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### The value of metaphorical reasoning in bioethics

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# The value of metaphorical reasoning in bioethics: An empirical-ethical study

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### Abstract

**Background:** Metaphors are often used within the context of ethics and healthcare but have hardly been explored in relation to moral reasoning.

**Objective:** To describe a central set of metaphors in one case and to explore their contribution to moral reasoning.

**Method:** Semi-structured interviews were conducted with 16 parents of a child suffering from the neurodegenerative disease CLN3. The interviews were recorded, transcribed, and metaphors were analyzed. The researchers wrote memos and discussed about their analyses until they reached consensus.

**Ethical considerations:** Participants gave oral and written consent and their confidentiality and anonymity were respected.

**Findings:** A central set of metaphors referred to the semantic field of the hands and arms and consisted of two central metaphors that existed in a dialectical relationship: grasping versus letting go. Participants used these metaphors to describe their child's experiences, who had to "let go" of abilities, while "clinging" to structures and the relationship with their parent(s). They also used it to describe their own experiences: participants tried to "grab" the good moments with their child and had to "let go" of their child when (s)he approached death. Participants, in addition, "held" onto caring for their child while being confronted with the necessity to "let go" of this care, leaving it to professional caregivers.

**Discussion:** The ethical analysis of the findings shows that thinking in terms of the dialectical relationship between "grasping" and "letting go" helps professional caregivers to critically think about images of good care for children with CLN3. It also helps them to bear witness to the vulnerable, dependent, and embodied nature of the moral self of children with CLN3 and their parents.

**Conclusion:** Metaphorical reasoning may support the inclusion of marginalized perspectives in moral reasoning. Future studies should further explore the contribution of metaphorical reasoning to moral reasoning in other cases.

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## Keywords

Empirical approaches, ethics, metaphor, neuronal ceroid lipofuscinoses, parents, qualitative research

## Introduction

Metaphors are often used within the context of healthcare, as illustrated by, for example, *the fight against* a disease.<sup>1</sup> Bioethicists, speaking about *balancing* values, or *weighing* several perspectives, regularly use metaphors as well. A metaphor is a transference of meaning between two semantic fields, and a semantic field is a linguistic field of interconnected signs, which is covered by a shared term.<sup>2</sup> For example, *fight* (shared term) includes winning and losing (interconnected signs). Clinically, metaphorical communication may open up new perspectives and coping strategies,<sup>3</sup> and it may improve medical communication.<sup>4</sup> It is useful to examine how metaphors shape actions and thoughts,<sup>5–7</sup> and metaphor analysis may offer insight into relationships between metaphorical and other discourses,<sup>8</sup> which cannot be reduced to each other.<sup>9,10</sup>

Despite their common use and their clinical and bioethical significance, metaphors have hardly been explored empirically. Furthermore, narratives and metaphors both redescribe experiences,<sup>11</sup> and the bioethical implications of narratives have been explored in a variety of ways.<sup>12–16</sup> However, the bioethical implications of metaphors have hardly been examined. The objective of this study is to describe a central set of metaphors in one case, consisting of the stories of parents caring for a child with CLN3, and to explore its implications for bioethical reasoning. In so doing, this study is an empirical-ethical study, in which the moral dimensions of metaphors found in empirical data are articulated and relationships with normative-theoretical insights are discussed.<sup>17</sup>

CLN3 is a neurodegenerative disease that is caused by mutations in the CLN3 gene. Also known as Juvenile Neuronal Ceroid Lipofuscinosis or Batten disease, CLN3 starts with visual decline around the age of 4–8, leading to death, usually during patients' third decade. CLN3 includes blindness, cognitive and motor regression, epilepsy, communication problems, and psychiatric problems. CLN3 patients' behavioral problems include angry outbursts and anxiety, and related complaints, such as depression and sleeping disorders.<sup>18–22</sup> A serious disease of course affects not only patients but also their family members,<sup>23</sup> who may experience sorrow, despair, and distress, on one hand, while experiencing joy, hope, and satisfaction, on the other hand.<sup>24–26</sup> In this article, we will focus on the perspectives of parents, by answering the following research question: how does a central set of metaphors, spontaneously used by parents with a child suffering from the neurodegenerative disease CLN3, contribute to bioethical reasoning?

