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Informal caregiver motivations, values, challenges and gains: A photovoice and interpretative phenomenological analysis of interrelationships

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Abstract

The adoption of a caregiving role in the context of illness and disability is often taken for granted. This study explores caregivers' motivations to provide care and how these relate to values, and to the challenges and gains of caregiving. Eight semi-structured interviews were conducted with caregivers and photographs were taken by caregivers to exemplify their caregiving experiences. This photo-elicitation method complemented the use of Interpretative Phenomenological Analysis when applied to verbatim transcripts. Superordinate themes included: *caregiver's life story*; *significance of family*; *caregiving obligations*; *caring relationship*; *challenges and gains associated with caregiver motivations*. Intrinsic and extrinsic motivations were less distinct in caregivers' lived experiences than previously suggested, and were influenced by family values and specific challenges and gains of caregiving. The coexistence of different motivations and the nature of single complex motivations is discussed. The importance of caregiver assessment and support planning, and regular breaks from caregiving are highlighted.

Keywords: informal caregiving, motivations, values, interpretative phenomenological analysis (IPA), photovoice, caregiving gains, caregiving challenges

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Introduction

Changing demographics, which include rising life expectancy and smaller family size (Börsch-Supan, 2019), place considerable demands on formal health and social care systems and on informal caregivers who provide care to relatives or friends with care needs (Revenson et al., 2016).

Motivations to provide informal care describe the reasons why people engage in caregiving (Zarzycki & Morrison, 2021). Motivations are central to many psychological studies of behaviour (e.g., Ryan & Deci, 2000) and can be categorised as *initiation* or *continuation* motives. The former type refers to the reason(s) why people decide to initially take on the caregiving role, whilst the latter refers to continued motivations for caring over time (Zarzycki & Morrison, 2021). Whilst research offers some insights into the motivations underlying a caregiver's role adoption or continuation (e.g., Faucher and Garner, 2015; Greenwood and Smith, 2019; Morrison and Williams, 2020), many questions remain. Little is known about whether or how caregiver values, the challenges and the gains (perceived or actual) of caregiving interact with motivations to initiate or continue caring.

Personal values may influence perceptions of caregiving challenges and gains and a person's motivations to care (e.g., Losada et al., 2010; Lu et al., 2019; Quinn et al., 2010). As evidenced in a meta-ethnography describing cultural motivations to care (Zarzycki, Seddon, Bei, Dekel, et al., 2022), values play an important role in shaping caregiving motivations and that role varies cross-culturally. Understanding how values may play differing roles in shaping motivations is an area worthy of further study as this may provide a better understanding of caregivers' unique needs and facilitate the development of personalised caregiver support (Winston et al., 2017).

The perceived challenges and gains of caregiving are influenced by many individual and contextual factors (e.g., Allen et al., 2017; Yu et al., 2018), with evidence of influence also from personal values (Losada et al., 2010; Marquez-Gonzalez et al., 2010) and caregiving motivations (Al-Janabi et al., 2018; Khalaila & Litwin, 2012; H. Yu et al., 2016). Whilst caregiving gains (e.g., self-growth) have received less research attention than caregiving burden and strain (Quinn & Toms, 2019; D. S. F. Yu et al., 2018), it is likely that there is a reciprocal relationship between caregiving motivations and caregiving experiences of gains or challenges.

The complex nature of values and caregiving motivations calls for in-depth qualitative exploration so that the significance of values to the individual concerned is understood in the context of their personal caregiving experience/motivations. This study employs a Photovoice storytelling methodology (Wang & Burris, 1994, 1997; Williams et al., 2014) and Interpretative Phenomenological Analysis (IPA; Smith et al., 2009). The former is a relatively new methodology within health psychology allowing the participant to take photos that express their individual perceptions and experiences of the subject under study. The latter seeks to

describe and interpret how individuals make sense of their unique lived experiences whilst taking into account their developmental, social and cultural contexts. Both methodologies enable the caregiver to express themselves metaphorically, enabling fuller reflections which could not have been achieved through rhetoric (conversation only). From a policy and practice perspective, this multimethodological design can produce findings of greater ecological validity as compared to other qualitative designs (Brunsden & Goatcher, 2007).

