

**“You Pray for Him a Bit More”: Young Adults’ Positive Aspects of
Caregiving (PAC) Towards Parental Cancer**

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Abstract

Young adult caregivers are growing in number, yet there is a paucity of literature on their role in informal family caregiving. The Positive Aspects of Caregiving (PAC) framework has been developed within Dementia carers to indicate positive outcomes of the caring experience. The current study specifically explored the narratives of four young adult carers' lived experience of caring towards their parents with cancer, using Interpretative Phenomenological Analysis (IPA) through the lens of PAC. Main themes developed from this study were unfolding the child-parent dyad, character building and affirmation of value systems, time reframed, and sustaining caregiving continuity with subthemes surrounding responsibility, appreciation beyond the role reversal, acceptance and sources of comfort. This small-scaled study contributes towards a new understanding of the young adult population, their perception of caregiving and briefly informs the PAC beyond a dementia population.

Keywords: caregiving, positive aspects of caregiving (PAC), Interpretative Phenomenological Analysis (IPA), parental cancer, young adult

Positive Aspects of Caregiving (PAC) seeks to explain experiences which result in caregivers perceiving positive outcomes from their caring role (Schulz & Sherwood, 2008). Such outcomes include the strengthening of relationships between the carer and the care receiver, increased self-esteem, and the ability to learn new skills (Schulz & Sherwood, 2008). Caregiving activities place additional daily demands upon the care giver and include managing the recipient's medication, emotional support, personal hygiene care or communications with healthcare professionals amongst others (Hooymans & Kiyak, 2005). Folkman (1997) identified when caring for their partners living with AIDS caregivers experienced both positive and negative emotions simultaneously. Amidst the adversity, caregivers were able to construct the caregiving journey with an enhanced sense of meaning.

PAC has been studied widely in family caregivers of individuals living with dementia (Yu, Cheng & Wang 2017; Lloyd, Patterson & Muers, 2016, Gaugler, Mittelman, Hepburn & Newcomer, 2010), schizophrenia (Chen & Greenberg 2004; Kate, Grover, Kulhara & Nehra, 2013), and cancer (Li, Mak & Loke 2012; Li & Loke, 2013; Kim, Schulz & Carver, 2007, Houldin, 2007). The first conceptual framework of Positive Aspects of Caregiving (CFPAC) was developed by Carbonneau, Caron and Desrosiers (2010) for dementia caregivers and was later adapted by Li and Loke (2013) in a review of literature for cancer carers. Central positive aspects within the model were improvement in self-efficacy, increase in relationship quality shared between caregiver-recipient, and personal meaning making. Both the CFPAC framework developed for dementia carers and its adaptation towards a review of cancer carer literature, provided an insight to expanding the framework for inclusion of different carer groups and long-term illnesses.

Although the CFPAC was developed from several studies of family cancer carers, its foundation is that of the CFPAC in dementia caregivers (Carbonneau, Caron & Desrosiers, 2010). Dementia is an irreversible, progressive condition, and as such, there were aspects within the framework which were not applicable in the cancer caregiving population (Li & Murray, 2014). The experience and nurturance of hope is a trait prevalent in cancer carers in relation to better quality of life and death, alongside hope through religion and spirituality (Holtslander & Duggleby, 2009; Clayton, et al., 2005). Cancer carers also shared the need to persevere in their caregiving role to make the care recipient's life as normal as possible in every promising way (Whisenant, 2011).

Parental Cancer and Young Caregivers

In the last two decades, it is acknowledged that family members become "second-order patients" with specific needs of their own, as cancer affects the whole family ecosystem (Levesque & Maybery, 2012, p.397). Statistically out of seven million carers in the United Kingdom, 376,000 are young adult carers aging from 16 to 25 years old (Carers Trust, 2015). Unfortunately, the current available support is aimed mainly towards young carers up to the age of 18, and this is reflected in 80% of young carers being concerned about continuing their caregiving role beyond 18, due to a perceived lack of support (Carers Trust, 2015). Lawton, et al. (1991), suggests various societal changes will mean caregiving roles in a family system will eventually become an intergenerational responsibility consisting of younger individuals. With growing numbers of young adults choosing to engage in marriages much later in their life and delayed childbearing, ill or aging parents will high likely be looked after by their children (Levine, et al. 2005). A paucity of literature currently exists on the experience of young adult children engaging in caregiving activities, particularly considering the typical need for autonomy at this point in life.

With parental cancer, young people mentioned feeling a sense of vulnerability towards themselves, and people around them (Finch & Gibson, 2009). The parent-child relationship starts being a threat, potentially through the perception of role reversal. Conversely, positive relationship attributes such as stronger family values, higher family cohesion and less conflict are also observed within adolescents' experiences towards parental cancer, along with the perception of personal growth (Pope, Baldwin & Lee, 2018; Gazendam-Donofrio et al., 2007).

PAC has been explored in spousal caregivers (Li & Loke, 2014; Porter et al., 2012; Kim et al., 2008; Hagedoorn et al., 2008), parent caregivers (Las Hayas, de Arroyabe & Calvete, 2014), and the elderly population (Houldin, 2007). It was highlighted by Levine et al. (2005), that within the caregiver population 12 to 18% are young adults. Therefore, the aim of our paper is to provide an understanding of the lived experience of the neglected population of young adult carers. As the mainstay of the current cancer literature takes a deficit approach, by using an exploration of PAC in the dyadic parent-child relationship we provide a positive lens through which understand young carers experiences.

