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Everlasting dependency

A study of aging persons with profound intellectual and multiple disabilities and their families

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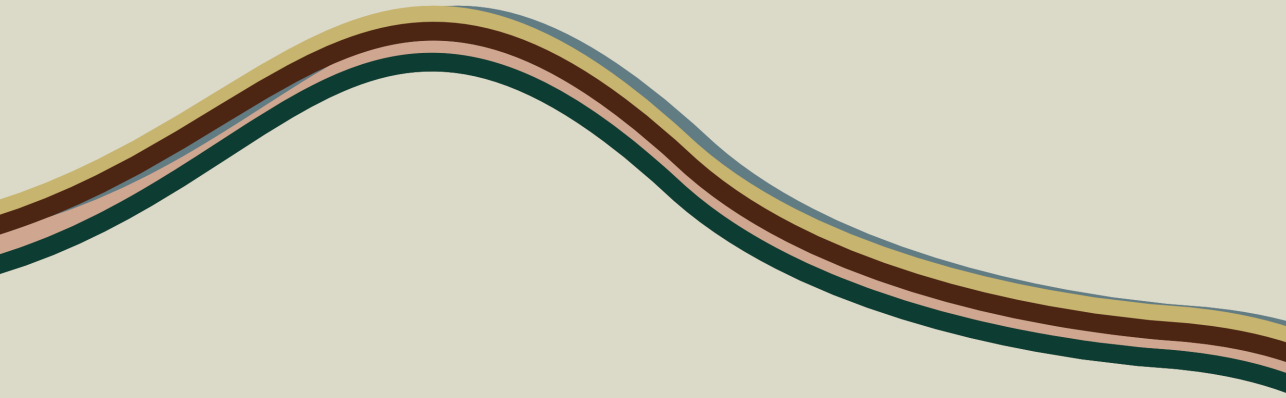
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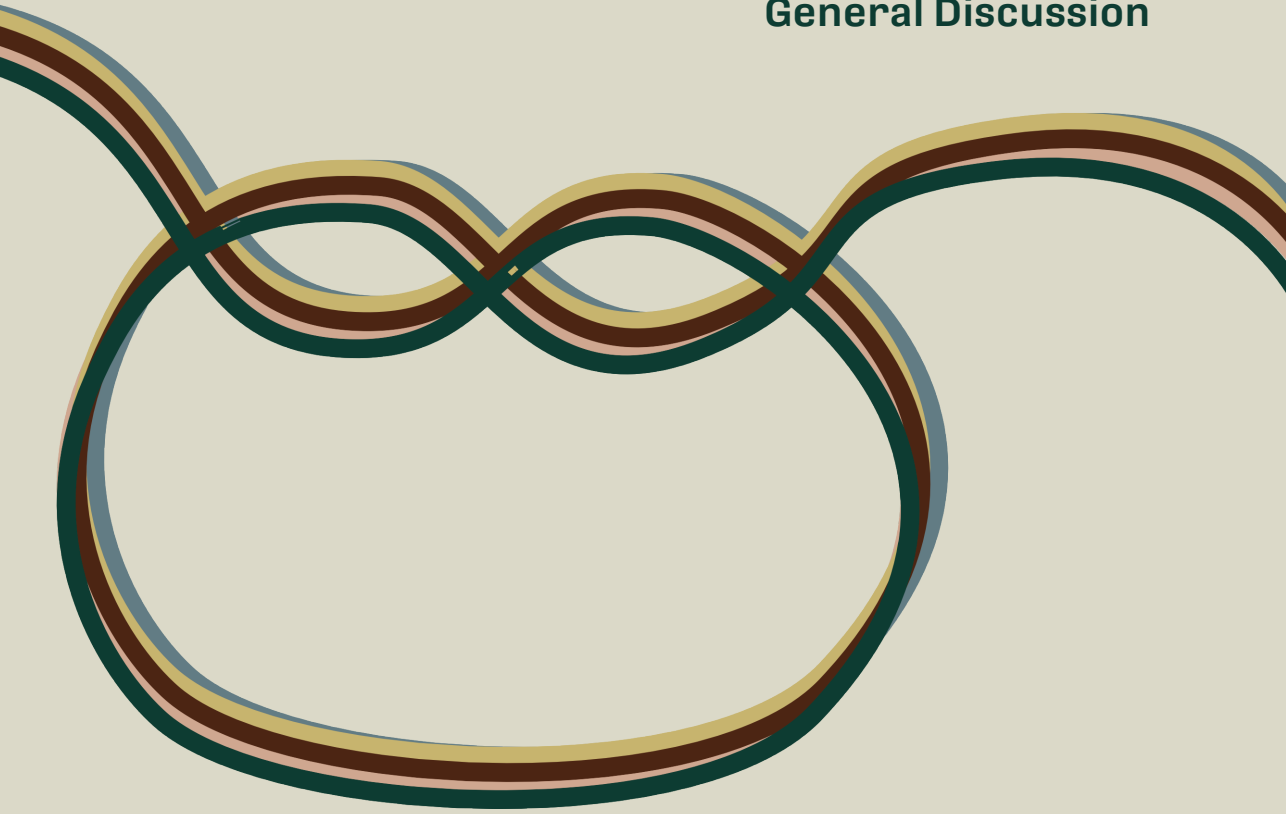
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General Discussion