The study explored the perceptions, meanings, and experiences underpinning caregivers' motivations and how these relate to values, and the challenges and gains (perceived and actual) associated with caregiving.

Methods

Participants

Participants were family members (N=8) including parents supporting their adult son or daughter (N=4), spouses (N=2) and a sibling and her spouse caring for a brother (-in-law; N=2). Six caregivers were female, two were male. All participants identified as White British. Caregivers' age ranged from 43 to 65 years and the care recipients' age ranged from 22 to 70 years. The supported individuals had a primary diagnosis of an acquired brain injury. Caregiving duration ranged from 1 year to 13 years. Information about their care recipient's diagnosis was provided by the caregiver. Participants were identified via the *Headway Brain Injury Association* and *Stroke Association*, with local chairs facilitating the contact with caregivers during the charities' regularly organised support sessions. To be eligible, individuals had to identify as the primary caregiver. Only those with capacity to understand the purpose of the research and provide their informed consent to take part were included.

Design

We adopted a cross-sectional multimethodological qualitative design using photograph elicitation and conducting semi-structured interviews aligned to the IPA framework.

Data Collection

Prior to recruitment, full ethical approval was obtained from the Bangor University School of Psychology Ethics Committee (reference number 2019-16561-A14834). Interviews were conducted in an authorised room at the university with one exception where, at their request, one caregiver was interviewed in their own home.

Photovoice methodology

Caregivers took photographs over a 2-week period depicting their experiences as a caregiver, with instructions to take photographs reflecting their values and motivations for being a

caregiver and any challenges and gains (see online S1 Supplementary File for Photovoice prompts). Participants could use their own mobile device to take photos or a colour disposable camera which was provided. Subsequently, participants were invited to take part in a single semi-structured interview where they reflected on the photographs they had taken as part of an interview discussion.

Interview procedure

Caregivers selected up to five photographs to elicit discussion. Narrative reflections for the self-selected pictures were elicited, representing the values and motivations for caring and the challenges and gains (perceived or actual) of caregiving. The interviews were open-ended and contained non-directive questions designed for the study which were informed by an understanding of the existing literature about caregiver motivations, values, and the negative and positive outcomes of caregiving (e.g., Losada et al., 2010; Quinn et al., 2010; Williams et al., 2014; see online S2 Supplementary File for the semi-structured interview schedule). Focusing on individuals' lived experience, interviews were participant-led, exploring topics of personal significance. The order of interview questions was not predetermined. Interviews were recorded using an encrypted voice recorder. Field notes recorded the researcher's immediate thoughts and observations. Interview length ranged from 60 to 180 minutes (M=112 mins). Interview transcripts were anonymised.

Analysis

Interviews were transcribed verbatim (including pauses, sighs, stutters, tone and laughs) and analysed by the lead author. Transcripts were read and re-read to facilitate immersion in the data. During analysis the descriptive, linguistic and conceptual elements of the data were noted (Smith et al., 2009). This facilitated the next stages of developing emergent themes within the transcript and identifying connections across them. Analysis continued consecutively across the remaining transcripts, before identifying patterns across transcripts to develop superordinate themes. The process was reviewed by the research supervisors, providing an audit of quality, validity and transparency (Smith et al. 2009, p. 184).

Results

We describe the photographs caregivers selected to discuss and present the results from the IPA analysis of the caregiver interviews.

Six superordinate themes were identified:

1. Caregiver's life story
2. Significance of family
3. Caregiving obligations and responsibility
4. Caring relationship
5. Challenges (perceived and actual) and caregiving motivations
6. Gains (perceived and actual) and caregiving motivations

The superordinate themes (in bold) and their subthemes (italicised) are presented, with illustrative quotes included.

Photograph choice

Some photographs included the person with the acquired brain injury to represent reasons for caregiving, such as affectionate feelings, relationship quality, family values or to signify their deterioration, stabilisation or improvement. Some caregivers chose photographs of themselves or photographs with their care recipient to symbolise their obligations/responsibility to provide care or gratitude for the support they provided. For example, a photo depicting a caregiver holding hands with their relative with a visible wedding ring represented a caregiver's sense of marital obligation as a motive for caring. Caregivers often chose photographs of objects, which had various meanings attached, i.e., some symbolised the significance of family and/or obligations, e.g., photos of home symbolising the importance of family bonds; some symbolised the strains or challenges they were experiencing at the time of the interview. Photographs of objects also depicted gains from caregiving. The online S3 Supplementary File depicts some examples of the photographs taken.

