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Disclosure and plan of care at end of life: Perspectives of people with intellectual disabilities and families in Ireland

Kumaresan Cithambaram1 | Mel Duffy2 | Eileen Courtney2

1School of Nursing and Midwifery, Medical Biology Centre, Queen’s University Belfast, Belfast, UK
2School of Nursing, Psychotherapy and Community Health, Dublin City University, Dublin, Ireland

Correspondence
Kumaresan Cithambaram, School of Nursing and Midwifery, Medical Biology Centre, Queen’s University Belfast, 97, Lisburn Road, Belfast, Co. Antrim, Northern Ireland BT9 7BL, UK.
Email: k.cithambaram@qub.ac.uk

Accessible summary
- Professionals are reluctant to discuss sensitive information with people with intellectual disabilities.
- People with intellectual disabilities and families wish to engage in end-of-life discussions.
- People with intellectual disabilities expressed how they could handle bad news and they felt that this information could be used to help make choices.
- People with intellectual disabilities and families want to develop a plan based on their choices and wishes and there is a need to respect this at the end of life.

Abstract
Background: Recently, more and more people with intellectual disabilities have been dying from life-limiting conditions, and on many occasions, people with intellectual disabilities have not been informed of this. There is limited evidence concerning the views and opinions of this cohort regarding the information that is needed in order for decision-making to occur at the end of life. Therefore, this study aimed to explore the perceptions of people with intellectual disabilities and families in terms of the information that is needed as part of end-of-life decision-making.

Materials and Methods: A qualitative approach was employed to explore the information needed by, and the decision-making ability of, people with intellectual disabilities at the end-of-life phase. One-to-one interviews were carried out with nineteen people following the obtaining of ethical approval. The constant comparative method was used to analyse the data.

Results: It was found that people with intellectual disabilities were comfortable with, and wished to know about, what was happening in their lives, including the existence of life-limiting conditions, so that they would be able to create a good plan for their future care. It was also expressed how it was essential to create a plan of care that allowed professionals to provide excellent care and use of which prevented the occurrence of any ambiguity.

Conclusions: The study found that people with intellectual disabilities, especially those with mild and moderate, are able to handle complex and sensitive information...
1 | INTRODUCTION

In recent decades, the life expectancy of people with intellectual disabilities has increased due to improvements in the provision of health and social care (Glover, Williams, Heslop, Oyiniola, & Grey, 2017; Heslop & Glover, 2015). Due to their increased lifespan, it can be seen how people with intellectual disabilities similarly suffer from many health problems and die of the same life-limiting illnesses as experienced by their nondisabled ageing counterparts. Such illnesses include respiratory disease, circulatory disease, cancer and dementia (O’Leary, Cooper, & Hughes-McCormack, 2018). As they are dying of the same life-limiting illnesses as experienced by the general population, people with intellectual disabilities also require the same end-of-life care that the rest of the population are being provided with (Coppus, 2013; Tuffrey-Wijne et al., 2016). Furthermore, it must be pointed out that during such an uncertain time, effective communication is essential between patients, family members and service providers in order to improve the quality of care provided at the end of life (Anderson, Bloch, Amstrong, Stone, & Low, 2019; Brinkman-Stoppenburg, Rietjens, & van der Heide, 2014). Also, such conversation helps people with intellectual disabilities understand their clinical situation, decide what kind of care they require, and how they wish to plan towards the end of their life (Ryan, Guerin, Dodd, & McEvoy, 2011; Wagemans et al., 2015). In addition, the plan developed from this conversation helps to reduce the anxiety of people with intellectual disabilities and minimise their stress alongside lowering costs for service providers by reducing unnecessary interventions (Codling, Knowles, & Vevers, 2014; Wiese, Stancliffe, Read, Jeltes, & Clayton, 2015). However, previous research has shown that professionals are reluctant to have an end-of-life discussion with people with intellectual disabilities (Bekkema et al., 2014; Ryan et al., 2011; Watson, Voss, & Bloomer, 2019), despite the ability of the latter to complete an end-of-life care plan (Stancliffe, Wiese, Read, Jeltes, & Clayton, 2017).

