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Perspective

Unique Grief During a Pandemic: First-Hand Experience at a Residential Aged Care Facility

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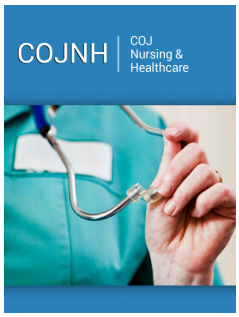

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Introduction

When someone moves into an aged care facility, it is most often the final move of their life. Loss is experienced at every level. There is disease progression that has worsened, and which is only likely to deteriorate further, and family dynamics have altered forever. An admission is required, and we encourage all involved that a new lease on life can be found. But before there is joy, first comes sadness that needs to be acknowledged. What leads up to admission, is complicated grief. What follows admission is anticipatory grief. Therefore, what we in aged care help people through is truly unique grief. It is widely understood that pain and depression are two of the most under-recognized ailments of the elderly. We propose that unique grief underpins both and its acknowledgement and management would significantly improve quality of life for those living in aged care including their families.

Over the 24 months we have seen more than our share of human tragedy. Some five million people have died because of the COVID-19 pandemic, and over 40 million have been bereaved. Grief is the natural and inevitable response, but for many it has been aggravated by the wider effects of the pandemic with poor experiences at the end of life, limited contact in the days before death, being unable to say goodbye in person, social isolation, loneliness, and the disruption to funerals and collective mourning [1].

Healthcare practitioners have a shared passion, providing care to those in our communities who are most vulnerable and frail. Nurses are honored to have a caring profession that has woven us in an out of specialties such as elder health rehab, oncology and hospice care that have all prepared us for our biggest role to date-being a nurse in aged care. When a nurse decides to join aged care it likely to be for the desire to have a nice, relaxed role that could easily be done with lots of time for your personal freedom and family. Needless to say, this has proven wrong as aged care has many unexpected challenges that can never be anticipated. These include limited resources, immense workload and the demeaning reaction from friends and family when we tell them we work in aged care. It is for the later reason that the authors of this article joined aged care, to prove these uninformed critics wrong.

There have been many wonderful learnings and fabulously joyous experiences. But what has had the biggest negative impact on age care health professionals, is the depth of the sadness, grief and loss faced daily that we believe is not fully acknowledged. It is pain that goes beyond, but is not without, the physical. It is sadness that goes beyond an acute illness or impairment. It is loss of an entire life moved into one room. This is not the pain seen on a medical ward, or the sadness seen in an oncology clinic, or the grief found in a paediatric hospice. What we deal with in aged care is a truly unique grief. In his practice-changing book [2] Atul Gawande enlightens us with the following thoughts:

"All we ask is to be allowed to remain the writers of our own story. That story is ever changing. Over the course of our lives, we may encounter unimaginable difficulties. Our concerns and desires may shift. But whatever happens, we want to retain the freedom to shape our lives in ways consistent with our character and loyalties. Therefore, the betrayals of body and mind that threaten to erase our character and memory remain among our most awful tortures. The battle of being mortal is the battle to maintain the integrity of one's life-to avoid becoming so diminished or dissipated or subjugated that who you are becomes disconnected from who you were or who you want to be."

Of course, there is risk in quoting someone as profoundly wise as Atul Gawande because there is the possibility that his one quote has stated what we are going to try and convey in the next few paragraphs.

What we hope you all get from this reflection is a reawakening to the realities that the people we are caring for and their families are experiencing when they transition into living in an aged care facility. This might be from the home perspective or as a practitioner in a supporting service from the community or part of discharge from the hospital. Sometimes working in stretched sectors, no matter how much our hearts are in a role, we can end up seeing an admission as just another admission that was booked in with the family last week, approved by the facility manager, arranged with the ward, and approved by needs assessment and service coordinator. If we are honest with ourselves, how often do we stand back and say "today I am going to welcome someone into this home who is making the final move of their lives. They have had a huge part of who they are stripped away, there has been a gigantic shift in the dynamics of their family, and we are instrumental in helping this be the best version of a life-altering moment".

We have had to challenge how we conduct ourselves and how we see our roles in the experience of those who walk through the doors. We have been shocked by the brokenness of families who walk through our office door looking at the prospect of aged care for their loved ones. As nurses, we build professional lives of caring for others. We have chosen to walk alongside those who are vulnerable. When we provide palliative care, whatever setting we are working in, we are caring for people struggling with finding meaning in their own lives as they face their own mortality. It can be hard when our shifts are so busy and there are so many pressures from every direction to explore the meaning and provide the care talked about in palliative care education. In aged care, we are in the privileged position to truly get to know the people we are caring for. It is not a short stay where the end is focused on a planned discharge, but yet it can be hard to find the time to truly care as we would desire to.

