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Personal relationships during end-of-life care: Support staff views of issues for individuals with intellectual disability

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ABSTRACT

Background: Life expectancy for persons with intellectual disability has increased dramatically over the past decade, which has seen an associated rise in the need for end-of-life care. However, little is known regarding how end-of-life affects the individual's personal relationships with family, friends and staff.

Methods: Focus group interviews were undertaken with 35 disability support workers from four rural and two metropolitan locations in NSW and Queensland, Australia. A semi-structured interview guide was used, with a focus on the gaining an understanding of the impact that end-of-life has on personal relationships for persons with intellectual disability.

Results: The thematic analysis identified three key thematic areas: *Relationships with Family, Relationships with Friends and Staff Roles*. Relationships with Family had three sub-themes of 'Active and Ongoing', 'Active but Limited' and 'After Death'. Relationships with Friends had two sub-themes of 'Positive Experiences' and 'Negative Experiences', and Staff Roles had two sub-themes of 'Loss of Contact' and 'Default Decision Making'.

Discussion: The frequency of family contact was not reported as increasing or decreasing following the diagnosis of a life-ending illness and during an individual's end-of-life. A lack of counselling support was noted as potentially impairing the individual's friends' ability to cope with death. Staff also reported a number of concerns regarding how their relationships with the individual changed, particularly when end-of-life entailed potential movement of the individual with intellectual disability to a new residential setting.

What this paper adds

This paper explores how paid disability support services staff in rural and metropolitan NSW and Queensland, Australia, perceive the impact of end-of-life on the personal relationships of individuals with intellectual disability. A qualitative in-depth analysis of the results of focus groups identified three key thematic areas, each of which had a number of sub-themes. This paper provides information on how end-of-life may impact on both individuals with intellectual disability and their family, friends and support staff. This knowledge may facilitate better understanding of how personal relationships change during end-of-life, and also provide insight into how family members and disability services can better meet the needs of individuals during this stage of life.

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1. Introduction

1.1. Increasing life expectancy

It has been consistently identified that people with intellectual disabilities now have the longest life expectancy of any time in history in developed countries (Australian Bureau of Statistics, 2015; Coppus, 2013). The past century has seen dramatic improvements following the implementation of better medical and social models of support for children and adults with lifelong intellectual disability (Arvio, Salokivi, & Bjelogrlic-Laakso, 2016; Bittles et al., 2002). However, associated with this very positive outcome has been the emergence of many diseases, such as cancer and non-ischemic heart disease, among this cohort of the community (Coppus, 2013; Goddard, Davidson, Daly, & Mackey, 2008; Sullivan, Hussain, Glasson, & Bittles, 2007; van den Akker, Maaskant, & van der Meijden, 2006). The relatively recent increase in life expectancy, combined with the emergence of potentially life-ending conditions, has resulted in the need for palliative or end-of-life care support that is not always well recognised or readily available (Todd, 2013; Todd, Bernal, & Forrester-Jones, 2013; Wiese, Dew, Stancliffe, Howarth, & Balandin, 2013).

1.2. End-of-life care

There is currently ambiguity around the best approaches to providing end-of-life care for people with intellectual disability in Australia, and even what supports are most required (Wark, Hussain, & Edwards, 2014; Wiese, Stancliffe, Balandin, Howarth, & Dew, 2012). Government policy and funding-related artificial barriers can be an impediment for individuals with intellectual disability and/or their carers to access end-of-life care available to the mainstream population, resulting in sub-optimal care and less than ideal outcomes (Read & Todd, 2010; Read, 2013; Todd, 2003; Wark, Hussain, & Edwards, 2014). In particular, ongoing support within the individual's longstanding home in the community may be compromised, resulting in premature and inappropriate admission to residential aged care (Wark, Hussain, & Edwards, 2013). Government models have not yet adapted to meet the emerging needs of these groups which is resulting in ongoing indecision with regard to what assistance best supports quality of life outcome (Wiese, Stancliffe, Dew, Balandin, & Howarth, 2013; Wiese, Stancliffe, Read, Jeltes, & Clayton, 2015).

