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article

because we care:

exploring care and well-being with siblings of children with life-limiting conditions through philosophical inquiry

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abstract
The experiences of siblings of children with life-limiting conditions have received increasing attention in recent years. However, their conceptualisation of well-being and care has received limited attention. This article shares findings from a project with a small group of children who have siblings with life-limiting conditions. Uniquely, the siblings explored concepts of care and well-being through a series of philosophical dialogues and complementary art activities. Four main themes were central to the siblings' ways of thinking about care and well-being: being your own person, life is an emotional rollercoaster, love is complex, and together we are stronger. The key message that was central to the ways in which the siblings understand care and well-being is that love drives caring behaviour, and that we should care for others, not because they have particular needs, but because we are human. Understanding how siblings of children with life-limiting conditions think about notions of care and well-being ensure that this under-represented group is heard, and that in attending to them, families and others who care for and about them are better able to meet their needs with a view to them living well.

keywords: well-being; care; siblings; life-limiting conditions; philosophical inquiry.

porque nos importamos:
pensando o cuidado e o bem-estar de irmãos de crianças com doenças terminais através de uma investigação filosófica

resumo
As experiências dos irmãos de crianças com doenças terminais têm recebido uma atenção cada vez maior nos últimos anos. No entanto, a conceitualização de bem-estar e cuidado tem recebido atenção limitada. Esse artigo apresenta os resultados de um projeto desenvolvido com um pequeno grupo de crianças que têm irmãos com doenças terminais. De forma singular, os irmãos exploraram os conceitos de cuidado e bem-estar através de uma série de diálogos filosóficos e atividades artísticas complementares. Quatro temas principais fundamentaram o modo como os irmãos pensaram sobre cuidado e bem-estar: ser você mesmo, a vida é uma montanha russa emocional, o amor é complexo e juntos somos mais fortes. A mensagem principal dos irmãos sobre o cuidado e o bem-estar é que o amor estimula comportamentos solidários e que devemos cuidar uns dos outros, não porque tenham necessidades específicas, mas porque somos seres humanos. Compreender como os irmãos de crianças com doenças terminais pensam sobre cuidado e bem-estar garante que esse grupo sub-representado seja ouvido e que, ao atendê-los, as famílias e outras pessoas que cuidam e se preocupam com eles possam melhor satisfazer suas necessidades, de modo que vivam bem.

palavras-chave: bem-estar; cuidado; irmãos; doenças terminais; investigação filosófica.

porque cuidamos:
una reflexión filosófica sobre el cuidado y el bienestar de los hermanos de niños con enfermedades terminales

resumen
En los últimos años, las experiencias de los hermanos y hermanas de niños y niñas con enfermedades terminales han recibido una atención cada vez mayor. Sin embargo, su concepción del bienestar y el cuidado ha sido objeto de interés limitado. Este artículo presenta los resultados de un proyecto llevado a cabo con un pequeño grupo de niños y niñas que tienen hermanos y hermanas con enfermedades terminales. De forma singular, los hermanos y hermanas exploraron los conceptos de cuidado y bienestar a través de una serie de diálogos filosóficos y actividades artísticas complementarias. Cuatro temas principales fueron fundamentales en la forma de pensar de los hermanos y hermanas sobre el cuidado y el bienestar: ser uno mismo, la vida es una montaña rusa emocional, el amor es complejo y juntos somos más fuertes. El mensaje clave de los hermanos y heramnas sobre el cuidado y el bienestar, es que el amor impulsa el comportamiento solidario, y que debemos cuidar de los demás, no porque tengan necesidades particulares, sino porque somos humanos. Comprender cómo piensan los hermanos y hermanas de niños y niñas con enfermedades terminales sobre los conceptos de cuidado y bienestar garantiza que se escuche a este grupo infrarrepresentado y que, al atenderlos, las familias y otras personas que los cuidan y se preocupan por ellos puedan satisfacer mejor sus necesidades con el fin de que vivan bien.

palabras clave: bienestar; cuidado; hermanos y hermanas; enfermedades terminales; investigación filosófica.

because we care: exploring care and well-being with siblings of children with life-limiting conditions through philosophical inquiry

introduction

One of the children in Tasker and Stonebridge's (2016) study of siblings of children with cancer bemoaned that no-one ever asked about his well-being; they always asked about his brother. This sentiment was shared by others in the study and is indicative of the experiences of siblings with a life-limiting condition (LLC). Gregory et al. (2022) note that the academic literature on sibling experiences has grown since Tasker and Stonebridge's study, moving to investigate the services and opportunities that are offered to provide emotional support and well-being, reaching beyond what might be seen as a simple identification of siblings' needs. However, there remains a clear indication that research related to well-siblings is somewhat 'understudied' (Tasker & Stonebridge, 2016).

