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What Constitutes Good Quality End-of-Life Care? Perspectives of People With Intellectual Disabilities and Their Families

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Abstract

Background: Due to increased life expectancy, just as with the general population, people with intellectual disabilities are experiencing, and dying from, chronic and life-limiting conditions. This has led to an increase in the need for end-of-life care for people with intellectual disabilities. However, there is limited evidence as to what constitutes good end-of-life care from the perspectives of people with intellectual disabilities and their family members.

Methods: The study reported here aimed to find out the care needs of people with intellectual disabilities at the end of life in Ireland. A grounded theory approach was employed to explore the perspectives of the participants. After obtaining appropriate ethical approval, 19 semi-structured individual interviews were carried out with 11 people with mild and moderate intellectual disabilities and eight family members to collect data which was subsequently analyzed through constant comparative analysis.

Results: The views of the participants suggested that providing personal care while vulnerable and dying, being with and communicating with the dying person, and meeting their spiritual needs, were considered as being essential at the end of life for people with intellectual disabilities.

Conclusion: The findings from this study have shown that people with intellectual disabilities can engage with those around them and demonstrate how they would like to be cared for, and discuss what would be considered as being good care at the end of life.

Keywords: end-of-life care, holistic care, intellectual disabilities, quality care

Introduction

It is estimated that nearly 6.5 million people in the United States have intellectual disabilities (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011) while in the United Kingdom, the number is around 1.5 million (Mencap, 2019). These numbers are steadily growing, and people with intellectual disabilities are living longer than ever before due to improvements in health technologies and the provision of health and social care services (Emerson & Hatton, 2014). While those with intellectual disabilities are living longer, they are experiencing, and dying from, the same life-limiting illnesses as the general population. These include, for example, respiratory disease, cardiac disease, chronic kidney disease, cancer and dementia (Glover, Williams, Heslop, Oyinola, & Grey, 2017; Ng, Wallén, & Ahlström, 2017). When facing death from such illnesses, they require good quality end-of-life care (Forrester - Jones et al., 2017). Despite this need, the provision of good end-of-life care is sometimes hampered due to a late diagnosis of life-limiting conditions. The delayed diagnosis may be caused by diagnostic overshadowing, multimorbidity,

communication difficulties, and cognitive disability (Tuffrey-Wijne, Bernal, Hubert, Butler, & Hollins, 2009). Furthermore, Todd et al. (2020) reported that the vast majority of deaths within the intellectual disability population are sudden and unexpected. As a result, the time between diagnosis of chronic illness and time of death is often very short; consequently, people with intellectual disabilities and their families cannot produce a care plan and this is challenging for professionals in terms of providing appropriate care at the end of life.

In the United Kingdom, the National End of Life Programme (2011) was implemented to ensure good end-of-life care to people who are dying, including people with intellectual disabilities; however, the Care Quality Commission (2016) reported concerns regarding the provision of quality end-of-life care to this population. Also, Heslop et al. (2013) found that people with intellectual disabilities receive poor end-of-life care when compared with their nondisabled counterparts. The provision of quality end-of-life care to this population is affected by factors such as inadequate resources, the unpreparedness of organizations, late referrals and a lack of collaboratively working with other stakeholders, especially specialist palliative care services (Wark, Hussain, Müller, Ryan, & Parmenter, 2017; Tuffrey-Wijne et al., 2009; Kirkendall, Linton, & Farris, 2019; Bekkema, Veer, Hertogh, & Francke, 2015; McLaughlin, Barr, Sonja McIlpatrick, & McConkey, 2014; Bailey, Doody, & Lyons,

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2014; Ryan, Guerin, Dodd, & McEvoy, 2011; Read & Cartlidge, 2012; Cartlidge & Read, 2010).