Caregiver's life story

Past experiences. Caregivers reflected on their past life experiences when explaining their motivations for caregiving (initial or continued), connecting the selected past experiences with their current caregiving. For some, having previously been a caregiver for a different family member was an important factor that related to their current caregiving situation. Alice, Siân, Ceri and Florence drew links between these past experiences and their current situation.

So, I was the only one that used to deal with him [her dad who had Alzheimer's disease] before we had to put him in the [care] home because my sister, my brother, they couldn't

face it. So, I think that's where the caregiving comes from. So, it's just automatic. [...]
So, I think that's just, just the way, that's just my care. (Siân)

Personal characteristics. Personal characteristics mentioned by caregivers included their caring nature, patience, dispositional optimism, and independent nature. These characteristics encouraged individuals to assume the caring role and to sustain continued motivation for caring. For instance, Alice related to a predisposing characteristic of being caring.

I'm too soft and I care too much for them, but I don't know if you can get too much for anybody? (Alice)

Situational circumstances. Caregivers referred to the importance of situational and contextual factors that made caregiving possible in the first place and facilitated the continuation of the caregiving role, including: having the ability to retire and being eligible for a state pension, having financial resources, and the caregiver's own health status.

We have pensions and things like that. So, we're not that restricted. [...] but because I was so close, I was able to access my works pension. So, it wasn't a case of woman as working and next minute I had nothing else nothing, no money coming in. (Siân)

Changing trajectories in the care recipient's health condition. Findings consistently illustrated that caring was a complex and dynamic experience, shaped by a myriad of factors including changes in the care recipients' health and their associated care and support needs. Unsurprisingly, there was less motivation to continue caring amongst those caregivers who had less optimism about the prospects for care recipient recovery (Josephine, Siân, Florence, Will), compared to those who perceived recovery as more likely (Emma, Alice, Paul, Ceri).

It's changed, you know, something that was really bad that's got better over time. And so, it just depends with what stage. It went from, I would say, almost paralysing to now, mostly absolutely fine. [...] The overriding thing is just wanting things to carry on getting better or at least just stay the same. (Emma)

Significance of family

Family values. Family was highly valued by caregivers and they strongly identified themselves with an idea of family.

Well, family first and after that, other things, you know, sorting into line. (Paul)

Family values were exemplified as spending quality time together, maintaining a sense of 'home' (i.e., keeping family close by, emotionally and physically), and familial solidarity. Family values underpinned a sense of responsibility for family members (see theme

‘Caregiving obligations and responsibility’) and as such influenced both initial and continued motivations for caregiving.

We feel that all family *should* look after each other. (Florence)

Kin-keeper. The term ‘kin-keeper’ refers to a caregiver’s perceived responsibility for keeping family members connected, for the continuity and integrity of family relationships and of the caring relationship. For example, through facilitating communication and interaction between family members, Emma, Josephine and Siân were acting as kin-keepers - taking responsibility for the continuity of family relationships, including with the care recipient. Assuming the role seemed to have its roots in their life histories (see theme ‘Caregiver’s life story’) with caregivers associating their ‘kin-keeping’ characteristics with an anticipation to provide care.

So, everything was always left to me. So, I thought... my father always used to turn to me for that, you know. Different things like you know, it always was me that he always turned to. That's just, that's just a general background just for me to think why I'm the person I am, where the caregiving comes from. (Siân)

Caregiving... I was just trying to make things okay, you know, for the children, for the rest of the family. (Emma)

Familial support. Received familial support motivated caregivers to continue to provide care with family networks supporting them emotionally, socially and practically and helping to uphold their investment in caregiving.

Because although we've got a fantastic family. There might come a day when I might need help, ask them for help. They will be there like a shot. So yeah, they're pretty important. (Ceri)

Caregiving obligations and responsibility

Parental obligation. Parental obligation to provide care to an ill child was related to the social norm of being responsible for ‘the life you bore’ with caregiving seen as an extension of a perceived parental obligation to support a child.