General Discussion

In the previous chapters of this thesis, I have described how the increased life expectancy of persons with profound intellectual and multiple disabilities (PIMD) influences their lives and quality of life (QoL), as well as that of their families. We have explored the scenario of persons with PIMD (potentially) outliving their parents, and parents' views on medical decisions related to life and death for their aging child with PIMD. Until here, I have presented the studies we have conducted to answer the research questions mentioned in chapter one, separately and in detail. In this final chapter, I will discuss the main findings presented in the different chapters together, describe how these findings can be understood in light of the existing literature, and what they imply for both practice and research. Before I do this, I will reflect briefly on the research methodology that we have used to come to our findings.

Research methodology

I have addressed both the strengths and limitations of our methodological choices regarding the studies we have conducted in the corresponding chapters. Here, I will mention some overarching matters that should be taken into account when reviewing the meaning and implications of this body of work as a whole. The main one is that we have conducted qualitative studies to answer our research questions, which means that we do not know how quantitatively widespread the findings we have described are. At the same time, our qualitative approach has enabled us to gather rich data on sensitive issues, such as parents being outlived by their child with PIMD, and making medical decisions related to life and death for people who cannot decide for themselves. Our qualitative approach allowed us to describe and interpret these topics in all their complexity, thereby doing justice to the nuances that are inherent to the sensitive issues we have addressed.

While we did reflect on the ethical questions prompted by our studies, such as questions regarding the implications of a relational view on QoL for persons with PIMD or the desirability of physician-assisted death for aging persons with PIMD, we have done this by remaining close to the empirical data. We have given a voice to parents, siblings and other involved parties, rather than approaching these ethical questions purely theoretically. Parents described the ethical questions they face and experience in relation to their child's aging. That it was involved parties themselves raising these ethical questions, emphasizes the importance of these questions for (medical) practice.

In our studies, we have predominantly focused on parents' and siblings' experiences, while professional caregivers and medical professionals play important roles as well in relation to the topics we have discussed in our studies. Professional caregivers, of whom we only included a few in our studies, play an important role in the care and support for aging persons with

PIMD, maybe even more so when persons with PIMD have outlived their parents. Medical professionals, of whom we have not included any in our studies, play an important role in the medical decision-making processes for persons with PIMD as they need to make sure these decisions take place in accordance with the interests of their patients (Nieuwenhuijse et al., 2020; Schuller, 2019). Future research should further scrutinize the views of professional caregivers on the care and support for aging persons with PIMD, and the views of medical professionals on medical decision-making for aging persons with PIMD.