Further, the research that exists, though worthwhile, tends to focus on children's experiences of having a sibling with an LLC (see, for example: Brennan et al., 2012; Fullerton et al., 2017; Gregory et al., 2022; Dunbar et al., 2024; Tay et al., 2024; Baena et al., 2025) and/or it takes the form of systematic literature reviews (see, for example: Knecht et al., 2015; Yang et al., 2016; Booth et al., 2018; McKenzie Smith et al., 2018), with the criticism that "the reviews were mainly descriptive and less explanatory" (Knecht et al., 2015, p.115). Experiences are often presented through a proxy, either a family member or someone who works with the child (Knecht et al., 2015). Additionally, the research tends to be published in journals directed at health professionals.

This article seeks to advance the research on siblings of children with LLCs by uniquely exploring, not their experiences or feelings, but their conceptual understanding of care and well-being. In doing so, the study set out to amplify the voices of children in this under-represented group to speak to those who care for and about them across a range of disciplines and professions, including those outwith "the healthcare sectors such as social workers, priests/chaplains and teachers" (Booth et al., 2018, p.1563), thereby extending the support afforded to well-siblings. Innovatively, within the project, the children engaged in philosophical dialogue (Cassidy et al., 2017; Cassidy et al., 2019) and art-based activities around questions of care and well-being with a view to influencing policy, theory or practice for those working in palliative care and/or who have responsibility for caring for children with an LLC and their siblings (Fraser et al., 2021).

background

The term life-limiting condition (LLC) is generally used for health conditions that have little likelihood of cure and from which those with the condition will likely die (Fullerton et al., 2017; Booth et al., 2018; Fraser et al., 2021). According to Fraser and colleagues (2021), the number of children who have LLCs is rising. In England alone, sixty-six per 10,000 children aged up to nineteen have an LLC (Fraser et al., 2021), and around 21 million globally (Connor et al., 2017; Booth et al., 2018). There is no good estimate of how many siblings of children with LLCs there are, though it is likely to be relatively large. Appropriate support for siblings of children with LLCs is required from families, health professionals, teachers, and others with whom they have contact for any length of time. Given that children spend so much of their time in school, Robinson and Summers (2012) are clear that not only should teachers know about the conditions from which children in their class may suffer and how this might affect their learning, they should also understand the needs and support required for siblings of children with LLCs. Tasker and Stonebridge (2016) identify a lack of understanding or sensitivity on the part of some teachers, which may diminish siblings' school experience.

The literature points to the negative impact of being a sibling of a child with an LLC on schooling. Dunbar et al. (2024) recognise the importance of school in their lives, though they report challenges experienced through absences due to an unwell sibling's hospital visits or difficulty concentrating due to tiredness. This arguably leads to them falling behind in their academic studies and even becoming "disengaged from their classmates" (Yang et al., 2016, p.20). There are also suggestions that children separate their home and school lives (Brennan et al., 2012); this, though, need not be unique to siblings of those with LLCs, nor need it be an entirely negative attribute as seen in Tasker and Stonebridge's (2016) study where participants suggested that they sometimes need to "get away from the 'situation'" (p.718).

Some studies identify the negative impact on children's mental health due to having a sibling with an LLC. Jaaniste et al. (2021) highlight that well-siblings "face the emotional turmoil likely to be associated with having a seriously ill brother or sister" (p.270), but that they might also have challenges in their social lives. They are, when compared with their peers, more inclined to have "significantly poorer psychosocial functioning" (ibid, p.270). A range of studies suggest that they are likely to experience mental health difficulties and social challenges (Brennan et al., 2012; Lane & Mason, 2014; Yang et al., 2016; McKenzie Smith et al., 2018; Jaaniste et al., 2021; Dunbar et al., 2024; Tay et al., 2024). Well-siblings may, for example, miss out on opportunities such as joining clubs or attending activities (Lane & Mason, 2014; Dunbar et al, 2024), they may experience grief or altered relationships (Yang et al., 2016; Coffman et al., 2021; Gregory et al., 2022), and they can feel like a burden to their families who need to care for their unwell sibling, particularly as they cannot or do not wish "to share their emotional stress" (Tasker & Stonebridge, 2016, p.713).

Well-siblings also report a negative impact on their self-identity (Yang et al., 2016; Gregory et al., 2022). This may be because they see their sibling (necessarily) receiving more parental attention (Gregory et al., 2022), or because they put their sibling's needs before their own, adopting a role that might otherwise be assigned to an adult carer such as a parent (Brennan et al., 2012; Knecht et al., 2015). Special camps and dedicated groups have shown some positive impact, however, on well-siblings' well-being and identity because they are able to relax, have fun and engage with others like them with respect to their family circumstances (Lane & Mason, 2014; Tasker & Stonebridge, 2016; Jaaniste et al., 2021; Gregory et al., 2022). Well-siblings find these opportunities helpful in acknowledging that they have needs, that they can speak with peers about their lives, and that they can have a break from the pressures of being the sibling of someone with an LLC. Of course, opportunities such as camps for well-siblings run into the usual challenge of insufficient funding or that the demands of an unwell sibling may make it more difficult for well-siblings to attend (Gregory et al., 2022). It is worth mentioning that well-being in the context of such camps and activities appears to focus on the siblings' emotional and social well-being by offering opportunities to talk with others about their experiences and to play together. This aims to build "community… mutual respect, shared responsibility and an emotionally safe environment" (ibid, p.1343), with the opportunity to make social connections with peers being particularly important.