Many studies have been carried out to explore how to improve the quality of end-of-life care provided to people with intellectual disabilities, but these have tended to explore the experiences of paid carers and other health professionals (Arrey, Kirshbaum, & Finn, 2019; McCallion et al., 2017; Ryan et al., 2011; Vrijmoeth et al., 2016). These studies have shown that professionals experience difficulties in meeting the end-of-life care needs of people with intellectual disabilities, often failing to understand their needs. Also, it has been suggested that establishing communication with those with intellectual disabilities, the emotional and physical impact of providing care, and dealing with family members, are considered as being challenges faced in delivering good end-of-life care. Research has suggested that people with intellectual disabilities have differing perspectives from their proxies. For example, Koch et al. (2015) and Schmidt et al. (2010) reported that people with intellectual disabilities recorded their quality of life at a higher level than their proxies. Further, Scott and Haverkamp (2018) found that people with intellectual disabilities provided higher ratings than their proxies regarding the support they received from their friends. Given the divergence in terms of perceptions of people with intellectual disabilities when compared to their proxies, it is important to capture the perspectives of those with intellectual disabilities as to what they think good quality care is at the end of life.

Studies carried out among the general population have suggested that good end-of-life care consists of many factors such as the timely planning of care, initiation of early palliative care, effective pain and symptom management, good coordination of care, where the care takes place, and the place of death (Bamford et al., 2018; Estabrooks et al., 2015). Even though the concept of good care is fluid and highly complex, perceptions of service users and their family members are taken into account and considered as another indicator of quality, and these can be successfully used to shape policy and service delivery (Gonella et al., 2019,b; Gott et al., 2019). This extends to people with intellectual disabilities and their family members; however, there can be assumptions and paternalistic leanings from professionals, and family members can view talking about death and dying in relation to people with intellectual disabilities as a taboo and sensitive topic. Therefore, their views are not well-known; instead, the opinions and perceptions of professionals and carers have received more attention. However, there are good examples available from the research where people with intellectual disabilities have been willing to discuss death, dying and care needs at the end of life (Tuffrey-Wijne, 2010). Therefore, the central question driving this study was what people with intellectual disabilities and their family members believed was good care at the end of life for people with intellectual disabilities.

Methods

The study aimed to understand what constitutes good care at the end of life for people with intellectual disabilities from the perspectives of both those with intellectual disabilities and their

families. In order to achieve this, perceptions and views were explored from 11 people with mild and moderate intellectual disabilities and eight family members in an intellectual disability service that provides residential and community care to people with intellectual disabilities in Ireland. This study adopted a grounded theory research design and was ethically approved by an academic institution and research site.

Setting and Sample

The sample was drawn from an intellectual disability service which provides residential and community services for adults with an intellectual disability. This service was chosen as it provides care for adults with varying degrees of intellectual disability. This service provides care for 150 residential adults with intellectual disabilities and nearly 185 adults with intellectual disabilities who live with their family in the community. This service is part of the National Health Service Executive (HSE), and its catchment area is the north side of Dublin.

After obtaining ethical approval from both a university and a research site, potential participants with intellectual disabilities were approached through nurse managers in each unit. Following approval from the managers, a group discussion was held with prospective participants in order to explain the study. After the meeting, easy-to-read information sheets containing information regarding the nature and purpose of the study were left with them. After two weeks, the first author met with the participants, and their interest in participating was noted and a date, time and venue for an interview was agreed. In this study, only people with a mild or moderate intellectual disability were included. While we fully acknowledge the importance of the views and perspectives of those with profound and severe learning disabilities in terms of shaping health-care provision, we were unable to include this population due to ethical, methodological, and time issues. Instead, we included their family members so that they could advocate for their needs. Some researchers have cautioned that people with intellectual disabilities disagree about their health needs and well-being when compared with their proxies (such as their carers and family members) (Cummins, 2002; Simõesa & Santosb, 2016). Despite this warning, Verdugo, Schalock, Keith, and Stancliffe (2005) have stressed that when people with intellectual disabilities, particularly at a severe or profound level, cannot articulate their needs then their proxy's views are the best alternative.