Of course, you look after your children, don't you? No matter how old they are. They're always your children till the day you die. So why would you expect somebody else to look after them? (Alice)

Marital obligation. Spousal caregiving comprised the fulfilment of marital vows and perceived norms of being a spouse (‘a natural part of marriage’):

I'm not his carer, I'm his wife, you know, in a marriage, it's mutual love and respect. So, this label of carer, I struggle with it, I don't see myself as a carer. I'm just his wife, and we go on with it. (Ceri)

Although Siân acknowledged spousal obligation as one of the motives for initially providing care, she felt that it was not a sufficient motivator to continue caring. Her desire to relinquish the caregiving responsibility contradicted her sense of spousal obligation and affectionate feelings toward her husband.

I think it is a natural part of marriage - caregiving. In marriage even if there's nobody, you know, nobody's had a stroke or whatever. It's just that when [something happens] you just automatically step up. So that's part of it - yes. Caregiving. Definitely. (Siân)

I find it sometimes... it's frustrating because I'm, I think to myself: by now he should... he should have developed his own routines for doing things but he still hasn't, but *I'm done with it*. I feel sometimes a bit selfish. [...] Yeah, well because he, because obviously he had been ill like and here am I thinking to myself: I must be selfish person if I can't think about. (Siân)

Caring responsibility. Responsibility should be distinguished from *obligation*. Responsibility can still imply the presence of choice, for example, a choice to care or to relinquish care to others. Personal responsibility seemed to underpin Will's sense of agency, his caregiving motivation. The inferred difference between responsibility and obligation was derived from the discussion between the caregiving couple, Florence and Will, who reflected on the *choice* to care for Florence's brother. Both of them reported that caregiving was motivated by a sense of familial obligation/responsibility, however, Will disagreed with Florence's view that familial obligation entailed a lack of choice. Even though obligation may imply no choice, the individual's perception of obligation may not support this assumption. It may be hard to challenge the existing perceived norms, obligations, expectations and circumstances (e.g., societal and cultural ones around family-based caregiving), suggesting a perceived lack of choice. However, Will's perception of having a choice in providing care viewed against his wife's perception of having no choice in caregiving comprised a powerful example of attributing caregiving motivation to *personal* responsibility, i.e., responsibility that is not guided by general caregiving expectations or norms (e.g., that family should provide informal care), but by one's *own decision*, whether to provide care or not.

We didn't have a choice... [...] it was left down to... [us], we had no choice but to do it. It was basically forced upon us. (Florence)

No, I think it was a choice. There was a choice. [...] We had everything in place that we could do it so we said, 'well, if we can do it, why are we not doing it?' So, we just did it anyway. I suppose it is an obligation, because he's family. I mean if he wasn't family, I don't think we'd have done it for anybody else. [...] But there was a choice. (Will)

Caring relationship

Affectionate feelings. The emotions of love and affection toward the care recipient were amongst the most commonly reported motivations for initial and continued caregiving. Some caregivers described love as a primordial and natural force, making them act ‘without thinking’ or ‘without questioning’, i.e., non-cognitively, although cognitive aspects of emotion were also evident. Affection could be seen as an embodied emotion that drove the caregiving and which existed before the caregiving commenced (‘I love’ and ‘I care’ as entwined in caregiving action).

I think you would call it - if you love somebody, you will automatically give them care. You know, you look after them. Give them the care, caregiving. (Siân)

Affection was also experienced as a cognition (belief) amongst most of the caregivers, e.g., that love *should* be part of familial relationships (love as an expectation). Love as a cognition seemed a more logically thought-through decision or part of existing role expectations (and thus responsibilities) as compared to a natural, automatic, emotionally-based experience of love.

But yes, it's mutual love and respect. It's being together. It's sharing things. It's sharing your problems, listening to him. He listens to me. Discussing everything. It's just your life together. (Ceri)

Often, it was noticeable in the caregivers’ language that an affective state such as love brought with it responsibility and obligation which elicited both positive and negative effects. Given that the caregivers’ accounts were replete with diverse caring motivations, it is perhaps not surprising that caregivers described love and obligation simultaneously. Siân pointed to both the obligation arising from the marital role and affection.