There has been debate whether often-used metaphors do still count as (living) metaphors or not.<sup>6,10</sup> We see often-used metaphors as metaphors because it is hard to decide when a metaphor is dead or petrified, and more importantly, these often-used metaphors, providing insight into how we understand the world, blur clear boundaries between conceptual and metaphorical reasoning.<sup>10</sup> Even if someone would describe them as templates instead of metaphors, they are worth considering because what “conventional metaphors and templates have in common is that they involve figuring one object or event, or whole domain, through another.”<sup>27</sup>

## Method

Semi-structured interviews were conducted with parents of a child suffering from CLN3. Purposive sampling aimed to obtain variation in participants' gender and stage of their child's disease (diagnosis until after death).

In accordance with Dutch law on Research Involving Human Subjects, this study did not need to be reviewed by an ethics committee, which was confirmed by the ethics committee of the [Academic Medical

**Table 1.** Characteristics of participants (n = 16).

	Mean	SD	Range
Age	50.1	3.3	43–57
	N	%	
Gender			
Female	8	50	
Male	8	50	
Education			
High	7	44	
Middle	5	31	
Low	4	25	
Spirituality			
Non	5	31	
Christian	5	31	
Muslim	2	13	
Other	4	25	

SD: standard deviation.

Center, University of Amsterdam] (W14\_030#14.17.0047). When parents gave permission, their name and address was given to the researchers, who asked eligible participants to participate in the study and gave them oral and written information. Participants gave oral consent and signed an informed consent form and their confidentiality and anonymity were respected. Two interviewers, who had experience in conducting qualitative research, together interviewed them. A total of 16 parents participated in the study. For demographic information, see Table 1.

Each interview started with the open-ended question: “Could you tell me your story and the role that your child with CLN3 plays in it?” Participants were invited to take as little or as much time as they needed. Subsequently, the interviewers explored themes that had been brought up by participants in their stories, and after that, they used a topic list. For the full interview guide, see Supplementary File 1. All interviews were audiotaped and transcribed, and they lasted 1–2 h. The interviews took place at participants’ home, between March 2014 and January 2015, at a time that was convenient for them. The researchers discussed and wrote memos on, for example, interview setting and preliminary thoughts, which helped them to reflect during the research process.<sup>28,29</sup>

Interviews were thematically analyzed and metaphors were analyzed as well. This article focuses on the analysis and results of the metaphor analysis, by presenting a central set of metaphors. Metaphors were analyzed when they could be understood beyond their meaning in context of what was being said: they were seen as transferences of meanings between two semantic fields.<sup>2,30</sup> The identification of metaphors, however, remained an act of interpretation because metaphorical and literal utterance are part of one continuum with a loose utterance in the middle.<sup>31</sup> Therefore, E.O. and B.V. analyzed all interviews apart from each other, and they compared similarities and differences between their analyses and discussed about the differences until they reached consensus. The coded metaphors were clustered on the basis of their referral to the same semantic field.

Participants used a variety of metaphors but amidst this variety, a pattern emerged during the metaphor analysis: each participant used metaphors that referred to the same semantic field, namely the field of the hands and arms, which led to the description of a central set of metaphors. This set of metaphors was compared to the results of the thematic analysis, and the results presented in this article were confirmed during this comparison, which triangulated our findings.<sup>32</sup> For an example of the code tree, see Supplementary File 2.

## Results

Several metaphors, spontaneously used by participants, referred to the hands and arms, and comparing and contrasting these metaphors led to the description of a central dialectic: “grasping” versus “letting go.” Participants used this dialectic to illustrate their child’s experiences and their own experiences, which included their caring experiences.<sup>i</sup>

### *Their child’s experiences*

Many participants described how, due to neurodegeneration, their child had to “let go” of abilities, and how their child “grasped for” continuity. One couple expressed how the neurodegeneration led to their child being forced to “let go” of caring for himself:

He’s cried a hundred times “I’m falling!” you know, but he hasn’t fallen yet. (F7; F = Father)  
Yes, but you have to understand what he’s trying to say. (M7; M = Mother)