Participants for this study were initially purposively selected with strict inclusion and exclusion criteria to reflect the diversity of the participants in order to explore the views of people with intellectual disabilities and their family members regarding end-of-life care needs. People with mild or moderate intellectual disabilities, who were able to articulate their views and engage in a conversation, who were over 40 years old, and were able to provide informed consent, and family members of people with intellectual disabilities whose adult children or relatives receive care from the service, were included. The level of intellectual disability of the participants was assessed and recorded by the service; however, their capacity to participate in the study was also independently assessed. It was agreed by the research panel to include people with intellectual disabilities who were 40 years

TABLE 1
Profile of person with intellectual disabilities

Name	Age	Nationality	Level of intellectual disability	Living arrangement
Conor	56	Irish	Mild	Independent living
Sean	51	Irish	Moderate	Supported living
Jack	54	Irish	Mild	Independent living
Aoife	52	Irish	Moderate	Supported living
Sarah	65	Irish	Moderate	Supported living
Ciara	67	Irish	Moderate	Supported living
Rebecca	72	Irish	Mild	Independent living
Lauren	63	Irish	Moderate	Supported living
Katie	67	Irish	Mild	Independent living
Emma	63	Irish	Moderate	Supported living
Rachel	58	Irish	Mild	Independent living

TABLE 2
Profile of family members

Name	Age	Sex	Status
James	72	Male	Father
Adam	68	Male	Father
Michael	81	Male	Father
Emily	49	Female	Sister
Nicole	62	Female	Mother
Roisin	71	Female	Mother
Tara	65	Female	Sister
Eimear	62	Female	Mother

old and above as they may have some experience of witnessing death and dying and be able to construct some insights regarding best care at the end of life. Therefore, the research panel agreed to set the age limit at 40 and above. People with intellectual disabilities and family members who had suffered bereavement during the previous six months, people with intellectual disabilities who could not verbalize, and people with intellectual disabilities and family members who were unwilling or unable to give informed consent, were excluded from this study. Ultimately, we recruited 11 people with intellectual disabilities and eight family members. Table 1 shows the profile of participants with intellectual disabilities and Table 2 shows the profile of the family members.

Ethical Issues

Informed consent was obtained from each participant. In order to obtain informed consent from those with an intellectual disability, an easy-to-read version of the information leaflet and consent form was developed which contained information regarding the study, the expectations and rights of participants, and the data collection process. Their right to confidentiality and to remain anonymous was respected, and support was

offered in the form of a counseling service if any of the participants felt upset as a result of the contents of the interview.

Data Collection

Data collection commenced with two pilot interviews with people with intellectual disabilities to ensure that high-quality information was collected, but these data were not used in the final sample. The pilot was a beneficial exercise as it led to the interview guide being modified and refined based on feedback before the commencement of the actual data collection. The first author collected data through conducting in-depth, one-to-one semi-structured interviews with each individual. The interviews each lasted for 40–60 minutes. Overall, 19 participants, including 11 participants with an intellectual disability and eight family members, were included. Out of 11 participants with intellectual disabilities, six of them were present at different times over the course of their friends or housemates dying and observed the care received at the end of life. The remaining participants were familiar with deaths that others around them had experienced. The family members had some knowledge about elements of end-of-life care through their experiences of providing care to, or witnessing the receiving of care by, their relatives.

A semi-structured interview guide and prompts were used during interviews. The interview guide was originally constructed by reviewing important literature, and having discussions with colleagues who had been involved in providing end-of-life care as well as the research team. The interview guide was then modified based on the information gathered from participants. The interview guide covered physical, social and spiritual care, pain and symptom management, place of care and place of death. Participants with mild intellectual disabilities demonstrated an understanding that end-of-life care is when somebody has a disease that cannot be cured and they will die soon but they are unaware of the time frame. However, it was emphasized to them that end-of-life care is the care that is provided to someone who may die in a year's time. While interviewing people with moderate intellectual disabilities, initially the contents in the interview guide were discussed. Then, to

facilitate the conversation, a story from the book *Am I Going to Die?* (Hollins & Tuffrey-Wijne, 2009) was narrated. In this story, the character John is terminally ill and the story sensitively discusses the physical decline, social connectedness, emotional attachment and spiritual aspects of his dying. As John gets weaker, he reflects on his life and chooses how to spend his remaining time. The story explains the importance of going on special outings, remembering good times, and saying proper goodbyes to family and friends (Hollins & Tuffrey-Wijne, 2009). The story was briefed to them and questions were raised from it (including, for instance, questions around what good care was, and how they should be looked after, etc.) in order to facilitate their thinking (Aldridge, 2007; Booth & Booth, 2004).

