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TITLE

PALLIATIVE AND END OF LIFE CARE FOR A CHILD: UNDERSTANDING PARENTS' COPING STRATEGIES

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Short title: Parents' coping at end of life

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ABSTRACT

Aim

Understanding of coping strategies that parents use before the death of their child is crucial, and will enable us to best provide support. The current study aimed to explore parents' coping strategies, and map these onto an existing theoretical framework.

Methods

Bereaved parents and parents of a child with a life-limiting/threatening condition were interviewed to investigate coping strategies, recruited through Intensive Care Units (2 Neonatal, 2 Paediatric, 1 Paediatric Cardiac), and a children's hospice. Analysis focused on coping strategies, and mapping these onto the framework.

Results

24 parents of 20 children were interviewed, and identified Parents use a variety of coping strategies (n=25) such as humour, staying positive, advocating and staying strong for others, expressing emotions and preparing, while also living life to the full, supported by others. The themes were successfully mapped onto the theoretical framework, which focuses on the constructs of approach and avoidance, as well as coping for self and others.

Conclusion

The findings have provided a detailed account of the breadth and depth of coping strategies parents use, including those classed as avoidance. The strategies were successfully mapped onto the theoretical framework. Future research should investigate changes over times, and associations to negative long-term outcomes.

KEY NOTES

- Very little is known about parents' coping strategies before the death of their child.
- A wide range of coping strategies were identified, as well as the importance of coping strategies often classed as avoidance.

- Accepted Article
- The overview of the coping strategies can be used in clinical practice to support end of life care and advance care discussions.

LIST OF ABBREVIATIONS

EOL: end of life care

NICU: neonatal intensive care unit

PICU: paediatric intensive care unit

CICU: cardiac intensive care unit

HCP: health care professional

INTRODUCTION

Many children with complex and life-threatening or life-limiting conditions are living longer.(1,2) A significant proportion, however, still die. Caring for a child with a life-limiting illness encompasses nursing, technical and emotional tasks, communication with health professionals alongside routine childcare,(3) paired with disruptions in roles and routines.(4) Parents will need to employ a range of coping strategies to manage their child's physical deterioration, come to terms with the news of their child's poor prognosis and to confront the reality of their child's eventual death.

By increasing our understanding of the coping strategies that parents use under such challenging circumstances, we can better support families, which in turn will enable better outcomes before and after the child's death.(5) Understanding coping strategies is important as they may be amenable to psychosocial interventions and therefore present an opportunity to improve support to parents and families, as well as guide pre-death risk identification.(5,6)

Current evidence about parents' coping strategies with a child at end of life (EOL) is scarce. Parental adjustment and coping with having a child with a chronic illness (e.g.(7) or bereavement is well described (e.g. (8). However, little is known about parental coping as their child health status declines and they are faced with their child's death.

Recent studies have started to describe the different coping strategies that parents use to process and deal with the reality of their child's imminent death. Studies for example have shown the importance of the parenting role,(9) holding the fort,(10) 'being a good parent',(11) keeping positive,(12), hope (13), suppressing emotions, and seeking support.(14) However, the majority of studies were not designed to explicitly explore coping strategies but rather to explore experiences and changes over time.

The premise in the current manuscript is that the gradual recognition of the child's death requires a range of coping behaviours and cognitions from parents. Traditional models of coping may not adequately describe patients and caregivers unique experiences.(15,16). In a current theoretical framework,(16) the constructs of approach and avoidance are centrally important: it is posited that avoidance, while often characterised as a negative coping strategy,(17) allows parents respite from the cognitive and emotional burden.(18) The hypotheses are the following: 1) parental coping under these circumstances is exemplified by avoidance and as well as approach focused coping, 2) parents employ

coping strategies for themselves as well as for others, and 3) parents employ several coping strategies simultaneously.(16)

The aim of the current study was to interview parents to explore coping strategies. In addition, the current study aimed to map the emergent themes from the interviews onto the existing theoretical framework of parental coping with a child at end of life.(16)