Method

A qualitative approach was taken to understand our research question: "What are the positive aspects of caregiving of young adults' towards parental cancer?". We analyzed in-depth interviews via a guided interview schedule (Appendix A), using Interpretative Phenomenological Analysis (IPA) (Smith, Flowers, & Larkin 2009). IPA captured the core components of the caregiving experience on an individual level, including sense-making of their personal and social experiences. Additionally, IPA allows inclusion for pre-conceived knowledge during data collection resulting in a person-centred appreciation of participants' caregiving experience; explaining the double hermeneutics known as the theory of interpretation (Smith & Osborn, 2007: 53).

Participants

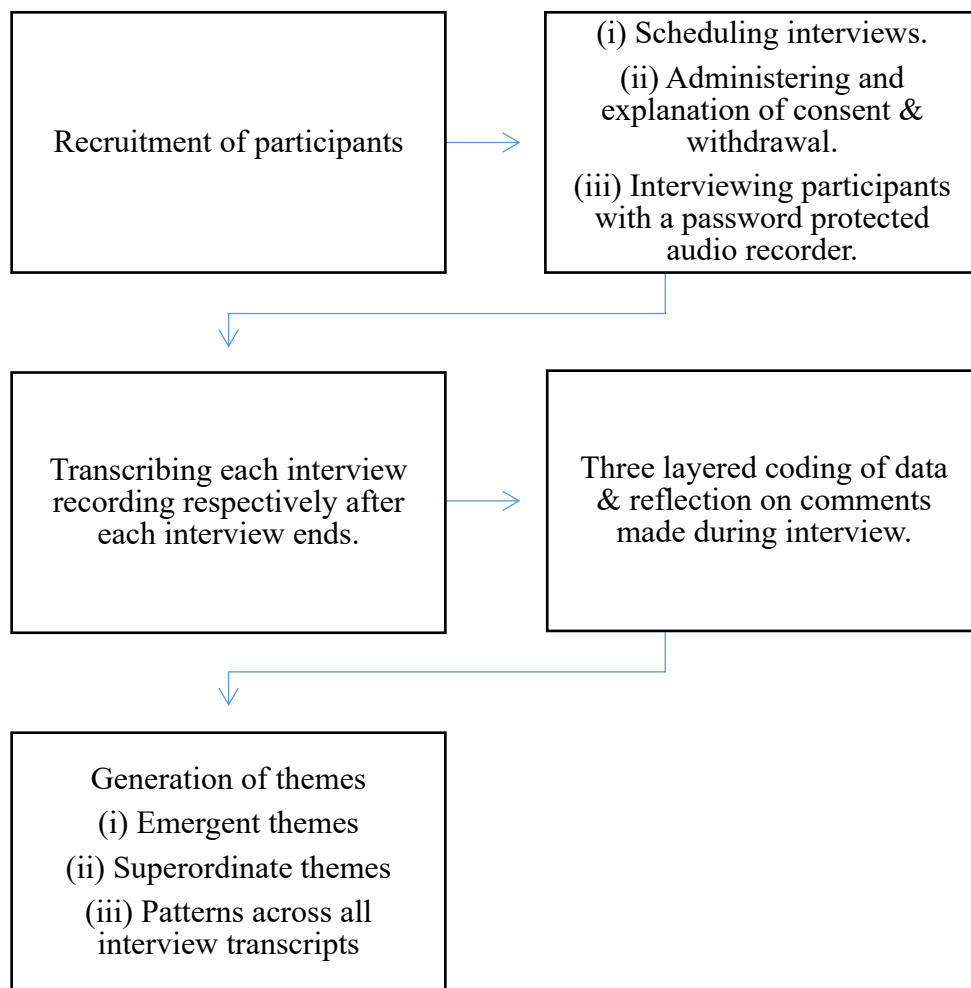
There were four participants in this study: three men and one woman, lacking a minimum two to meet the ideal six participant criteria for an IPA study (Smith, Flowers, & Larkin 2009). All participants were within the ages of 18 to 25 during the caregiving phase. Further demographic information can be found in Table 1. Participation in this study were voluntary and withdrawal from study were permitted at any time during the interview, or two weeks after data collection.

Table 1
Demographic Information During Caregiving Phase

Pseudonym	Age	Gender	Employment status	Caregiver status	Caregiving duration (years)	Status of parent
Lisa	18	F	Full-time student	Previously a caregiver	2	Mother, breast cancer survivor
Berklee	24	M	Part-time student	Previously a caregiver	1.5	Father, Kidney cancer, deceased
Jackson	23	M	Full-time employment	Previously a caregiver	1 month	Father, Liver cancer, Deceased
Bob	25	M	Full-time employment	Presently a caregiver	8	Mother, thyroid cancer