Research has found that an early discussion regarding illness among people with intellectual disabilities is an essential tool for providing excellent medical and nursing care, and this is especially important when providing end-of-life care (Dunkley & Sales, 2014). However, often professionals struggle to communicate with a dying person with intellectual disabilities, or their family members, due to cultural prejudices, the individual’s complex clinical conditions, and a lack of knowledge and skills regarding how to hold such a conversation (Sue, Mazzotta, & Grier, 2019). Furthermore, despite patients’ evident willingness to know about, and to be able to familiarise themselves with, their clinical issues, family members often act as a communication channel between patients and physicians. Some of the parents are willing to expose their loved ones through dying experiences; however, this depends on the parental motivation (McMaugh, Wiese, & Stancliffe, 2017). As a consequence of this, they may be passing selective information to patients and controlling what they feel a person with intellectual disabilities should and should not know (Lee et al., 2015). This is due to a fear from family members that their loved ones may suffer from anxiety and depression when made fully aware of their clinical condition. Ultimately, it can be seen how there is a lack of evidence as to what kind of information people with intellectual disabilities require at the end of life, as well as an understanding of how they use this information in order to make an appropriate decision regarding the receiving of good quality care at the end of life.

2 | METHODS AND MATERIALS

2.1 | Aim

The study aimed to illustrate the accounts of people with intellectual disabilities and families regarding the need for information and decision-making at the end of life. An explorative qualitative research design was used to explore the views and perceptions of people with intellectual disabilities and families of people with severe and profound intellectual disabilities regarding the end-of-life communication and decision-making.

2.2 | Setting and sample

The study was carried out in an intellectual disability service, which provides care for people with intellectual disabilities in both a residential and a community setting. A purposive sample of eleven people with mild and moderate intellectual disabilities, and eight family members of people with severe and profound intellectual disabilities were identified through communicating with managers of the intellectual disability service. After gaining ethical approval, people with intellectual disabilities were contacted through unit managers, and a group meeting with potential participants was held in different locations. At the end of each session, clear information was provided by reading out an easy-to-understand information sheet in order to promote a better level of awareness for each participant. Finally, an invitation letter was provided to potential participants with intellectual disabilities, which they were asked to complete and give to their manager if they were willing to participate in the study. The managers were not involved
in the study, did not discuss the study with potential participants and were not made aware of the identity of any participants. This was to reduce the coercion or demand effect a person with intellectual disabilities may feel if the manager was involved in the study. After a week, the invitation letters were collected from each unit. Following this, those who indicated a willingness to take part in the study were contacted via telephone, and times and venues for interviews were arranged. To recruit family members of people with severe and profound intellectual disabilities, a letter containing information about the study, participant acceptance card and pre-paid self-addressed envelope was given to the managers of each unit and asked them to send it to the family members. Then, the family members who expressed an interest in participating were contacted, and time and venues for interviews were arranged. The participants involved in this study were not receiving end-of-life care; however, some participants witnessed their friends and loved ones receiving end-of-life care. The information they provided was based on what they had seen or likely account of what they would consider as necessary concerning disclosure and decision-making. The participants’ profile is included in Tables 1 and 2.

2.3 | Ethical issues

The study received ethical approval from the university’s Ethics Committee and approval from the research site. Participant autonomy was upheld by providing accessible information and obtaining informed consent, while anonymity was protected by assigning pseudonyms. Participants were also given reassurance, with support being provided and referrals being available to a free counselling clinic should that have been required after a sensitive discussion had taken place.

2.4 | Data collection and analysis

Before commencing the data collection, participants’ queries were addressed, and informed consent was obtained. In order to aid understanding, an easy-to-read consent form with a pictorial explanation was used for people with intellectual disabilities. Participants were selected with strict inclusion and exclusion criteria, as follows in Table 3.