METHODS

A qualitative interview study was carried out with bereaved parents and parents of a child with a life-limiting/threatening condition, and health care professionals (HCPs) to explore experiences of quality of EOL care, organ and tissue donation and coping strategies. In this manuscript, findings about parents' coping strategies are reported. Methods of the study have been reported elsewhere in additional detail.(19) Parents were interviewed individually. In addition, focus groups and individual interviews (where participation in a focus group was not feasible) were carried out with HCPs. Participants were recruited through two large academic hospitals and a children's hospice in the UK, specifically via: two neonatal intensive care units (NICU), two Paediatric intensive care units (PICU), one children's Cardiac intensive care, and a children's hospice.

Participant selection and recruitment

Parents whose child had died in 2013 or 2014 (with a small number in 2011 and 2012) were identified through the clinical teams. Parents were excluded if there were particular issues raised about the child or family (e.g. difficult interactions with the clinical team, court cases or other difficulties that were sensitive). Parents identified were sent a study invitation letter and a participant information sheet. Every effort was made to avoid contacting parents near significant dates such as birthdays, and Christmas. If parents were willing to consider being involved in the study they could return a reply slip, contact the researcher by e-mail/phone, or contact the identified nurse specialist on the given unit. A positive response was followed-up by the researcher. Parents were given at least 24 hours to think about participation.

Key HCPs from a variety of backgrounds (e.g. consultants, nurses, family support workers), were approached. HCPs were asked to participate in a focus group discussion (organised around team meetings - to increase participation), or individual interviews. Purposive sampling was used to include a wide variety of clinicians, with adequate representation from doctors and nurses.

Procedure

Parents were interviewed by telephone, by experienced practitioner researchers, a method previously used with bereaved parents.(20) Consent was gained at the start of the interview, by parents verbally consenting to a series of statements, which were audio-recorded. Parents were asked about their coping strategies (*Could you tell me how you managed/coped/dealt with everything during that time?* Including further prompts). The interview schedule and topic guide was developed based on the current literature and the team's clinical and research expertise. An appropriate HCP was available for support if parents became distressed. HCPs were interviewed in focus groups facilitated by two researchers, and individual face-to-face interviews.

All interviews were audio recorded and professionally transcribed. Ethical approval was gained through the University of Southampton, the UK Integrated Research Application System (IRAS; 15/SC/0492), the children's hospice ethics committee, and hospital R&D departments.

Analysis

The data were organised using Nvivo software (21) and thematically coded (22) by two members of the research team independently. A preliminary coding list and a master code list were developed inductively. Codes were grouped and compared and themes agreed, evaluated separately by a third member of the team. An audit trail of all meetings, review of coding notes and iterative discussions were used to enhance rigour. As a second stage, codes were mapped onto the theoretical framework focused on parents' coping .(16) This framework (Figure 1) contains four quadrants that are guided by four dimensions, which two sets of dimensions that represent two ends of a continuum: Approach versus Avoidance, and Coping for Self versus Coping for Family (family/friends- representing the social dimension of coping). Each quadrant represents particular coping strategies. In Figure 1 the themes of the current study have been mapped onto the Framework. In addition, HCP codes were compared with parents' codes in terms of overlap, and additional codes identified and described.

FIGURE 1 ABOUT HERE

RESULTS

Participants

Parents

104 parents were approached to participate, 39 (37.5%) from NICU, 39 (37.5%) from PICU, 10 (10%) from CICU and 16 (15%) from the children's hospice. Seven parents were approached while their child was alive, and the majority of participants were bereaved parents. Twenty-six parents of 26 children (25% response rate) indicated that they were potentially interested in the study. A total of 24 parents of 20 children were interviewed: 21 bereaved parents and 3 parents of children with a life-limiting/threatening condition. Seventy percent were mothers, and seven fathers were interviewed. Children had a range of diagnoses, such as a brain tumour, spinal muscular atrophy, preterm birth with brain damage and cerebral palsy, and congenital cardiac conditions (details in (28)).