Caring for aging persons with PIMD

Interpretation

Our literature review helped us to grasp what is lost when parents are being outlived by their child with PIMD. Their children's inability to communicate their immediate needs and to speak up for their (medical) interests, makes that parents play an important, and often lifelong, role in their child's life. Based on the literature, we described how parents use their knowledge as expert of their child's communication and wellbeing and as advocate of their child's (medical) interests. Moreover, the synthesis of the literature elucidates the often implicit character of parents' knowledge. Parents' knowledge was described as a 'sense of knowing' through 'continuous presence'; they 'read' their child, making use of their 'gut feelings' and a 'sixth sense' (Carter et al., 2017; Zaal-Schuller, Willems, et al., 2016). These findings can be understood as parents describing a relation between their knowledge and their body, which is known as embodiment. This made us, in line with Reinders (2010), speak of 'tacit knowledge' (Polanyi, 2009) when we interpreted this deep experience-driven, but often implicit and embodied knowledge of parents. The personal character of this type of knowledge (Polanyi, 2009) makes it difficult to grasp, or to transfer to others, which underscores its fragility, and consequentially emphasizes the negative impact that the loss of a parent may have on persons with PIMD.

The large role parents play in the life of their child with PIMD was further illustrated by our empirical studies. Our findings consistently highlight the large responsibility parents feel towards their child, and their lifelong dedication to guard their child's QoL. The roles we presented based on the synthesis of the literature became apparent in our empirical studies as well. Parents were described, by themselves and others, as experts and advocates of their child with PIMD (Kruithof et al., 2021a; Kruithof et al., 2022b). Parents described how they "read" their children as experts to assess their immediate needs or wellbeing, and "fought like lions" as their advocates. An additional parental role that parents described was that of providing love and

attention (Kruithof et al., 2021a). Parents feared that the roles they had always performed in their child's life would not be taken over by others, when they would pass away prior to their child. They were not sure if someone else could or would be their child's expert, they were afraid no one would be able to assess and defend their child's individual interests, and they expected that the amount of love and personal attention for their child would decrease. Therefore, parents expected that being outlived by their child with PIMD, would result in a diminished QoL of their child.

Thus, parents viewed their child's QoL as relational, in the sense that they saw a direct link between their own presence in their child's life and their child's QoL, which made many of them speak out the hope to outlive their child. Parents described that their child could not undertake actions to increase her/his own QoL, but needed others to do so (Axelsson et al., 2014; Kamstra et al., 2015), by taking care of them, by looking out for them, and by loving them. Some mothers described themselves and their child as inseparable. They mentioned 'an uncut umbilical cord' between them and their child, being their child's ears and eyes, or referred to the potential loss of a child as the loss of an arm (Kruithof et al., 2021a). This furthered our understanding of their experienced embodied entanglement. While this experienced entanglement may ask for a reflection on the possibility of parents overestimating their own importance in their child's life, it does underscore the responsibility parents feel to make the life of their child with PIMD as good as possible, and their infinite dedication in aiming to protect their child's interests.

Siblings were often named as potential caregivers, both by parents and in the literature (Griffiths & Unger, 1994; Hall & Rossetti, 2018; Lashewicz, 2018; Orsmond & Seltzer, 2000). Therefore, we specifically addressed the role of siblings in two separate publications (Kruithof et al., 2021b; Kruithof et al., 2022b). In one, we explored how both siblings and parents of the same family view the role of siblings in the future care for their family member with PIMD. In the other, we explored how the care and support for persons with PIMD who have actually outlived their parents is arranged, by interviewing siblings, professional legal guardians, and professional caregivers. We found that siblings, just as parents, felt a strong responsibility towards their brother or sister with PIMD, and anticipated future involvement. Both siblings and professional caregivers emphasized the importance of siblings when persons with PIMD outlive their parents, because family is 'the constant factor' while 'professionals come and go' (Kruithof et al., 2022b). While siblings feel able and responsible to take on a role in the care and support for their sister or brother with PIMD, parents are hesitant to place the burden of responsibility on their children without disabilities (Griffiths & Unger, 1994; Heller & Kramer, 2009; Leane, 2020), who 'deserve to have their own lives' (Lee & Burke, 2020). This reluctance of parents complicates explicit family communication regarding the future care for their family member with PIMD (Leane, 2020). This lack of explicit communication was also brought up