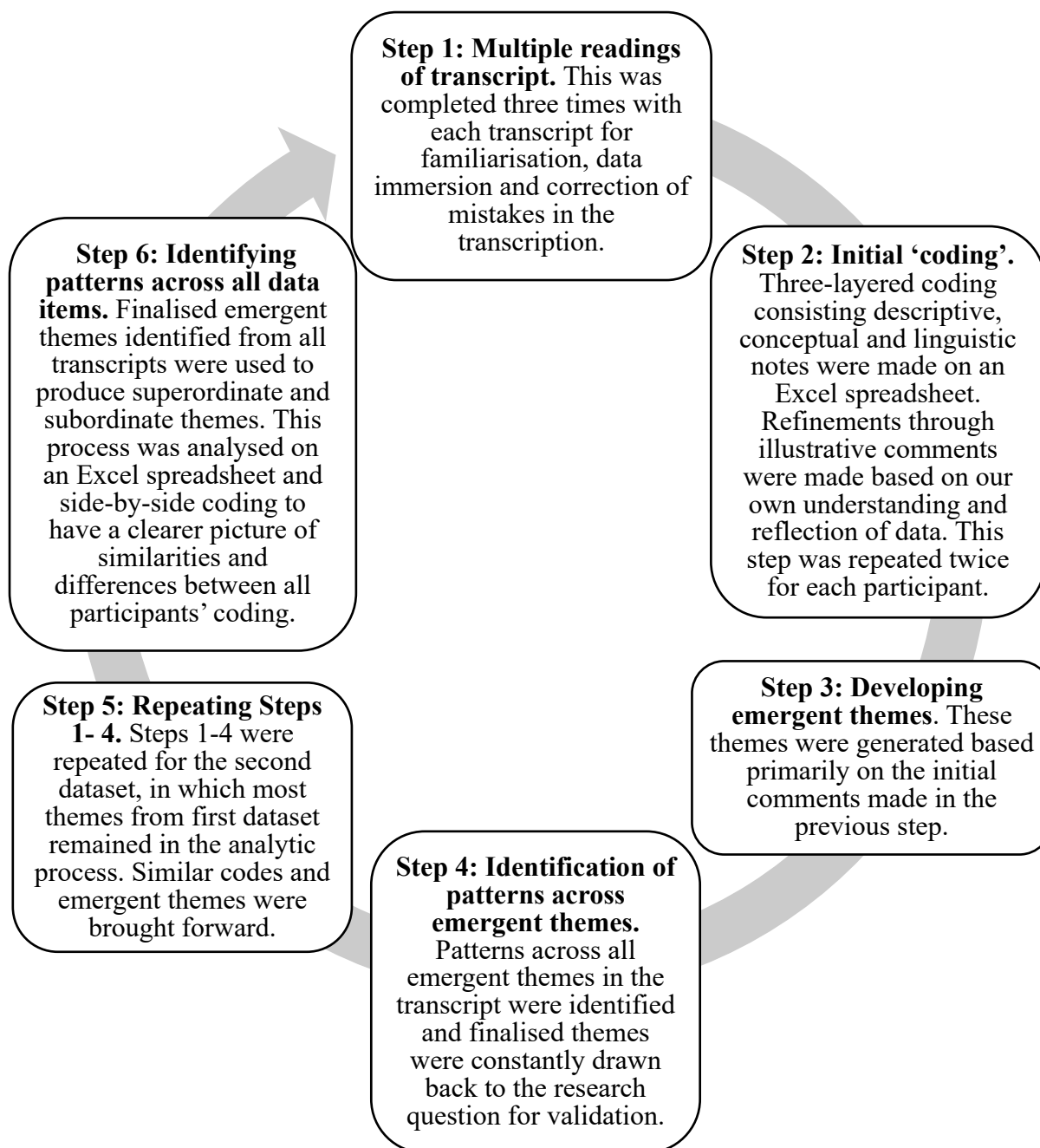
Data Collection

Ethical approval was gained from the university ethics board. Two datasets were collected through semi-structured interview sessions, while the other two were collected via a telephone interview; all interviews were audio recorded. Interviews lasted between 40 and 60 minutes per person. All audio recordings were transcribed verbatim prior to analysis. A summary of the data collection process is illustrated below (see Figure 1).

Figure 1*Flow Chart for Data Collection***Data Analysis**

Our analysis followed the six step-by-step guidelines towards coding and analytic process by Smith, Flowers and Larkin (2009). Illustration below shows the coding processes (see Figure 2).

