GRIEF IN RESIDENTIAL SETTINGS

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AGENDA

RESEARCH AND SURVEY RESULTS

SUPPORTING RESIDENTS WITH PWS THROUGH GRIEF AND LOSS

WORKGROUPS

REPORTING OUT

SUMMATION

PART I: DEATH OF A LOVED ONE

PART I
SURVEY RESPONDENTS: SUPPORTING A RESIDENT WHO HAS LOST A LOVED ONE

SURVEY RESPONSE BY COUNTRY

- US = 9
- UK = 7
- NZ = 1
- DENMARK = 1
- IRELAND = 1
- AUSTRALIA = 1
- ISRAEL = 1
- GERMANY = 1

POSITIONS

CAREWORKER/DSP = 8

RES DIRECTOR = 8

PROGRAM MGR = 3

BEH THERAPIST = 2

SOCIAL WORKER =1

ASS'T RES DIR = 1

POSITION CATEGORIES

ADMIN/MGT 47.8%

DIRECT CARE 34.7%

CLINICAL 17.3%

TOTAL RESPONDENTS = 23

PERSON WHO DIED: RELATIONSHIP TO RESIDENT

HOUSEMATE---8

PARENT---8

FRIEND OUTSIDE OF RESIDENCE---3

SIBLING/STEPSIBLING---1

GRANDPARENT---1

AUNT---1

STAFF---1

Related = 11 (48%) Non-related = 12 (52%)

CONTACT WITH A TERMINALLY ILL LOVED ONE

Survey

Of the loved ones who died, 61%were ill prior to death.

All residents had some form of contact with the person who was ill and were kept, at least, partially informed of the person's condition throughout the illness.

STAFF PREPAREDNESS TO SUPPORT A BEREAVED RESIDENT

Most staff claimed to have had both **personal and professional experience** with bereavement with **70%feeling prepared** to support a bereaved resident.

This is consistent with **the literature** which, in one study, reports that **63.4%of staff felt confident** in working with bereaved residents

Not surprisingly, **more experienced staff had more confidence** in supporting bereaved people with IDD

HOWEVER…

Only 26%of staff had received any training in supporting residents who were grieving. This is consistent also with **the literature** which reported just **22%of staff having received training** on bereavement.

RESIDENTS' GENERAL RESPONSE TO LEARNING OF DEATH OF A LOVED ONE

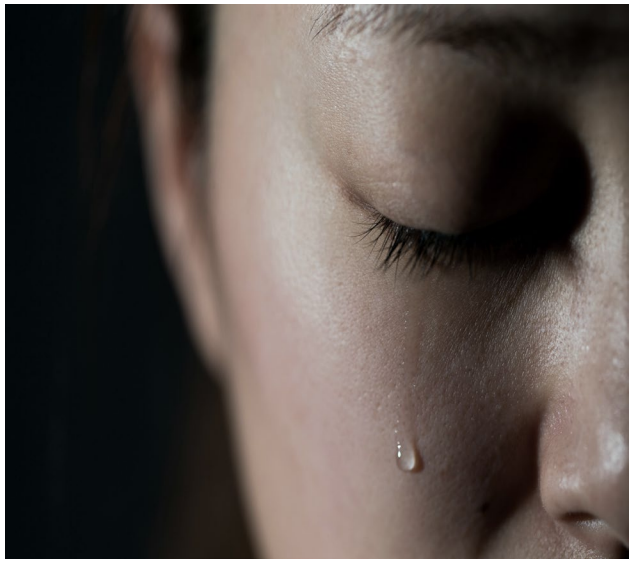
Survey

- Responses varied widely across residents from more **typical reactions such as sadness and crying** to more **angry expressions of grief.** They would talk about their loved one and then seemed to **recover rather quickly.**
- Some **talked about the death**. Others asked **questions specific to the effect of the death on themselves** and then seemed to move on.
- Residents **wanted to participate in rituals and services** around the death. **Most did,** unless distance or identified behavior issues precluded participation.
- There were **no significant differences** in response to the death **regardless of the relationship between the resident and loved one.**

RESIDENTS' BEHAVIORS FOLLOWING HEARING OF THE DEATH OF A LOVED ONE

Survey

Sad*
Withdrawal*
Crying*
Scared they might die
Devastated, SIB (pulling at hair, headbanging)
Anxiety
Bewildered and confused
Initially shocked when death was sudden
Increase in food drive
Increase in self-neglect



Staff reported they did not perceive any long term (one month or more) behavior issues in the residents who lost a loved one.