Despite the apparent negative consequences or experiences of having a sibling with an LLC, it is important to note that in the limited range of studies relating to siblings of children with an LLC, positive elements arise. Well-siblings might be seen to demonstrate compassionate behaviour, where sensitivity and empathy are evidenced with a seemingly unexpected element of maturity, particularly in their adoption of caring responsibilities (Brennan et al., 2012; Lane & Mason, 2014; Fullerton et al., 2017; Coffman et al., 2021). Confronting the emotional and even physical challenges of having a chronically unwell sibling might also breed resilience, that is "the ability to maintain functionality despite significant adversities that have the potential to disrupt the normal processes in life" (Lane & Mason, 2014, p.220), where individuals might have personal strategies to cope with the circumstances in which they find themselves, and for finding support beyond their immediate resources. The literature shows that siblings sharing their experiences and feelings and learning from their peers breeds a sense of connectedness or closeness that leads to acceptance and recognition, which creates a sense of belonging (Gregory et al., 2022). Aside from having support to deal with the emotional challenges of having a sibling with an LLC, simple opportunities for laughter, humour, and "being a kid" (Tasker & Stonebridge, 2016, p.716) are crucial. This is particularly important in recognising that these siblings are at risk of being unwittingly forgotten.

The requirement that children are consulted in matters that affect them is articulated within Article 12 of the United Nations Convention on the Rights of the Child (UNCRC) (United Nations, 1989), Here, the assumption is made that children not only have the capacity to express their views but that they have something worth hearing. Lundy (2007) argues that "voice is not enough", that space must be created for children to express their views, that there must be an audience to listen, and that the views must hold influence. Of course, voice is more than the verbal articulation of views. Increasingly, it is also recognised through, for instance, body language, gesture, glance and art (Wall et al., 2019; Robinson, 2021). Significantly, silence may also be considered an element of voice, making attending to this an important aspect of listening to children and young people (Spyrou, 2016; Hanna, 2022), not least to ensure the epistemic injustice of children's views not being recognised as credible are addressed, or the hermeneutical injustice that might arise from 'structural silence', whereby the child struggles to articulate or make sense of their social experience for themselves or others (Hanna, 2022).

well-being

Children's well-being is important to their parents, families, wider society and, obviously, to children themselves, though they tend not to have many opportunities to influence this. Often the literature suggests that well-being is a challenging concept to define, assuming a definition is offered at all (see, for example: Thomas et al., 2016; Amerijckx & Humblet, 2014; Marshford-Scott et al., 2012; Camfield et al., 2009; Bourke & Geldins, 2007). There is some consensus, however, that it pertains to one's social, emotional, intellectual, mental and physical wellness, linking well-being to health. Cassidy (2017) notes that agency, autonomy, community, relationships, happiness, satisfaction, respect, and being valued tend to feature when emotional, intellectual, social, physical and mental wellness is considered. A hedonistic version of well-being, one in which the individual's own pleasure is often advanced (Thorburn, 2017; Parkinson et al., 2025), against the eudaimonic view, which derives from Aristotle (2020), where flourishing is key and the individual aims to live a good life (Amerijickx & Humblet, 2014). This resonates with what Cassidy (2017, 2024) calls being well, which encompasses the ideas of well-being shared above while also recognising that we exist in-relation.

The importance adults place on children's physical well-being is evidenced in its prominence in school curricula. Increasingly, their emotional and mental well-being has drawn attention, perhaps due to the impact of the Covid pandemic lockdown restrictions on children's mental health. Fattore and Mason (2017) note that research often misses "the emotional complexity of lived experiences of well-being" (p.278). They unpack children's well-being through exploring children's experiences and what might contribute to this. The children's responses expose that adult/child power dynamics are at play in their lives, with adults dominating decision-making. This is in tension with the children's views on society, where the social dimension is important in realising their well-being, an element that is, according to Fattore and Mason, relatively unrecognised in the research literature and practice. It echoes Conrad et al.'s (2015) study where they engaged children in philosophical dialogues about what they considered the good life to be. Like those in Fattore and Mason's study, the children highlighted their lack of power in influencing society, yet they positioned a good life as one that embraces social justice and equality, where community is central and the rights of community members should be respected through the attitudes and relationships on display; one, it could be said, that situates well-being at the centre.