The information they provided was based on what they had seen or likely accounts of what they would consider as necessary to make someone comfortable at the end of life. The family members were interviewed with an interview guide which encompassed a number of concepts, as well as their experiences and views. Prompts were used to explore further their responses to the understanding of care needs at the end of life. All interviews were voice recorded and were then transcribed verbatim. Names were removed, and pseudonyms were created to ensure anonymity and confidentiality. Data were analyzed as it was collected. While analyzing the 18th interview, it was found that there were no new insights being generated; however, it was decided to still conduct the 19th interview with the aim of exploring further understanding. However, the new data rendered neither fresh insights nor expanded on existing concepts. As a result, data collection was ceased and it was assumed that the data had been saturated.

Data Analysis

The data were analyzed by using constant comparative analysis (Charmaz, 2014). In keeping with the principle, emerging codes and categories were always compared and contrasted against the data, codes, and categories that had emerged. To ensure consistency and reduce bias, the first three interviews were analyzed by three authors. This analysis was then compared and discussed, and findings were agreed on. After the third interview, the first author analyzed the data but was overseen by the other authors. Throughout the process, the first author had regular discussions with the other authors regarding each stage of the data analysis including coding, developing themes, and looking at the relationships between them, and received feedback from the other authors. Eventually, the findings were agreed upon through explicit discussion between the authors.

Findings

The data analysis identified three key thematic areas. These thematic categories included “personal attention,” “social connectedness,” and “spiritual reconciliation.” These are discussed in turn below. To protect the confidentiality and anonymity of the individual participants, all potentially identifiable

information has been removed and pseudonyms have been used for the quotes.

Personal Attention

People with intellectual disabilities, toward the end of their lives, require close supervision because they tend to be vulnerable and unable to look after themselves. One concern expressed by participants was the surrendering of their independence due to a decreasing ability and capacity to look after themselves, combined with an increasing demand for care towards the end of life. It is perceived that people become fragile and lose their physical and mental capacity towards the end of life. The theme of personal attention constitutes two sub-themes: physical care and vigilant monitoring.

Physical care. People with intellectual disabilities believed that decreased mental and physical capacity due to progressive illness, combined with increased care demands towards the end of life, forces them to physically rely on others, especially their carers, to fulfill their needs. This reliance in terms of care is based on the hope and expectation that carers will provide optimal care toward the end of life. Many participants acknowledged that toward the end of their life, they would be physically dependent on other people to maintain their everyday routine, which can include bathing, brushing their teeth, managing incontinence and feeding. This also includes medical care assistance, such as receiving tablets and tube feeding. Therefore, the expectation of receiving physical care was one of the concerns related to dying for people with intellectual disabilities.

Participants agreed that some people with intellectual disabilities have multiple disabilities including sensory and physical difficulties; therefore, carers should ensure that they are well looked after and that they are treated equally to everyone else. Some people, especially those who have severe and profound intellectual disabilities, have complex problems and cannot interact with carers and communicate their needs; therefore, they are highly reliant on carers identifying and providing appropriate care. As one participant described:

Some people here have no speech and cannot hear, so we should be giving them more care than everybody else. The people who are dying should be looked after, by bathing them, feeding them, giving them plenty of fluids. I want them to be looked after as much as possible and care for them as everybody else. They all need attention. All I want to say is the people like us should be looked after well.
(Rebecca, a person with an intellectual disability)

There are people with intellectual disabilities who do not have family members available to assist with their care; therefore, this population depends totally on professional carers for all of their needs. Also, sometimes they have no contact with their remaining family members once their parents have died because their siblings are reluctant to participate in their care. The result can be that some people with intellectual disabilities feel isolated and abandoned:

Sick and dying people with special needs can't talk, eat, and walk. We have to feed them, help them to walk. They should be looked after all the time. They have nobody, only nurses and carers to look after them. (Sarah, a family member)

People with intellectual disabilities at this juncture require both professional assistance and the help of those they live with. It is possible that professionals can transfer skills or “up-skill” others who are living with people with intellectual disabilities in order for them to be involved in the caring process and help care for their friends. This was highlighted by one participant:

Other people can show how handicapped [sic] people are looked after and other people can keep an eye on them, say like other people who live in the house. (Conor, a person with an intellectual disability)

People with intellectual disabilities, in this study, believed that participation in everyday activities, inclusive of dying, is a part of life that they want to engage in. Most households in the general public would have members who were there and able to help dying people. Therefore, this kind of help could occur in houses where people with intellectual disabilities live also. Thus, the study found that people with intellectual disabilities would be proud to help and care for their friends during this process. They perceived and recognized the importance of their peers being involved in their care and also felt it would be an honor to help their friends at the end of their lives.