Because he's my husband. [laughing] I still love him. Yeah, 'cause he's my husband I care about him because I want his life to be happy. So, I try to do as much as I can to make his life happy. (Siân)

Relationship quality. Relationship quality, including the perceived quality of current interactions and the strength of the bond between the caregiver and their care recipient (past and current), was another factor influencing initial and continued motivations to provide care.

Another motivator I've got with her is - since she was a very young child... maybe from one year old onwards, we would always take her out. We would never go out without her. We never asked anybody to babysit. [...] The bond that we have as a father and

daughter is endless all times and even this week because I have to spend so much time in bed now with my leg elevated, she bought me a fire stick. (Paul)

Care recipient's gratitude. Caregivers' perception of their care recipient's gratitude for their caregiving appeared consistently as motivation to continue caring after having been in the role for some time.

The best reward that I get out of that challenge for me, is her face and her thankfulness for doing it. Because you know she'll, she'll come and give me a kiss or a hug which is worth a million pounds for me. (Paul)

Challenges (perceived and actual) and caregiving motivations

Negotiating roles. Care and support needs arising from the sudden and traumatic onset of stroke/brain injury were the cue for the caregivers to assume their role (initial motivation). This required caregivers to take on different and varying degrees of responsibility over aspects of their care recipients' lives and, at times, temporarily make decisions on their behalf (both initially and later in their caring role).

He [John] was going to the library to do maths – 2nd chance Maths and 2nd chance English, and we would sit here and try and help him with his reading, and it's almost like looking after a 5-year-old child, yeah, but he's in a grown-up body so... (Will)

It was difficult for caregivers to establish boundaries in the caregiving roles; they were not certain how to re-negotiate the boundaries in a relationship and expressed doubts whether they were doing 'it' correctly. This renegotiation underpinned caregiving motives. For example, Siân recognised that by increasing Dylan's independence she could prepare him, hypothetically, for a situation in which she would no longer need to provide his care.

Probably that he will take a bit more control over certain things. I mean, I've tried to push him, push him regarding monetary things like paying, paying the bills. He has his own, he has a credit card. [...] But it's just... he.... just to get him a bit more independence as well because, I mean, I'm not gonna always be there for him. You know, for some reason, you can never tell. So, he needs to start moving away from being totally dependent on me. (Siân)

Feelings about support from services. All caregivers, except for Emma (who did not mention support services at all), expressed dissatisfaction with the support received from services. A feeling of abandonment appeared to underpin caregivers' dissatisfaction with services. Discharge of their care recipient from hospital prompted the caregivers to 'step in' and assume a caregiving role they felt ill-prepared for, leaving them with a sense of being left to their own devices. Caregivers' ability and willingness to provide care seemed to be taken for granted by

professionals involved in assessment and support planning at the point of hospital discharge. Limited service provision left caregivers feeling they had little choice but to care.

They all just left us. Well, what do we do now? You know, how do we manage? Nobody gave us any advice as to how to go forward with John or do anything like that. They just said, 'Well, that's not up to me, that's somebody else', and well, 'but, who do I talk to?' (Florence)

Florence and Will felt that healthcare and social care practitioners were supportive to the care recipient, however, the caregivers' story/voice was not heard. They felt unsupported/unacknowledged by them and this feeling might have contributed to the perception of the lack of choice in providing care that Florence expressed, effectively narrowing down other potential caregiving options/arrangements (see subtheme 'Caring responsibility'). Tacitly, in her case this seemed to sustain her caregiving motivation (rather than demotivate her).

When they build up, they become big problems. And if you go and try to discuss that with Gary, he seems to side with a person with a brain injury rather than listen to what the carer has to say. And so, we stopped we didn't really want to go after that. So far, I didn't. So, we stopped really going. (Florence)

Positive feedback and recognition of the caregiving role by professionals worked as a positive motivator to continue to provide care.

All the doctors and the dentists and practitioners know that every time we've taken him to see them, all they've said is 'Well, he's looking good, whatever you're doing, keep doing it'. So, to us, that's just encouragement. (Florence)

Coping with caregiving challenges. The range of coping strategies described by carers reflected the dynamic and contextual nature of appraisals, coping and the use of coping resources such as support systems. Persevering in the face of challenge was described by Florence and Will who, by focusing on the present moment, felt they were gaining more control and understanding of the impact of caregiving on their lives. Focusing on the present moment helped maintain motivations to provide care.