It’s “trusting in someone else,” of course. And it’s also what he’s said before, “All by myself!” “All by myself!”  
*But that is something he has to let go of.* So bathing was a big problem, probably also because the lady or the helpers saw him naked, and “only Mom and Dad are allowed to see that.” (F7)

Many participants spoke about their child, who, when facing neurodegeneration, “clung to” structures and thoughts:

You see that a lot with other parents too: their children have so much structure, that *they’re clinging on to structure* [they are completely dependent on the structure], and because *they’re so desperately hanging on to it* [they are so completely dependent on it], life is just a bit better for them. (F3)

Yes, absolutely. (M3)

That’s their—*that’s their only hold* [that is their only stability] in the life that they have, you know. That *they, uh, can keep falling back on* what they have always known and understood. Because that crumbles, you know, then . . . then *each thread that you can grab a hold of, you hang on to it.* (F3)

Well, *he’s very clingy to* [he is very attached to], um, certain things. Santa Claus, for example. That first, um, like over the years, he’s been really obsessed, just like every kid has in the months before. But he’s in the phase that *he actually can’t let go anymore. He’s really clingy* [he is really attached], and um, often when he wakes up, the first thing he says is, “Presents, presents!” It’s always on his mind [ . . . ]. It seems *like he’s holding onto it, like he’s grabbing it.* (M5)

One mother in our study had the idea that her daughter was already aware of her upcoming deterioration at an early age. She expressed how her daughter tried to “grab” the good moments of her life:

I have the idea that at this age [the first years of her life] she’s had the thought: I have to live now, do everything while *I can still grab a hold of the present* [do everything while I still can]. And sure, you get that feeling every now and again. And then you think: wow, she has felt that in one way or another. (M1)

### *Participants’ experiences*

Several participants explained how they “held on to” things, like the possibility of treatments, or the help being offered to them, for instance during the months after the diagnosis:

But if we had told them: “Hey, we’re going for it [an experimental treatment],” then she would have been the first in the Netherlands that would have, um, tried it. (F1)

But then suddenly *you hold on to this little thought*: yeah, if it could really work. But then, if it then does absolutely nothing . . . (M1)

She [my mother] said, “Dude, *grab* [accept] *it* [help offered], because you really need it!” Just *take the advice* from your parents, right?! [everyone laughing] [. . .]. I hope to be able to encourage other people by um, by saying, “Please *catch the help* because you need it so badly.” (F3)

Almost all participants emphasized how they tried to live in the moment with their child: they “grasped” the present with their child and they “squeezed” the most out of things that were still going well, in spite of deterioration:

You see it [the weeks after the diagnosis] as a serious problem, as life-threatening, acute life-threatening problem. So you, so we got this feeling of: we have [emphatically:] now [normal]: *squeezing the most out of it* [get the most out of it]. (F2)

They [health care providers] noticed some declining, that for [daughter’s name] it’s better *to grab a good night of sleep* [have a good night of sleep] again, that she would then . . . But from our perspective we had the feeling of: nice, she’s still able [to sleep over]. Because you want *to hold onto what is going well as long as you can*. (M1)

However, in several stories, the other side of the dialectic, which was the process of “letting go,” became visible as well. Over the course of the interview, one mother addressed this as follows:

[They were] something like: she’s the mother, *she can’t let her go*, she wants to . . . And I kept saying, “That’s not true.” Of course I don’t want her to die, and I don’t want her to suffer either. What mother does [want that]? I mean, you love your child so very much, you don’t want that, and it’s not going to happen. But I wanted them to trust me in this. (M6)

I want to keep caring for her for months still, that’s not what it’s about. But all of a sudden I thought: now maybe . . . maybe she’s already . . . maybe she has already . . . or maybe she’ll get a lung infection or . . . *Maybe then I have to let go a little already*, you know? And then if it becomes really serious really soon, that cough, you know, then we really will say, in the coming week or so, okay, we proceed to sedation. (M6)

## Caring

When their child further deteriorated, participants’ care load increased. Several participants described how their child, while being necessitated to “let go” of abilities, “grabbed” their attention, which limited participants’ freedom:

But at some point I just had the idea that *I was kind of a slave to my own child*, you know? It’s also a bit of dominance, you know, it’s all there, and I hear that from the support group too, something like, *he grabs all of the attention for himself* [he seeks all of the attention for himself], that you have to be careful that you also have time to give the others. (F7)

