 years post completion of the study to support publication of findings, service, and policy development. All details will be destroyed as per General Data Protection Regulations (GDPR) following this period.

The University of Salford will keep identifiable information about you until the study has finished. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible. The data will only be used for non-commercial, scholarly research and teaching. Anything that may identify you will not be used or reported such as your email or IP address. False names (pseudonyms) will be used, and you will not be identifiable in any material that will be made available to the public through research publications.

You can find out more about how we use your information by contacting Angela Ditchfield

(Email: angela.ditchfield@nhsbt.nhs.uk, Phone: [redacted])

6. What are the possible disadvantages and risks of taking part?

We do not expect there to be any disadvantages or risks to you by being involved in this small study. We do accept that by being part of the group as a difficult time in your life, you might come across challenging or upsetting information from other people, and different views. Group moderators will try to ensure the group is friendly and you would be asked to report any online behaviour, which you think is unsuitable, to be resolved. We will provide support to facilitate conversations and ensure different views are respected within the group discussions. Group moderators will signpost you to additional information and support at this difficult time and help if required during your involvement in the group.

7. What are the possible benefits of taking part?

Being involved in an online community of peers may have a direct benefit on you at this difficult time. You will be able to share experiences hopefully within a supportive, trusted, and friendly community that may help your bereavement. You will receive regular information about how the study is progressing and have opportunities to share any ideas you may have about the service.

8. Will my taking part in the study be kept confidential?

The research data will remain confidential between you and researchers and the moderators. Any information stored which you provide will be anonymous and not identifiable to you, but we must highlight that if you do share anything on-line that is suggests risk to yourself or others, the researcher is duty bound to report it to the appropriate people.

9. What will happen if I don't carry on with the study?

You can at any time choose to withdraw just from the online group. Any information you have shared in the group up to the point of withdrawal, will be retained and used for the research.

At the time you chose to withdraw, we may ask you to complete a very short survey so we can understand your reasons for not wanting to continue, which will help us better understand the issues people face participating in research trials.

10. Expenses and payments?

Through this study no expenses or payments will be covered.

11. What if there is a problem or I want to raise a concern/make a complaint?

The researchers have experience of being involved in projects exploring social media, so please feel free to email with any concerns/enquiries. They will respond during the hours of 9am to 5pm (Mon-Fri). If you have a complaint or concern that cannot be resolved by the researcher, it will be escalated to the following: Ethics Panel Chair, a.clark@salford.ac.uk; Tel: 0161 2954109

12. Who is organising or sponsoring the research?

The University of Salford is a lead organisation undertaking responsibility for this small study. In partnership with NHS Blood & Transplant

13. Who to contact for more information?

Angela Ditchfield,

Email: Angela.ditchfield@nhsbt.nhs.uk

Phone: [redacted]

Or

Lead Nurse-Family Aftercare NHSBT

Email: ben.cole@nhsbt.nhs.uk

Appendix 4 - Participants consent form

CONSENT FORM - Research Participants

Title of study: Evaluate the impact of an on-line peer to peer support network for the family and friends of proceeding deceased organ donors

Please complete this form **after** you have read and understood the participant information sheet [version 1 / 30.10.19]. Read the following statements and select 'Yes' or 'No' in the box on the right-hand side.

I agree that any information and content on the online community group to which I will be a group member can be used as part of this research study	YES	NO
I agree to respect the group members and abide by the Netiquette guidelines of good online behaviour	YES	NO
I understand that any information used from the online group will be anonymous and not attributable to me	YES	NO
I understand that –if I choose to post a blog, the blog will be made available on the study website and data included in the research	YES	NO
I understand I will be provided with individual access to a secret closed online group and must not share access with any other person	YES	NO
I understand that I can withdraw from the online group at any time	YES	NO
I understand that this study is sponsored by Salford university and is being carried out in partnership with NHSBT	YES	NO
I understand that if I withdraw from the study, data collected prior to me leaving will not be removed from the study	YES	NO
I understand that any disclosure of criminal activity or other disclosures requiring action will have to be reported to the appropriate authorities	YES	NO
I understand that by providing my email address to the researcher, consenting via email, and joining the group, I provide consent to join the study	YES	NO

If you have any further questions, then please contact the researcher via email **angela.ditchfield@nhsbt.nhs.uk**

Name of Participant………………………………………………………Date……………. Signature…………………………

Name of person taking consent……………………………………. Date……………. Signature…………………………

Appendix 5 - Netiquette guidance

IRAS ID: 277370 **NETIQUETTE**

A **netiquette** refers to a set of rules for behaviour within online groups. Within this group making occasional mistakes is acceptable as this is a difficult time but sustained negative behaviour is not appreciated. It is important that we treat each other with politeness and respect, and by following a few simple rules we are less likely to make mistakes that others find upsetting.

As a member of this group, you will be expected to:

Be supportive towards each other at this difficult time and share information to help support each other. Everyone in the group has lost a loved one who went on to become an organ donor just like you - respect them. Treat everybody with respect, regardless of differences in culture, ability, race, gender, age, sexual orientation, or social class. Respect that we all have different views and opinions. *Please remember the following:*

- Think before you press send.