by siblings, professional caregivers and professional legal guardians who were involved in the care and support for persons with PIMD without parents (Kruithof et al., 2022b). Some siblings mentioned that they had not spoken about taking over certain roles from their parents until their parent's dying bed. Professional caregivers and professional legal guardians described how they felt more confident about providing good care for their clients with PIMD without parents, when parents had, prior to their death, expressed specific wishes regarding their child's care.

Implications

Parents were concerned about who would take over their roles if they would be no longer able to care for their child. Indeed, the role parents play in the life of their child with PIMD is large (Geuze et al., 2022; Kruithof et al., 2021a; Luijkx et al., 2017), which makes them not easily replaceable. Therefore, different parties should explore together, possibly with the support of social workers, how they could form a network of support for persons with PIMD without parents. This could result in more feasible and durable ways of supporting and caring for aging persons with PIMD, thereby mitigating the impact of the loss of parents. Our division in roles may help to support parents and other involved parties in exploring which parental roles can be transferred to others, and to whom. Since siblings intend to play a large role in the future care and support for their brother or sister with PIMD (Hall & Rossetti, 2018; Lindahl et al., 2019), health care professionals should support parents and siblings to discuss the future care and support for their family member with PIMD. A lack of explicit and detailed communication may result in siblings feeling unprepared for the future and parents to be more concerned for the future than necessary – because of an overestimation of the expected burden for siblings (Kruithof et al., 2021b). At the same time, parents' fear of burdening their child without disabilities seems to play an important role in their reluctance to discuss this 'difficult topic' with their child(ren) without disabilities (Leane, 2020). Therefore, we argue that healthcare providers should address these parental fears to successfully support families in future caregiving planning for their family member with PIMD.

We have made a start in offering such support by designing a structured group conversation for family members and care professionals in residential care facilities (RCF's) about care and support for persons with PIMD without parents, and parents' concerns to be outlived by their child. We have described and evaluated this group conversation in chapter seven (Kruithof et al., submitted). Our findings suggest that the structured group conversation may be an effective strategy to encourage parents to make their future plans more explicit. Special attention for the inclusion of parents with children living at home and the inclusion

of siblings, and creating the possibility of a durable exchange between parents and the care facilities regarding future care, could be ways to improve the group conversation. While future studies may strengthen the understanding of the group conversation's efficacy, we hope it to be a first step in making the care and support for persons with PIMD future-proof. Another initiative in the Netherlands that is worthwhile to mention in this regard, is the workshop to support parents in drafting a "care-testament" (Netwerk Rndom, n.d.) to describe their wishes and preferences for the future care and support for their child with disabilities.

One of the parental roles that may come under pressure when parents are being outlived by their child with PIMD we have addressed in our studies, is that of expert. Our findings suggest that this expert role of parents stems from their history of proximity and interaction with their child. The knowledge they have acquired can be characterized as personal, sometimes embodied knowledge, which made us speak of tacit knowledge (Polanyi, 2009). While its implicit and personal character, makes that this parental tacit knowledge may not be readily transferable to others, such knowledge may be acquired by others as well through intensive interactions over time with a person with PIMD (Hunt et al., 2003). Our empirical findings underscore this, as parents saw professional caregivers as potential experts of their child. However, they were unsure if this expertise would prove retainable for care organizations due to the high turnover of personnel (Axelsson et al., 2014). This may imply that, in order to provide 'good care', RCF's may have to work with a smaller pool of personnel and limit the rearranging of groups, to allow professional caregivers to develop a close enough bond with people with PIMD to read their signals and fulfil the expert role (Kruithof et al., 2020).