1.3. Personal relationships during end-of-life

Social networks and meaningful communication are important components underpinning the quality of life of older people in general (Bahramnezhad, Chalik, Bastani, Taherpour, & Navab, 2017; Moorman, 2011), and particularly for those with chronic life-threatening conditions (Gott et al., 2017; Leonard, Horsfall, & Noonan, 2015). These issues are intrinsically linked to the maintenance of personal relationships (Steinhauser et al., 2000). Similarly, it is well known that personal relationships are very important for many individuals with intellectual disability (e.g. Emerson & McVilly, 2004; McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006), but that their social networks may be limited (Forrester-Jones et al., 2017). However, while there has been some research that has examined personal relationships during end-of-life for people with physical disabilities, such as cerebral palsy (Ballin & Balandin, 2007), the issues have not been well explored in Australian settings for individuals with intellectual disability (Wiese, Stancliffe et al., 2013). This failure to consider how end-of-life impacts on personal relationships potentially limits the capacity of the sector to proactively provide people with intellectual disability with the support they need.

1.4. Current project

This article reports on findings from a series of seven focus groups with direct care staff of local disability agencies in locations in both rural and metropolitan regions of Queensland and New South Wales, Australia, with a focus on the perceived impacts that the end-of-life had upon the personal relationships of individuals with lifelong intellectual disability. This paper is part of an ongoing study examining short- and longer-term impacts, both positive and negative, associated with end-of-life issues for individuals with lifelong intellectual disability and associated complex healthcare needs. The continuing project has previously included both quantitative surveys and qualitative personal in-depth interview protocols with individuals, family members and carers.

In the prior research we have identified that availability of specialist support for people with intellectual disability is inadequate, and that, in a geographically large country like Australia, health and social care services to assist with end-of-life are particularly limited in rural locations. Furthermore, we found that the need for movement to another residential service, when services closer to home are either unavailable or inaccessible, can result in considerable trauma for individuals with intellectual disability due to the separation from friends and family (Wark, Hussain & Edwards, 2013a,2013b,2016; Wark, Canon-Vanry et al., 2015; Wark, Hussain, Müller, Ryan & Parmenter, 2017). The need to specifically include geographically diverse locations within Australian research is considered vital, as any conclusions or recommendations for people with intellectual disability drawn from studies that have not proactively considered any geographic impact, must be considered questionable for a large proportion of the population (Wark, 2018).

2. Methods

Formal ethical approval for this project was provided by the University of New England's Human Research Ethics Committee (Approval No. HE13-271) prior to commencement. A focus group interview model (Ritchie, Lewis, McNaughton Nichols, & Ormston,

2014) was chosen as the study methodology, as it was deemed the most appropriate mechanism to gain direct input from support staff across a range of geographic areas in a setting that facilitates reflection and discussion (Krueger & Casey, 2015). This approach builds upon the previous work undertaken by the authors in the ongoing study that had used other quantitative (surveys) and qualitative (personal in-depth interviews) methodologies. A thematic analysis methodological approach (Braun & Clarke, 2006) was chosen as the research framework to analyse the data from the focus groups.

While the participants in the focus groups were paid care staff, the instructions to the focus groups were that the over-arching focus should be on the perceived experiences of people with intellectual disability, and not that of the staff members. Personal relationships were contextualised for participants as any close connections of the individual with intellectual disability, and which could therefore include, amongst others, family members, friends, housemates and support staff. In order to provide a structure across the focus group interviews and to initiate discussions, a semi-structured question guide was developed, based on the findings of the previous research and with input from a steering committee composed of people with intellectual disability, family carers and service providers.

2.1. Recruitment of participants

As the goal of the project was to explore the perspectives in both rural and metropolitan areas of Australia, a purposive-sample using a typical-case model approach (Palys, 2008) was selected. This allowed the research team to recruit appropriate representation from across geographically diverse areas, and to ensure that all participants had been personally involved in supporting individuals during their end-of-life. The project steering committee initially identified six locations in New South Wales and Queensland that were considered to provide a range of respondents. In order to gain representation from a range of perspectives, the nominated sites included two smaller rural towns with populations up to 15 000 people, a small rural city with a population of between 15 000–50 000, a regional centre with between 50 000 and 150 000, and the two metropolitan locations with over 1 million people. One metropolitan location was an inner-city suburb, while the second metropolitan site was in an outer-city region. The rationale for including two smaller rural towns was that it was perceived that it might be harder to recruit participants in these locations.