[And then he also says] “When am I going back to school?” I said, “You’ll go back next Monday.” And then he’s immediately frustrated, saying: “I want to go to school now.” Or, “I want to go to school tomorrow.” *He’s lost his structure, completely*. He’s asking every ten minutes, “What time is it?” Because, sure, these kinds of days are so long. (M4)

Another issue was participants' attitude toward their child's suffering, in which the metaphorical expressions referred to the hands and arms as well. Some parents tried to "keep" their child "away" from the suffering, whereas others expressed their inability to "take away" the suffering from their child:

From the onset [of the illness] I very much had something like from the film "La vita è bella." [...] The man keeps it up through the whole film, *to keep the little boy away from the misery of war* [sobbing]. [...] *Staying away from the drama* from what, um, of what the disease involves, actually. [...] *To keep it away from her*, that is what, that is what the metaphor from the film is saying, to um, how you can do this with your child. (F6)

I think: sure, my daughter has gone through all of it [deterioration and medical tests] and just did it [...]. (F1) She has been so terribly sick and we have learned so much from her. We could only comfort her and provide security, *but we couldn't take away anything* [from the burden]. (M1)

### Sharing the care

Many participants spoke about (partly) "letting go" of the care for their child, which was a difficult process because they wanted to "hold onto" the care for their child:

But they've said [health care professionals]: "Gosh, just bring your daughter a little earlier, because then we can also can get to know her better." *But as parents you want to hold onto your child as long as possible*. But in retrospect we realized: we should have done it earlier. It is so, so important! And that's a natural response, *holding on versus giving up something to someone else*, so that the health care professionals can learn the child better, teaching them, guiding them. (F1)

Sure now, he has all kinds of drugs [sleeping pills] and it can't do much harm. I said: "So, then can we reduce the amount." [Doctor]: "Yes, we're going to talk about this." And this same conversation three times, you know? Then I think, okay, your point is clear. But I'm a parent, you know, *it is just like I'm letting go of everything*. (F7)

Look, the others know him well. But they don't know him as well as we do. So, yes, *we haven't been able to, uh, ever really let him go, like, to really give him over to someone else*. And yeah, that takes sacrifice, of course. (M5)

One father felt sorrow when thinking about the moment of letting his son go and leave him with other (professional) caregivers:

He [F4] *has to let him [son with CLN3] he has to let him, we have to let him go* a little. Otherwise you can't keep going on. (M4)

I had this feeling when I was at [name of institution], sure, I picked him up Fridays, and Sundays I brought him back [to the institution]. So, that's something you definitely don't want to experience, leaving your child somewhere [...]. (F4)

And then he was standing with his fists like this [gesturing], he stood banging on the window, like this, and cried: "Papa, papa, papa!" And then [choking up], then you just have the feeling: I have to get him out of there, because it's just not good. (F4)

In summary, participants used the central dialectic of "grasping" and "letting go." This dialectic consisted of children with CLN3 who, according to participants, had to "let go" of abilities on the one hand, and "clung to" structures, thoughts, and the relationship with their parent(s), on the other. The dialectic also entailed that participants tried to "grab" the good moments in their life with their child, and the necessity of "letting go" of their child when (s)he approached death. In the last place, the dialectic reflected participants'

desire to “hold onto” caring for their child, while being confronted with the necessity to “let go” of this care, leaving it to others, like professional caregivers.

## Discussion

By ethically analyzing the empirical results presented in this article, we will argue that, like Frank proposes in relation to stories,<sup>33</sup> we should think *with* or *in terms of* these metaphors, instead of thinking *about* them. Thinking in terms of the presented metaphors, we will argue, helps to critically think about images of good care and to bear witness to the moral self.