Data were collected through individual face-to-face semi-structured interviews from participants by using an interview guide, and on average, each interview lasted between 30 and 45 min. The interview was audio-recorded and was discontinued when the information being collected failed to provide any new insight or help with expanding the existing concept. During the interview, participants were asked about the information which they felt they needed at the end of life, the purpose of such information and how they would utilise it. The data were transcribed and analysed through the use of constant comparative data analysis, as advised by Charmaz (2006). Two interviews were independently analysed between the authors, and a coding frame was developed: this includes initial coding and focused coding. Subsequently, the remaining interviews were analysed by the first author by adopting the coding frame. During this process, the first author met regularly and discussed each stage of the data analysis, including coding, development of themes and relationships between them with other authors and received feedback. Finally, the consensus was achieved through explicit discussion among authors.

3 | FINDINGS

The data analysis produced a broad theme, which reflected how information and communication, as provided by professionals, helps people with intellectual disabilities to understand their clinical situation.

3.1 | Making a plan

Within this study, people with intellectual disabilities and families highlighted the importance of developing a plan that would help them receive good end-of-life care. They also discussed how they valued the communication which they received from professionals as this would help them to make appropriate decisions and devise a

| 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 |

| 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 |
### TABLE 3 Inclusion and exclusion criteria

| Inclusion criteria                                                                 | Exclusion criteria                                                                 |
|-----------------------------------------------------------------------------------|-------------------------------------------------------------------------------------|
| People with mild or moderate intellectual disabilities, who can articulate, are able to engage in a conversation, are aged over 40 years and are able to give informed consent to participate in the study | People with intellectual disabilities who cannot verbalise and were unwilling to give informed consent |
| People with intellectual disabilities who receive services from the specific service provider | People with intellectual disabilities who have suffered bereavement in the last six months |
| Family members of people with profound and severe intellectual disabilities whose relatives receive services from the specific service provider | Family members of people with intellectual disabilities who have suffered bereavement in the last six months |

plan. This overall theme consists of two subthemes, which include “Decision-making through communication” and “Plan ensures good care,” and these will be further discussed below.

#### 3.1.1 Decision-making through communication

It was found within the research that people with an intellectual disability felt that care providers should establish communication with them regarding what they are experiencing. This is imperative as it could help them make a number of crucial decisions in relation to their caring process. There was also an expectation that care providers should listen to them and respect their wishes. It was also discovered that people with mild and moderate intellectual disabilities are willing to be openly aware of their diagnosis and the consequences of this, thus enabling them to make a plan in terms of their day-to-day activities. They assumed that knowing about their clinical condition and the caring process was not only their right but could also help to predict their future:

> *People like us should know what is happening to us because... we have choices to make like... where to die, how to die, how to be buried. Yah... the person who is dying should know everything and people should let them make choices. Listen to them and we should do whatever they ask.*

(Conor, a person with intellectual disability)

The participants expect that the professionals have a responsibility and are obliged to inform people with intellectual disabilities about their clinical situation and care options. Furthermore, professionals should find an appropriate way to communicate with people with intellectual disabilities in order to make them aware of how they have done everything in their power to cure their disease, and how the choices being presented to them are genuine and evidence-based. There should also be adequate and appropriate support given by professionals to the person with an intellectual disability and families. Knowing helps people with intellectual disabilities understand their changing physiological processes and prepares them for these unavoidable changes, which in turn reduces their anxiety and stress. As one participant highlighted:

> *The nurses and doctors should make people realise they are dying. They definitely need a lot of support; the family and the person who is dying should know that nothing more could be done for them. When there is no cure, the family needs a lot of support. They need to be there all the way through and the person who is dying needs a lot of support and care and helps to make a plan.*

(Jack, a person with intellectual disability)

The communication flow between families and professionals is essential at the end of life, and this communication should be concerned with disease conditions, prognosis and future possible care choices for their loved ones. The interviews demonstrated how this is a clear indication that families are willing to be part of the caring process:

> *Communication is very essential and there are different ways, some people say total communication and some say no. I think communication is crucial, especially with family members, as to what is happening so, the professionals should let family members know what is happening to their loved ones.*

(Michael, a family member)

However, it was found in the study that one family member disagreed with the wishes of people with intellectual disabilities to be informed about their clinical situation as the family member assumed that it would be difficult for those with intellectual disabilities to understand what was happening and, even if they understood, it would be hard for them to manage the situation. Therefore, it can be seen that family members may feel that it is better to withhold information as they believe that this would help people with intellectual disabilities to live happily and be free from stress:

> *Mm... I would say certainly not because it is difficult for them to understand and even if they understand it will be very hard for them to take. I prefer not to tell them anything.*

(Roisin, a family member)

It was also found in this study that people with intellectual disabilities expressed that they had a right to know what was happening to them. However, family members wanted to protect their loved ones from knowing the truth. Furthermore, it is understood form the findings that the colluding of professionals with family members, and the subsequent withholding of clinical information, will undermine the
autonomy of people with intellectual disabilities and compromise their rights. Such paternalistic attitudes of family members in this study may be due to their belief that they know what is best for their loved ones. However, people with intellectual disabilities can decide what they want and how much they want to know, and indeed, within this study they expressed a desire for openness from professionals and families. Family members, however, demonstrated how they feared that telling the truth would cause emotional pain, distress, and anxiety and that it would be a burden to people with intellectual disabilities.

3.1.2 Plan ensures good care

Ultimately, it can be seen how a document consisting of a person’s wishes, preferences and needs would be an excellent resource for healthcare providers to utilise in order to give appropriate care. This document would eliminate any confusion among professionals, and they would know what to do and what was expected of them in terms of caring for that patient. This ensures the receipt of person-centred care. As one participant stated:

Also, they have to make us write down our wishes in a paper or tell the nurses, doctors and parents what are our wishes. This will clear all confusions and everybody will be in the same line of care.

(Ciara, a person with intellectual disability)

Katie, another person with intellectual disability, concurred that the documented wishes would be a good resource for health providers to give appropriate care, because this document would eliminate any confusion related to end-of-life care and everybody involved would know what to do and what was expected of them:

Also, they have to make us write down our wishes in a paper or tell the nurses, doctors and parents what are our wishes. This will clear all confusions and everybody will be in the same line of care.

(Katie, a person with intellectual disability)

This was further echoed by a family member of people with severe intellectual disability who argued that a plan of care, based on the wishes and preferences of a person with intellectual disabilities and families, would help everyone involved in that person’s care. It could help with overall understanding and provide direction for all professionals regarding the kinds of decisions which should be made in the event of an uncertain situation. The information would help not only in the usual setting of a person with intellectual disabilities, but also when they are transferred to other care settings, such as acute hospitals or specialist palliative care units. As outlined by one participant:

I think it is a very good idea to have everything on the clinical file. It will give a clear direction to the professionals about what to do at the time of emergencies and everybody knows what to do and what is expected of them. This information will be very helpful for the professional to provide good care at the end of life.

(Adam, a family member)

Furthermore, the views and opinions of people with intellectual disabilities and families should be respected and carried out. This practice is not only good for people with intellectual disabilities but also for professionals in terms of providing care that is congruent with the wishes of the person with an intellectual disability and families:

I definitely think that family members’ views and opinions should be respected and followed during this period. This is not only good for us but also for professionals to be clear and provide excellent care at the end of life.

(James, a family member)

It is clear from the views of people with intellectual disabilities and family members of people with severe and profound intellectual disabilities that people within this cohort receive good care at the end of life when they have a plan of care in place. Participants within this study who had an intellectual disability confirmed that their registered wishes should be respected and carried out and they believed that recording an individual’s wishes would help professionals to provide person-centred care, causing less tension and confusion.