So that, yeah, we had a major challenge. We do get through it. And it does take its toll, but we move on. And we wait and take each day at a time. That's the only way we can live, by taking one day at a time. (Florence)

With time, the changes in lives of both caregivers and care recipients were accommodated and some of them knew better how to deal with them., i.e., either the care recipient's condition improved and/or caregivers felt better able to cope having gained knowledge and experience of the health condition and ways of dealing it with. An emerging sense of self-efficacy in the

caring role (i.e. a belief that they can successfully meet the challenges of caring) motivated continued caring.

Yeah, I'm getting used to... I probably got used to it now over the last 12 months. So, it doesn't, doesn't get me frustrated, doesn't get me annoyed as it used to. (Siân)

Acceptance of the caregiving situation limiting one's daily life and impacting the relationship with the care recipient featured in Florence's account. Similarly, it helped sustain caregiving motivations.

We take life... we take each challenge as it comes, that's what we do. (Florence)

Having short breaks from caregiving helped to manage caregiver strain and enabled the caregiver to maintain a life alongside caring, which helped to sustain their continued willingness to provide care. Ceri, Siân and Paul managed to take personalised short breaks from caregiving which had a positive impact on their wellbeing, helped them attend to their own needs and re-energise, and facilitated their willingness to continue caring.

I mean, if I want to get out of the house, just myself, then I can at least say: Right, I'm going to go into town or something like that just to go, get somewhere or something like that. That just gives me a small break away from him. So, I've half an hour or something like that, but it's just that breakaway. (Siân)

Gains (perceived and actual) and caregiving motivations

Gaining new experience and skills. Caregiving was described as a learning process in which challenges were either overcome or managed, thus leading to subjective feelings of gain, which in turn supported motivations to continue to care.

I think it's a definite gain and another gain is also that me and Luke meet different people at [name of the charity organisation], different people at appointments. He's been to different brain injury units to help other people that are suffering. So that's all a gain. For all of us really. And that's also a part of being caregiver, what I keep doing and wanna do. (Josephine)

Reflections on life: post-traumatic growth and resilience. For some caregivers, difficult moments turned out to offer an opportunity for reflection, underpinning a sense of happiness, relief at having coped, or a sense of achievement. This form of happiness highlighted the eudaemonic, rather than the hedonistic nature of wellbeing. Caregivers were often surprised to discover that the experienced trauma or burden enabled them to become stronger and to grow, i.e., led to edification, personal growth, and resilience. For instance, Paul reflected on the trauma, anxiety and depression that he experienced as a result of the challenges following his

daughter's brain injury; for him, being engulfed in caregiving became a way to grow as a person and find new ways to appreciate life.

...motivation to help is a motivator to keep on helping. Because I enjoy it and now, like with solitude, solitude... [I] feel free to plan the life I want for us as a family. (Paul)

Patience, understanding and empathy. Caregiving experiences shaped carers' personalities and, bidirectionally, their personalities influenced their caregiving experience, including their motivations. The most often cited changes (that were manifest as behaviours) included having more patience, higher compassion and empathy toward others; all of which comprised a tacit motivator to provide care.

So, the strengths, definitely, patience and empathy. (Emma)

Yeah, you more understand it, and you've got more of an understanding... (Florence)

Paul found meaning in helping his daughter and this self-growth translated into the experience of caregiving gain – which he embraced as his 'main motivator' for continuing caring for Julia.

So that is my main motivator, that I can find purpose in helping her - and that motivates me that I've done a good job. And if everybody's happy in the house as I said. (Paul)

Discussion

Summary of findings

A broad range of contextual, psychological and social caregiving motivations were identified, and these motivations were multiply determined. This study confirms previously described motives for caring identified in our large-scale review of the existing literature (Zarzycki, Seddon, Bei, & Morrison, 2022), namely: contextual influences, family values and familial context; love and affection; relationship quality; gratitude; obligations and responsibility to provide care. Caregivers' personal values, centred around family values, obligations/responsibility and the nature of caring relationship, constituted motivations for caring (see Themes 2-4). Context-based personal factors facilitated or hindered undertaking the caring role and its continuation (see Theme 1). Caregivers' experience of caregiving challenges, opportunities and gains was associated with their caring role, and with caregiving motivations (see Themes 5-6). This study shows how motivations relate to personal values, and how some motives interact with each other (e.g., affectionate feelings, obligations, and situational circumstances).