Figure 2
Data Analysis in Sequence

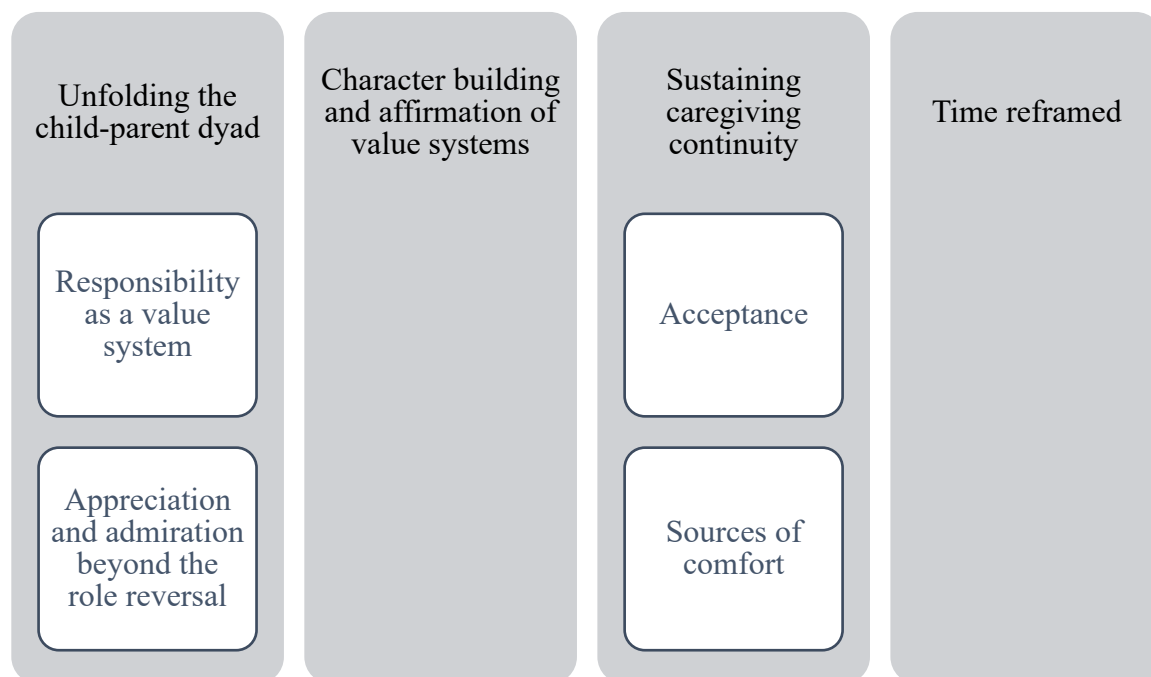


Findings

The analysis of the data revealed a detailed exploratory superordinate and subordinate themes related to PAC in young adulthood. The themes were: (1) unfolding the child-parent dyad, character building and affirmation of value systems, (3) sustaining caregiving continuity, and time reframed; of which themes (1) and (3) had two subordinate themes respectively. An illustration of the organised themes is seen in Figure 3 below.

Figure 3

Superordinate and Subordinate Themes Developed from IPA Transcript



Unfolding the Child-Parent Dyad

The most salient theme from all four interviews was focused on the relationship transaction between the caregiver and their parent. Nuance in experience is reflected in the two subordinate themes, describing the varied lived experiences across the participants.

Responsibility as a Value System

Lisa, Berklee and Jackson had taken up their role as young adult caregivers due to familial circumstantial reasons and thus, not allowing them to prepare themselves mentally or physically before taking up the role.

"[...] belonged to familial circumstances because my father was working most of the time, my brother was in another school... So, he barely had the time to come home and look after my mum. I was the only one available to take care of my mother so there was no choice." (Lisa)

"My dad will never request that (caregiving). My mum was getting tired. So, she was balancing her job and taking care of my dad. My younger brother was in national service, older brother was committed to his job. So, I was in the most flexible situation – my job requires me to stay home." (Berklee)

“No one asked me to do it. It is like a responsibility, it (caregiving role) just came along with it.” (Jackson)

Nonetheless, there was the shared perception that although the role was not a choice and was an exhausting undertaking, they were not forced into the role. Despite the discomfort, they had responsibilities to their ill parent, signaling a need to act in accordance with an internal value system. For Lisa, responsibility was highlighted twice in the aspects of a child-parent dyad and a gender specific, mother-daughter dyad due to the nature of her parent’s cancer. Lisa felt that caring responsibilities would have caused even more discomfort to the other male family members in the household and she felt compelled towards the role despite her own discomfort.

“Most of the time it’s because it’s my mother, because of that – just because she is my mother, I have to do this. Nobody will do it except you because my father was working – he had to provide for us when my mum was on a break, my brother forever disappearing – he was still studying.” (Lisa on the child-parent dyad)

“After breast cancer you had surgery, you have to clean the pus and everything... I had no choice but to do it, because I’m female so my brother won’t feel comfortable doing it, so I took on the role seeing that...” (Lisa on the mother-daughter dyad)

For Berklee and Jackson on the other hand, although it was acknowledged that their relationship with their respective parents were not close; they did not feel forced towards their caring role. This was mainly due to the strong grounding for responsibility of a child towards a parent that they held on to as a value system. The gender specific caregiving transaction was present here too; while it was more physical for Lisa, there was a patriarchal reasoning for Berklee when he considered the father-son transaction, whereby he felt there was the expectation of a male child to take on the caring responsibility. Responsibility to Berklee was the centre of his entire caregiving journey; a driving factor, motivation and was gathered as the only reason to his successful fulfilment of the caregiving role:

“Because it’s not an option. It’s a responsibility. You can do things to be nice to people, you can be kind to one another, but responsibility is one value that cannot fall, and it was his responsibility to hold up the family and now it’s my responsibility to hold up as much as I can.” (Berklee)

Appreciation and Admiration Beyond the Role Reversal

The second subordinate theme focuses on feeling valued and encouraged by their parent for the caregiving activities carried out and the reinforcement this provided to continue with the course of their caregiving journey. The norm is usually for a parent to care and provide in most aspects, however the role reversal though admitted as uncomfortable; as quoted by Berklee, *“it was acknowledged that it was a role reversal and it was quite awkward, going into it”*; was also regarded later as a reason to better understand their parent resulting in greater respect for their parent; as quoted by Lisa, *“[...]cancer, cancer relapse...all of this, so it helped me like gain more respect for her. She’s such fighter.”*

The following extracts describes the acknowledgement and appreciation three participants felt for their parent. Though Berklee admitted that *“the relationship remains the same”*, in the child-parent transaction before and after the caregiving experience, it still provided the comfort needed possibly due to the absence of adaptation efforts required for both child and parent. In contrast, Lisa and Bob understood their mothers better and felt there was an improved child-

parent transaction compared to before the caregiving journey. It was a meaningful period for both these participants as they finally felt they could perform and achieve the expectations of their parent; with Lisa learning new skills and Bob gaining a new sense of maturity.