Healthcare Professionals

41 HCPs were part of either one of the four focus groups or one of the three individual interviews. Focus groups were carried with 1) critical care nurses, 2) critical care physicians, 3) palliative care HCPs and 4) hospice staff. Overall 14 doctors (34%), 24 nurses (59%) and 3 allied health professionals (e.g. family support worker 7%) were included.

Themes

A variety of themes were identified and are presented below, under the headings of the quadrants within the framework (Figure 1). Representative quotes are displayed in Table 1. HCPs reiterated many of the themes highlighted by parents and also added more detail or new themes – only the new themes and elaborations are presented from the HCP findings.

Quadrant 1: Avoidance - Family

Advocating for child

Parents described focusing on fighting for their child, believing in doing what is best for their child, being the main hub of information for the child, and ensuring that their child had the best care. Parents would make decisions for them and be with them.

Siblings

Parents focus their attention on siblings as a way of coping, ensuring that siblings are ok, that they as parents are able to keep things normal for siblings, organise things for siblings at home (e.g. in case of a child being frightened by the thought of their sibling dying at home), organise activities for siblings, as well as help with childcare.

Worry about others

In line with the subtheme of 'siblings' parents expressed that they worried about others and described '*throwing themselves*' into focusing on others.

Staying strong

Parents describe having to stay strong for the child, putting on a brave face, feeling that they '*have to do this*' for their son or daughter, to make things perfect for them. Parent recognised that while they may not want to do this, they would (doing it for the child), and described the importance to keep fighting.

Pet

Pets were mentioned as a source of distraction in terms of something to care for, and something that is constant and can be therapeutic.

Normality

Many parents described striving to maintain normality, such as doing some cleaning. They also described that in striving for normality they would find stability. Routine is an important aspect of this.

Quadrant 2: Avoidance - Self

Joking/humour

Parents describe joking, laughing and using black humour to get through, and finding the lighter side of things.

Positive

Parents engaged in staying positive, thinking that the day has to get better.

Taking a break

Physical and mental exhaustion are highly prevalent for parents and they would highlight that they would seek a break from their caring responsibilities by requesting respite care, going to work, going out and getting something to eat, or going to the pub.

Getting on with it

Parent expressed that they often did not have a choice and they had to get through it. They would go into autopilot, or just '*get on with it*' as they described it. They would also go into a different mode, and indicated that often a very practical side of them would kick in.

Avoiding thoughts and feelings

Parents described a range of thoughts which seemed to help them get through, such as blind optimism, pushing thoughts to the back of their mind, and trying not to think too much.

Narrow focus

Parents describe shutting the outside world out and prioritising the child.

Comparing to others

Parents indicated that they would compare themselves to others and would think about other people, and thinking that there are people who are far worse off.

Quadrant 3: Approach - Self

Expressing emotions

Parents found it helpful to express their emotions with others (vent), as well as breaking down and letting it all out by crying and screaming.

Blame

Parent blaming themselves (e.g. feeling guilty about not asking questions or asking for actions of others), or others such as a healthcare professional.

Trust

Trust in HCPs and others helped parents cope, in the knowledge that HCPs knew best.

Child is special

Parents indicated that they felt that their child was '*special*', that their child was not like all other children, which contributes to making sense of what is happening.

Preparing

Preparing for things not to get better, preparing for two futures, which allows parents some control over the situation.

Faith

Faith being a source of support for some parents, as it can give parents meaning and a community of support.

Hope

Parents report the importance of staying hopeful, and not giving up. Parents expressed being hopeful while experiencing emotions and thoughts in parallel, through preparing for two futures.

Quadrant 4: Approach – Family

Living life to the full

Parents were determined to live life to the full, to give their child many experiences. Parents would mention trying to make things happen for the child and other family members. Parent also expressed that they would focus on making memories (such as going to concerts or theme parks).