* Most typical responses. Consistent with research.

RESIDENTS' COMMENTS ON BEING TOLD ABOUT THE DEATH OF A LOVED ONE

Survey

Comments following expressions of grief were often about who would fulfill the role of their loved one.

- "Who will be my guardian now?"
- "What about going out to dinner with my mom?"
- "Where will I go for Christmas?"
- "Who will take me to horror movies?"

Other comments had to do with their immediate circumstances

- "I'm so sad, I need a treat to make me feel better (about the death of staff person)"
- "Are we still going to the movies tomorrow?"

PARTICIPATION IN DEATH RITUALS/MEMORIAL SERVICES

YES

Eighteen (78%) of the residents participated in out-of-house death rituals/memorial celebrations

NO

Five (22%) of the residents did not participate in-out-of house death rituals or memorial celebrations.

Reasons for not participating:

Resident chose not to = 2

Prevented by family (behavior concerns) = 2

Services too far away = 1

IN-HOUSE SUPPORT PROVIDED TO RESIDENTS

For Death of a Close Loved One (not housemate)

- Most often a staff person close to the resident would make themselves available for on-going discussions
- Discussion groups for all the residents to support their housemate in their grief and share their memories of the person.
- In-house memorials
- Celebrations of life
- Nature walks
- Arts and crafts to express feelings

IN-HOUSE SUPPORT PROVIDED TO RESIDENTS

For Death of a Housemate

- **Structured in-house memorials** were held for residents and staff to share stories and feelings
- **On-going discussions and memory sharing** about deceased resident
- **Luncheon at the house with family** of deceased resident, staff and housemates
- **A bench with a plaque** was placed in the garden so that residents and staff could go there and "talk" to the deceased resident
- **Family provided a keepsake to each resident** as they cleared out their deceased child's room
- **A professional** was brought in **to facilitate a grief discussion** with residents and staff
- **Celebrating the birthday** of the deceased every year with his **favorite meal**
- **Visiting the grave** on anniversary of death
- **Renaming fishing club** to deceased resident's name and wore **T-shirts with his name** on fishing excursions

ORGANIZATIONAL SUPPORT PROVIDED TO THE RESIDENTS

- Consistent with the research, in most cases, the **organization did not provide any formal support** to residents or staff when a resident's loved one died.
- Administrative and Managerial staff may have participated in the in-house memorials and discussions, but there were **no agency-initiated acknowledgements, even when it involved the death of a resident**
- They did, however, offer **opportunities or resources** for **individual or group grief counseling** for residents and staff **if requested**
- In our survey and in the literature on grief and people with IDD, it was the **direct care staff who provided on-going support to the residents.** They made themselves available to talk, listen, answer questions, and offer comfort whenever the resident expressed the need.
- **Staff** felt they were **more effective at supporting the residents** through their grief **than trained clinicians** who didn't have the same emotional relationship and were not present when feelings or questions spontaneously arose.

PART II: DEATH OF A RESIDENT

PART II
SURVEY RESPONDENTS: STAFF WHO EXPERIENCED DEATH OF A RESIDENT

COUNTRIES

- US = 7
- UK = 5
- NZ = 1
- DENMARK = 1
- ISRAEL = 1
- GERMANY = 1

TOTAL RESPONDENTS = 16

POSITIONS

CAREWORKER/DSP = 6

RES DIRECTOR = 5

PROGRAM MGR = 1

BEH THERAPIST = 1

SOCIAL WORKER =1

ASSOC/ASS'T RES DIR = 2

POSITION CATEGORIES

ADMIN/MGT 50%

DIRECT CARE 37.5%

CLINICAL 12.5%

HOW LONG WORKING WITH RESIDENT

6-12 mos = 1 (6.25%)

1-3 yrs = 1 (6.25%)

3-5 yrs = 4 (25%)

Over 5 yrs = 10 (62.5%)

87.5%HAD BEEN WORKING WITH THE RESIDENT FROM 3-5 YRS AND OF THOSE 25% FOR =LONGER THAN 5 YEARS (62.5%)

AGE OF STAFF AT TIME OF DEATH

18-25 = 1 (6.25%)

25-30 = 1 (6.25%)

30-35 = 1 (6.25%)

35-40 = 6 (37.5%)

0VER 40 = 7 (43.75%)