The findings show that caregiving motivations can influence the experience of gains and challenges, but in turn can be influenced *by* the specific challenges and gains associated with caregiving. This aligns with previous studies and review findings. Adding to this evidence base is an identification of post-traumatic growth (as a gain) and role negotiation (as a challenge) as importantly related to caregiving motivations. Indeed, for some caregivers the experience of challenges enabled them to become stronger and to grow as a person, facilitating subsequent satisfaction derived from the caring role and enhancing continued motivations (see below for discussion of the theoretical implications). The challenging renegotiation of roles referred to difficulties in establishing and keeping the balance between the care recipients' dependence and independence, as required by their new roles (of caregiver and care recipient). This renegotiation of roles underpinned caregiving motives (see subtheme 'Negotiating roles').

Implications of current findings for theory

Schulz et al. (1989) proposed three perspectives on caregiving motivations: social biology, social norms, and psychological motives. This qualitative study *does not* provide data pertaining to biological or sociobiological motivations (e.g., Barber, 2010; Humphrey, 1997), but it does examine the latter two by considering psychological and social motivations for caring. Interestingly, the issue of reciprocity presented in *Social Exchange Theory* (Adams et al., 1976) was rarely mentioned by caregivers in this study, which is surprising given the prevalence of this motivation in existing literature (Zarzycki, Seddon, Bei, & Morrison, 2022). Contrary to *Social Exchange Theory*, the current data supports the importance of motivations other than reciprocity, i.e., affection or perceived obligation. Perhaps a model of social exchange is overly formal/contractual, a model not true of all caregiving situations, and not reflected in the lived experience. Neither parents, nor spouses in the current sample mentioned

the idea that they ‘owe’ the support provided to their care recipients. It may be that reciprocity was a latent motive, not recognised or elicited in this study, or that its presence depends on different contextual factors, e.g., socio-demographic, including caregiver age or no adult child caregivers of parents in this sample.

Self-determination Theory (SDT; Ryan and Deci, 2000) distinguishes between intrinsic and extrinsic motivations. Intrinsic motivations refer to people’s spontaneous tendency to engage in a particular behaviour for its own sake. Extrinsic motivations are governed by the expectancy of instrumental consequence, i.e., gain and loss. Intrinsic and extrinsic motivations were not found to be distinct in caregivers’ accounts. Caregiving motivations appeared to be multiply determined and in any one individual could include intrinsic and extrinsic motivations that need not be mutually exclusive, for example, caregiving out of both love and perceived obligation. It was often difficult to establish whether an expressed motive should be considered intrinsic or extrinsic and it may not be necessary to consider motives in this dichotomous manner. Our findings suggest that we should move beyond the dichotomy of intrinsic and extrinsic motivations toward more comprehensive and inclusive theoretical frameworks of caregiving motivations that reflect the complexities of relationships and peoples’ everyday lives.

We cannot conclude what the salience of different motives were within a person, but our study provides evidence that caregivers did present multiple strong motivations for caring at a given time, and could also reflect on their past and future motivations. In line with the phenomenological method of analysis applied (Smith et al., 2009), Frankl's (1988) phenomenological theory helps to understand (a) the coexistence of different motivations and (b) the nature of single complex motivations which sometimes may seem to be contradictory, mutually exclusive or ambiguous, e.g., caring out of love and obligation described at the same time by Siân, or love described as intuitive/embodied/irrational versus logical/rational/an informed decision as described by Ceri. Motivations may be discerned on different ontological dimensions. As such, *the same motive* ‘projected out of its own dimension into different dimensions’ (Frankl, 1988, p. 23) may result in different contradictory descriptions (projections) of the motive - as seen for example in the two types of love differentiated in this study, i.e., love as affect versus love as cognition (irrational versus rational). Furthermore, *different motives* projected out of their own dimension (Frankl, 1988) into a different dimension may lead to ambiguous descriptions (projections) of these motives, such as seen in two different caregiving motivations - caring out of love and obligation, i.e., the juxtaposition of caring out of love and obligation does not have one obvious meaning and is open to more than one interpretation. Are perceived obligations inherent parts of love or are they separable from the experience of love? Depending on the ontological dimension of the experience under investigation, both can be true (Frankl, 1988). Frankl’s *Laws of Dimensional Ontology* (Frankl, 1988) may prevent us from drawing unequivocal, exclusive conclusions from caregivers’ accounts of motivations to provide care. Likewise, it is erroneous to assume that love reflects only the dynamics of psychological affective-cognitive processes or to assume that love is merely a collection of neurochemicals. Revenson et al. (2016) note that research on emotions