The steering committee then identified disability support services in each of the locations, and the research team made an approach to each organisation to see if they had supported an individual during end-of-life within the past three years, and if they were willing to support the project. The research team provided information packages to each organisation that met the inclusion criteria, who in-turn then directly distributed it to their staff. Research team members then did a face-to-face information session for any potential participants at each location prior to the focus groups commencing.

2.2. Conducting the focus groups

The size of each focus group was pre-nominated to be between 4–12 people (Sim, 1998). However, we felt that smaller groups of 6–8 were preferable to ensure all participants had the opportunity to contribute their views. A member of the research team moderated each focus group, while a second member of the team provided administrative and technical support. After gaining approval from all participants, the interviews were recorded on two separate digital devices.

As part of the study design, only gender and location was noted to limit to the possibility of coincidental identification of participants from smaller rural agencies. Both the moderator and note taker completed a separate field-note summary immediately following each session to assist with subsequent transcription and data analyses. More detail on both the recruitment processes and geographic sites has been previously published (Wark et al., 2017).

2.3. Analyses

The thematic analysis was based upon the framework of Braun and Clarke (2006), and was undertaken by three members of the research team. To ensure anonymity, all participants were given the opportunity at the time of the interview to select a specific pseudonym if they wanted. No-one chose to do so and the research team therefore retrospectively allocated a pseudonym to each participant. The analysis began with each researcher independently familiarising themselves with the data and then establishing initial thematic codes. Discussion then followed between the team members to seek agreement on a final coding structure for the analysis of the full data. Any disagreements over coding were resolved through discussion, and while a fourth member of the research team was nominated to act as an independent arbiter, this was not required. Themes were identified across the collated data from the focus groups, with a goal of identifying the positive and negative impacts that end-of-life had upon the personal relationships of individuals with lifelong intellectual disability. Members of the research team then undertook the full thematic analysis using this coding structure to refine the data into thematic areas. Member checking was undertaken by sending a draft version of collated findings to four disparate focus group discussants (Charmaz, 2006). None of them identified any problems or requested any changes.

3. Results

3.1. Participants and observations of the focus groups

The recruitment process resulted in 35 participants in seven focus groups, with a split of 13 metropolitan and 22 rural participants. In one location, there were two focus groups conducted to allow all interested staff to participate. The seven focus groups showed a gender bias, with more than twice as many females as males [24 females – 11 males]. However, this imbalance is generally representative of the Australian disability workforce (Martin & Healy, 2010). The mean number of participants in each focus group was five, with a range between four and seven. The sessions went for an average of 61 min (not including introductions and 'housekeeping') with a range between 31–73 minutes, and the data were independently transcribed.

All of the focus groups were noted as being generally enthusiastic or keen to discuss the issues, and no particular hesitancy or uncomfortableness was identified. This is perhaps not surprising, as the staff who participated had self-nominated to do so and therefore had an interest in the area. The majority of the sessions concluded around the sixty-minute mark. The smallest group of four participants was also the shortest session in duration (31 min). In this case, the discussion covered all the issues, and all participants commented and had the opportunity to actively contribute. Across all seven groups, it was reported that every participant had provided their thoughts on numerous occasions.

At the conclusions of each session, the facilitators confirmed with all participants that they did not have any additional issues they wished to raise, and a verbal check that no participants were distressed was undertaken. Furthermore, options for referral for counselling support were also offered, but no participants indicated that they required this assistance. The moderator and note taker's field-note summaries made specific observations on how the focus groups performed, as well as monitoring individual participation.

3.2. Data themes

The analysis of data identified three over-arching thematic categories, each of which had several sub-themes. The three categories were:

- Personal relationships with Family;
- Personal relationships with Friends or Housemates; and
- Personal relationships with Staff.

These categories and sub-themes are outlined below in Fig. 1.

As noted earlier, previous research had found potential for differences in findings based upon the geographic location of participants. Therefore, the rural and metropolitan data were compared to establish whether there was any major disparity in the reporting of issues. This analysis showed no patterns of consistent differences based on the location of participants, with similarities and overlaps in the identified issues across all sites.

The main findings are presented sequentially below. To provide context to the reader, a pseudonym, gender and geographic identifier for each quoted participant is included. For reasons of readability, included quotes are from single individuals but were chosen as being representative of the wider discussion between multiple group members being undertaken at that point in time. In order to protect the confidentiality and anonymity of individuals with intellectual disability, all potentially identifiable details have been removed from direct quotes and replaced with a string of asterisks [********].