Moreover, professional caregivers should be allowed the time and space to build up knowledge of their clients through trial and error (Hoogsteyns et al., 2023; Kruithof et al., 2020). Working with a smaller pool of employees and allowing space for trial and error may prove difficult in care organizations, however, as they want to counteract organizational vulnerabilities, need to be cost-effective, and are responsible for the safety of their clients. While this is understandable, and safety and efficiency are important values in relation to providing good care, our findings emphasize that a balance between efficiency and safety on the one hand, and the possibility to foster long-lasting relationships with clients as well as having the discretionary space for trial and error on the other, may be at the core of realizing good care for persons with PIMD. How this balance should be realized, should be a topic of further investigation. We hope to play a role in this ourselves, with our current project on tacit knowledge in the care and support for persons with PIMD.

Medical decision-making for aging persons with PIMD

Interpretation

The potential loss of one or more parental roles in the life of aging persons with PIMD was also mentioned in relation to medical decision-making. As part of the role of advocate – and related to the role of expert – the monitoring of the situation of their child with PIMD and the medical decision-making related to life and death that has to be done on his/her behalf was often named by parents (Kruithof et al., 2021a). Parents were unsure who would explore their child's interests and who would dare to make (difficult) decisions on their child's behalf. They were fearful that their child would suffer more than necessary when their child would near the end of her/his life (de Vos et al., 2014), and hoped they would be able to accompany their child during her/his last moments. Some parents, mostly the ones with a child living at home, experienced despair when they contemplated the possibility to be outlived by their child. These parents described their children's QoL as problematic and kept them home, sometimes out of dissatisfaction with the care and support provided by RCF's, to offer them a life in which their QoL could at least be retained. Parents' despair manifested itself most palpably when they mentioned the possibility of restricting treatment to prevent being outlived by their child, while some even contemplated the option to actively end their child's life as a last resort. This does not only underscore the gravity of parents' concerns to be outlived by their child with PIMD, but also the importance of their role in their child's life, and their mutual entanglement. Parents' importance became increasingly evident when we explored the situation of persons with PIMD without parents, because siblings, and especially professional legal guardians, were less inclined than parents to explore and defend the medical interests of their family member or clients with PIMD.

We further explored how parents estimate their child's wellbeing and medical interests in our publication on parents' views on medical decisions related to life and death for their aging child with PIMD (Kruithof et al., 2022a). Parents based their medical decisions related to life and death on their estimations of their child's current and/or future QoL, saw themselves as best equipped to make such decisions for their child, and felt responsible for doing so. Parents were fearful of medical professionals overruling their medical decisions related to life and death for their aging child (Winters, 2018; Zaal-Schuller et al., 2016). This applied to both the parents who wanted life prolonging treatments for their child and to the ones who did not see such treatments as being in accordance with their child's interests any longer.

The uncertainty of the interests of persons with PIMD makes it hard to make medical decisions related to life and death on their behalf, especially if these decisions would entail actively ending their lives. It is important to note, however, that this uncertainty of their interests

may result in potential harm for individuals with PIMD both in the scenario of shortening their life and the scenario of prolonging, or not shortening, their life. As our findings indicate, some parents believe that not allowing physician-assisted death for people with PIMD, can be harmful for their child, because it may result in a life or a dying process of unbearable suffering (Griffiths et al., 2008). These parents mentioned how withholding treatment may not always be an option to shorten life. Their children, just as others, may survive infections and other medical situations without receiving treatment, or their QoL may deteriorate gradually over time to the point that their life may be no longer worth living without there ever have been a need for receiving life-prolonging treatment. This made that some parents considered the option to withdraw medically provided nutrition and hydration from their child to shorten their child's life, which may occur when there is consensus that the provision of fluids and nutrition do not confer a net benefit to their child (Diekema & Botkin, 2009). However, they saw this as a worse option than physician-assisted death as it would be accompanied by additional (emotional) suffering for their child and themselves. Therefore, these parents made the case for an extension of the existing criteria regarding physician-assisted death in the Netherlands so that persons with PIMD would be eligible to potentially qualify for it.