“I understood my mum better. She used to scold me a lot, but now realised it’s for my own good. I take it better now and my relationship with her has improved. I think she felt appreciative because she knew she couldn’t do it herself I think she felt really proud of me at that point of time.” (Lisa)

“I better understand my mother now, it is also because I have the maturity to understand the situation better now.” (Bob)

Character Building and Affirmation of Value Systems

This theme captures the extent to which their parental caregiving experiences as young adults have provided character growth and, a test and validation of their value systems. For Lisa, the caregiving process is said to have *“helped me to grow a lot”*. In comparison, Berklee when asked about personal development, there was a short but profound response of, *“nothing I don’t know about myself already”*. Jackson as the only child found himself *“to be more organized”*, and Bob strongly admits that the reason behind his caregiving *“is not responsibility, it’s just my love towards my mother as an eldest son”*; with further exploration from the extracts below:

“I feel more confident after he passed, I was able to organize everything; to make sure all procedures were done smoothly including the responsibility of carrying out a smooth funeral, and I feel I did a good job. I didn’t disappoint anyone, I hope.” (Jackson; post caregiving)

“Naturally wanted to do it. I had a thought if I don’t do it who will? If my father took care, will he do a good job? As an eldest son, I felt I should care for my mother. [...] emotionally I was drawn to taking up the role.” (Bob)

“[...] Self-esteem I used to be, in the past I used to be bullied in school, so my self-esteem was very low [...], so helping my mum helped increase it because I felt like I was wanted and needed at that point of time. So that actually helped me find a purpose ...” (Lisa)

Lisa described an increase in of self-esteem which in return gave her a better communication pathway, *“in a way it helped us communicate better”*. Although the caregiving transaction was taxing, it allowed for improvements of communication between Lisa and her parent. Bob with the longest caregiving years wondered if anyone else could care for his mother better; and later felt that *“main purpose was for her to feel good, but in the end, it made me feel better too”*. Overall, all participants experienced positive approaches to caregiving in terms of personal growth which aided a comfortable caregiving journey between the young adult and ill parent.

Time Reframed

Time as a theme was developed as a positive attribute of caregiving for three participants based on individual reasonings and self-reflection. Time, an objective yet abstract term was narrated differently by Lisa, Berklee and Jackson. However, they shared a mutual feeling that wasted time will never return.

“I did feel better, but it also made me feel like... I was taking life for granted, because here I was surrounded by cancer survivors, but they were so much more optimistic than me. Then there’s me wondering what I’m doing with my life... It helped me analyse my life and introspect.” (Lisa)

For Lisa, spending time with her mother through the first and second breast cancer caregiving journey had strong association towards becoming more aware of how she has taken previous chapters of her life very lightly. Lisa reflects upon herself when she meets other cancer survivors on how she would appreciate time better now.

“Well you don’t view time the same way anymore... most people are comfortable working 9-5, but now the idea you’re wasting your life away [...] becomes even more concrete. Because he was working all the way till the end, and I felt like ‘wow that’s not how I wanna go’. It’s more of a realisation to go after what you want, and I don’t want to be part of the rat race. I’m more confident now that if I don’t want to be a part of the rat race, I don’t have to be a part of it” (Berklee)

Living the unexceptional career cycle was an exposure that will cost time, in a negative connotation for Berklee. Having observed his father work the typical work cycle up till his cancer death bed was a wakeup call and confirmation that breaking out of the norm was necessary towards having a better perspective and utilization of the limited and mysterious living time we have.

“Yea, there was more open conversations. We know the time is counting, it’s worthless to continue arguing [...]. We just treasured our time and say as many things with honesty [...].” (Jackson)

For Jackson, witnessing time slipping by too quickly in the face of stage 4 liver cancer was a realisation that there was no point in keeping up with the arguments of the past. Experiencing the shortest caregiving period from all other participants, Jackson managed to be “*more expressive*” with his father although there was a said discomfort in the father-son relationship before, “*treasured time with family*”, and lastly admitted an increased “*quality of relationship*”.

The test of time at the expense of parental cancer provided a space for these participants to reflect how time was viewed differently in the past, and when passage of time becomes more salient; the need to embrace and make sure it is spent with great quality became a priority.

Sustaining Caregiving Continuity

This theme was established across all participants’ data and provided understanding towards how they sustained their caregiving journeys whether it was thru achieving and maintaining quality of life and death for both the ill parent and in the coming times, for themselves or through their social supports. The parental caregiving experience was a reality checker and gave the opportunity for future conceptualization through self-reflection.

Acceptance

Berklee’s excerpts below encompasses his caregiving journey with his father towards his death bed and later, made him accept that there are occurrences in the present which cannot be fixed. He hopes that the mentality to fix illness at the expense of life quality should be changed in the aim of providing quality of death to his ill parent. There was a sense of pressure for Berklee

and the hope his family members would understand his urge for a better experience of death for his father in accordance with his wishes. Being in his early twenties, Berklee projected strength and emotional empowerment to come to terms of not only the illness itself, but similarly to provide the last rights hoped for by his parent.