3.3. Relationships with family

Not unexpectedly, there were disparate reports of the personal relationships with family members during an individual's end of life. As identified by Sally [female, metropolitan] "*Some families are highly involved; other families you hardly ever see. There's some who don't have any family*." The family relationships could be separated into three distinct categories:

- **Ongoing active involvement;**

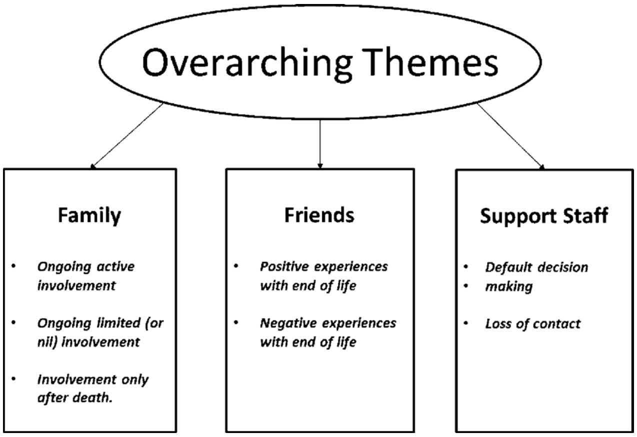

Fig. 1. Perspective of disability staff about end-of-life issues for people with intellectual disabilities.

- **Ongoing limited (or nil) involvement; and**
- **Involvement only after death.**

Each categories refers to the level of personal contact that the family [e.g. parents, children, siblings] had with the individual during their final months of life. It is perhaps surprising that there were no identified examples where family members either significantly increased or decreased personal contact with an individual after they were diagnosed with a life-ending illness and prior to death.

The focus group participants recognised many family members as being very involved in supporting an individual during the end-of-life. However, discussion indicated that these situations were a continuation of the status quo and reflected what had occurred throughout the person's life. For example, Jenny [female, metropolitan] outlined a typical situation in commenting that across the person's lifespan "*the family was very, very involved …. they have a lot of say, and every day activities and everything from meal times to sleeping times*." Even if the family did not continue to live in close proximity, such as when an individual had moved to a new location to receive additional support, maintaining contact was not an insurmountable problem for family to stay involved if they wished. Cassie [female, small regional centre] commented, *"Mum is not local, or not as local, but is still very involved and knows exactly what's going on*", and Bronte [female, small regional centre] agreed that it was "*possible to keep somebody just as involved, just through different means, better phone communication*".

In contrast to these situations, the focus groups also identified that some families remained isolated from the individual, and continued to have minimal or no involvement after the diagnosis of a life-ending health condition. In some cases, particularly for older people, this was partially explained by the fact that their parents had pre-deceased them and no other family member had subsequently assumed that role. Jim [male, large regional centre] stated:

> "*I've found that mostly it's the parents in the family who are the primary contact, and once the parents pass away, the siblings are not there for them. Like with *******, [his/her] parents have passed away and [she/he] didn't have anyone else*".

Isabella [female, large regional centre] provided further clarity to this discussion by noting:

> "*I think family members can be aged themselves, with their own issues and whatever that might entail, or they've already passed on and the guardian is now somebody who may not know the client as well*".

In other cases, the lack of regular personal involvement could be a longstanding problem of geographic distance. Jessica [female, metropolitan] described a situation in which a resident lived in Australia, but the family was overseas, "*[his/her] mother lives in Holland … We hope for the best that we can get her on the phone, otherwise it's email*".

In general, family involvement appeared to be appreciated by staff but it did also have the potential to cause problems. A lack of contact between the individual and their family was a cause of distress for some staff. One participant noted:

> "*Why I was upset was that [she/he] was obsessed with [his/her] sister and [his/her] brother-in-law, [she/he] just adored them. That was [his/her] life, and I thought, you can't get here? [She/he]'s not going to be alive in the morning. You can't get here?*" [Steven, male, metropolitan].

