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# 5 Supplementary Materials

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# 8 Table 7 :Translation table of metaphors from original studies

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| Storyline 1 | My children will carry out everything for me: Trust dependence and importance of family |
| Descriptor metaphors | In vivo Metaphors |
| Basically, you have to take care of me Importance of family | **Reciprocal** *Q1. I give them love so they will do the same with me (12); Q2. There was a common understanding among families that if a family member became sick, especially an elder, the family/children would naturally take care of them (13):Q3. ‘‘Since I am the mother of my children, I think they will honor my wishes completely’’; ‘‘Children will honor our wishes .. . as a filial duty.’’(5) Q4. For me, if I go to the hospital and something happens to me, I can always hope .. . and depend on my children .. . I decided that my life is with my children (6) We have a good value system within our families and they are not worried that their families will not take care of them.(13)*  Refutational ( distrust in children) *Q1 If I have property, I may really think they are just contemplating how to get my property after I die (11)* |
| My family will do right by me  Trust in family for care and decision making | Q1. *‘‘I will depend on my children. I trust my children the best. Even if my children make a decision to take off the oxygen mask, I believe they made a decision in order for me not to be in pain. That is why I would like to let my children handle everything.’’ (5) Q2. ‘‘I have to let them do whatever they want to do. How can I direct them in what to do when I am dying? I am going to let them handle it.’’(5) When something happens to one of our relatives, I just highlight things that have happened. I don’t think it is necessary to bring up the topic with the children out of nowhere (11)* |
| They will know what to do  Trust in family’s decision making | *Q1. No I never thought of discussing my death... My family lives with me, and according to them, they know what to do (10) Q2. “I did not have a speciﬁc conversation with them, but they know what I want.” “My people will take care of me. They know.” [Leader: Well, have you talked to them?] “No, but they know what is best for me.” (3) Q3. “We haven’t discussed it, but I know that at the moment that it has to be done, he [her son] will make that decision.” (2) Q4. “My daughters will make those decisions when the time comes.”(3) “When anyone in the family is faced with a difficult situation, everyone intuitively knows what their role is and what to do, and then right decisions are just made without us planning ahead.”(13) Q5 ‘‘As a ‘dori’ [obligation] of the children, she may decide to put me on a ventilator .. . I will allow her to do it, but ask her not to put me on a ventilator for more than 3 days. In the relationship between parents and children, children may not want to let their parents go. That is why I suggested it the way I did.’’(5) Q6 No. I did not. I have my children with me to decide. When the stage comes, I will tell them about my preferences. When I go to their house, I will tell them that I want to go back to India and die, like my husband (10) Q7 My family will make my health decisions, but we have not talked about it.(13) Q8 MV: Have you spoken these decisions to anyone? Malar: No. I never spoke [laughs]. I used to keep it in my heart. I did not tell my daughter. Yesterday, I gave some money to them and told them to keep the money, and If anything happens to me, they should use that money. MV: So, you made some decisions? Malar: No. I did not. I* |