Graham and Fitzgerald (2011) also focus on children 'having something to say' about emotional and social well-being. They assert that children having opportunities to say what they think about well-being has the potential to advance their actual well-being, something that acknowledges their relationships with others, including with adults. Our project recognises that children are often missing from discussions about health and care, with (adult) proxies speaking for them (Jaaniste et al., 2021) or that there are assumptions that children share the same views or similar experiences. This is even more the case with respect to siblings of children with LLCs, where the literature is limited in quantity and scope. Not to disregard the research that exists, but it tends to focus on children's experiences of being a sibling rather than exploring with children what they think care and well-being is, which will support understanding of what their needs might be, and how they might be realised. To uncover the children's conceptual understanding of care and well-being in our study, Community of Philosophical Inquiry (Cassidy, 2007; McCall, 2009; Cassidy et al., 2017, 2019; Conrad et al., 2015) was used.

methods

One of the project's aims was to amplify the voices of children with siblings who have LLCs. This is grounded in children's rights, with Article 12 of the UNCRC stating that children have the right to express their views in matters that affect them. The likes of Pascal and Bertram (2014) assert that research and practice must evolve to take account of children's rights, and Horgan (2017) highlights the need for appropriate research methods when working with children. It is in this context, one that recognises that children have something to say that is worth listening to and that what they say can have influence, as Lundy (2007) would expect, that Community of Philosophical Inquiry (CoPI) was considered a helpful approach to exploring children's conceptualisation of well-being and care.

community of philosophical inquiry

CoPI is an approach to philosophising with children that grew from Philosophy for Children (Lipman, 2003; McCall, 2009). Lipman's Philosophy for Children and subsequent approaches to Philosophy with Children were originally pedagogical in nature. However, CoPI as a rights-based approach ensures "conceptual autonomy and a means for collaborating" (Cassidy et al., 2019, p.38) and recognises children's agency, a non-negotiable element of a rights-based approach to research with children. Adopting CoPI with complementary art-based activities and associated discussions "allows for the exploration of ideas and participants' representation of the world rather than an investigation into experiences" (ibid., p.42). Unlike common approaches to research such as focus groups or one-to-one interviews, philosophical inquiry goes beyond the narrative or experiential account to a more conceptual exploration of particular phenomena, in this instance, care and well-being. Indeed, the philosophical nature of the approach requires that it reaches beyond accounts and examples of experiences to unpack concepts and assumptions held by those participating in the inquiry. This was seen in the study on children's conceptualisation of childhood across seven countries in five continents, where one stimulus was used to provoke explorations of child and childhood through philosophical inquiry (Cassidy et al., 2017) or in Conrad et al.'s (2015) research that unpacked the kind of society in which children would like to live. In each of these studies, contradictions, agreements, assumptions, tensions, examples, counter-examples, definitions, distinctions, explanations, and concepts surfaced.

Cassidy et al. (2019) argue that employing philosophical dialogue as a research method provides a unique insight into children's thinking because the approach reveals reasoning and allows participants to work together to create meaning. It does not, however, require that participants agree a conclusion or present their views as finite; it allows shared consideration of ideas and encourages disagreement via contrasting views. In employing philosophical inquiry as a research method, contrasting views enable not only the children but the researcher to identify where tensions might exist between ideas, where examples may work – or not – and to surface connections, assumptions and understanding. Further, it reveals what is not said, an important element of listening to children generally, and in research specifically.

CoPI follows a structure. The session begins with reading a stimulus to provoke philosophical questions from the participants. In our study, short stories were written to prompt questions relating to care and well-being. The stories were not about hospices or children with LLCs. They revolved around a dog, the family she lives with and her friends, where issues related to care and well-being were raised. The stories prompted questions related to love, the good life and who cares. The person whose question is chosen is the first to speak. Thereafter, participants raise their hand should they wish to contribute to the dialogue; they will not necessarily be called by the facilitator in the order in which they indicated their desire to speak as the facilitator juxtaposes the different perspectives, only intervening for questions of clarity or to maintain the rules. Speakers begin their contribution by saying 'I agree/I disagree with [person's name] because [give reason]', thereby making connections to previous contributions. They may not use technical language or jargon, nor may they refer to an authority such as a teacher, a book, or the internet for their reasons. They should present their own thinking, though not necessarily their own opinion. When a session ends (after thirty minutes to an hour), there is no search for consensus or conclusion as this is seen to close down the inquiry (Cassidy, 2007; Cassidy et al., 2019; McCall, 2009). Due to the limited number of meetings with the children, and the small number of participants, the dialogues in our study lasted between twenty and thirty minutes.

participants

We recruited children through an e-mail to families from CHAS (Children's Hospices Across Scotland). Accompanying the e-mail was a short video explaining what CoPI is and the proposed project. Potential participants and their families were invited to a meeting held at a CHAS hospice. To help parents and children understand the nature of philosophical dialogue, a one-off CoPI session was held for the attending group of adults and another for the children. The topic of these dialogues was unrelated to the project's topic.

Following the information session, seven children, aged seven to eleven, opted to participate in the project. Two sets of siblings were in the group. This was not considered problematic given the focus on conceptual understanding rather than experiences, which may have been similar.

the sessions

The children met on five Saturdays in the hospice's staff training room. Each week, the children participated in CoPI sessions and art-based activities. The art activities and CoPI worked in tandem, with the art activities being designed to elicit further discussion on the week's topic. Often the art activity of one week was informed by the philosophy from the previous week, or vice versa. For example, one week, the children explored the question What is love? Following this, the children created love letters where they wrote to someone they love explaining why they love them. Other art activities included: all about me pictures, creating superheroes, 'caring moments' sculptures, 'memories to keep' plasticine models, and mask-making. There was always a 'show and tell' to share artwork, which allowed further exploration of the topics under consideration. The philosophy dialogues and the discussions of the artwork were audio-recorded and transcribed to support research analysis.

analysis

Three members of the team undertook thematic analysis (Braun & Clarke, 2021) to explore the children's perspectives. It consisted of six stages: familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report.

