

Exploring the meaning and practice of 'family' for young people when a parent is at the end of life



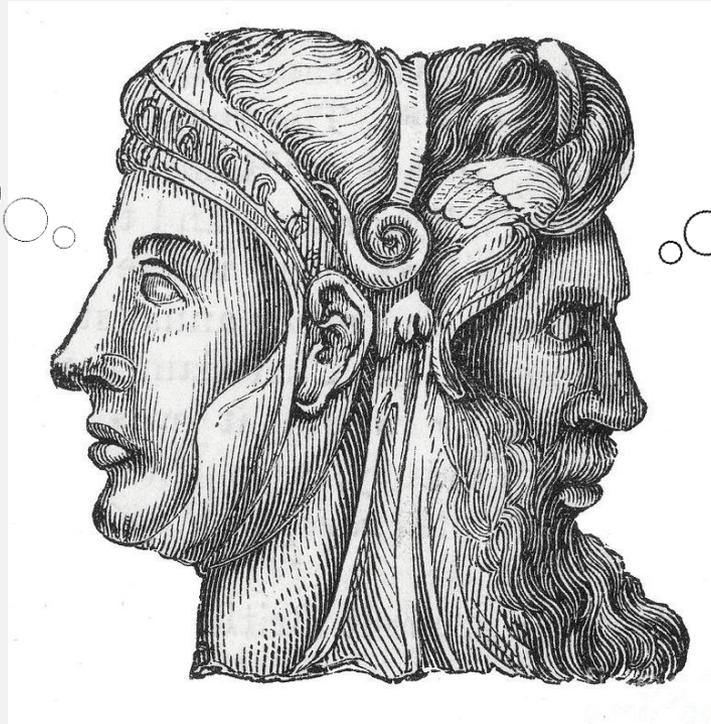
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Family Troubles, Care and Change

1. Meanings of 'family'
2. Changes in practices of care
3. Responses to change

**'doing
family'**



**'doing
death'**

death in / and the family

Conceptual tools

1. change, including death is 'normal'
2. living with dying, not living with death
3. care as a lens to explore 'doing family'

Study design

Semi-structured interviews with 10 young people

- age 13 -21
- 7 male, 3 female,
- 9 mother with illness, 1 father with illness
- 9 parent with cancer, 1 parent with MND
- 5 living with both parents, 5 living with one parent

1. Meanings of 'family'

My Mum's illness has obviously like brought us closer, and my friends obviously mean a lot to me, but my family will always be there.

(Ellie, 16)

Obviously with everything with my Mum we've been through a lot, which I suppose in certain senses has brought us closer as a family.

(Luke, 18)

‘being there’

I guess it's just, they'll always be there for you. I know that if I have a problem I can text my cousin and she'd, if she needed to be here, she'd be here, however long it takes.

(Lauren, 21)

I feel like I need to be there for both of them, my Mum and my Dad.

(Elliot, 18)

They're from [nearest town] but...I get the impression that they don't care that much. We barely ever see, barely ever hear from them.

(Luke, 18)

There's my Mum's side where, you just get the opinion that they don't really care. Her Mum hardly rings and never comes...She's only got a couple of years left in her and she wanted them there, but they, they just don't care.

(Dan, 16)

We're a bit weird I guess...Erm, yeh, it's strange to think about maybe how the dynamic of the family has changed.

(Elliot, 18)

It is strange, yeh. When we were growing up, there was always a safety net. Mum was always the safety net, you know.

(Lauren, 21)

2. Changes in practices of care



A 'proper way' to care for the dying?

Before Mum, yeh, had got the cancer it was quite different. For one, we didn't see even half as much of my Dad as what we do now; not even half, cos he'd be always at work...It immediately changed from that cos afterwards, Dad was never working. Within a few weeks my Mum had had her operation and my Dad was doing all the looking after us and that.

(Matthew, 20)

My Dad helps out quite a lot with [my Nan], but he's turned round and said that he can't cope with keep going down there with everything that's going on at home, so when I go I do stuff for her, like help with her shopping. (Dan, 16)

My Mum obviously does help [my Dad] a lot more. She's got a lot of experience in care, you know. I'm trying to take on a lot more chores than I had before to free my Mum up time to do what she needs to do. (Elliot, 18)

I would wake up earlier, have to make everything myself, find things, find my Mum's medicine then make my Mum's food. Wake my Mum up, give it to her, then leave for school. I'd wake up about half five, maybe a bit later, to get my Mum's stuff ready as well. Then come back from school, do all the chores really.

(Jay, 17)

I'll sit on the sofa and the TV will be on or music will be on or something, and she'll sleep and I'll just sit there and play on my phone or watch the TV or whatever's on. If she wants something, if she wants an ice lolly I'll get it, or fizzy water or whatever. Obviously as it's got more severe, she's sleeping say twenty-two hours a day. If she needs anything I'll be there.

(Lauren, 21)

Children first?

‘This is not merely a guideline for action, nor is it open to negotiation; it is an unquestioned and unquestionable imperative’

Ribbens McCarthy, Edwards and Gillies (2000:789)

Caring for children / caring for the dying

My Dad has two things on his mind. There's thinking about Mum and there's thinking about his mum, so it's a lot to deal with. Yeh, his mind's in two places and then...and then he realises he's got four kids and then he realises, 'Oh I haven't got time for them. What do I do?'

(Dan, 16)

3. Responses to change

I'd say I've just become a lot more cautious, you know, offering...I just offer my help a bit more and just, you know, try and take a more active role and start cooking for myself and stuff. I think...just trying to probably take up a more adult responsibility.

(James, 18)

‘Getting on’

I don't see it as I need the support kind of thing, so I give as much support as I can give and I get on with it.

(Luke, 18)

I'll just get on and do what I need to do

(Jess, 17)

I figured that, if I kept going and kept doing as best I can at school, that's one less thing for my Mum and Dad to be worrying about.

(Matthew, 20)

Conclusion

1. 'family' = being present + available to care

2. caring for children \leftrightarrow caring for dying

3. care of others  care of self



Caring to the End

Exploring the family
lives of young people
with a parent at the
end of life