Double check what you have written prior to posting.

- Remember others cannot see your facial expressions.

This is not face-to-face and other users cannot see your facial expressions, smiling or frowning. However, you may wish to use emoticons or smileys and explain your ideas. Always avoid sarcasm, people who don't know you may misinterpret its meaning.

- Remember others will read your comments.

  If you are not sure how your comments are being taken, ask for feedback. Sometimes electronic messages can be perceived as harsher than intended because there are no visual clues such as facial expression or body language. If you disagree with what someone has said, please bear this in mind as you express that disagreement. Ranting at other members is never acceptable. If you are offended by comments, please don’t post angry retorts. If you are concerned about anything posted within the group or feel offended, please message the moderator privately to express your concern.

- Use appropriate language.

Please avoid coarse, rough, rude, or derogatory language. Never use harassing, threatening, embarrassing, or abusive language or actions. Avoid online ‘shouting’ or sentences typed in all capitals.

- Respect others' confidentiality and privacy.

Please don’t share personal information with non-group members. Please don’t quote or forward personal messages without asking the original owner. Remember this group is meant to be a safe place to share.

- Your own privacy

Remember that you are part of a group, and your Facebook friends cannot see that. However, members of the group can see your posts on the main wall. You can make your posts private.

  - Click at the top right of any Facebook page and choose Settings.
  - Select Privacy from the left menu.
  - Under the Who can see my stuff?
  - Click Limit the audience for posts I've shared with friends of friends or Public?

- Data usage

The researcher involved in this project will use the data retrieved from the Facebook group as stated below:

a) Data will be downloaded on a university secure server and analyzed to evaluate the use of a peer-to-peer support group for organ donor families.
b) The data will be used for non-commercial, scholarly research and teaching, and deleted as soon as the project is completed.
c) The data will not be shared with any party and only used for this research.
d) None of the details and demographics of the group members will be revealed in the research. More precisely, Identifiers such as email, IP, pseudonyms, localisation of network, and direct quotes, which may be attributable via search engines will not be included in any material that will be made available to public.
e) We will respect the contextual integrity of data, maintaining the flow of information and the meaning of it.
f) The findings of the analysis will be shared with the administration team.

Email: **angela.ditchfield@nhsbt.nhs.uk**

Appendix 6 - Group Description

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Salford
MANCHESTER

IRAS ID: 277370 GROUP DESCRIPTION

Note: this will appear on the description of the Facebook group.

Welcome to the group.

This is a closed and secret group for organ donor families to share experiences and support each other through the difficult time following the death of their loved one. It cannot be accessed or searched for by non-members. Non-members cannot join without permission from us, cannot see what group members post, nor can they see that you are a member of the group from your Facebook group list.

Jay & Sina Patel, Liz Houghton, Nicola Logan, Joanne Marlor, Gill Drillsma, Ben Cole, David Anderson and Christina Woods are the group moderators. Angela Ditchfield is the lead researcher on the group. The group will be moderated during business hours Monday-Friday 9am-5pm **only.**

Angela is a Specialist Nurse Organ Donation and a student at the University of Salford and her role is to support you with any questions you may have about the group.

Jay & Sina, Liz and Nicola are donor families like you, who provide advice to the study. They are keen to provide a better experience for families involved in organ donation. Joanne is part of NHSBT communications department, Gill and Ben work within the Donor Records Department at NHSBT. David is a trained counsellor and works at East Lancashire NHS Trust along with Christina who is a trained bereavement nurse. As moderators, they will share updates on the study progress, answer questions related to the study where possible and join conversations.

We encourage you to openly share experiences, negative and/or positive and ask questions that other people using the group may be able to help you with but please refrain from naming people.

Here are a few simple guidelines to help the group run smoothly:

- Please be polite and respect others’ experiences and opinions.
- It may be helpful to double check what you have written before you press post to ensure your message comes across in the way it was intended.
- Please feel free to use emoji to help convey how you feel!
- Please respect the privacy of others by not sharing their information.
- Do not post anything rude, aggressive, or abusive.
- If you are concerned about anything posted, please private message the moderators.

The information you share on this group will be used for research and we will ensure all data will be anonymised.

The information you share on this group will be used for research and we will ensure:

- *All data is anonymised.*
- *None of the details and demographics of the group members will be revealed in the research.*
- *The contextual integrity of data, maintaining the flow of information and the meaning of it will be maintained.*

Please check our netiquette and the Participants Information Sheet for more details of the study.

Appendix 7 - Interview Consent Form

IRAS ID: 277370 **CONSENT FORM 2- Research Participants**

Title of study: Evaluate the impact of an on-line peer to peer support network for the family and friends of proceeding deceased organ donors

Please complete this form if you agree to take part in one to one interview as part of this research study. Read the following statements and select 'Yes' or 'No' in the box on the right-hand side.