4 DISCUSSION

It was found within this study that people with mild and moderate intellectual disabilities are expected to receive information regarding their clinical condition, prognosis, possible complications and expected outcomes when being diagnosed with life-limiting conditions. They expressed how this was not only their right, but could also help them to be in control of their life and assist with planning the time that was left for them. Furthermore, a clear understanding of their future gives them an insight into how their life can be, and consequently, it allows them to communicate in advance to healthcare providers and others regarding their wishes, preferences and expectations for care at the end of life when they may not be able to communicate due to a loss of cognitive ability. Similarly, Todd, Bernal, and Forrester-Jones (2013), Wiese, Dew, Stancliffe, Howarth, and Balandin (2013) and Tuffrey-Wijne et al. (2013) have suggested that some people with an intellectual disability would like to know about the nature of their illness, and possible complications and treatments, as they think it would help them to make choices, and consequently, this could prepare them for a more peaceful journey. However, they concluded that the capacity of some people with intellectual disabilities in terms of being able to understand would be a barrier to disclosure. Similarly, people with dementia have expressed how their views and opinions need to be listened to regarding their choice of care at the end of life even though their dementia affects their confidence in terms of such expression (Ingravallo et al., 2018).
In contrast to the wishes of people with intellectual disabilities, family members of people with severe and profound intellectual disabilities can be reluctant to let their loved one learn about their illness and impending death as they believe that they would be unable to cope with knowing about their life-limiting condition and information regarding their imminent death, suggesting that it may cause emotional distress, pain and depression. Therefore, they may try to insulate them from undergoing mental agony and other experiences of knowing. An earlier study by Ryan et al. (2011) showed that professionals felt that family members played a crucial role in communicating the clinical situation to their loved ones, and family members believed that hiding information might help people with intellectual disabilities to better cope with their illness. Tuffrey-Wijne (2010) and Tuffrey-Wijne et al. (2013) reported similar findings in that family members of people with intellectual disabilities were reluctant to speak to their loved ones about their diagnosis and risk of dying as they believed that this information would be upsetting and hard for them to understand and absorb. It is clear that there is a tension between people with intellectual disabilities who want to know the truth in terms of understanding their clinical issues and planning for their future, and family members of people with severe and profound intellectual disabilities who prefer to hide such bad news in order to protect their loved ones from upset.

There is an assumption that withholding information from people with intellectual disabilities is probably due to a fear of causing them distress and also uncertainty regarding how to support them. Ryan et al. (2011) have indicated that professionals who work with people with intellectual disabilities find it difficult to talk about the diagnosis and prognosis of life-limiting conditions due to poor preparation in terms of communicating challenging and complex news. Similarly, Tuffrey-Wijne and McEnhill (2008) reported that the unwillingness of family members, coupled with a lack of knowledge and skills of professionals in communicating the message, effectively prevented them from telling the truth to people with intellectual disabilities. Tuffrey-Wijne (2013) has discussed how family members fear that people with intellectual disabilities would not be able to understand the information provided to them regarding their clinical situation or that the receiving of such information would be too upsetting for them. As a consequence of not communicating information about their clinical condition and impending death, the voices of people with intellectual disabilities were therefore found to be absent from decision-making regarding their future care (Todd, 2013). Tuffrey-Wijne and Watchman (2015) suggested that before disclosing information to an individual with intellectual disabilities, their cognitive ability and how much information they want to know should be assessed in order to promote communication. They also advised that taking enough time to determine the ability of an individual with intellectual disabilities and using simple language in disclosing the information would make for a strong starting point in relation to a successful communication strategy.

While carrying out this research, people with mild and moderate intellectual disabilities demonstrated their willingness to know what was happening to them and to be able to make decisions for themselves with adequate and appropriate support. We have to be mindful that when a lack of information is provided regarding their clinical condition and future care, this can lead to inadequate preparation in terms of facing changes in their life and an inability to make informed choices. However, when an individual with an intellectual disability has stated that they would prefer not to receive information about their health, this needs to be respected, and someone should be appointed to make decisions and plans on their behalf. This needs to be documented in the clinical file of the individual with an intellectual disability.