“It just shifted my mind set a bit more, that we shouldn’t fix everything. When he was going through the end phases, they always ask, ‘if you want to keep him alive...’ and I realise there was a lack of focus on dying peacefully, [...] feel like we should have focused on the time left, better. He got it at the end of day. After a while everyone realise ‘okay it’s time’ [...]. I guess everyone wanted to hold on at first. I felt we should make it a wonderful process as far as possible, let his passing be exactly how he wants it to be. Let’s not worry about ‘go for this surgery, try that medicine...’ It reached a point where I wanna know that I’ll be able to die peacefully as well... and not let my family have a say in the future while they try to keep me alive [...].” (Berklee)

“That dying is not a bad thing. You get comfortable with the idea of death in general I guess. You don’t fear it as much because [...] kinda know how you would prefer to go. [...].” (Berklee)

Lisa on the other hand had an entirely different experience to Berklee as she saw her mother survive through two diagnosis of breast cancer and later, double mastectomy. Therefore, her comprehension of death is about realising the possibility of it happening to anyone is extremely vivid through cancer, and often without any warning signs. Hence, emphasising the caregiving process forced her to face reality and, the journey *helps me to grow a lot*; which in return allowed her to focus more on aspects of life quality in her mother and for herself after surviving the cancer journey.

“Before being a caregiver, I think I took everything very lightly...like I thought death will not occur to the people around me. Then having my mum being diagnosed, seeing the process of her getting her breast cut off one by one, she cut off both.” (Lisa)

For Bob, making sure his mother does not engage in unhealthy rumination was his point of acceptance, due to its consequences towards her illness. Although this has been a long-term caregiving journey for Bob; accepting and reminding his mother to strive for quality of life instead of ruminating matters that are out of physical control was a continuous effort – for the long-term betterment of his mother.

“I observe her changes. I try to divert her mind by talking to her about other things. I just don’t want her to overthink, as it makes things worse for her illness.” (Bob)

“When she worries, I tell her as a human we are all going to die, but we don’t know when and that is the suspense. We just spend the time we have; we only have one life.” (Bob)

Jackson’s experience with caring for his father came with understanding for the first time what transpires in the journey towards accepting ones’ illness; a two-way journey for both parent and he as a caregiver. Besides that, there was a sense of calmness in the air for Jackson whose father engaged in religious beliefs towards achieving acceptance and oneness with the course of death peacefully. This, provided a secondary transference of acceptance for Jackson as

witnessing his father at peace with reality, allowed him to also be one with the course of illness and later, death.

“It’s really an important experience for me. I understood what goes through the stages of accepting the illness [...], it was valuable.” (Jackson)

“Through the journey it (religion) was helpful for my father as it allowed him to be at peace about his death. I’m not that spiritual or religious. To have something to believe and help you get over these tough times; [...] I am thankful for this. Because he was at peace about his course of death, I was in a better place ...” (Jackson)

There were different associations to acceptance; Berklee and Jackson emphasized the hope for quality of death while, Lisa and Bob hoped for improvement on quality of life. Berklee’s comprehension of quality of death meant ending pain for his parent, perhaps from the adversity of the cancer treatment and similarly placing significance concerning his parent’s hope to end the continuity of treatment. Lisa, on the other end saw her mother survived through the cancer journey twice and therefore emphasizes quality of life more as she hopes of making sure her mother lives a healthier and happier life moving forward. When comparing Jackson and Bob ; the shortest and longest caregiving period respectively, Jackson took solace in the fact that his father was first able to accept the cancer diagnosis and therefore he too was able to achieve acceptance to focus on a better caregiving journey; while Bob made sure that the uncertainty of life does not come in between living life to the fullest, even in the adversity of an illness because it was not worth the deterioration negative thoughts would contribute.

Sources of comfort

Comfort and support came from two main sources: religion for one participant and social network for three other participants. Religion was based on one participant’s lived experience, but it was acknowledged to be a strong positive attribute that could be recognized further. Berklee’s quotes below narrates a selfless and compassionate engagement towards his religious practice differing from before the caregiving journey began. While his *attitude towards religion never changed*; religion was an *outlet*, in wanting his parent’s *pain to end*, and the *ability to rest once and for all*.

“You tend to pray for him a bit more. But I don’t pray for him to be alive longer, I just prayed for what’s best. And in theory god knows what’s best for him I guess, then again... supernatural entities... he is supposed to know everything. That’s the sole thing you can do, I was in capacity to ask for him to be provided what god believes he deserves I guess.” (Berklee)

“Religion became a bit more present in my life, but it wasn’t significant to me, okay maybe it comforts me knowing that technically speaking he is being taken care of, so it was more of a relieve factor I guess.” (Berklee)

Religion for Berklee was positively perceived as a relief factor towards himself and in his perception, also an indirect relieve factor for his parent. Resorting to prayers brought a sense of calmness and a safe, reliable space to express himself. Helpless in his position considering the circumstances, turning to religion felt like the *sole thing you can do*. Berklee felt his engagement towards religion also allowed him to be at ease with the view that there is a superior entity who may understand the circumstances better, possibly also taking care of his parent.

In addition, some took comfort in their social support. A strong support system made the caregiving journey more meaningful. Participants provided contrasting accounts of their understanding of their support system with two participants not discussing social support at all, while for another two it was a solid component of their positive caregiving journey.

“It’s not a war for my family alone. There was a lot of friends around us so wasn’t alone, though some were annoying.” (Jackson)

“I have a great group of friends. Even when I’m not around they will come visit my mother. I would just give them a call and they would go over to see my mum, and sometimes they even go over when I have not said anything.” (Bob)

Jackson highlights that the presence of a strong support system made navigating the long parental cancer journey feel less of a solo effort, despite some elements of negative social presence. Similarly, Bob admits having been “*very lucky*” when it comes to the reliability of his social support system, that has been of great help when initiated, also when he would receive help voluntary without him having to request.