Implications

In relation to medical decisions related to life and death for persons with PIMD, our findings raise a couple of points worth further mentioning here. First, parents viewed their child's QoL as relational, which made that they factored in their own presence in relation to their child's QoL and the way they viewed life prolonging interventions for their child. This asks for a reflection on the possibility of parents overestimating their own presence in the life of their child, something that was mentioned by a few siblings who had taken over guardianship for their brother or sister with PIMD from their parents (Kruithof et al., 2022b). At the same time, parents do play such an important role in the life of their child with PIMD, that their presence in their child's life may be an important aspect of their child's QoL. This may be even more so for persons with PIMD who live at the family home. Future research should further scrutinize the importance of parents for their child's QoL, and whether the presence (or absence) of parents may be seen as related to the medical interests of persons with PIMD (Wilkinson, 2013).

A second point related to medical decisions worth mentioning here is that some parents described how their attitudes towards these medical decisions had changed over time, and reported how they had "grown towards letting go". Their experiences with medical interventions – for both their own child and other children – had changed their perspective on

these interventions, and enabled them to substantiate their convictions regarding the desirability of life-prolonging treatments for their child. This points to the difference between parents' views on medical decisions for their newborn or young child with PIMD, on the one hand, and for their aging child with PIMD, on the other. Another way in which medical decisions are different for younger and older children with PIMD, is that parents may have built more expertise of their child over time, and thus may have become increasingly equipped to assess their child's wellbeing and medical interests. Future research could further specify the differences between medical decisions related to life and death for younger and older persons with PIMD, and whether these influence the amount of control parents want, and are offered, regarding such decisions.

Finally, some parents asserted that physician-assisted death may be in their child's (potential) interest. The always remaining uncertainty of their interests, and the irreversibility of physician-assisted death, make that the bar for possibly allowing physician-assisted death for persons with PIMD should be high. However, when parents and treating physicians are convinced that a person with PIMD is suffering unbearably and it is therefore likely to be in their interest to die, physician-assisted death could be seen as a way of shortening life with less potential suffering than withdrawing medically provided nutrition and hydration. While I deem it likely that physician-assisted death is in the interest of some specific individuals with PIMD at some point in time, providing a final answer about the desirability of allowing it for persons with PIMD in general is beyond the scope of this thesis. More research is necessary to explore the views and experiences of a larger group of parents, and also medical professionals, other persons involved in the care for persons with PIMD, and ethicists and lawyers, to come to such an answer. In such future research the potential benefits and potential harms of allowing physician-assisted death for persons with PIMD should be made explicit, as well as the criteria that should be met, i.e. the safeguards that should be installed, for persons with PIMD to be potentially eligible for physician-assisted death.

In conclusion

Based on all of the above, I would like to emphasize the importance of listening to parents' experiences and to take these experiences seriously, both in relation to medical decisions related to life and death for their child with PIMD, and in relation to their concerns about the care and support for their aging child. This is important since neglecting parents' experiences would prevent them from receiving support for their struggles with the issues presented above. Moreover, listening to parents as loving experts of their child who actively explore and defend their child's interest, allows us to better understand aging persons with PIMD who cannot

speaking for themselves. To further illustrate this, I would like to revisit the “ostrich under the sand metaphor” (Beckett, 1938) from chapter one. Parents, better than anyone else, can teach us about the situation of persons with PIMD, as they actively “look in the sand” their entire shared lives to understand and protect their child. We can never be fully aware of “what the ostrich sees in the sand” but the least we can do is to keep digging cautiously and not “turn a blind eye”, to further our understanding. By giving words to these parents, I have aimed to tell their story and that of their children. Therefore, I hope this thesis recognizes their views on, and experiences with, care, support, and medical decisions. In describing parents’ views and experiences, I have aimed to offer tools for (medical) care practitioners to deal with the issues that parents have raised, as well as offer food for thought for future research and discussions on these delicate issues. Let us continue to look in the sand.

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