Vigilant monitoring. People with intellectual disabilities, toward the end of their lives, require close supervision because they tend to be vulnerable and unable to look after themselves. During interviews, it was suggested that people should check on a person with intellectual disabilities at the end of life around the clock in order to make sure that they are safe:

Sick people need other people to check on them all the time, 24 hours a day. They have to check on them to see how they get on to make sure they are safe. (Conor, a person with an intellectual disability)

It was a common expectation from all participants that regular attention should be received from carers in order to provide a sense of safety and security, and that this was more important for people with intellectual disabilities as they were vulnerable and had complex needs. The people with intellectual disabilities believed that they, sometimes, could not express what they wanted and could not look after themselves; therefore, close attention from professional carers was crucial near the end of life:

Regular attention should be given to these people. That will be very, very important. I suppose myself, if I was bed-ridden, these are the things I will be looking for. This will give them a sense of security and safety; when you know somebody is sick and dying leave them alone to spend time on their own. (Eimear, a family member)

People with intellectual disabilities felt that help from nurses and doctors toward the end of life was very important. Indeed, the roles played by professionals in monitoring and providing support nearing the time of death was highly acknowledged. At the same time, they suggested that some people with intellectual disabilities preferred to be left alone, away from their family members and friends, to spend time on their own. It was their belief that dying people need to have a balance between being left alone, thinking about and cherishing events from their past while coming to terms with their present, and spending time with their friends and relatives in order to meet their current social needs.

Social Connectedness

Participants in this study felt that maintaining social connection was very important to help people with intellectual disabilities to maintain their self-worth and self-identity. It was their perception that social connectedness, or being with other people, preserved their self-identity and made them comfortable and happy. They also felt that, when nearing death, carers and professionals sometimes avoided the dying person because they had a fear of staying and making conversation with them. The dying person would then subsequently feel isolated and neglected. The theme of social connectedness constitutes two sub-themes: meaningful companionship and maintaining communication.

Meaningful companionship. Being in the company of people who love and care about them is very important for people with intellectual disabilities near the end of their life. They recognized that the simple act of physically touching, such as holding hands, provides a close personal message that makes people feel connected when they are nearing death, especially if language or verbal communication becomes an issue. It is evident from this study that people need love and companionship at the end of life. A lack of physical companionship creates feelings of isolation, neglect and desertion and most participants with intellectual disabilities stressed the importance of companionship, particularly when a person is nearing death. Physical isolation is difficult, and it can lead to feeling frightened and uncertain. As one participant explained:

Somebody who knows them should stay with dying people, sit with them and speak with them. If possible, people can stay with them some more time. (Conor, a person with an intellectual disability)

It was the expectation of people with intellectual disabilities that they would stay with somebody who they were comfortable with. They would, therefore, enjoy spending time and sitting with them, and this would give people with intellectual disabilities the reassurance and comfort that they may be craving. Being with somebody may provide a feeling of connectedness. Talking and sitting with people with intellectual disabilities toward the end of their life provides them with reassurance, and the act of holding hands provides hope and comfort. It is evident from this study that the participants who had an

intellectual disability wanted to have meaningful companionship with other people at the end of their life. It was also directly suggested that the act of touching during end-of-life care brings an emotional closeness and provides reassurance:

Stay with them. Talking to them, being with them, holding their hands. Visits from their own people like parents, uncles and friends. People should spend time with dying people and stay with them. Being with them and holding their hands will give lots of messages to them, even if they don't speak to them. (Sarah, a family member)

The participants perceived that the company of friends and family was essential, even in the absence of verbal communication, and that a physical presence towards the end of life was very important. It was found from participants' views that good care towards the end of life for people with intellectual disabilities consists of friends, parents, and carers staying with the person and providing them with support. It is their belief that some people who are in long-stay settings have no family; therefore, staff need to stay with them. There is a need for someone to stay with the person who is going to die in order to speak to them, hold their hands, and reassure them that people are there for them. Ideally, the dying person should be in a separate room, and people can go in and out to see them. This will ensure their privacy and comfort.