Organ donation

Some parents expressed that organ donation can give purpose to their situation and help them cope, as it can give meaning, and parents find comfort in the thought of their child's organs living on in another child.

Social support

Parents highlighted several sources of support, from friends who were 'just there', Facebook friends and groups, family members, their partner, their community (which could be the place they live or their church community), and other parents.

Being involved

Many parents indicate that being involved in care, '*getting stuck in*' (engaging in something with energy and commitment), was helpful.

Understanding different coping strategies

Parents expressed that they were aware that not everyone copes the same way, and that there is no right way to deal with their circumstances.

Additional themes from HCPs

Goals and parental role

HCPs describe how parents do everything possible for the child, and seek control in terms of what will happen, and need information about prognosis. HCPs describe parents taking the lead in terms of care for their child. Their role as a parent is also highlighted as being important, as is being able to be involved in their child's care. While it allowed them to be involved in their care, it also allowed parents to 'busy' themselves. An important goal for parents is to make the most of the time left.

Information and communication

Parents want access to HCPs, which includes good communication. When they receive information, they would like it to be clear, transparent and honest, while avoiding contradictory information. HCPs acknowledged that information needs may vary for different families and therefore they should make an assessment about the level of detail that is valued. In terms of communication HCPs highlighted several aspects that added more detail: 1) the value for parents of having '*normal discussions*' rather than just talking about '*bigger things*', 2) knowing that someone is listening and not being '*fobbed off*' (being given partial or incomplete information, which does not address all concerns/questions) .

Routine and familiarity

HCPs emphasised that it is important for parents to be around places and people they know. This also ties in with HCPs highlighting the importance of support from family and friends for parents. Moreover, HCPs mentioned the importance of connections with other parents (with a child with a similar condition).

Meaning

HCPs highlighted the importance of religion for some parents and the need, for parents, to look for something positive.

DISCUSSION

This is the first study specifically investigating coping strategies of parents at the end of their child's life. The findings of the study have provided a detailed account of the breadth of coping strategies parents use, as well as the importance of coping strategies that can be classed as avoidance. In addition, the coping strategies identified by parents were successfully mapped onto an existing theoretical framework identifying cognitive and emotional responses that provide depth to the coping framework it has been modelled on.

Figure 1 encapsulates the variety of coping strategies identified by parents. Parents use humour, staying positive, advocating and staying strong for others, expressing emotions and preparing, while also living life to the full with support from others. This array of strategies speaks to the notion of flexibility of the use of coping strategies, and steps away from the labelling of strategies as positive or negative. This

seems especially important when parents are faced with such taxing circumstances. There is evidence of the importance of balance in self-regulation,(23) as well as flexibility in coping.(24)

Coping strategies that can be classed as avoidance with a focus on family (Quadrant 1), include striving for normality, advocating and worrying about others (such as siblings), and staying strong. This focus on family and maintaining normality has been highlighted in the literature for children (8) and adults.(25) Focusing on family, by advocating for the child, or worrying about others also allows parents to keep busy and occupied. This aligns with the findings from HCPs in this study which show that parents will do everything possible for the child, taking the lead, being involved in care and maintaining their role as a parent, which in turn allows them to 'busy' themselves. This allows parents to be 'a good parent'.(11) Hope is also a central feature of these coping strategies.