Discussion

Our aim for this article was to gain rich, in-depth exploration towards the lived experiences of PAC in young adults towards parental cancer. Four main themes and four subthemes were produced from this study. The development of these aspects in-line with expected experiences that would have been shared by other types of caregivers, saw participants sharing both their positive and negative experiences. The current study chose to fill the gaps of exploring the understudied young adult care provider population and its association towards parental cancer. Both gaps are discussed below in relation to the present findings of this article which contributes towards a new light of caregiving comprehension. The following discussion should be carefully considered as they were analyzed within a very small sample population that while it produced vital life-changing experiences, it did not fulfill the minimum six for an IPA study as suggested by Smith, Flowers and Larkin (2009).

The parent-child dyad largely surfaced in understanding the roles in reverse, focusing more on the young adult child towards their parent. Caregiving was a responsibility towards their parent and similarly, appreciation and admiration of their parent and themselves despite the role reversal. Finch and Gibson (2009) identified vulnerability of the caregiver as one of six dimensions in teenage caregivers’ perceptions of parental cancer diagnosis. Our study also highlighted vulnerability in young adults through the perception of change in family dynamics and adaptations in family roles. However, we found the role reversal was perceived positively through the value system of responsibility across all participants. The expectation to take care of family members conforms to social norms (Lee, Netzer & Coward, 1994), and therefore slipping into the caregiver role could have been perceived as the most natural action to do by these young adults.

The variation in experience for the participants within our study is both consistent and inconsistent with Levesque and Mayberry (2012)’s growth study, as most participants in this study managed an improved relationship with their ill parent, but one did not see a difference in their parent-child relationship. However interestingly for the latter, the nature of relationship shared before the caregiving transaction may have influenced the different caregiving experience with quality of relationship before the caregiving journey is shown to affect the

overall caregiving satisfaction (Lyonette & Yardley, 2003). With mixed findings, a larger sample study is essential to identify underlying factors which could explain relationship characteristics and its effect on caregiving experiences. Among spousal and adult caregivers, males were more likely than females to have positive caregiving experiences due to the prevalent social norm that men are not typically expected to participate in caregiving activities in comparison to women (Lin, Fee & Hsueh-Sheng, 2012). The young men and women in our study discussed noteworthy positive experiences from the caregiving itself although gendered experiences were not explored in specific within this study therefore supporting the need for further exploration.

A mutual theme across all participants described was the acceptance of their parent for who they are and admiration for their endurance. Along the lines of child-parent dyad, disclosure, or communication pertaining to the illness, caregiving experience was seen in even representation for this data set. While communication pertaining to daily caregiving duties were normal, reciprocal communication such as expressing their emotions and thoughts were common only for two participants: the longest and shortest caregiving period respectively. Even though this was not presented as a negative experience for the current sample, the enhancement of positive reciprocal influences could potentially improve both caregiver and recipient's self-efficacy and assist in the adjustment to the role better (Li & Loke, 2014). Engagement with social support was highly influenced by expression adjustment based on the response received (Nolen-Hoeksema & Davis, 1999), which could be explained by emotional distress experienced by some participants in a more recent caregiving study when watching a family member suffering (Anderson & White, 2018).

Similarly, consistent with previous literature although some were not studied in the young adult population, character building and affirmation of value systems were mutually present for all individuals. In achieving a sense of accomplishment on the part of the caregiver and providing a caregiving transaction of quality, self-efficacy has a role to play (Carbonneau, Caron & Desrosiers, 2010). Although one participant within our study mentioned stepping into the role with low self-esteem, they fortunately still had high self-efficacy to fulfill their duties and with progression of time. Self-acceptance and validation of value systems were shared across participants and has been noted to be one of the predictors for positive psychological well-being in caregivers (Kramer, 1997; Anderson & White, 2018). Overall, intrinsic character traits such as increased level of patience, maturity and examples discussed above were growth that were present in current literature available which also studied a young adult sample, however ranging up to the ages of 40 (Pope, Baldwin & Lee, 2018).

The three elements that were present in cancer caregivers but were however unable to fit into the CFPAC framework for dementia caregivers; hope, religious coping and social support were present in this small sample through a unique narrative. Hope was manifested through acceptance as a subtheme towards quality of life and death. Two participants hoped that their family would understand that not everything can be fixed with illnesses and for another two, they hoped for the ability to regain life post-cancer. It is interesting to note these positive evaluations of life and death, as cancer is understood to be a unique stressor with high potential for deterioration of quality of life and/ or death (Putterman & Cadell, 2008). On the contrary, religious coping though only present in one participant brought the selfless trait of focusing prayer for their ill parent and not on themselves who were also in distress. It was an outlet of expression towards ending the cancer pain and allowing their ill parent to be at ease. Another participant experienced a secondary transference of religion with his ill parent, utilizing religion to accept the course of illness because their parent was religious, and this gave their

parent comfort. Themes of hope and spirituality were consistent with literatures targeting benefit finding in the cancer caregiver population although done in varied care provision population (Putterman & Cadell, 2008, Kim, Schulz & Carver, 2007). Religious and spiritual coping yielded mixed findings in our small sample study which encourages for further exploration.