I agree that any information discussed during one to one interview can be used as part of this research study	YES	NO
I understand that any information used will be anonymous and not attributable to me	YES	NO
I understand that I can withdraw from the research study at any time	YES	NO
I understand that this study is sponsored by Salford university and is being carried out in partnership with NHSBT	YES	NO
I understand that if I withdraw from the study, data collected prior to me leaving will not be removed from the study	YES	NO
I understand that any disclosure of criminal activity or other disclosures requiring action will have to be reported to the appropriate authorities	YES	NO
I agree to the audio recording of the one to one Interviews	YES	NO

If you have any further questions, then please contact the researcher via email **angela.ditchfield@nhsbt.nhs.uk**

Name of Participant……………………………………………………….Date…………….Signature…………………………

Name of person taking consent……………………………………Date…………….Signature…………………………

Appendix 8 - Exit poll

Exit Poll Questions

- Can we ask why you have decided to leave the group
………
………
………
………………………………………………………………………………
- Did you find the group useful?
………
………
………
……………………………………………………………………………………
- What could we have done differently?
………
………
………
……………………………………………………………………………………
- Has the research study impacted on your reason to leave?
………
………
- Would you have continued to engage with the group if this was not part of a research study?
………
………
- Have you experienced any challenges since you joined the group?
………
………
- Are there any suggestions of how we could improve/change the NHS Blood & Transplant aftercare service?
………
………
………
……

Appendix 9 - University of Salford ethics approval

University of
Salford
MANCHESTER

Research, Enterprise and Engagement
Ethical Approval Panel

Doctoral & Research Support
Research and Knowledge Exchange,
Room 827, Maxwell Building,
University of Salford,
Manchester
M5 4WT

T +44(0)161 295 2280

www.salford.ac.uk

23 March 2020

Dear Angela,

RE: ETHICS APPLICATION HSR1920-046 – 'Evaluating the Impact of an online peer to peer support network for deceased organ donor family and friends.'

Based on the information that you have provided, I am pleased to inform you that your application HSR1920-046 has been approved to go forward to NRES (HRA).

Once you have received it, please submit a copy of the NRES (HRA) approval letter to Health-ResearchEthics@salford.ac.uk so that it can be placed on your application file.

If there are any changes to the project and/or its methodology, then please inform the Health Research Ethics Support team as soon as possible.

Yours sincerely,

Professor Andrew Clark

Appendix 10 - NHS Research Ethics Committee

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Mrs Angela Ditchfield
Specialist Nurse Organ Donation
NHS Blood & Transplant
Estuary Banks
Speke
Liverpool
L24 8RB

Email: Wales.REC3@wales.nhs.uk

17 August 2020

Dear Mrs Ditchfield

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Evaluating the impact of an online peer to peer support network for deceased organ donor family and friends**
IRAS project ID:	**277370**
Protocol number:	**HSR 1920046**
REC reference:	**20/WA/0196**
Sponsor	**University of Salford**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Appendix 11 - Initial codes generated

Value of the group	Recommendations for change in practice
The need for recognition from recipients	Lack of aftercare
Sharing experience information/feelings/emotions/grief	
Peer Support	
Asking questions/Answering questions	

sense. Your children must be missing him too. Mine are too little to really understand but neither of them has slept in their own beds since Ben got taken into hospital. Dreading sending my daughter to school on Monday. Xx		
Lisa: Debbie my kids have all been in our bed since the night it happened. I need them there as much as they need me Only my youngest in back on Monday as only P1-3 are back here - dreading it as he is having real separation anxiety Thinking about you and your family	**Sharing similar feelings**	**Peer Support**
Mary: Hi, I assume you are in Northern Ireland like me. Might be nice to catch up in person once we are allowed even though my circumstances are different to yours x	**Need to connect outside the group** **Forming of friendships**	**Value of the group**
Lisa: Mary yes, I'm in Northern Ireland and would absolutely love to catch up - please stay in touch Xxx		**Value of the group**
Jodie: So sorry to hear about the loss of your husband and your husband Lisa. It's so heart-breaking to hear your stories x My partner had a cardiac arrest 15 weeks ago. My daughter and I gave him CPR and he was in intensive care for 4 days before he passed. I think I'm still trying to process it now and it hit hard last week that he's not coming back to us	**Difficulty of knowing the relatives isn't coming back**	**Sharing**
Debbie: Jodie I'm so sorry for you and your daughter. This is so shit. Xx	**Acknowledgement of the situation they are all in**	**Peer Support**
Lisa: So sorry to hear your story, Jodie. It's absolutely heart breaking - it just doesn't feel real, does it? I found the having to give CPR very traumatic and hard to get order I still have nightmares about it You and your daughter were so brave to do that. I keep checking A office (he worked from home) as I expect to see him there - it's so hard to process. Thinking about you and your family as you try to process things Xxx	**Dreamlike situation** **Sharing the experience of providing CPR like others in group** **traumatising experience** **Wanting them to come back hoping to see them**	**Peer support** **Sharing**
Debbie: I don't think I've processed the CPR bit yet, but I feel so guilty that as I was ringing	**Feeling of guilty**	**Sharing**