A regional centre focus group had a discussion around whether this lack of family contact during end-of-life was viewed negatively by the individual, and particularly when it was a continuation of the status quo. It was agreed that this varied between individuals, but it was nonetheless hard to determine. This viewpoint was summarised by Lachlan [male, large regional centre] who stated:

> "*It's very difficult to judge how, if a resident has expectations of family contact and is not getting it, it's very difficult to judge how that could be affecting them. Are they badly impacted by the fact that their nearest relatives are not interested in doing the bare minimum? We're not in a position to kind of judge whether that's having a major impact on their quality of life*."

End-of-life is a stressful time for all parties, and this could manifest in tension between the desires of the individual, the family and the support staff. Trying to maintain this balance between conflicting priorities was directly identified as causing difficulties for some staff:

> "*It did cause strain on the support team. My job was very hard, and maintaining, you know, positive interactions with the family, with the staff, with management" [Jenny, female, metropolitan*].

These issues were considered to be possible contributory factors in relation to problems in re-establishing family contact with the individual. Grace [female, metropolitan] noted how the wider historical background could have caused these problems to emerge, "There is a lot of historical things with the family, a lot of grief and loss on their part". Susie, [female, small regional centre] outlined how their service tried to proactively involve families as a mechanism to minimise these difficulties and to either maintain or re-establish the family relationship during end-of-life:

> *"they need to come to the palliative care conference …. In this particular instance it was mum, but it could have been mum, dad, brothers, sisters, any number of family members at the conference that wanted to be involved."*

Bronte [female, small regional centre] then followed on Susie's comment by clarifying, "*but it happens early, before we are talking palliative care, we have mum, dad any family member who wants to be involved in medical stuff that's going on*".

While less common that the first two sub-categories, participants did also describe situations in which family members emerged after the person had died, in spite of not having any significant recent involvement during the individual’s life. This situation generally occurred with older individuals who had lost regular contact with their family following the death of their parents. One staff member commented, “*I suppose, after death, people's names pop up then, don't they - if there's money around!*” [Stephanie, female, small rural town]. Jim [male, large regional centre] reported similar experiences with family members emerging at the funeral, “*You go to a funeral, you might see people there you haven't seen your whole life*”.

The discussion around family relationships highlighted an underlying conflict between staff and family regarding who best knew the individual’s desires. This lead to tension when the family, who the staff felt had little current knowledge of the individual, made decisions that contradicted what the staff felt was appropriate:

> “*I think they contacted me and said, ‘Look, we're just going to have a quiet funeral, just the family.’ … I thought, no way. I said, ‘[his/her] family's here. For thirty years with the twenty-five people [she/he] lives with.’ I said, ‘We're going to have a funeral and we're all going to attend.’ You know what? It was the best funeral*” [Steven, male, metropolitan].

3.4. Relationships with friends or housemates

The second major theme pertained to the personal relationships between people with intellectual disability and their friends or housemates. All the focus groups described how individuals receiving end-of-life support were positively supported to maintain their relationships with their friends. Linna [female, metropolitan] stated, “*He had a friend … he used to say "Let's go and visit him," and staff would support him with that.*” The main situation in which friendships were affected by end-of-life were after the individual had moved to another setting, but this scenario did not necessarily preclude ongoing contact. Lachlan [male, large regional centre] summarised an example of this situation by noting: “*We've got ********, who's not an old person, but they sent [him/her] to an old people's home …. but we take ******** to visit ******** in that home …. we can take one or two to visit.*” However, there were also some negative examples where individuals moved to new locations, and contact with friends and staff was completely lost.

Additional discussion was around the impact that the end-of-life experience had on the individual’s network of friends, rather than the individuals themselves. In some cases, this was seen as being positive, as it then directly assisted these friends when they subsequently went through their own end-of-life. For example, Jessica [female, metropolitan] stated:

> “*There were three people that had passed away before [she/he] did, in that house. So [she/he] had been through it before. [His/her] best friend, which we'll probably go on to talk about next, the other ********, they were [his/her] best friends, the two that passed away, and there was a lady next door that was [his/her friend] for thirty years*.”