THE STAFF WERE RELATIVELY MATURE WITH 81.25%FROM 35-OVER 40 AND 43.75% OVER 40 YEARS OLD

RESIDENT AGES AND CAUSE OF DEATH

RESIDENT AGES AT DEATH

18-25 = 0

25-30 = 0

30-35 = 5 (31.25%)

35-40 = 2 (12.5%)

40 + = 9 (56.25%)

CAUSE OF DEATH

ILL BEFORE DEATH

YES = 11 (69%)

NO = 5 (31%)

CAUSE OF DEATH

CANCER = 4

PULMONARY = 4

ORGAN FAILURE = 2

HEART = 1

SUDDEN DEATH

BOWEL OBSTRUCTION = 1

INTESTINAL RUPTURE = 1

GH INJECTIBLE = 1

PWS (NOT OBESE) = 1

ORGAN FAILURE

RELATED TO COVID/

OLD AGE = 1

RESIDENTS' REACTION TO DEATH OF A HOUSEMATE

- IT WAS AS IF A FAMILY MEMBER HAD DIED
- SEVERAL HAD LIVED TOGETHER FOR MANY YEARS (e.g., 30 yrs in 2 cases)
- EVERYONE UPSET AND EMOTIONAL
- SAD/WITHDRAWN
- PERSON WHO DIED HAD BIG PERSONALITY SO LEFT A HOLE
- SAD FOR BRIEF TIME- MORE INTERESTED IN WHO'D MOVE IN
- ANIMOSITY WHEN NEW RESIDENT MOVED INTO HIS ROOM
- SOME MISSED WORK
- UPSET FOR AWHILE, BUT WITH SUPPORT FROM STAFF- MOVED ON

RESIDENTS' COMMENTS UPON HEARING ABOUT THE DEATH OF A HOUSEMATE

Survey

- Can I still go to the pub tonight?
- Who will get his room?
- What are we going to do with his stuff?

Dinner??

Comment from Lit on people with IDD

"Just not too long ago, we had a client pass away in the home…The clients were upstairs when I went to tell them. They really didn't say anything. They just kept talking about- "What are we eating for dinner? Are we still going to the movies tomorrow?"

Note the similarity between responses of people with PWS & people with IDD.

STAFF REACTION TO DEATH OF A RESIDENT

- GUILT/ANGER- COULD HAVE DONE MORE
- SHOULD HAVE REALIZED SOONER THAT SOMETHING WAS WRONG
- WISH I HAD SPENT MORE TIME WITH HIM
- WISH I HAD BEEN IN TOUCH WITH THE FAMILY IN THE PAST YEAR
- SAD BUT GRATEFUL TO BE PART OF THEIR LIFE AND WITH THEM AT THE END
- ADMIN/MGT BELIEVE DIRECT CARE STAFF FELT GUILT/BLAME
- NO GUILT- JUST SADNESS
- CRYING

"You put a wall up. It's a wall you've got to put up to protect your own heart, your feelings."

"You don't have a choice. You just have to cope with it and keep moving."

GENERAL STAFF COMMENTS REGARDING DEATH OF A RESIDENT

- IT WAS REALLY DIFFICULT TO WORK AFTER HE PASSED. SOMETIMES I WOULD SIT IN HIS ROOM AND CRY. BUT IT'S BUSINESS AS USUAL AND COULDN'T LEAVE THE ROOM EMPTY.
- SOME RESIDENTS FELT THE NEW PERSON WAS TRYING TO REPLACE THE ONE WHO DIED WHICH RESULTED IN SOME INCREASE IN NEGATIVE BEHAVIORS
- WE (STAFF) HAD TO TRY AND BE HAPPY FOR THE NEW RESIDENT WHILE STILL GRIEVING.
- BE OPEN AND HONEST WITH THE RESIDENTS. THEY DESERVE TO HAVE THE OPPORTUNITY TO SAY GOODBYE
- VERY IMPORTANT TO ALLOW TIME FOR STAFF AND RESIDENTS TO PROCESS EMOTIONS.
- THEY'VE PASSED AWAY AND YOU HAVE TO KEEP WORKING. THAT'S WHERE IT'S COMPLICATED. I THINK WE SHOULD BE OFFERED SOME KIND OF SUPPORT WITH THAT.
- IF YOU WANT TO GRIEVE FOR THESE RESIDENTS, YOU DO IT ON YOUR OWN TIME. THAT'S THE BOTTOM LINE