First, each member independently read the transcripts noting potential themes and impressions of the data. Next, initial codes were generated based on the transcripts and then combined into preliminary themes. Throughout the analytic processes, we met to discuss data, codes, examples and themes. Discrepancies were addressed and critiqued until consensus was reached. Finally, these themes were reviewed and refined, organised into sub-themes and main themes, and illustrative extracts were selected. Each main theme had three or four sub-themes.

The first main theme contained the children's theorising around *the complexity of love*. The sub-theme, 'does anyone really know what love is?' involved questioning what love means. The next, 'hearts connect and then get bigger' involved ideas of how love begins from connections with others and how this can grow into something more. The third subtheme, 'feelings change, grow, and go' concerned the dynamics of love not being static but with the possibilities of deeper love developing. The final sub-theme, 'love is the missing piece' explored how love makes things complete.

The second main theme contained ideas around the importance of how to be in relationships, with *together we are stronger*. In the first sub-theme, 'importance of relational connections', the children recognised the need for others in their life. The second focused on us needing people when we are unwell, with 'company relieves aloneness and soothes pain'. The next sub-theme, 'we can all respond compassionately', involved the need for action and demonstration. In the final sub-theme, the children referenced their own actions of compassion, 'being selfless helps others'.

The third main theme, *life is an emotional roller-coaster,* related to the children's emotional states. The first sub-theme, 'joy and happiness', focused on positive feelings and enjoyment from life. The second, 'a powder keg waiting to explode', revolved around angry feelings and feelings of annoyance at others, particularly siblings. In the final sub-theme, 'when things get too much', the children recognised the need for others, particularly adults, for help and support.

The fourth main theme was *the complexity of love*. The first sub-theme, 'freedom to choose', recognised individuals' agency. The second, 'being the boss of me', saw the children expressing an element of push back with an assertion of their own wants and needs. The third, 'embracing difference', focused on the children's openness and acceptance to individual differences. In the final sub-theme, ‘having space to just be’, the children expressed their need to be alone and have quiet time to contemplate away from the constant noise.

ethics

Before the information event, the children and their parents received information sheets and consent forms, with ethical approval having been granted by the University’s Ethics Committee. The children selected their pseudonyms and used these names throughout the project. Had any of the children become upset or distressed during the sessions, the dialogues would have stopped. The hospice in which we worked always had qualified staff members who could support the children in the event of an upset, and one member of the team is a qualified counsellor. None of the children became upset or distressed during the sessions.

Even with pseudonyms, due to the small number of participants and the organisation through which they were recruited, the children are potentially identifiable. This means that data sharing of transcripts is not possible.

findings

The children explored five questions in the philosophical dialogues: What makes a good life? What would make a day perfect? What is love? Did having Heidi [the dog] beside her make Jenny feel any better? What kind of love was it? As noted above, the philosophical dialogues were complemented by art activities, and vice versa, and four main themes emerged.

the complexity of love

Love as an abstract concept was considered, while love as manifest in life was also explored through the art activity where the children made love letters for someone they love. The children chose to whom they wrote the letter and determined its content. Two children wrote to a parent, another couple to their girl or boyfriend, two to a well-sibling, and Grace wrote to Hollie, another member of the group she had not known previously. This example aligns with Grace’s contribution in the philosophy dialogue when, talking about the nature of love, she explains: “If I just met Hollie, we wouldn't know each other lots but as we know each other it [love] gets bigger because our hearts [are] getting more love inside and then finally, we could be friends or something; then we could love each other a lot.”

The *complexity of love* was also seen in contributions such as Wee Cillian’s, when he responded to Hollie’s idea that there are different kinds of love, saying “I agree with Hollie, there’s different kinds of love; you have friends’ love, and you have couples’ love… With friends’ love, you don’t want to marry them but with a couple’s love, you would want to marry them.” This may not appear to focus on care and well-being, but love was considered central to these ideas in that caring is part of love, and vice versa. According to the children, physical manifestations or sensations of love run alongside other emotions. This can be seen when Grace offers, “Say I was playing with Hollie, then you can see we’re starting to love each other. But then, if we’re just standing there, you can’t tell if we’re loving each other, ’cause we’re not playing with each other, we’re not talking about it, not doing any emotions and stuff, playing with each other.” Later in the dialogue she continues, “We don’t only care when things, people aren’t well or stuff because we can care anytime for people. They just need to feel the strength, and actually do it because what care means is that you’re loving somebody and showing respect.” In the art activity, she continued by saying that “even though somebody is different, you can still help each other, it doesn't really make a difference.” The sense that care and love are intertwined was evident in the children’s contributions. The thrust of the dialogues was that care is a duty, and it comes from love. Indeed, the children were firmer than this; they argued that one does not care for someone because they are sick and that we may have a connection to that person. Rather, the message was that care is a duty because we are human beings.