Nonetheless, responses from the focus groups indicated that the participants believed that people with intellectual disability were significantly negatively affected by the death of their friends, and often remained so for extended periods of time. Steven [male, metropolitan] noted:

> “*My point is that I still think [she/he]'s grieving …. I had a conversation with [him/her] this week, and once you get [him/her] talking, and if you ask [him/her] a question, usually ******** is very non-communicative in that [she/he] says, ‘I'm fine, it's all cool,’ or whatever, but if you delve a bit deeper and you start talking, [she/he] says, ‘I really miss ********’.*”

Linna [female, metropolitan] agreed with Steven and commented on the fact that some individuals were not supported to appropriately farewell their friends or housemates, “*Some of the residents weren't going to be given the opportunity to say goodbye, and they needed to.*” Ann [female, small rural town] also identified that loss was not dealt with quickly and easily, “*I guess ********’s death had such an impact on the other people. They really felt it, and I think they still - well, ******** does*” to which Claudia [female, small rural town] agreed by noting, *“Still does, yeah.*”

The lack of grief counselling support was identified as being one of the factors that may have contributed towards the problems persisting for longer periods of time, “*And I think that still affects [him/her]. [She/he]'s never had any counselling, never had any*” [Linna, female, metropolitan]. However, as part of the same discussion point, Jessica [female, metropolitan] also noted that inappropriate counselling was just as bad as no counselling at all:

> “*They actually listened to us and actually organised for [him/her] to see a grief counsellor, because [she/he]'s a very emotional person, but [she/he] got nothing out of it because this person doesn't understand people with intellectual disabilities, because they weren't speaking to [him/her] properly, they weren't making [him/her] feel comfortable. It was a waste of time*.”

3.5. Relationships with staff

Participants did not consistently comment on or identify any changes in their daily relationship that specifically resulted from them providing end-of-life care in addition to the existing disability support. However, staff did perceive that wider issues impacted on their roles and this affected both the individual and themselves. This theme had two sub-areas of **Loss of contact** and **Default decision making**. Both of these situations were described by participants as occurring during the final months of life, and primarily after the individual had lost capacity to make informed decisions on their own behalf.

The participants’ description of a family transferring the person with intellectual disability at the end-of-life to a completely new location led to the sub-thematic area of ‘losing contact’. Staff expressed their own sense of loss, not related to the actual death of the person with intellectual disability, but when individuals were suddenly moved out of their long-term home and into a new facility.

Many participants described how staff had often worked with individuals for many years, decades in some cases, but this relationship was sometimes abruptly cut and they did not necessarily know where the individual had gone. The individual’s friends and housemates were also left unsure of what had happened. Equally, due to the lack of any further contact, participants were unsure how this sudden change affected the individual including whether they understood the reason of why it happened. This issue of family members deciding to move an individual, and the impact that this had on both staff and friends, was discussed in depth within one metropolitan focus group, with Linna [female] commenting:

> “*If a person moves …. then between us, we can maintain that. We could come over for a cuppa, or have a barbeque, you know, we try to do that …. But when families take them, like you said, way yonder somewhere, we don't ever hear anything, and along the grapevine eventually you hear, ‘Oh, somebody passed away.’ You feel a bit cheated in that respect, because you've been with them for so long.*”

This sense of loss resulted in staff feeling as if the individuals with intellectual disability were forgotten once they moved to another setting, such as a residential aged care facility. Participants reported that they felt sidelined and their opinions disregarded. Lachlan [male, large regional centre] noted this scenario:

> “*You become a substitute family member. Which also, again, has that thing - a bit of a slap in the face. You've become such a family member, and you work with all your heart in the best interests of that person, yet still your judgement is dismissed as being not relevant, or your insights are not taken into consideration.*”

Sally [female, metropolitan] noted a similar experience, “*I'm being told I'm not a doctor, I'm not a nurse, I don't have the right to have an opinion.*” Sally then outlined how radical changes sometimes occurred when families suddenly assumed control and started making decisions:

> “*A lot of families, I think, in the end, especially with dementia patients, are forced into suddenly taking one hundred percent of this person, so they go, ‘Right! I'm making the decision! We're ripping 'em out. They're gone.’ And you get nothing. It's like they're gone. That's it.*”

These situations again highlighted the moral dimension to staff’ perceptions of family involvement, and how staff sometimes perceive themselves as being better placed than family members to make decisions about the most appropriate support during end-of-life.

