

Supplementary File 2

An Example of the Code Tree

Quotations	Metaphors	Source domain
M1: "She went on holiday [with health care organization]. But it was very difficult to let her go in that, you know? Because you also, they walk with a walking-stick, and she feels little, and she regularly had bruises."	let her go	hands / arms
F1: "We heard her screaming and crying." M1: "Yes, and when that happens, she couldn't grab it [what happened to her], it made her feel insecure, and she started screaming again and tried to grab it, powerlessness, you know."	grab it	hands / arms
F2: "You know what will come, but nevertheless I block that. You still hope against hope, that it won't happen." M2: "That it isn't true." F2: "Probably that's something to protect yourself."	block future (of neurodegen./death)	?
F3: "In the end, you see, that because of her deterioration, she clings to her younger sister."	cling to	hands / arms
M3: "It's just very important that they have a regularity. You've got at home, you know, all kids have that, you've got rules. But for them that's so important because if you don't have rules, they will totally derail."	derail	road / way
M3: "The holidays at home, that's a disaster for these children. Because they don't have a hold, they have their holidays. Well, if there is holiday in summer, six weeks, well, it's impossible to deal with them." F3: "Then they feel, they feel really disoriented. Then, they are really annoying, because they don't have their straw to clutch at."	child's hold / straw to clutch at (structure)	hands / arms
F4: "[The doctor said:] 'Well, thankfully it's no tumor but we did find something in his brains.' [pause] Well, then your world already collapses totally, because you know something is wrong."	world collapses	devastation / demolition
M4: "Well, the only hold we have is to stay together and fight to reach the best for our child."	hold; fight	hands / arms; fight
M5: "There has always been a support group here, for parents. Well, and there is another couple [privacy: with a child with CLN3]. Those people cheer you up, you know, they're partners in distress. But you also hold onto the child himself, you know: he has always been very happy and enthusiastic."	hold onto (time with) my child	hands / arms
F5: "You need to recharge your battery, is what I always say. (...) For me it's work (..) [and for my wife it's] the social things with others, her friends she spends time with."	recharge your battery	energy (electricity)
F6: "I've also sometimes thought: I need to look further than her death."	look further	eyes / vision
M6: "She got all sorts of symptoms, which showed that mentally she wasn't that sharp anymore. So her little sister exceeded her."	exceed	way; speed; game
F7: "I was thinking: isn't there another possibility of being in control again because we had let go [literally: out of our hands] the control a bit [by letting professionals take over the care]. (...)" M7: "I was thinking: I really want to do the care myself because his life is so short."	letting go [out of hands] versus control	hands / arms
F7: "Well, reading aloud, offers him a lot of grip. You start with that, reading aloud these little books, and then sometimes he laughs and is having fun."	offers grip	hands / arms
M8: "[Sorrow and sadness after the diagnosis] Our eldest son was living on his own, my husband was only running outside (...). And then I thought: I'm not only losing one of them [our daughter with CLN3], but my whole family."	losing my family	hands / arms ?
F8: "The first blow [diagnosis] is always difficult, but after that the other things [of the disease] come slowly."	blow	violence (and hands?)