It was also demonstrated in the study that people with intellectual disabilities wished to communicate their likes, preferences and desires about end-of-life care as they felt that this would help professionals to make an appropriate care decision if they were unable to do so themselves (Watson et al., 2019). Bollig, Gjengedal, and Roseland (2016), Wagemans et al. (2015) and Brinkman-Stoppenburg et al. (2014) have highlighted how care planning in advance would help service users to dictate treatment and other options so that they can attempt to receive care that is consistent with their preferences when they are no longer capable of making those decisions. Kastbom, Milberg and Karlsson (2019) and Huggins et al. (2019) reported similar findings, suggesting that service users who receive care consistent with their wishes and preferences are satisfied with their care.

5 | LIMITATIONS

Regarding limitations, the present study was only carried out with people with a mild and moderate level of intellectual disability and did not include the voices of people with severe and profound intellectual disabilities; instead, their family members were included. While recruiting, the participants with intellectual disabilities could have a perceived demand effect to participate in this study. To address this, the managers were asked not to discuss the study with potential participants and were not made aware of the identity of any participants. Also, participants were not involved in the process of data analysis, but participants with intellectual disabilities were included in the development of an easy-to-read information sheet and consent form. The participants included in this study were not suffering from life-limiting illnesses; however, they had witnessed and lived with people who had experienced life-limiting illnesses and died. Therefore, the opinions of the participants may not have reflected the actual experiences of having a life-limiting illness, but the perceptions and views expressed here reflect how they felt when their friends and loved ones suffered. Nevertheless, further research is needed with people with intellectual disabilities who are at the end-of-life phase. Also, the study was carried out in a specific location with a small sample, and therefore, the results may not be generalisable to a wide extent. A large random sample of people with intellectual disabilities, as well as family members and relevant professionals, might help address these concerns. Finally, the study did not include the views...
of professionals; often, they act as a mediator when communicating with people with intellectual disabilities, especially within a sensitive context.

6 | IMPLICATIONS FOR PRACTICE

This study is one of the few that has looked at the perspectives of people with intellectual disabilities regarding their communication needs at the end of life and is the first of its kind within the current geographical location. Even though generalisation of the study finding is difficult due to its small sample size, the findings have contributed to existing knowledge and the practitioners could gain an insight into the needs of being informed of their clinical situation. The participants with intellectual disabilities themselves have demanded to be provided with information regarding their clinical condition, care options and prognosis in order to help make future decisions and construct a plan. Guidelines developed by Tuffrey-Wijne et al. (2013) is a useful tool to use when communicating sensitive information to people with intellectual disabilities. Consequently, this plan facilitates the receiving of excellent care at the end of life. Furthermore, the findings of this study help inform those who are involved in providing end-of-life care to those with intellectual disabilities, including nurses and social and other healthcare workers, that people with intellectual disabilities can cope with sensitive and end-of-life communication. Thus, professionals who are responsible (key worker) to provide care to a person with an intellectual disability should engage in end-of-life communication, including details regarding treatment and other life choices, place of care, place of death and funeral arrangements, with people with intellectual disabilities and their families. People with intellectual disabilities should be able to decide on and develop an end-of-life plan; however, they need support from healthcare professionals and family members. Supporting people with intellectual disabilities at this time is challenging for staff but can be achieved with individual and organisational intervention.

7 | CONCLUSION

This study has shown how people with intellectual disabilities and family members presume that receiving adequate information and engaging in an advanced care planning process gives people with intellectual disabilities some control over their future care. The practitioners could infer from these findings that end-of-life decision-making could take an inclusive approach, whereby the wishes and views of people with mid and moderate intellectual disabilities are respected and recorded in their clinical file, which will accompany them wherever they are transferred to. Finally, the findings also added evidence to previous research that people with mild and moderate intellectual disabilities can convey a clear choice. To accumulate evidence, it is highly recommended to conduct studies involving a larger group of people with intellectual disabilities.

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ORCID

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