The strategies that were classified in this study as avoidance that was focused on the self (Quadrant 2), included humour, getting on with it, and taking a break. Interestingly in our interviews (not described in findings) parents described great difficulty in understanding what was going on, the messages and what it means, with parents saying they found it difficult to '*get their head around it*'. This highlights again, parents' needs for respite from these overwhelming thoughts,(18) time to process it and having the right information at the right time, as highlighted by the HCPs in our study. A narrow focus, as parents have described in our study, will allow parents to cope with the magnitude of what is happening and function.(12) From a clinical point of view, it is crucial that this state of mind is acknowledged, while often this can be interpreted as denial, which can lead HCPs to reiterate the message of bad news, in fear that parents have not understood. There is evidence that hope and acceptance are not mutually exclusive.(26) While the current study did not investigate outcomes in terms of which coping strategies lead to improved outcomes, the guiding hypothesis related to the framework is that all coping strategies can be positive, used in parallel, and not in isolation (e.g. denial as a single coping strategy for a prolonged period of time could be detrimental).(16)

Coping strategies that have an element of approach were also described by parents. Parents described an array of emotions, such as blame, feeling guilty and crying. In addition, parents would focus on the fact that their child was special, which can be seen as a sense-making process (10) and would attempt to prepare themselves mentally for what would come, in line with anticipatory grief.(27) Approach with a focus on family encompasses the aim to live life to the full, seeking social support and getting very involved in the care of the child. Families living life to the full allows the active creation of memories,(28) and activities such as engaging in a wish fulfilment experience can have a positive

impact.(29) Parents indicated that there were many sources of support. Support would occur through a partner being strong when they were not able to (and vice versa), support from health professionals, and friends just being there - while not 'doing' anything specific. This last point is an interesting description and is an important message for friends and family, as well as health professionals, as it shows that support does not always need to come in guise of something tangible, in terms of words and behaviours. Being with parents, alongside them, is often a useful and supportive strategy.(30)

Limitations of the study include recall bias, in relation to interviewing bereaved parents, and selection bias in terms of the self-selective sample which represented only 25% of parents approached. The findings are not generalizable due to the qualitative methods of the study, although generalisability was not the aim of the study. The mapping of the themes onto the framework were likely influenced the constraints on the model.

Future research should start relating the use of coping strategies at the end of life and long-term outcomes after death. The hypothesis of the framework (16) is that lack of flexibility of the use of a variety of coping strategies is likely to lead to relatively worse outcomes, such a complicated grief and depression after the death of the child, particularly expressed as predominantly using coping strategies in a certain quadrant, over a period of time. Future work should elucidate what this period of time might be and what this means for practice: i.e. when should HCPs be concerned for families and what coping pattern warrants the referral to additional support. Future work could also see the use of standardised coping measures and analysis in light of the framework, as well as longitudinal assessment of coping strategies to capture changes over time and assessment of flexibility. In terms of implications for practice, awareness among HCPs of parental coping strategies may aid palliative care discussions, in exploring and understanding strategies and their relationship to readiness to engage in advanced care planning discussions.

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CONFLICT OF INTEREST STATEMENT

The authors do not have any conflict of interest to declare.

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Table 1. Themes and representative quotes from parents

| Themes | Representative quotes |
|---|---|
| Quadrant 1: Avoidance - Family | |
| Advocating for child | <p><i>..you are trying to get the best thing for your child.. (09ICU)</i></p> <p><i>I mean he was fighting so hard every day so if such a tiny baby could fight or I've got to fight and not let everybody break me (15ICU)</i></p> |
| Siblings | <p><i>I make sure that we try and keep things as normal as possible for the other two and taking them out (16HOSP)</i></p> |
| Worry about others | <p><i>I think I was worried about everyone else, was mum ok? Was my partner ok? Was my daughter ok? I threw myself into that (04ICU)</i></p> |
| Staying strong | <p><i>You kind of pull yourself together and think no, I've got to keep fighting strong for him, I've got to get through that for him to make it perfect for him (15ICU)</i></p> <p><i>I think just putting a brave mummy face on. Just being strong for him...Holding everything together. (08ICU)</i></p> |
| Pet | <p><i>We got a dog as a kind of therapeutic input (17HOSP)</i></p> <p><i>She is a constant (18HOSP)</i></p> |
| Normality | <p><i>I like everything to be pristine. It gave me something to do you know, a bit of normality, it seems crazy that you'd want to do your own cleaning (04ICU)</i></p> <p><i>..can you imagine taking their school away as well so you'd end up</i></p> |