The focus group discussions also outlined how decision-making during the end-of-life changed their relationship with individuals when they remained in the same location. Typically, in this scenario staff were expected by the family, and sometimes health professionals, to act as the default decision maker regarding end-of-life and were looked to for guidance and advice. Participants expressed their discomfort with this de facto role, as technically they do not have any such legal status, and noted how it changed their relationship with the individual. A metropolitan focus group had a long discussion around a specific case in which the family indicated that they would not come to the hospital before the individual died. Steven [male, metropolitan] reacted to this situation by recognising, "*No, hang on a minute. [She/he] needs somebody there. You can't just leave [him/her] in the hospital [to die]*" and arranged for a staff member to go to the hospital. Sally [female, metropolitan], the staff member in question and also a member of the focus group, reported that health care staff at the hospital asked for her guidance at one point: “*for that split second, they turned to me and said, ‘Well, what are we going to do? What's your decision?’ I was like, ‘I can't make that decision. I'm not allowed to make that decision.*’” Sally also commented later,“*But it was just that second, even in your own head, you know, the thoughts that go through: oh, my god, someone's life is in my hands? And it always stays with you.*”

4. Discussion

Within the existing end-of-life and intellectual disability literature, there is a focus on service provision and planning, but there is limited examination of the complex human dimensions in this stage of life, and how death and dying can disrupt the existing social systems. The purpose of the current study was to begin to understand the impacts, both positive and negative, that end-of-life had upon the personal relationships of individuals with lifelong intellectual disability. The analysis identified three key thematic areas of **Relationships with Family**; **Relationships with Friends or Housemates**; and **Relationships with Staff**, and the following discussion is structured around these three themes.

4.1. Relationships with family

As with any other group in the community, people with intellectual disabilities have varying relationships with their families over the course of their life (Strnadová, Cumming, Knox, Parmenter, & Lee, 2015; Walmsley, 1996). Some individuals will have ongoing close linkages to their parents and siblings, while others will note no contact at all (Hillman et al., 2013). Interactions with family members will naturally vary over time; however, this study’s participants indicated that the individual’s end-of-life did not appear to change the regularity of the relationships. Family members who were strongly engaged before the diagnosis of life-ending illness remained involved and active in the individual’s life up to the point of death, and participated in the death rituals, such as the funeral. In general, the participants did not identify any significant or major issues associated with the relationships that continued to feature regular contact.

Similarly, families who had limited or no contact with the individual did not change their existing behaviours and establish regular communication during the individual’s end-of-life. There were no examples provided in which the family re-engaged contact after the individual was diagnosed with a life-ending illness, but prior to death, and there were also no cases of family members either reducing or cutting contact completely during the end-of-life.

One of the interesting emerging concepts was the moral judgements that many staff members made about the involvement of family. A lack of involvement seemed to cause some staff personal angst, as they felt distressed by families who either could not, or did not wish to, be more involved during the end-of-life. However, these same staff were not able to say whether the individual actually felt any distress by their family situation, and it is unclear whether the individuals would have necessarily wanted more contact with their family. It appeared that some participants viewed themselves as the person who ‘best knew’ the individual, and therefore felt able to make judgements about the perceived value of any contribution of family during the end-of-life and post-death. This included the cited example of a staff member effectively over-ruling the family who wished to designate the funeral as a family-only event. This is not to say that the staff member was incorrect in their assessment, as their intervention may have prevented the exclusion of friends and housemates, but it does highlight a disconnection between expectations of staff and family. There were also situations cited in which family members emerged, but only after the individual had died. Again, some participants ascribed ethical or moral motives to this action (i.e. the potential for financial gain), rather than out of a desire to ‘pay respect’ to the deceased. This situation also resulted in stress for staff and other residents when the family attempted to influence the death rituals without staff believing that the family members knew what the individual or their network of friends would have wanted. Further examination of the beliefs of family versus staff would be appropriate in future research.

The end-of-life process did not appear to present an impediment to the continuation of positive family relationships, but neither did it enhance it in situations where it may have been lacking. The identified issues that were believed to lead to poor family involvement, namely prior parental death and geographic separation, do not appear to be related specifically to end-of-life, and were a continuation of an existing situation. Some participants discussed how their service specifically attempted to proactively engage families at the early stages of palliative care planning, but the participants were not certain on whether this approach increased the level of involvement.