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|  | *have my children with me to decide. When the stage comes, I will tell them about my preferences. When I go to their house, I will tell them that I want to go back to India and die, like my husband.* |
| If you designate others instead of designating the eldest son, it will cause trouble.’’  Family Roles | Reciprocal Q1 *“The belief system and the culture is that you marry a family. You give away your daughter. So when you give away your daughter, she's no more your own. She now belongs to that family. Your son stays with you, is a part of your family. So when the situation like a terminal illness comes, you expect your own to take care of yourself. So that means, sons should take care of you, not someone who is now a member of another family (8) Q2 'Who's going to look after us?' It's very selfish for us to expect that our children will come or move closer to us just to take care of us. At the same time, we expect that they should be there when we need them (8)*  Refutable ( awareness children may not be there for them) : *Family rarely together* (4) |
| Storyline 2. | No Mum, don’t talk like that; Burden and Protection |
| If I talk about it they will suffer.  Protection of children Burden on children | *Q1 “I can’t talk to my family about this.” “My children probably wouldn’t want to listen about this.” (3) Q2 I don’t know when I am going to die. Whether I will be here or in India at the time? Yes. It is good to plan these things, but it would be better to start planning now, although it may not be a good plan in the future. But I don’t want to discuss anything now. MV: OK? Yes, because, my daughter is getting married this year. So I don’t want to upset her (10) Q if we suddenly talk it about it to the children when nothing happens yet, it just kills the mood of everyone (11)* |
| No Mum don’t talk like that  Attitudes of children | *Q1 “They don’t want to hear us.” One woman said her daughter spent two years crying because she, the mother, was sick. She said when she “specified everything,” her daughter did not want to listen. Another woman explained how her own daughter did not want to hear: She’s like, “Don’t speak to me about that.” I said, “What do you mean don’t speak to you about that? I already turned 70 years old. (2) Q2 “We’re all educated, but we don’t want to talk about that [end of life] . . . Mom and Dad are not going to die.”(2) Q3‘‘When I tried to talk about this topic, my children were not willing to listen to me. They said, ‘Mom, please do not talk about such things.’’’ Yet another participant commented: ‘‘When I talked about it with my children .. . they told me not to talk about it.’’(5) Q4‘My children asked me why I am already planning for death. They told me that they hope I would live for a few decades more. If I talk about death, it frustrates them, so they do not want me to talk about it.’’(5) Q5 how their family had asked them not to ‘think about it yet’,(10) Q6 No. I try to talk to my son. But he does not like to discuss these things. He says that you have only turned sixty. He is soft*  *and he is a completely diﬀerent type of child. He doesn’t want to discuss things related to death. He doesn’t even want to listen(10) Q7 So you don’t discuss anything with your family then? No. They’re not interested. They won’t want to. They see me the way I am, and won’t understand why I’m thinking about things that haven’t happened yet(10) Q8 “When I anticipate any unfortunate scenario, I*  *am immediately told to shut up and not to dwell upon it, so we don’t prepare for problems, we just face them.”(biondo) Q2 Wealth vs*  *health: “When I fall ill, I make sure that my finances are in order, so that my family doesn’t fight over it.”(13)* |

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| Storyline 3 | I leave it in God’s hands; Spiritual reassurance |
| I leave it in God’s | *Q1 I left the hospital ...I didn’t go to see anyone. I left and went in a church that was open. And the only thing I decided to do was* |
| hands | *speak with God. I told him you are the doctor of all doctors. Give me health. Thank you. But if not, make wise decisions about my* |
| Spirituality & | *life. (2) Q2 In my family, they’re all Christians, Evangelicals, and if ... someone in my family were in a coma ... we say that removing* |
| Religosity | *someone from life support is killing them and we believe that God gives life and God has to be the one to take it away .. .(6) Q3 ‘If you* |
|  | *are God-fearing’’ and=or ‘‘a true believer’’ .. . ‘‘you will wait on the Lord.’’(7) Q4 Those who ‘‘believe’’ do not ‘‘hasten death’’ through* |
|  | *the use of advance directives and hospice care plans.(7) Q5“I don’t want those machines ...If I am sick, I want God’s will to be done.”* |
|  | *(2) Q6 God would “take care of everything” if they were to fall ill or something “bad” was to happen: Faith in God is a strong factor* |
|  | *due to which we don’t take care of our death and health plans (13) Q7 stated “God gives you the sickness and he gives you the* |
|  | *health(15) Q8 “Dios tiene el control y el me lo da ami” [God has the control and he gives it to me]. (15 God can give us some control)* |
|  | Q9 “I don’t worry about when I’m going to die. I’m prepared to meet my maker.”(1) |
| I will go when it is time to go - Fatalism | Q2 “I live in life’s terms. If it happens, it happens,” (12) I don’t know about these things |
| We don’t talk about those things  Not speaking the negative into existence Better not discussed/preferences for disclosure | *Q1 Maybe it’s just a taboo ...it gets transferred down to generations. We don’t talk about that. Mami is going to die, my Papi is going die and that’s it. We’re not going to talk about that.(2) Q8 We cannot speak of bad things or else we shall make them happen. We don’t plan for death and it is not discussed in our family. We are brought up in such a way that death is not discussed. We don’t like to think that anything will happen to us and, therefore, fail to plan our health decisions. (13) Q9 You know, we talk about this, you’re going to bring it on. I’m going to walk outside, I’m going to keel over.(2) Q2 another woman expressed that she is just like her mother. “I’m like Mom. Leave me alone. I don’t want to talk about that [end of life].” (2) Q3 ‘‘I don’t think it would help at all’’ ‘‘there is really no need to talk about it or plan for it.’’ (7) Q4 We don’t plan for death. Today, it is highly unusual for me to be talking about death (10) Q5 MV: Could you tell me why you do not like to talk about such topics? I think you don’t want to die. You know (laughs) you don’t want to die, or even think about it. MV: If not, what will happen? ‘My children will carry out everything for me. MV: Is it belief or expectations? ‘It is trust’(10) Q6 I don’t think people ask where you die. I think the family makes that decision (10)*  *Q1 It is not a trend in our society to discuss ACP, it is so alien to their minds.(13) Q2 We have never heard about ACP before, even our doctors have never told us anything about it.(13)*  It’s called hiding (too busy to think about this)  *Q1 discussing the experience she had with a life threatening illness, explained, “In order for you to have a united family and a happy family, you have to sacrifice yourself.”. One participant observed, “This is classic of the Latino family, the hiding.” (2)* |
| Refutable  I have already told my son about insurance policies  ( some have had planned discussions | *Q1 “If I do have to go in the hospital, I’ve already told my son what I want done; he knows everything. He knows about my [insurance] policies.” (1) Q2 “I’m going to make sure I have enough money to have a decent funeral when I’m gone. My wife [and them] won’t have to worry about paying it. I got it all taken care of.”(1) Q3 “I decided everything and discussed it with them [her children] and I put my two sons to be contacted in case I can’t do or talk.”(2) Q4 ‘‘Isn’t a last will and testament the same thing?’’ (6) Q5. I have my will, which states clearly how I want to have everything arranged after I die. I have a life trust to arrange the distribution of my property.”(11) Q6* “I have already written a [living] will, if I really have an incurable disease, I have my attorney |