ORGANIZATIONAL SUPPORT

- ACCESS TO EMPLOYEE ASSISTANCE PROGRAMS OFFERING COUNSELING
- LIST OF COUNSELING RESOURCES OUTSIDE OF ORGANIZATION
- OPPORTUNITIES TO TALK/PROCESS AS A GROUP
- ONLY ONE STAFF PERSON SOUGHT OUTSIDE COUNSELING

PAID TIME OFF

YES = 4 (2-3 DAYS) NO = 9 DON'T KNOW = 3

ALL STAFF WHO CHOSE TO, DID ATTEND FUNERAL SERVICE

INFORMAL SUPPORT

Staff turned to each other for support and understanding. They provided coverage for each other when someone was just too sad to work. They talked and told stories about the resident who died and established rituals like celebrating the person's birthday with their favorite meal.

Staff also reported that the **residents provided a source of support** in their resiliency- their ability to go on with their lives. Seeing them be happy gave the staff energy to move on in their own grief.

WHAT COULD HAVE IMPROVED YOUR GRIEF EXPERIENCE

SURVEY

Nothing really (5)

I think we managed the situation very well (2)

Everything was handled appropriately (1)

Wouldn't change much about this experience(1)

I think what we did was very helpful (1)

I can't think of any more ways to help (1)

RECOMMENDATIONS

Prior formal training on grieving

More End-of-Life training

More time to grieve

STAFF RELATIONSHIP WITH THE RESIDENTS

- Many staff **view the residents** they support **as family**, especially those who have been with them for many years, as was the case in our survey and in the literature.
- Indeed, there are residents who have no family or whose family is distant who are routinely **invited by staff to join their family for holidays and special occasions**
- This may be in **conflict with agency policy** and practice that recommends maintaining an **emotional distance** from the people they serve. Of course, there must be boundaries around how one interacts with the residents, **but how can emotional boundaries be dictated when there is day to day contact?**

STAFF RELATIONSHIP WITH RESIDENTS

Staff Comments

" And you can't help but to get attached. If you have any kind of feelings or compassion, you can't help but to get attached."

"I had one particular client that I lost. She was just like a family member…The impact she had on my life…"

"Some people are attached to their pets..but why can't we be attached to somebody we've cared for ten years plus?"

"For me, it was different. Although I had just started, I was here maybe about a year and a half and he was such a joy and I got attached to him fairly quick."

In general, survey respondents and staff from the research indicate that **their organizations did not fully recognize and acknowledge the deep dedication** and efforts in prioritizing the well-being and needs of their residents at all times. At times, this **put staff in an emotional predicament of holding in their grief while performing their expected work duties.**

END OF LIFE TRAINING

While End–of-Life training was **not specifically addressed in our survey**, two survey respondents discussed the policies their organizations had developed.

For all other respondents, **end-of-life training was identified as a growing need** as the residents we serve continue to live into old age and are more likely to need care through a terminal illness.

Yet, **preparation** of staff who are the primary caretakers is lar**gely absent.**

In a study by Tuffrey-Wijne et al, (2020), carers who had supported a resident with IDD during a terminal illness, reported that **78%of the deceased persons were "not aware" or "probably not aware" that they were going to die.**

The vast majority of staff belief that **residents have a right to understand their condition** and be given the opportunity to participate in end-of-life planning and decision-making

END OF LIFE TRAINING

End-of-life training may not be necessary for all staff, as those situations may not arise for a number of years within a particular setting. However, organizations do need to ensure all staff can access adequate support if a person with PWS has end of life care needs.

- Ad hoc training
- Support from outside resources (hospice, palliative care services, specialized nursing care)
- End of Life Care policies and practices so staff know what to do and who to turn to for information and support, including support and supervision as they implement procedures.

RECOMMENDATIONS FOR STAFF SUPPORT DURING RESIDENTS' LOSS OF A LOVED ONE AND DEATH OF A RESIDENT

- DEVELOP **PERSON-CENTERED END OF LIFE TRAINING**, POLICIES AND PRACTICES TO PREPARE STAFF FOR SUPPORTING THE RESIDENT DURING THEIR TERMINAL ILLNESS
- **FORMAL ACKNOWLEDGEMENT** OF DEATH: Celebrations of life, Tangible mementos (e.g., collages to planting gardens, benches, memory boxes…). INCLUDE FAMILIES IN REMEMBRANCES.
- **PAID TIME OFF**
- GREATER **UTILIZATION OF SPECIALIST SERVICES** AND EXTERNAL ORGANIZATIONS (e.g., hospice) TO SUPPORT A TERMINALLY ILL RESIDENT.
- **POLICIES/PRACTICES/FORMAL GUIDANCE** IN SUPPORTING INDIVIDUALS WITH IDD/PWS DURING THE ILLNESS OF A LOVED ONE AND THE GRIEVING PROCESS
- **DEVELOPMENTALLY APPROPRIATE MATERIALS** FOR PEOPLE WITH IDD/PWS TO DISCUSS DEATH AND DYING WITH RESIDENTS