4.2. Relationships with friends or housemates

Friends and housemates often form the basis of the social network for individuals with intellectual disability (Kamstra, Van Der Putten, Post, & Vlaskamp, 2015; Van Asselt-Goverts, Embregts, Hendriks, Wegman, & Teunisse, 2015). The current study indicated that there were at least some positive outcomes for individuals who had experienced the death of a friend. Particularly, it was seen by some participants as providing some familiarity and context for the individual when they themselves subsequently went through their own end-of-life. In spite of this positive aspect, it was still recognised that the final stages of life are distressing for both the individual and their friends (Read & Todd, 2010), and most of the participants identified largely negative outcomes regarding friendships during end-of-life. It is clear that assistance in dealing with grief and loss are still not particularly well supported for people with intellectual disability. This pertains to both pre- and post-death, with participants identifying issues around the lack of appropriate time and space for friends to say goodbye. The lack of specialised grief counselling for people with intellectual disability is a clear problem, and was identified consistently across the focus groups.

4.3. Relationships with staff

The main concern raised by participants related to the complete loss of the relationship, particularly after they moved from a long-standing community setting into either a palliative or aged-care placement. The sense of loss associated with death was recognised and acknowledged, but equally it appeared to be relatively well accepted as part of the normal life cycle. However, there was much more expressed emotion regarding ambiguous loss, whereby individuals had been moved to another setting and the disability staff and friends were not kept informed of their progress. The ongoing uncertainty about what had happened after an individual had moved appeared to be more of an issue than an actual death of the co-residents. This lack of ongoing knowledge meant that it was also unclear whether the individual who had been moved experienced any grief or emotional upset associated with the loss of their friends and familiar disability support staff.

Participants also noted that the provision of end-of-life care changed their work role and that this potentially impacted on their relationships with the individual. Specifically some participants noted that they were asked, in the absence of anyone else, to be the default decision maker and effectively take on a guardian’s role regarding serious health issues. This situation raises some serious ethical and professional concerns, as in both NSW and Queensland, paid disability workers cannot be legal guardians for people with intellectual disability that they provide care for (e.g. NSW Government - Justice - Public Guardian, 2017a). In the absence of any family members to take on this role, often due to the parents being already deceased (e.g. Llewellyn, Gething, Kendig, & Cant, 2003), there is a void that appears difficult to fill without seeking to obtain formal guardianship through options such as the Public Guardian (NSW Government - Justice - Public Guardian, 2017b). Mainstream health workers in Australia are often either unfamiliar or uncomfortable in supporting individuals with intellectual disability within general health settings (e.g. Wark, Canon-Vanry et al., 2015; Wark, Hussain et al., 2015) and may therefore seek reassurance or assistance from the disability support worker in decision making during end-of-life. In many instances, this approach may on face value be quite an appropriate one, as the disability worker will often have a comprehensive understanding of both the individual’s needs and also possibly their wishes. However, with the current legislation, it places the disability worker into a legally fraught position.

4.4. Limitations

The study was designed and undertaken with a specific focus on both rural and metropolitan locations in two states of Australia, NSW and Queensland. As such, any comparisons to other settings, even within Australia, should be carefully considered in light of the variations in state-based legislation. It must also be acknowledged that, although it was a deliberate strategy to give voice to staff from rural areas who are under-represented in the literature, the decision to seek greater representation from rural areas resulted in an overall bias towards non-metropolitan respondents. However, no differences between rural and metropolitan participants could be identified in relation to major themes presented in this paper.

This project examined the views of direct care workers regarding the impact of end-of-life on personal relationships. While the focus of the questions were structured around the impact on the individual with intellectual disability, it is clear from the responses that many times the participants were commenting on how the issues affected themselves or other staff, rather than the person. It is worth noting that much of the existing knowledge base around end-of-life care for people with intellectual disability, as with this current project, has been derived from proxy respondents rather than individuals with intellectual disability themselves. It is acknowledged that gaining the direct voice of individuals with intellectual disability, particularly those going through end-of-life, is problematic for many human research ethics committees. As such, this remains a clear gap in the research literature and is an area of need for future research to address.

5. Conclusions

End-of-life has only recently emerged as a priority area for the intellectual disability sector. Little focus has been placed on understanding how people with intellectual disability react and respond during their end-of-life, and how their personal relationships with friends, family and staff may be affected. The current project has provided additional understanding of the issues facing individuals during their end-of-life, but more research is required, both generally about how end-of-life support should be structured, and specifically around supporting individuals experiencing end-of-life to maintain their existing friendships and linkages with their family networks. The issues around the moral judgements of staff on the lack of family involvement during end of life, and the potential distress that this caused, is another area that requires further investigation.

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