together we are stronger

The complexity of love is related to the theme that *together we are stronger*. Connecting with others was important, with Zoe, for example, stating that “…when they [people] need help, they can get help by [from] grown-ups or someone. Say…that I needed help getting one of my toys, but I was stuck in bed because I wasn’t well, her [Zoe’s sister] would help me so I could feel better.” Here, Zoe was building on previous contributions that suggested the need to demonstrate that one cares, such as Wee Cillian’s comment where he proposes two types of instance when one might evidence one cares such as when someone is being bullied or when someone is unwell: “you do need to do something to show you care ’cause this is showing… you would go and check if they were okay or not. I would go and check if they were okay and if they wanted anything.” Later in the dialogue, he expands, “you know caring for someone, you’re there for them if they’re upset. There’s a couple of ways, actually. You can say if you’re scared to do something, you can encourage them and if they’re unwell, you can look after them.” When making her model to illustrate caring, Grace explained that “I'm going to put my brother in it because I care for him a lot because he's been in hospital and he's getting lots of medicine and stuff. Finally, he's off chemo now. I'm going to be doing my arm around him and his arm around mine, and I'm going to put a love heart in the middle.”

It need not matter that the person who cares or the person being cared for is a relation, for Grace it is that “sometimes… you feel alone and then you just want to be with somebody.” She agreed with Wee Cillian in emphasising the demonstrable element of love and care, that we should “Show love to them [other people]”, but it need not be a family member. Throughout the dialogues the children proposed that care reaches beyond family to friends and even strangers. However, the selflessness that the children seemed to highlight was complemented by suggestions that it is important to “actually care for yourself as well as in helping other people” (Grace).

life is an emotional rollercoaster

When the children created their superheroes with powers to help their siblings, aside from some invented superheroes, one child’s superhero was a hospice team member they see regularly, another was a well-sibling, and two portrayed themselves as superheroes. For each superhero, emotions featured strongly, which contributed to the theme that *life is an emotional rollercoaster*. Rose, in selecting the staff member as her superhero, said that “If you touch her hair, you’ll feel emotions and if cuddle her, you’ll get superpowers. Touch her jeans and you’ll never feel sad again.” King Bob’s superhero also focused on emotions, with him making a distinction between physical health and mental health, saying "mental health is when you get stressed out a lot and you get kind of exhausted. I don't know how to explain it; kind of anger, I would say."

The children spoke more about their own emotions in the art activities that raised issues of their siblings or of visiting the hospice. The superheroes had powers to help their unwell siblings, and the masks the children made related to feelings they might expect other siblings to have arriving at a hospice for the first time. Certainly, the children spoke about feelings that suggested a level of worry, with Grace explaining that "Freya [from the hospice] helps me because I get worried a lot about things, but I could also help other people who are like me who's getting worried because I think I could care for them as well". Wee Cillian, similarly, had his worries, such that when creating his superhero, he gave it the power to "see into the future to stop bad things happening," and his mask had big ears so that "I will listen if you need to tell me anything" but it also had symbols for "joy and happiness." King Bob's superhero also centred around emotions, notably of joy, as did his mask, where he made explicit references to love, saying "joy and then it's love, and then we've got banana. On different planets banana is happiness and joy, and then we've got, it says up there 'join happy.' Then we've got a sign here and it says, 'we love you'. So, if you're new to the Centre, it says 'we love you' to the new people." Zoe's mask also focused on positive emotions, giving it a cross on its nose "because it reminds me of the doctors my brother has," which made her happy.

In the philosophical dialogues, the children spoke more about a range of emotions, though these did not explicitly pertain to their personal lives, and they were used illustratively to exemplify a point being made. Aside from love, emotions included anger, frustration, hate, annoyance, excitement, joy, worry and anxiety. The complexity of emotions can be seen in Grace's comment in one of the dialogues: "Her [her sister] is annoying, so sometimes I feel like I hate her…in the end I love her but, then, when it's the start, I feel like I hate her, but then once it comes altogether, like, when I see her upset and stuff, I go to help her because everybody does care."

When discussing what makes a good life, happiness was central. The facilitator asked Wee Cillian what he meant by 'happy'; he responded that "The definition of happy is when you enjoy doing something. So, I would say, what do you like doing. That's what you call happy. Say I like running around, that makes me happy." Grace agreed that being happy meant doing something one enjoys, such as drawing, but Zoe took this further to explain that doing something one enjoys might make one happy, and that this may offset feeling frustrated or annoyed: "I think happy, see if you're frustrated that someone is trying to annoy you. For example, if I was walking down the road and then someone came up and then they just started yelling at me. I would get frustrated. So, when I go back home, I can colour and stuff. It would make me happier." The things that suggested happiness to the children, in the dialogues and in the art activities were simple. They are happy creating art, playing video games, doing gymnastics, cheer leading and playing football.

being your own person

Being with friends or family was not a strong feature in the dialogues in relation to one's emotions. Indeed, the fourth theme – *being your own person* – explains this somewhat. In the dialogues, Hollie, for instance, spoke about the good life and how there are "too many clubs and stuff". A good life is not about material goods or a full calendar of activities. The children valued quiet time, with Grace building on others' ideas of this saying, "I mostly, sometimes, I just like to get away in the quietness because there's less noise everywhere, like dancing, swimming. I have gymnastics, three classes, so there's noise everywhere really, and then at school." The children agreed, though, that a good life is subjective.