Lastly, with social support, the young adult population seemed to have experienced a divided sense of connectedness with outlets around them. In the context of this study, there were friends in specific that were termed as “disappointing” and, surprisingly have also shared the hesitant in partaking or confiding in their friends through the caregiving journey. It was argued that most healthcare settings’ focus is commonly on the care recipient and therefore, one would expect young carers to seek support from their close network; friends and family (Pakenham, Chiu, Bursnall & Cannon, 2007). On the contrary, the two participants with the longest and shortest caregiving period respectively experienced a very positive experience with their social support – even to the extent of not requiring them to be physically present to benefit from said social support; supported by Kim et al. (2007) who found carers with more support from their social circle experienced higher perceived caregiving benefits. Our study saw two extremes of the role of social support and it is noteworthy for further exploration within a broad range of young adult population. It was however consistent in the light of this article that some participants could not seek as much support from their peers, suggesting an additional stressor to their caregiving journey. Some caregivers felt none of their peers would have been able to comprehend the circumstances, thus choosing not to seek support from their exterior circle. Filtering of social support was shared in this study and therefore caregiving benefits can be seen in a different light. Social support provides a positive resource for spousal caregivers and individuals in the older population (Chen & Greenberg, 2004), but the partial absence in this study could potentially be due to the limited exposure by young adults to such adverse circumstances observed around them.

Limitations and Recommendations

To our best knowledge, this study represents the first to explore young adults within the realm of caregiving towards parental cancer. However, the greatest limitation of this study was in its inability to recruit a larger sample, which yielded important results that are therefore non-conclusive but could be used for further exploration and replication with stronger sample size and interview methods. Similarly, to understand gendered experiences better, it is advisable to achieve a balanced recruitment ratio between men and women caregivers as this study did not achieve such balance. Besides all that has been discussed above, future studies could focus on the influence of death and bereavement towards the conceptualization of positive aspects of caregiving (PAC) in young adults as the current study found unique understandings between duration of bereavement towards PAC, and varied perspectives of PAC for young adults that have experienced the passing of their parent and those that are in long term cancer caregiving.

The current study contributes towards the practical development of support currently available for young adult carers towards their parent in a similar way that highlights accessible outlets for spousal carers. Inability to seek support from external social circle due to perceived shared universality of experience could suggest that proposing young adult caregiver support groups in medical or social work settings could be beneficial. While death and bereavement were shared through a unique positive lens in our study, it adds towards accepting and fulfilling the patient’s journey to the end of pain and achieving quality of death. Although the debated Liverpool Care Pathway was phased out in 2014, it is possible to still execute such end of life

care pathways respectfully by placing consent and ethical collaborative effort from all healthcare professionals. Lastly, as the current PAC review was only done with spousal caregivers checking suitability with the Dementia CFPAC; this study could be replicated in wider and larger young adult population to understand further specificity within the demographics and soon, conceptualize a PAC framework that would best fit cancer carers.

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Appendix A

Interview Schedule

Opening

Hello there. First of all, thank you for taking the time and interest to be part of this study and allowing me to interview you. This interview is being done to contribute towards the aim of understanding and exploring the positive aspects of caregiving (PAC) in individuals like yourself that have experienced being caregivers towards parental cancer. At any point throughout this interview if you feel any form of discomfort, feel free to end the session at your own pace. Do you have questions for me before I begin the interview?

A. Positive Aspects of Caregiving (PAC)

- 1) Could you tell me how you came about being a carer to your parent?
- 2) How would you describe the ways you cared for your parent?
Prompt: characteristics that made you feel good about yourself or your parent.
- 3) How did you care for your parent in the ways that you mentioned?
Prompt: from yourself or due to parental request?
- 4) What aspects of your caregiving experience that made you feel good or wanted to improve on?
Prompt: improved relationship with parent, feeling less burden.
- 5) How do you think your caregiving transaction helped your ill parent?
Prompt: parent felt more comfortable, open conversations.
- 6) Overall, how has this caregiving journey been meaningful or beneficial to you?
Prompt: by taking care of an ill parent, sense of fulfilment, better understanding of self and parent.

B. The Self and Others

- 1) What changes did you see in yourself during the caregiving journey?
Prompt: mentally, physically or emotionally.
- 2) What have you learned about yourself with this caregiving experience?
Prompt: personal development, self-esteem, caregiving skills, and mood.
- 3) What is your perception of cancer caregiving?
Prompt: Has this changed since you became a carer?
- 4) How has this caregiving experience influence your parent-child dynamics?
Prompt: if you got along well/ did not get along before the illness, how has it changed during the caregiving phase?
- 5) How has this experience influence the relationship with your social circle?
Prompt: friends, relationships, college/university or work.
- 6) How did you balance your caregiving role with your personal life?
Prompt: caregiving and university, caregiving and work, or caregiving and social life.

C. Coping

- 1) What coping mechanisms did you use when caring for your parent?
Prompt: seeking information about the illness, support from family/relatives/friends, having conversations with your parent about the both of you feel.
- 2) What were some of your coping activities?
- 3) How have other people (family members, relatives, and friends) helped in your caregiving experience?
- 4) Did spirituality or religion have a role to play in your coping? If yes, how?
- 5) What motivated you to continue your caregiving role?
Prompt: Any particular thoughts you had during the experience.
- 6) Was your motivation towards the role consistent, or did it fluctuate at times? If it did fluctuate, in what ways and why?
Prompt: to make sure you could fulfil your caregiving duties every day, without fail. (Continuity)