### *Bearing witness to the moral self*

Thinking in terms of the “grasping” and “letting go” helps to think about participants’ moral self. One participant for example expressed: “*As parents you want to hold onto your child as long as possible. [ . . . ] That’s a natural response, holding on versus giving up something to someone else.*” The identity of a parent is here, and in several other quotations, characterized by the dialectic of wanting to “grasp” versus the necessity to “let go.” In this regard, it is worth mentioning Taylor<sup>34</sup> who argued that identities presuppose a certain view on constitutive goods, even when these views remain implicit. We interpret this dialectic in participants’ moral self as a reflection of the dialectical relationship between vulnerability and autonomy, which characterizes the (hermeneutics of) the moral self.<sup>35</sup> For example, the necessity to “let go” of their child reflects parents’ vulnerability, whereas their capacity to “squeeze the most out of the present” reflects their autonomy, helping them to organize their life in accordance with their values.

However, compared to children who grow up and become adults, as it happens, children with CLN3 have to live with ongoing neurodegeneration, which necessitates their parents to “hold onto” their child “as long as possible,” thereby increasing their care load. Furthermore, (the prospective of) losing their child is a traumatic experience for parents, which threatens their view on themselves, others and their world.<sup>36</sup> Thinking in terms of the dialectic of the two metaphors thus helps healthcare professionals to bear witness to parents’ threatened moral self<sup>33,37,38</sup> that is characterized by an intense dialectic of “grasping” and “letting go.” For healthcare professionals this means that thinking in terms of the two metaphors helps them to take into account two sides of the coin: they are encouraged not only to support parents when they experience sorrow but also to support these parents in finding new grip on their lives. In so doing, they acknowledge parents’ moral self, which includes autonomy and vulnerability.

Another participant told how he, during a period when his son went through cognitive decline, felt “a slave” to his own child. He felt stuck by his son, who took a dominant role by constantly “grabbing” his father’s attention. Metaphorical reasoning about this relationship helps to bear witness to the mutual dependency of moral selves and to address power imbalances in their mutual relationships.<sup>39</sup> Practitioners may help parents to find out the boundary between power balance and imbalance. One way of doing so, is that parents videotape situations, in which parent(s) and child interact in their natural environment, and then select fragments that make them feel uncomfortable, and subsequently discuss these fragments with the healthcare practitioner(s). The healthcare practitioner may ask questions such as: What is it in this situation that makes you feel “grabbed” by your child? What could be other ways of dealing with this situation?

Thinking in terms of the presented metaphors also helps to bear witness to the fact that this mutual dependent relationship is embodied because these metaphors referred to a part of the body (hands and arms). Others have also addressed relationships between metaphors and the body.<sup>40,41</sup> This implies that we bear witness to the embodied process of neurodegenerative decline, which necessitates children to “let go” of physical functions, like motoric ones. Second, recognition of the embodiedness of parents’ moral self is important because the increasing care for their child with CLN3 is *physically* and morally demanding labor,



depriving parents of sleep, physical energy, money, leisure time, career opportunities, and so on.<sup>42</sup> In this regard, the word “slave,” used by one of the participating fathers quoted above, is striking because it denotes the forced physical labor slaves had to do because others “held” them under control without “releasing” them. Thinking in terms of the dialectical relationship between “grasping” and “letting go” supports healthcare professionals to bear witness to the needs of informal caregivers, which are easily forgotten when others only pay attention to the seriously ill patient. Thinking in these terms supports practitioners, in addition, to ask themselves (and maybe parents): who takes responsibility for the needs of parents and who is competent to do so?<sup>39</sup>

In summary, metaphorical reasoning, or more specifically, thinking in terms of the metaphors of “grasping” and “letting go” helps to bear witness to the moral self of children with CLN3 and their parents, which is an embodied, dependent, and vulnerable self.

### *Critically thinking about images of good care*

Thinking in terms of the two presented metaphors helps to think critically about images of good care as well. One of the mothers in our study, in the first place, was accused by her healthcare professional of not wanting to “let go” of her child. This reaction of the professional reflects an image of good care, in which the mother should let go of her child. Such a way of reasoning shapes good care as a process that follows a linear stage model, in which acceptance seems to be the last phase. Stage models of coping with loss, however, have been criticized.<sup>43</sup> Our empirical findings, in addition, suggest that parents’ “grasping” and “letting go” reflect an ongoing dialectic during different stages of the child’s disease, which may not have a clear endpoint at all.