Indeed, the children generally thought that if people all do the same thing it is 'boring', with Wee Cillian suggesting that "Basically, the full world is playing Simon Says… it's basically like someone is bossing you around." Simon Says is a game where the players must do as 'Simon' tells them. Hollie agreed with Wee Cillian, noting that "They [people] have to let you do your own thing… Because you have your own life, and you can choose what you want to do because you're the boss of yourself". King Bob spoke about control, saying, "You can't control everything. You can control some things like your own body, your movement; I can control, for example, my footsteps. I can control my hands, or I can control my head. I can control all of that. But I can't control Wee Cillian, I can't control Alison, I can't control Hollie because they're their own personality. And they're in control of theirself.” Individual personalities being what makes people special was important in the sessions. However, there was some disagreement that one might always want to be oneself, such as when Grace said, “Some people might not want to be their selves because maybe at one point Sophie wants to be as good as Zoe at gymnastics, then maybe that’s why her [she] doesn’t want to be her own life.”

In discussion during the art activities, the children spoke about sharing their emotions. There is overlap, here, with the theme of life being an emotional rollercoaster, but they are also linked to ideas of who one is. Wee Cillian was clear that he did not like talking about sad emotions and Sophie echoed this, saying “well, sometimes not about when I'm feeling sad or anything, but if I'm feeling happy. I definitely would be talking about if I'm happy”. When asked why she was keen to share her happiness, Sophie went on to say “because happy, it just feels more joyful and I really like talking about happy stuff because then maybe if your other friends think it's happy and, if you tell them, maybe they'll feel happy about it if they're sad, but if you talk about sad things to them maybe they'll feel sad for you.” The preference expressed for keeping an element of oneself private was evident in speaking about emotions and feelings, complementing the desire to be oneself in terms of hobbies, interests or even which weather one likes.

discussion

In some ways, the four themes resonate with current literature on siblings of children with LLCs. They focus, though, on something new. While current research focuses on siblings’ experiences, the present project adopted a different approach to explore children’s perspectives on care and well-being. Graham and Fitzgerald’s (2011) claim that children have something to say about well-being was further evidenced by the children in our project.

As with the camps reported by Brennan et al. (2012) and Knecht et al. (2015), the siblings built positive relationships in the sessions and beyond, with the children organising their parents to arrange outings outoutwith the Saturday meetings. The sessions allowed the children to have fun, make friends and be with others like them (Gregory et al., 2022); however, the purpose of our sessions was not to share their feelings or experiences of being a well-sibling. Indeed, the children were clear in their project recommendations that they wanted to be asked if they wished to share what was happening in their lives, asserting that sometimes what happens at home should stay in the home. They did not share the 'emotional turmoil' they might experience at home (Jaaniste et al., 2021); this may have been because the dialogues and art activities did not explicitly invite this.

The children spoke about feelings and emotions in relation to care and well-being, arguably demonstrating the compassion and sensitivity that previous studies suggest exists for well-siblings (Brennan et al., 2012; Lane & Mason, 2014; Fullerton et al., 2017). Love was central to their notions of care and well-being. While self-care was raised as important, the key message was that one has a duty to care for others. This is achieved and demonstrated through love, a feeling that grows and brings people together to demonstrate that they have concern for others' well-being. Well-being, for the children, relates to happiness and joy, emotions that may arise from doing things one likes such as playing computer games, playing football, fishing with a family member or participating in gymnastics such as the children described. However, these are not for everyone; the children were clear, it is important that people have space to do and be what they want to be as this will lead to a fulfilling life, one in which one is well. The children, unlike in other studies (Yang et al., 2016; Gregory et al., 2022), seemed to suggest a clear sense of identity, and one that was not conflated with friends or family members. In fact, the children never spoke about well-being in relation to having unwell siblings; instead, they spoke in more global terms of looking after someone if they are sick, have fallen and hurt themselves or if they are being bullied. The sense of duty for others with respect to care was conspicuous.