| | |
|---|--|
| | <i>with two very unstable children as it is. Somethings have to stay consistent don't they (16HOSP)</i> |
| Quadrant 2: Avoidance - Self | |
| Joking/humour | <p><i>My default mode is I did it with humour, I was joking and laughing (01ICU)</i></p> <p><i>We were really happy to entertain ourselves with very dark jokes (02ICU)</i></p> <p><i>We said things to cheer us up....get ourselves through it really (23ICU)</i></p> |
| Staying positive | <i>Now we were preparing ourselves that things were not going to get better. We tried all the way through to be positive but it became more and more difficult (23ICU)</i> |
| Taking a break | <p><i>Isn't it a positive side to it (work), it's a coping, well OK a good side of that is also that it's a coping mechanism and it gives you a way of coming out of the all consuming thing of looking after *child*...it gives you the ability to come back in and bring something fresh (18HOSP)</i></p> <p><i>..they told us sometimes to go away in a nice way. You can't stay at the bed all the time, you have to go out and get something to eat (24ICU)</i></p> |
| Getting on with it | <p><i>I think as parents you just get through it don't you really, you don't have a choice do you? (24ICU)</i></p> <p><i>I think I just went into autopilot and just focused on the fact that</i></p> |

| | |
|--|--|
| | <p><i>right this where we are at and this is what we're doing. (08ICU)</i></p> <p><i>You just get on with it, eventually you just get on with it (11HOSP)</i></p> <p><i>Well the practical side of me kind of kicked in (05ICU)</i></p> <p><i>You go in a different mode, it's like I've got no choice, this is what is happening to me, I haven't got time to sit at home and get upset (14ICU)</i></p> |
| Avoiding thoughts and feelings | <p><i>You just get on with it and you have to have this blind optimism that everything's going to be ok (24ICU)</i></p> <p><i>But you get to a stage where you have to, for your own sanity, just push it to the back of your mind and think, that's not going to be her, she's going to be fine, because otherwise you just wouldn't get through (24ICU)</i></p> |
| Narrow focus | <p><i>I had to shut the outside world off entirely...I couldn't even speak to my best friendbecause I would focus purely on her (child) (12ICU)</i></p> <p><i>He's my number one priority at the moment and we'll just go headlong into that and just keep going.(08ICU)</i></p> |
| Comparing to others | <p><i>But you look around and there are a lot of people far worse than us but sometimes that doesn't make much of a difference (11HOSP)</i></p> |
| Quadrant 3: Approach - Self | |
| Expressing emotions | <p><i>I think it's just sitting with people who are going through it themselves and you can vent and you can say things what you wouldn't say in front of someone else (24ICU)</i></p> |