Caring for those who are frail, and elderly is what we do and so we must see the unique grief that is being experienced by residents and family alike and help to navigate that with them. There is no insignificance in what those who transition into aged care face. Both our residents and their families are wrapped in anticipatory grief and complicated grief. These combined, is what makes unique grief. It is a grief where so much has been lost, yet a person has not gone. Relationships have changed, and yet the loved one is still there. The family home has gone, and yet there is still a place to visit mum or dad. We are still married, and yet we live apart. There are over a hundred people living in the same building, and yet loneliness is felt and there is still an anticipation that things are only going to get worse. The dementia will progress, and recognition of loved ones will go. The motor neuron disease will progress and little by little bodily function will decline. Frailty will only make one more diminished from who they once were. And yet in this, we are trying to convince people that they can have a new quality of life. After all, "what is the point in having years of life when there is no life in those years".

So, let's take the notion of grief and think about the people we meet every day we are working – the frail elderly and their relatives. Without rehashing what most of you already know, let's quickly recap what grief is in the context of residential aged care:

A. Mental suffering or distress over affliction or loss; sharp sorrow; painful regret.

B. Although conventionally focused on the emotional response to loss, it also has physical, cognitive, behavioural, social, and philosophical dimensions.

C. While the terms are often used interchangeably, bereavement refers to the state of loss, and grief being the reaction to loss.

Think of the symptoms of grief and then think of those you know who have transitioned into care and their families. The family you might subtly avoid because they are intense, or the resident that has challenging behaviour or has been a resident of concern. Those new residents who are hard to get to know, or who won't eat the food or a not wanting to join in with the wider home activities.

The experience of moving into an aged care facility is an emotionally traumatic experience. It is not done in isolation, it is the final step in what has often been a grueling journey with much loss felt beforehand through illness, cognitive decline, or disability. Another perspective is that, it is not death that the old tell us they fear, it is what happens short of death-losing their hearing, their memory, their best friends, their way of life. Old age is a continuous series of losses, old age is not a battle, old age is a massacre.

What one gets taught at nursing school still rings true today that "there is no such thing as a challenging patient, but a patient with unmet needs", this is true for both our residents and their families. It is quite likely that as those we are supporting to get u sed to their new reality are exhibiting challenging behaviors as a reflection of the grieving process. Think of the grief cycle, it has many components which we acknowledge is not a perfect circle. One does not usually transition from one phase to another then magically move out of grieving. Grief is not just crying for a few days and then we fit into our new reality. Grief is a personal process and like all other care we provide, we need to approach the individual and meet them where they are at with compassion. Compassion

may be defined as the capacity to be attentive to the experience of others, to wish the best for others, and to sense what will truly serve others to ease their suffering.

It is therefore, 100% imperative that we meet each of our residents where they are at in their grief and support them in this. Sit with them, be with them and let them process what has happened to them. Even in instances when moving into an aged care facility is the best choice for someone, it does not come without loss and change. One of the aspects of grief clinicians struggle with most, is denial. We challenge clinicians to look at denial in a different light. Denial helps us to pace our feelings of grief. There is a grace in denial. It is nature's way of letting in only as much as we can handle.

The premise of this article is not to make you feel depressed about getting older or having to move into aged residential care. Aged care is a brilliant place to work, it's an honour and is terribly rewarding seeing the transformations that do happen in the lives of residents for whom we provide care. But that is not without purposeful nursing. A useful analogy of grief is wound healing. An experience of loss will create grief and how significant the loss will determine how deep the wound of the grief. The care and support given during the person's healing phase will alter the person's grief cycle. Just like a scar, the grief will always be part of the person.

If we think about "wounds" that our residents and families come to us with, we've got some of the big ones: dementia, Parkinson disease, motor neuron, emphysema or heart failure. From a practical perspective, it is hard to be with people who are in complicated or anticipatory grief. It can be hard for nurses as we are 'wired' to fix things. It is such an important gift to give someone who is hurting and grieving to simply just "be".

Therefore,

A. Let their story be the most important thing in that moment

B. Do not be tempted to always compare to something that happened to you or someone else you know

C. Their pain is real-let them feel it and let it be ok for them to feel it

D. The experiences we have with grief make us who we are

E. They also allow for other people to show they care and show that while we have lost, we have also gained

F. People who are grieving cannot always see that at the time, so we are simply to be part of the dressing for the wound to see that the wound of grief heals from the bottom up, infection free for the most robust scar tissue we can achieve

In our practice, we have tried to meet the needs of those families who are experiencing the unique grief of having a loved one move into an aged residential care facility. We have started up family support evenings where they can come and process all the change that has happened for them and is still going to happen. Originally, we thought it was just going to be for those families of people who had been newly admitted, but soon opened it up to families of all residents. We found that there were people who had been part of the home family for years who had never been able to sit down and say, "what I am going through is hard or I don't know how to process this, or I didn't think anyone else felt this way''. These family support evenings have been practice-changing for us as we see the impact that healthcare professionals have on how families experience the life and death of their loved ones. This makes us nurses amazing people and when we go to work with the right intentions, we do amazing things for our residents. As Amy Price writes, "Extending imperfect but unconditional love to grieving people and ourselves may be all we can offer, but it may be enough" [3]. "After all grief is the price, we pay for love".

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