Maintaining communication. Talking to people with intellectual disabilities at the end of life was thought to be very important as it created a feeling of comfort. This was the expectation of people with intellectual disabilities, and they held the view that talking to dying people is essential as people with intellectual disabilities, most often, want to talk about what matters to them, including their concerns and feelings:

Talk to them, you know what I mean? We have to talk to them and let them know that we are here for them. If they are very sick, give them tablets, you know?... If they are dying, there is nothing more we can do. Talk to them. People should stay with him, speak to him; this will give them comfort. Sit with him, you know? The people come to him. (Ciara, a person with an intellectual disability)

The people with intellectual disabilities expected that professionals should listen to those with intellectual disabilities near the end of life as this would give them hope, and provide them with an opportunity to ask questions, seek clarification, and share concerns about their care. There was a preference for the participants to have a conversation with family members, friends or care providers. It is a reasonable expectation from people with intellectual disabilities that they are able to have a conversation, especially when they are ill and dying:

People should be at peace and happy in their last days of life. We have to look after the dying people well. You know what I mean? We have to talk to them, I think that makes the person happy, and sit with them, you know? Staff are wonderful to the dying people, you know? I think everybody

has to do his or her own part. (Rachel, a person with an intellectual disability)

Spiritual Reconciliation

Providing spiritual care near the end of life is as essential as any other type of care as this will help the dying person to find meaning in their life and, if possible, to reconcile disagreements with others and the self. The dying person may find peace by resolving and ending unsettled business with their friends or family. Such resolution can be achieved through receiving visits from a social worker, counselor or any other person whom the dying person trusts. In this study, participants with intellectual disabilities expressed their spirituality through religious faith, such as believing in God and using prayer. This may be due to the participants coming from a Catholic background and from a country in which the role of the Catholic church and faith is still hugely important. The theme of spiritual reconciliation consists of two sub-themes: suggesting solace and seeking prayers.

Suggesting solace. The study findings suggest that praying for dying people with intellectual disabilities at the end of life provided hope and brought peace to the dying person, and there was a firm belief among them that being with, and praying for, dying people was very important:

Pray for the dying people and be with them. It is important, and this will give them hope and peace. This is one of the ways to connect with God. (Michael, a family member)

Saying prayers was viewed as being the last thing that anyone could do for a dying person, and it was suggested by the participants that praying and caring for the person who is dying brings comfort. They felt that praying for a dying individual, along with caring for them, provides spiritual comfort and reduces agitation and anxiety. People with intellectual disabilities recognized that prayer was the only act which others could carry out for a dying person, and it was believed that prayers gave the dying person peace:

Talk to them, you know what I mean? We have to pray for them, if anybody dies, and pray for them. This is the only thing we can do for them. This will help them to be in peace. (Lauren, a person with an intellectual disability)

The participants believed that prayer has a unique power that brings psychological comfort, peacefulness, harmony and optimism to the dying person, and that this is the only hope when everything else fails. It was evident that people with intellectual disabilities expected to have spiritual comfort at the time of death, and they believed that saying prayers was one of the ways of achieving this.

Seeking blessings. Achieving a sense of inner peace before death was found to be important to most people with intellectual disabilities. They believed that reconciliation with God,

other people, or within themselves, was important in order to resolve conflict either with other people or within themselves. Consequently, they assumed that this was one of the best ways to achieve inner peace before dying. Resolving conflict and achieving inner peace was found to be one of the spiritual needs of participants towards the end of life. One participant stated that having a priest at the time of dying, and asking him to bless the dying person, would lead to that person feeling happy and peaceful. Thus, they directly suggested that the dying person should be anointed and blessed by a priest:

Bring a priest in and ask the priest to bless the dying person. It may make the sick people happy and give them peace. Let me think...the person should get anointed. The priest should come and bless the person. (Conor, a person with an intellectual disability)

People with intellectual disabilities perceived that blessings and prayers from a priest could make the dying person comfortable and peaceful. The findings suggested that blessings from a priest would help to absolve the sins which people had committed during their lives, and that dying people should find a way to resolve conflict with others. As another participant demonstrated, it was an expectation that a priest should talk to and bless the dying person:

Any person who is dying, the priest is always coming with you. They stay with the person who is dying and bless him all the way through and talk to him. (Ciara, a person with an intellectual disability)

Thus, the study found that a priest or another member from an individual's religious faith should bless a person with intellectual disabilities who is dying.

Discussion

This article sought to explore elements of good care for people with intellectual disabilities at the end of life from the perspectives of both those with intellectual disabilities and their family members. It is evident from the participants' perspectives that providing physical, social and spiritual care are considered as being some of the elements of good care at the end of life for people with intellectual disabilities. As the data suggest, a person-centred approach to end-of-life care would allow people with intellectual disabilities to receive optimal care. Participants in this study expected to receive good physical care, due to a perceived and increasing loss of their physical abilities, and they placed particular emphasis on personal care. McPherson, Milligan, and Stevens (2020) found in their study among a general population that the provision of personal care and making life as normal as possible are regarded as being important at the end of life.

Participants with intellectual disabilities in this study expected to have a "real presence" of other people when they are dying. They suggested that this could be achieved through touch, gaze, a lingering presence, and silent immersion. They also expressed how listening was a way of responding to the needs of people at the

end of life, as they perceived that it was akin to relaxing and chatting with others, which provided comfort and reduced psychological distress. Todd, Bernal, and Forrester-Jones (2013) highlight the importance of being with and providing a real presence for people with intellectual disabilities who are dying. They believe that this promotes a tremendous unintentional inter-human relationship, as well as unconditional loving, and witnessing the changing needs of the dying person and their family.

The participants in this study highlighted the importance of having other people present when a person is suffering; comfort can be conveyed through holding their hands and being with them. Lopes Verissimo and Cruz-Pontífice Sousa (2014) and Nicholls, Chang, Johnson, and Edenborough (2013) found in their studies that people who are dying wanted to have a conversation with others and this was a necessary part of understanding their emotional and mental state. Todd et al. (2013) believe that being with, rather than doing things for, a dying person promotes a good death. Therefore, professionals need to understand the relationship between the dying person and their friends and family so that they can improve care for the dying person.

The studies conducted by Koper, Pasman, Schweitzer, Kuin, and Onwuteaka-Philipsen (2019) and Nelson-Becker et al. (2015) found that understanding spiritual distress and responding to spiritual needs at the end of life is essential. The findings in this study acknowledged the importance of spiritual care at the end of life and assumed that the act of praying could bring hope, comfort, and strength. Spiritual care helps a dying person to find meaning in their life's events and have a sense of connectedness and feelings of transcendence (Lee & Ramaswamy, 2020; Rhodes, Batchelor, Lee, & Halm, 2015). In this study, both participants with an intellectual disability and their family members had a clear understanding of religious spirituality, such as saying prayers and receiving blessings, and this was reflected throughout their conversations. They may have acquired this kind of religious spirituality due to their strong affinity with Catholic beliefs and religious observation. Carter and Boehm (2019) agreed that people with intellectual disabilities express their spirituality through prayers, scripture reading, devotion and fasting as they believe this will help them to connect with it.

Consistent with existing literature, including Benito, Gomis, and Barbero (2016), Van der Steen, Gijsberts, Hertogh, and Deliens (2014) and Balboni et al. (2014), the findings of the current study indicated that spiritual care was a crucial aspect in end-of-life care which helped to maintain the physical, social, and psychological health of the dying person. These findings also reflected those of McDonald, Murray, and Atkin (2014) and Payne (2014), who found that praying and meeting the spiritual needs of dying people is necessary at the end of life in order to prevent dying people from suffering spiritual pain. Despite the importance of providing spiritual care at the end of life, Balboni et al. (2014) and Ronaldson, Hays, Aggar, Green, and Carey (2012) reported that a lack of available time, inadequate private space, and lack of training and education, were barriers to providing spiritual care to patients at the end of life.