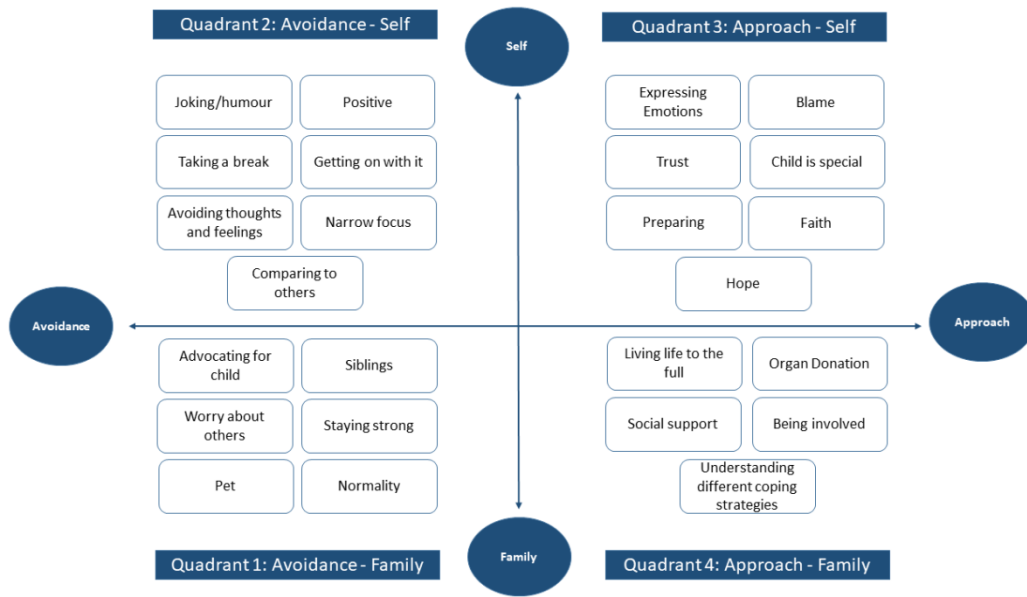
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| | <i>I get really emotional. I cry. I cry quite a lot..(16HOSP)</i> |
| Blame | <p><i>I felt very let down but then I wanted to blame someone. In those days I was just trying to find, I think you want to blame someone because it's easier to put the blame on someone else (15ICU)</i></p> <p><i>First of all you blame yourself (15ICU)</i></p> <p><i>You are sort of designed to think that it's your fault in a way if a child is not perfectly healthy (02ICU)</i></p> |
| Trust | <i>There's something about trusting people's... the professionals knowing best and the individual knowing best (17HOSP)</i> |
| Child is special | <i>I know you hear it, all children are special, you say it about all your kids, but she was one of these children, unless you met her, you couldn't fully explain her (12ICU)</i> |
| Preparing | <i>There isn't an end date on anybody's life but equally we have to prepare for two futures (16HOSP)</i> |
| Faith | <i>I think for me my faith is really important (10ICU)</i> |
| Hope | <p><i>I would not give up, I had every hope, I kept saying to everyone he's just going to open his eyes again as if nothing has happened (01ICU)</i></p> <p><i>I never for one moment thought he wasn't going to make it. It was my naivety and my hope and even when they said you've got to come in I thought he'd get through it (03ICU)</i></p> |
| Quadrant 4: | |

| Approach - Family | |
|-------------------------|--|
| Living life to the full | <p><i>We would go on holiday with a determined mind so we were very determined for *child name* to experience life to the full, which we all benefited from (18HOSP)</i></p> <p><i>If you want to go to Disneyland, we'll make it happen, because it's possible, these things are possible (14ICU)</i></p> |
| Organ Donation | <p><i>Donating organs as well that has been, it just gives purpose to the whole thing (02ICU)</i></p> |
| Social Support | <p><i>Just having my best friend there I think... she sat with me the whole time (01ICU)</i></p> <p><i>Was glued to Facebook with everyone's well wishes...that kept me going and it was distraction (01ICU)</i></p> <p><i>I think we were very lucky in the fact that we have a very close family (08ICU)</i></p> <p><i>My sister has been my rock really (22ICU)</i></p> <p><i>Everyone's important as in I love living where I live because everyone knows us. Those people, the community is important to me (13HOSP)</i></p> <p><i>I think Church has helped ...the support that we've got from the Church is something I would never underestimate because I think that is what's kept us together...we've always had a community around us (17HOSP)</i></p> <p><i>All the parents are all in there (ward) for the long haul and you go to</i></p> |

| | |
|---|--|
| | <i>the shared kitchen facilities and you all talk...so you form this quite good support network with those people (09ICU)</i> |
| Being involved | <i>But for my husband that was the best thing anybody could have said, get stuck in, the more you do, because that was his coping, the whole way through that was how he coped. He wanted to be that person to do everything (14ICU)</i> |
| Understanding different coping strategies | <i>There is no right way to deal with these things is it, everybody does it differently (04ICU)</i> |

Legend

Figure 1: Overview of coping strategies in Parental Coping Framework



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