Moreover, other studies have suggested that caring for a family member with a neurodegenerative disease is an *ambiguous* process,<sup>24–26</sup> and even seriously ill patients themselves may live with contradicting experiences, like hope for cure and preparation for death.<sup>44,45</sup> Hence, thinking in terms of “grasping” and “letting go” implies that good care should not be seen as a linear and static process, but rather as an ongoing dialectic that, over time, evolves in various ways. Thinking in terms of the presented metaphors helps here to keep in mind a dynamic conception of good care and supports professional caregivers to bring up new perspectives, for example during a team meeting, which is particularly important when the dominant opinion is that the mother “should accept the nearing loss of her child,” reflecting the linear thinking in which acceptance is the normative end stage.

Second, one study described, among other things, ways to compensate deteriorating functions in children with CLN3, including the refreshment of memories and the utilization of tools that support functions.<sup>22</sup> The importance of compensating these functions can hardly be underestimated because it aims at the development of children with CLN3. However, metaphorical reasoning or more specifically, thinking in terms of the metaphors described in this article, we see in Von Tetzchner et al.’s study a one-sided focus on “grasping” of memories and tools.

Thinking in terms of the other side of the dialectic, however, helps us to critically approach a one-sided focus by also focusing our attention on images of good care that support children when they feel sad, for example, when they have to “let go” of abilities or competencies. That is, thinking in terms of the two metaphors adds a second image of good care, namely an image that acknowledges the vulnerability and “letting go” that comes along with a serious disease. Thinking in terms of the dialectic may support practitioners to ask parents questions not only about how their child “grasps” memories and tools and continues doing what (s)he is good at, but also by asking them how their child deals with the losses, if and when (s)he feels sad about these losses, and how the parents respond to their child when (s)he feels sad.

Third, images (of good care) often have historical origins.<sup>15,46</sup> One such historical origin may be Horace’s descriptions of “*carpe diem*,” which means “seize” the day. “*Carpe diem*” in the antique writings of Horace implied the awareness that time was moving fast,<sup>47</sup> thereby reflecting the “*memento mori*,” which

means “remember that you will die.” The parallels with our findings, particularly parents’ focus on the present with their child, are striking: “carpe” literally means “grasp!”, and the imperative “memento mori” and “letting go” both refer to the transience of life.

If these antique backgrounds indeed shape current ideas about good care, including “grasping” and “letting go,” we should be critical so that these ideas and metaphors are not imposed on us.<sup>15</sup> Treating these ideas as moral imperatives may inadvertently force people and may not respect their own views on good care. Contrary to reducing these antique ideas and metaphors to moral imperatives, we should rather reason metaphorically *in terms of* the presented metaphors, in order to open up a variety of images on good care. In that case, they become options to “think with” instead of moral obligations.

In summary, the power of thinking in terms of the two metaphors is that they support critical thinking on images of good care. This metaphorical reasoning implies that both linear (care) models and an emphasis on only one of these two metaphors are approached critically and that they are enriched with other images.

## Conclusion

The results presented in this article have provided insight into a central set of metaphors that describe the experiences of parents caring for a child with CLN3 and the ethical analysis of these empirical findings led to the suggestion to think in terms of these metaphors. Thinking in terms of metaphors may support healthcare professionals to bear witness to the moral self of parents and children with CLN3, which includes autonomy and vulnerability. It also supports them to acknowledge a variety of images of good care. In conclusion, metaphorical reasoning may help to recognize a variety of perspectives, including marginalized ones, all of which enlarges the space of moral imagination.<sup>48</sup>

Evidently, this article had a particular focus, which requires future research that reinforces, reconstructs, or critiques our empirical findings and ethical analyses. The overall value of empirical-ethical studies is that they closely attune to people’s daily lives and language use, and in so doing, they encourage bioethical reasoning that is embedded within daily practices.<sup>49</sup> Our hope is that future studies, together with the results presented here, will contribute to bioethical reasoning on good care. Such reasoning takes into account the needs and capacities of all those involved in the caring process, including children with a serious disease and their parents.

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## Conflict of interest

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Ethical approval

According to Dutch law on Research Involving Human Subjects, this study did not need to be reviewed by an ethics committee (see: <http://www.ccmo.nl/en/national-legislation-dutch>), which was confirmed by the ethics review committee of the Academic Medical Center, University of Amsterdam (W14\_030#14.17.0047). Participants gave oral consent and signed an informed consent form. For details on research ethics, see section “Method.”

