



‘Donor Families Together’

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

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Introduction

Working as a Specialist Nurse Organ Donation for over 12 years placed me in some of the most painful situations when meeting families and friends of organ donors. Over the years I have seen first-hand and I have been part of the agonising family experiences at the time of death. My professional experience and personal reflections provided me with the motivation and drive to explore the post donation support offered families of organ donors. The project was supported by NHS Blood & Transplant and University of Salford,



University of
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Blood and Transplant



The background of the slide is a blurred photograph of several wooden figures, possibly representing people, standing in a row. The figures are light-colored wood and have a simple, rounded head and a tapered body. They are positioned in the foreground, with some in focus and others blurred in the background.

Creating an Online Community

- The study aimed to explore the influence of an online group which would support the needs and grief 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.

Review of the literature

- 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
- 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).



Methodology

- 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).
- In addition to the conversational data, I also conducted six in-depth one-to-one interview with a subset of participants to gain a deeper understanding of their personal experiences and perspectives. Thematic analysis of group and individual narrative data generated rich integrated findings and new knowledge to inform practice.
- 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 and has been difficult to read at times.



A Community for the Bereaved



- **Sharing lived experiences: connection through death:**

'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 and supporting the pain of grief:**

'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)

— A Community for the Bereaved

Sharing and supporting with information and resources:

'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)

Acknowledgment of the 'Gift of Life':

'Today marks 8 weeks since my son gained his angel wings. He helped 5 people live on and 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)

Aftercare: What do families need or want:

'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)



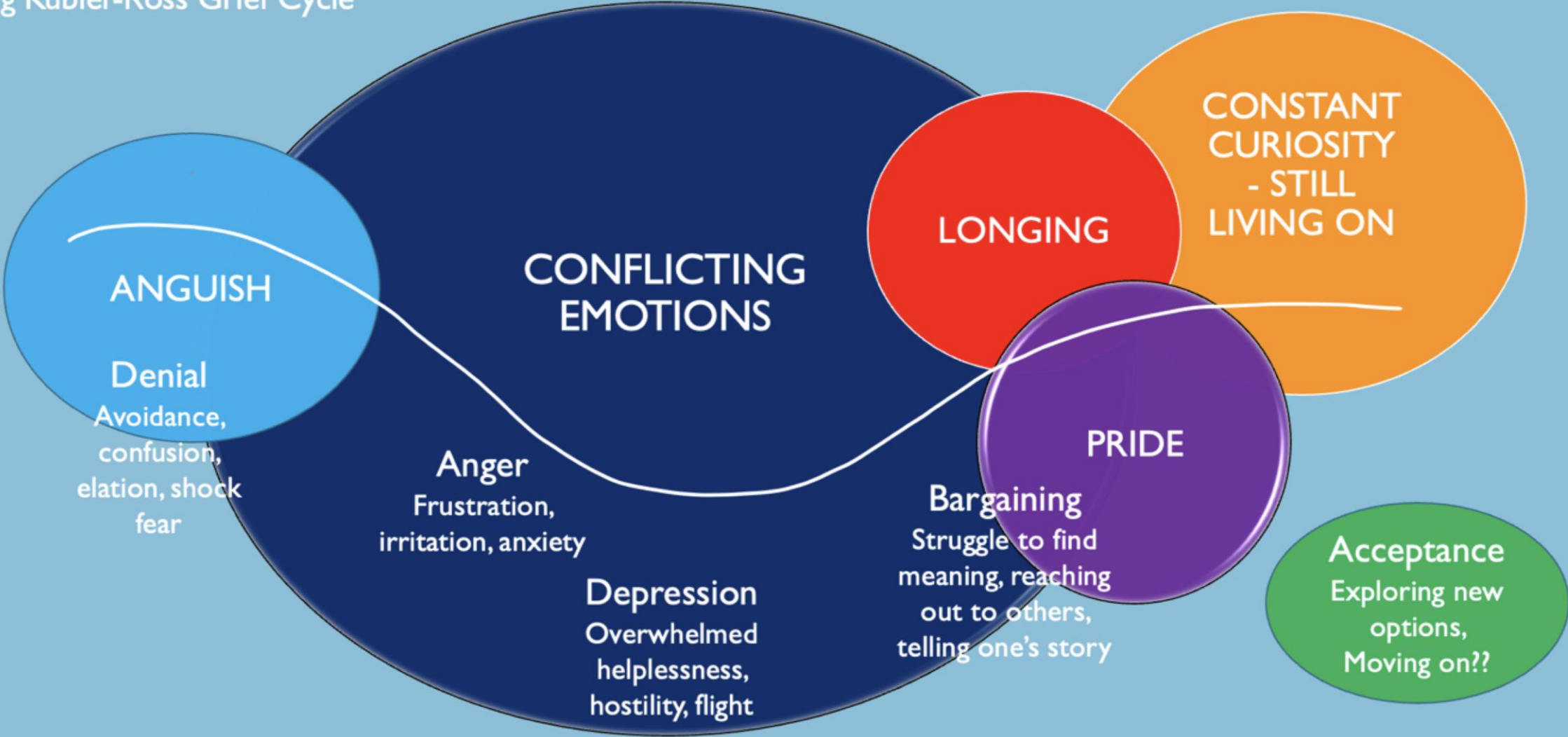
Discussion

Lived Experience: Connection through death

Social Media: Aftercare to meet the need of donor families

Grief theory: The complexities of organ donation

Mapping Organ Donor Family Grief
Redefining Kubler-Ross Grief Cycle



SOCIAL MEDIA PEER SUPPORT GROUP

INFORMATION & COMMUNICATION

EMOTIONAL SUPPORT

GUIDANCE & DIRECTION

Conclusions & Recommendations

- New knowledge
- Use of social media
- Organ Donor Family Aftercare Strategies
- Professional Strategies
- “Donor Families Together” The Future
- Recommendations



**THANK YOU
FOR
LISTENING
ANY
QUESTIONS?**



REFERENCES

Dicks, S.G., Ranse, K., Northam, H., Boer, D.P., Van Haren, F.M.P. (2017a). The development of a narrative describing the bereavement of families of potential organ donors: A systematic review. *Health Psychology Open*, 1, 1-17.

Holtkamp, S., Nuckolls, E. S. (1993). Completing the gift exchange: a study of bereavement services for donor families. *Journal of Transplant Coordination*, 3, 80-84.

Sque, M., Walker, W., Long-Sutehall, T., Morgan, M., Randhawa, G. (2018). Bereaved donor family's experiences of organ and tissue donation, and perceived influences on their decision making. *Journal of Critical Care*; Philadelphia, 45(18), 82-89.

Walker, W., Broderick, A., Sque, M. (2013). Factors influencing bereaved family's decisions about organ donation: An integrative literature review. *Western Journal of Nursing Research*, 35 (10), 1339-1359.