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| and have been clear about their wishes) | write it down in my will already, I don’t want any resuscitation, and I have told my family about it already.”(11) *Q7 “[O]ur children need to know what we think. It’s our own business, our decision. Just tell them not to prolong [our life] or procrastinate [our death]”—(11)* |
| I don’t want those machines ..if I am sick | ( 2)  *Q1 “I don’t want any tubes or anything to preserve my life. If I have to go, let me go. Let me go, if it’s time to go. Don’t try to save me. And I’m ready to go if today is the day.”(3) According to one Latino participant,*  *I wouldn’t want extreme measures. If .. . it’s a quality of life issue, it’s not just how long you live, it’s .. . how alive are you? ( 10) One participant described a compromise, whereby she would allow her daughter to request life-sustaining treatment, but only for a very brief period: ‘‘As a ‘dori’ [obligation] of the children, she may decide to put me on a ventilator .. . I will allow her to do it, but ask her not to put me on a ventilator for more than 3 days (5) Our children need to know what we think. It’s our own business, our decision. Just tell them not to prolong our life or procrastinate [our death]”—Mandarin-speaking woman (11) Not wanting to be “on machines for weeks” (13)* |
| Role of HCP | *Q1 No he did not say anything to me or my husband. But, because he too was not able to speak English, the doctors might have been able to discuss this with my children. But they did not tell us because we felt very bad. But from the way they spoke and their faces, I was able to understand that my husband was serious. But he did not know what the doctor said (10) Q2 “I did not [have a conversation with my doctor] because I am still in good health. So my doctor never say, hi, you have high blood pressure, what do you want to do when you are dead or whatever? So I never talk to her about that.”(11)Q3 “My doctor never asked me, so I never brought it up.” “The doctor should bring it up.”(3)* |
| Storyline 4 | Who’s going to look after us? Ambiguity and Change |
|  | Benefits of acp  *Q1 ” “I think maybe, if a group of people in our community could get together and tell us [that would be helpful]. I’ve learned a lot about what to do [when faced with death] from the people in this group today.” (1) Q2 It’s a good idea (3) Q3 Maybe you can have .. . like you have diabetes class, maybe you want to have a class for this [advance care directives] where you get ten or twenty people in the same place with somebody who’s knowledgeable (6) Q4 I went in .. . a couple of weeks before to have the pre-op .. . and they gave me those papers to sign and bring back with me. I brought it back with me but I didn’t have them signed ... the nurse told me that ‘‘we can’t do nothing until you sign those papers.’’ My step-daughter was with me, so I signed her because she had to wait for me anyway ( 6) Q5 ‘I think my children will follow what I direct them to do in a written document ... I have to state what I want in advance. That way, they will honor my wishes.’’(5) Q6 I don’t want my family making decisions for me at the end. The reality is, if the doctor decides to take me off the machine, then I die. I don’t want them [family] to keep me alive just because they don’t have the courage to say ‘‘pull the plug.’’ I’m putting it in writing so there will be no questions about what I wanted. White participant in (7) Q8 “Such a great thing we are doing by bringing this awareness and that more should be done.”(13)* |

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