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## Note

- i. The translation of the metaphors from (language authors) to English, in participants' quotations, overrode correct English. When this led to unnatural English, the correct English was placed between brackets.

## References

1. Wiggins NM. Stop using military metaphors for disease. *BMJ* 2012; 345: e4706.
2. Kittay EF. *Metaphor: its cognitive force and linguistic structure*. 2nd ed. Oxford: Clarendon Press, 2007, pp. 214–300.
3. Southall D. The patient's use of metaphor within a palliative care setting: theory, function and efficacy. A narrative literature review. *Palliat Med* 2013; 27: 304–313.
4. Casarett D, Pickard A, Fishman JM, et al. Can metaphors and analogies improve communication with seriously ill patients? *J Palliat Med* 2010; 13: 255–260.
5. Coveney CM, Nerlich B and Martin P. Modafinil in the media: metaphors, medicalization and the body. *Soc Sci Med* 2009; 68: 487–495.
6. Ricoeur P. *The rule of metaphor: the creation of meaning in language*. London; New York: Routledge, 2003, pp. 8–48.
7. Sherwin S. Feminist ethics and the metaphor of AIDS. *J Med Philos* 2001; 26: 343–364.
8. Cazeaux C. *Metaphor and continental philosophy: from Kant to Derrida*. New York; London: Routledge, 2007.
9. Johnson M. Philosophy's debt to metaphor. In: Gibbs RW (ed.) *The Cambridge handbook of metaphor and thought*. New York: Cambridge University Press, 2008, pp. 39–52.
10. Derrida J. La mythologie blanche. La métaphore dans le texte philosophique [White mythology. Metaphor in the text of philosophy]. In: Derrida J (ed.) *Marges de la philosophie [Margins of philosophy]*. Paris: Seuil, 1972, pp. 247–324.
11. Ricoeur P. *Time and narrative*, vol. 1. Chicago, IL: University of Chicago Press, 1990, p. xi.
12. Atkins K. *Narrative identity and moral identity: a practical perspective*. New York; London: Routledge, 2010.
13. Charon R and Montello M. *Stories matter: the role of narrative in medical ethics*. New York; London: Routledge, 2004.
14. Lindemann Nelson H. *Stories and their limits: narrative approaches to bioethics*. London; New York: Routledge, 2014.
15. MacIntyre A. *After virtue: a study in moral theory*. London: Duckworth, 2007.
16. Ricoeur P. *Oneself as another*. Chicago, IL; London: University of Chicago Press, 1995.
17. Leget C, Borry P and de Vries R. "Nobody tosses a dwarf!" The relation between the empirical and the normative reexamined. *Bioethics* 2009; 23: 226–235.
18. Adams HR, Kwon J, Marshall FJ, et al. Neuropsychological symptoms of Juvenile-onset Batten disease: experiences from 2 studies. *J Child Neurol* 2007; 22: 621–627.
19. Backman ML, Santavuori PR, Aberg LE, et al. Psychiatric symptoms of children and adolescents with juvenile neuronal ceroid lipofuscinosis. *J Intellect Disabil Res* 2005; 49: 25–32.
20. Kollmann K, Uusi-Rauva K, Scifo E, et al. Cell biology and function of neuronal ceroid lipofuscinosis-related proteins. *Biochim Biophys Acta* 2013; 1832: 1866–1881.
21. Schulz A, Kohlschütter A, Mink J, et al. NCL diseases—clinical perspectives. *Biochim Biophys Acta* 2013; 1832: 1801–1806.
22. Von Tetzchner S, Fosse P and Elmerskog B. Juvenile neuronal ceroid lipofuscinosis and education. *Biochim Biophys Acta* 2013; 1832: 1894–1905.
23. Pelentsov LJ, Laws TA and Esterman AJ. The supportive care needs of parents caring for a child with a rare disease: a scoping review. *Disabil Health J* 2015; 8: 475–491.
24. Pangalila RF, van den Bos GA, Stam HJ, et al. Subjective caregiver burden of parents of adults with Duchenne muscular dystrophy. *Disabil Rehabil* 2012; 34: 988–996.