While it might be suggested that the children's sense of duty was strong because of their personal lives, and that they put their siblings' needs before their own (Brennan et al., 2012; Knecht et al., 2015), it is not possible to be sure. The moral obligation to care was expressed in terms of love driving behaviour without the children making any reference to personal experiences. It was, though, important that caring is demonstrated, that love is made visible; we must show that we care. And, although the children spoke about various emotions in their dialogues, the key to well-being is found in positive emotions such as joy, happiness and love, all elements that can grow and that allow us to be stronger together. The children recognised that difference is important and that individual personalities should be encouraged, that we should not be 'bossed around' or like the same things, or that time alone is important in busy schedules. However, the needs of others, the building of relationships and having an interest in others' well-being overtook individualism.

practical implications

While it is important that children with LLCs receive the attention they need, their siblings often go unnoticed and, therefore, unheard. The project demonstrated that the group of children with whom we worked were not always heard. Although the siblings were not ignored, time had not been taken, and space had not been created to understand how they think of care and well-being. Assumptions may be made about what this means for children generally and for siblings in particular. However, having a clearer sense of the ways in which children make sense of these ideas offers an insight that will make it easier to ensure their needs are met. It may also support practitioners and families in their discussions with children about their siblings with an LLC by providing a vocabulary for them to begin these conversations. While it is important to explore siblings' experiences, these do not tell the full story. Philosophical dialogue provides opportunities to grapple with ideas that are central to our lives and the way in which we wish to live. This is as true for siblings of children with LLCs as it is for those (adults) with whom they live.

The implications from the study are, therefore, clear. It is of primary importance to make time to listen to and engage children in dialogue about ideas that are central to their lives. Further, knowing that children in the study prioritised love as the key to well-being and that demonstrating love is a sign of caring, practitioners and families might consider the ways in which they conspicuously show love to siblings. This seems like a simple recommendation, and it is not to suggest that the siblings do not experience love from their families and those who support their siblings, but the focus on happy emotions and deliberate acts of love were seen to be important for the children in the study. Being mindful of this, especially in the face of challenging family circumstances, may lead to enhanced siblings' well-being.

To ensure that siblings' voices are heard with a view to enhancing their lives, it is important that practitioners and policy makers consider the places and opportunities they provide for engaging with siblings. This means not taking adult views as a proxy of the child's or assuming we all share what it means to care and be well. It recognises siblings as distinct from their families, including their unwell siblings. Stimulating dialogue with siblings, attending carefully to their thinking and engaging them in meaningful dialogue about ideas that are important in their lives may, therefore, require an element of training.

limitations

As the siblings' families have many demands on them in relation to the child with LLCs, opportunities for their participation were challenging. This meant that of the number of siblings invited to participate, only seven were able to commit to the sessions. This is a relatively small group. However, because the focus was on philosophical understandings of care and well-being rather than individual experiences of care and well-being, the findings may be considered representative of other siblings. Structured, philosophical dialogue allows for a range of perspectives to be shared, and these need not correspond to experiences.

The children also had no prior experience of philosophical inquiry, so this was new to them. With a more experienced group, dialogues may have been longer, thereby offering even richer explorations of the ideas. Ideally, we would have welcomed a few additional weeks to allow some further exploration of the ideas; however, this was not possible within the constraints of the funding or the commitment that families could promise in coming to the venue on Saturdays. The art-based activities, though, were used to extend some of the ideas shared in the dialogues, highlighting elements of these that had been particularly interesting.

conclusions

The project set out to explore notions of care and well-being with a group of children who have siblings with LLCs. While it is important to know about siblings' experiences to advance their well-being, it is also helpful to understand what they think it is to be well and to care. This provides an insight for those who care for and about them. This understanding, as seen through the children's dialogues, illuminates what is important to them in their lives in terms of being well and caring. Arguably, through engaging in philosophical dialogue about well-being and care, as opposed to exploring their experiences, it has allowed an insight into what siblings consider important to a good life, one that has well-being at its core. In their study into siblings' emotional and behavioural trajectories, Tay et al. (2024) conclude that social aspects of siblings' lives are important and that elements such as school community and the family might positively impact on their behaviour. This is helpful advice, though perhaps it misses a step where the siblings are invited into dialogue and where adults listen to what is important to them. These approaches are not mutually exclusive; indeed, they may be complementary.

According to the children, being able to be one's own person without having their identity elided into that of others is important to being well. Having space for one's personality to be recognised helps generate happiness. Happiness, the children suggested, comes from doing things one enjoys and from love, embodying a more eudaimonic view of well-being, something they have in common with participants with chronic conditions in Parkinson et al.'s (2025) study. Love is a more powerful emotion than any other; it brings people together, it makes them happy, it grows with time and familiarity and drives us to care for others. Love can happen without us being aware of it, but care, according to the children, is deliberate and conscious. This was a key driver in considering being well, with the children exhorting that people should demonstrate care and love, not because of a familial relationship or an individual's needs, but because we are human.

As humans, we should care for, look after and love others because that is, according to the children in the project, what it means to live well, to enjoy well-being. To translate this, therefore, into meeting the needs of siblings of children with LLCs, it would suggest that adults perhaps need to be more overt in demonstrating caring behaviour. It may require us to be more explicit about our humanity, showing that we care for *all* and that we attend to eudaimonic well-being when considering what it means to be well. The specific needs of siblings are such that they seek behaviour that is conscious and deliberate with respect to demonstrating love and a desire to ensure their well-being and that of others, with the pursuit of happiness and love being the priority in doing so.

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