KEY TAKEAWAYS

- **There is no research specific to individuals with Prader-Willi Syndrome** or their staff (to my knowledge) **regarding grief.**
- The research on people with IDD and our survey results suggest that **both groups are alike in their experience with grief** (whether a loved one or a housemate) making **the research with IDD relevant to work with PWS.**
- The experience of staff supporting people with IDD and staff supporting people PWS who **experience the death of a resident is comparable.**
- The experience of staff working with people with IDD and staff working with people with PWS regarding **organizational support is equally lacking** in terms of training and acknowledgement of the grief experience.
- **All staff are deeply committed to supporting their residents** and often have a **deep emotional bond** with them magnifying their grief experience when a resident dies.

KEY TAKEAWAYS (CON'T)

- **Lack of research on cultural differences** in expressing grief and grief rituals
- **Lack of research on end-of-life care** compared to bereavement practices
- Importance of residents **knowing who will fulfill the role of the person who died-** whether that be family member, housemate, or staff
- Residents are best supported by **maintaining existing routines** to the greatest extent possible
- **Residents are resilient**- perhaps more so than staff: *"I would've . . really predicted the worst with Debbie. . but she completely proved me wrong. . I know Debbie years but. . she really was resilient like, she really coped with it fantastically."*

LIMITATIONS OF SURVEY RESEARCH

SAMPLE SIZE TOO SMALL (23)

INADEQUATE REPRESENTATION FROM DIFFERENT COUNTRIES TO GENERALIZE FINDINGS TO ALL COUNTRIES

OVERREPRESENTATION OF ADMINISTRATIVE (47.8%) AND CLINICAL (17.3) STAFF VS DIRECT CARE WORKERS (34.7%) WHICH LIKELY INFLATED SCORES AROUND CONFIDENCE LEVELS IN SUPPORTING RESIDENTS WHO HAD LOST A LOVED ONE.

FUTURE RESEARCH

- Development and testing of **support strategies for people with PWS who face their own death** or death of someone close to them.
- Development of resources that enable people with PWS to talk about dying and to be meaningfully **involved in end-of-life decision making.**
- How to talk about death and dying with residents with **different cognitive levels and communication needs**
- The experience of staff when there is **a sudden death of a resident vs. one who dies following an illness**
- **Qualitative research with people with PWS/IDD** describing their experience of grief and their need for support
- Assessment of **existing training resources** and tools and their practical application as viewed by staff

FUTURE RESEARCH

- **Disenfranchised grief** (grief not recognized by others) and its relationship to both staff and residents experiencing loss and death
- Is there an identifiable **grief process for people with PWS?**
- Effectiveness of using various **art forms as a means to express grief**
- The various **types of grief** (beyond people close to them) experienced by people with PWS/IDD (e.g., death of a pet, job loss, staff leaving, loss of preferred activity, romantic breakup…)
- Identification of **expressions of extended or delayed grief vs characteristics of diagnosis** or resident specific behavior characteristics

QUESTIONS/CONSIDERATIONS

- ❑ Does religion have an effect on how residents' grieve and how best for staff to support them?
  - ➢ For example, in the Jewish and Muslim faiths, grieving rituals include sitting shiva for 3-7 days, being in mourning for one year culminating to a visit to the grave site at the end of the year and annually thereafter
  - ➢ Most Christian faiths have a wake for viewing and a funeral within several days or even no viewing or funeral for others. Memorial services for friends and relatives are increasingly common.

- ❑ Cultural aspect of the grief process and rituals
- ❑ Differences in grieving and support when an expected death (terminally ill) vs. a sudden death.
- ❑ Differences in the grief experience for residents with a range of intellectual ability and how best to provide support

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THANKS FOR CONTRIBUTING TO THIS TOPIC… AND FOR ALL YOU DO

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