25. Rallison LB and Raffin-Bouchal S. Living in the in-between: families caring for a child with a progressive neurodegenerative disease. *Qual Health Res* 2013; 23: 194–206.
26. Samson A, Tomiak E, Dimillo J, et al. The lived experience of hope among parents of a child with Duchenne muscular dystrophy: perceiving the human being beyond the illness. *Chronic Illn* 2009; 5: 103–114.
27. Taylor C. *The language animal: the full shape of the human linguistic capacity*. Cambridge; London: The Belknap Press of Harvard University Press, 2016, p. 160.
28. Malterud K. The art and science of clinical knowledge: evidence beyond measures and numbers. *Lancet* 2001; 358: 397–400.
29. Tong A, Sainsbury P and Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007; 19: 349–357.
30. Schmitt R. Systematic metaphor analysis as a method of qualitative research. *Qual Rep* 2005; 10: 358–394.
31. Sperber D and Wilson D. A deflationary account of metaphors. In: Gibbs RW (ed.) *The Cambridge handbook of metaphor and thought*. New York: Cambridge University Press, 2008, pp. 84–105.
32. Armstrong SL, Davis HS and Paulson EJ. The subjectivity problem: improving triangulation approaches in metaphor analysis studies. *Int J Qual Meth* 2011; 10: 151–163.
33. Frank AW. *The wounded storyteller: body, illness, and ethics*. 2nd ed. Chicago, IL: University of Chicago Press, 2013, pp. 20–25.
34. Taylor C. *Sources of the self: the making of modern identity*. Cambridge: Cambridge University Press, 2006.
35. Hetteema TL. Autonomy and its vulnerability: Ricoeur’s view on justice as a contribution to care ethics. *Med Health Care Philos* 2014; 14: 493–498.
36. Janoff-Bulman R. *Shattered assumptions towards a new psychology of trauma*. New York: The Free Press, 1992.
37. Charon R. *Narrative medicine: honoring the stories of illness*. New York: Oxford University Press, 2006.
38. Olsman E, Willems D and Leget C. Solitude: balancing compassion and empowerment in a relational ethics of hope. An empirical-ethical study in palliative care. *Med Health Care Philos* 2016; 19: 11–20.
39. Tronto JC. *Moral boundaries: a political argument for an ethic of care*. 2nd ed. London: Routledge, 2009.
40. Lakoff G. The neural theory of metaphor. In: Gibbs RW (ed.) *The Cambridge handbook of metaphor and thought*. New York: Cambridge University Press, 2008, pp. 17–38.
41. Olsman E, Duggleby W, Nekolaichuk C, et al. Improving communication on hope in palliative care. A qualitative study of palliative care professionals’ metaphors of hope: grip, source, tune, and vision. *J Pain Symptom Manage* 2014; 48: 831–838.
42. Kittay EF. *Love’s labor: essays on women, equality, and dependency*. New York: Routledge, 1999.
43. Corr CA. Coping with dying: lessons that we should and should not learn from the work of Elisabeth Kübler-Ross. *Death Stud* 1993; 68: 487–495.
44. Olsman E, Leget C, Duggleby W and Willems D. A singing choir: Understanding the dynamics of hope, hopelessness, and despair in palliative care patients. A longitudinal qualitative study. *Palliat Support Care* 2015; 13: 1643–1650.
45. Sachs E, Kolva E, Pessin H, et al. On sinking and swimming: the dialectic of hope, hopelessness and acceptance in terminal cancer. *Am J Hosp Palliat Care* 2013; 30: 121–127.
46. Gadamer HG. *Wahrheit und methode. Grundzüge einer philosophischen hermeneutik* [Truth and method. Outlines of a philosophical hermeneutics]. Tübingen: Mohr Siebeck, 2010.
47. Barber D. Presence and the future tense in Horace’s odes. *Class J* 2014; 109: 333–361.
48. Fesmire S. Morality as art: Dewey, metaphor, and moral imagination. *Trans Charles Peirce Soc* 1999; 35: 527–550.
49. Lindemann Nelson H, Verkerk M and Urban Walker M. *Naturalized bioethics toward responsible knowing and practice*. Cambridge: Cambridge University Press, 2009.