Good care at the end of life incorporates many elements for people with intellectual disabilities. Professionals and family members consider good care as providing comfortable care, assessing and managing pain and other symptoms, assisting in

making decisions, considering the place of care, place of death, and spiritual care (Bekkema et al., 2015; McCarron, McCallion, Fahey-McCarthy, & Connaire, 2010; Segerlantz, Axmon, & Ahlström, 2020). It has been expressed how in the general population, facilitating maximum independence, providing comfort, and helping to minimize suffering are commonly acknowledged as being good care aspects at the end of life (Kisvetrová, Klugar, & Kabelka, 2013; Kastbom, Milberg, & Karlsson, 2017). Virdun, Luckett, Davidson, and Phillips (2015) further acknowledged that the timely involvement of patients and their families in end of life discussions and care planning, as well as responding to dying patients' emotional needs, are crucial at the end of life. As with previous research, the findings from this study suggest that care providers should focus on developing more patient-centred interventions to meet physical needs that promote comfort, address social difficulties and keep patients connected, and consider spiritual concerns at the end of life.

Strengths and Limitations

In terms of the strengths of this study, first, it included the perceptions and views of people with intellectual disabilities regarding the care needs of this population at the end of life and is the first of its kind within Ireland. Second, this study adopted a qualitative approach that helped to capture the views, opinions, and perceptions of people with intellectual disabilities in relation to their own care needs and provided an opportunity for them to express these. During the interviews, a few people with mild intellectual disabilities briefly stopped talking and then recalled the deaths of their friends or family members. They were given support and continued the interview once they had confirmed that they were happy to proceed. The participants with intellectual disabilities demonstrated how they were happy to engage in conversations about death and dying. The methodological issues are discussed in a separate paper (Cithambaram, Duffy, & Courtney, 2019). They felt that this kind of conversation helps to develop best practice guidelines that will eventually improve the quality of care which they and their peers receive.

It is also acknowledged that there are some limitations to the study. First, findings from this study cannot be generalized due to its small sample size and limited geographical location; however, the findings from this study have contributed to existing knowledge. Second, although this study included the voices of people with a mild or moderate level of intellectual disability, it excluded people with severe and profound intellectual disabilities. However, to redress this, their family members were included. Third, some individuals with intellectual disabilities who were living with their family members could not be included as their family members were not willing to let their loved ones participate in this study. This was due to their family members feeling that the conversation would be very sensitive and may upset them. Fourth, the participants with intellectual disabilities who shared their views in the study were not receiving end-of-life care but they had witnessed their friends or housemates or family members receiving end-of-life care. Therefore, the views and opinions shared in this study may not have reflected actual experiences but are a true reflection of how

participants felt when their friends, housemates or family members suffered. Finally, this study missed an opportunity to include the perceptions of professionals, especially nurses; their views are also important in terms of deciding on what good care would be for people with intellectual disabilities at the end of life.

Implications for Practice and Research

In this study, participants with intellectual disabilities have directly discussed what they would consider to be good care at the end of their lives; consequently, this will help ensure that they receive excellent care at the end of life. Furthermore, the findings discussed here will help inform policy makers and professionals who are directly involved in providing end-of-life care to develop a plan to improve the care provided. In relation to further research, a large study that includes people with intellectual disabilities, their family members, and relevant professionals, should be carried out across multiple settings. Also, further research could be carried out with people with intellectual disabilities who are at the end of life phase examining the impact of the articulation of spiritual care expectations at the end of life; this would create interesting findings.

Conclusion

This study has found that, as with most individuals when considering the end of life, progressive physical and functional decline and the surrendering of independence were concerns for people with intellectual disabilities. In addition, some people with intellectual disabilities have multiple disabilities with complex needs and, therefore, they also require comprehensive physical care. The research also found that populations which include people with intellectual disabilities expect to be socially connected with other people when approaching death, including via physical and psychological companionship, and to be able to engage in meaningful conversation. The study also confirmed that spiritual care at the end of life provides peace and comfort to people with intellectual disabilities.

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