as motivations for caregiving is highly limited, and our study findings point to the acknowledgment of the complexity of the affective properties of caregiver motivations.

Caregivers in this study described positive aspects of caregiving (e.g., personal self-growth) which could be seen as essential factors maintaining caregivers' wellbeing, as depicted in a multidimensional model of psychological wellbeing (Ryff, 1989). This model recalls the ancient Greek notion of *eudaimonia* (Aristotle, 1985) to challenge prevailing conceptions of subjective wellbeing focused on feeling good, contentment, life satisfaction (*hedonia*). Continued growth and self-realisation, having quality ties to others, living a life rich in purpose and meaning are concerned with psychological wellbeing (Ryff & Singer, 2008). All of these were documented in this study and within some caregiver accounts, where participants' wellbeing had been challenged to the point where their experience was described as traumatic. Facing challenges enabled some caregivers to become stronger and to grow. This could be related to the concepts of 'adversity hypothesis' or 'post-traumatic growth' claiming that '[...] people need [...] even trauma to reach the highest levels of strength, fulfilment, and personal development' (Haidt, 2006, p. 136).

The findings also suggest that responsibility and obligation should not be considered equivalent caregiving motivations. *Personal responsibility* is not guided by general caregiving expectations or norms (e.g., that family should provide informal care), but by one's own decision, regardless of perceived *caregiving obligations*, understood here as general norms and expectations that make people undertake the caregiving 'responsibility'. According to existential legacy in psychology (Camus, 1965; Frankl, 1988; Sartre, 1948; Van Deurzen, 2009), people are required to make choices and their freedom implies that they are responsible for the decisions they make. Becoming a caregiver entails a decision and when this is being made, a person is confronted with answering life's questions (e.g., whether one should provide care for a relative initially or not, and the consequences thereof), which in turn creates the necessity to discover what is meaningful to them.

Implications for research

Further investigation of the salience of different caregiver motivations at different points in the caregiving experience is required. However, the salience of one motive over another should not overshadow the importance of understanding the nature of the motives, i.e., their dimensions and possible inclusive operationalisations. Some examples that support this view were illustrated in this study (such as two types of love as caregiver motives). Moreover, further research is needed to understand how caregiver challenges and gains (perceived and actual) impact on motivations to care, as this carries implications for the design of evidence-informed tools to help health and social care practitioners engage more effectively with caregivers when assessing their needs and planning support. Finally, the perception of choice in becoming a caregiver may impact on caregiver motivations, and possibly also their psychological and physical health. Future research should focus on the role perceived choice plays in caregiving motivations, willingness and caregiver outcomes (e.g., wellbeing, burden).

Implications for policy and care practice

Some caregivers felt that their personal story had not been heard by formal services. The importance of supporting caring relationships should be key for policy and underpin health and social care practice. Despite heightened policy commitments to supporting caregivers in the UK (e.g., Welsh Government, 2015) and other countries (e.g., Australian Government, 2019; Swedish Government, 2010), our findings suggest that caregivers feel neglected and unheard.

Some caregivers highlighted the impact personalised short breaks from caregiving had on their wellbeing, facilitating their motivation to continue caring. Being able to access regular, personalised breaks from caregiving is vital, helping caregivers relieve their stress, look after their own health, enhance their wellbeing and enjoy a life alongside caregiving. Breaks from caregiving should be seen as an essential preventive measure, not a luxury (Carers UK, 2021; Seddon & Prendergast, 2019; Shared Care Scotland, 2020).

Consistent with previous studies the findings show that assessment and support planning at the point of hospital discharge remains problematic. Caregivers' reported that their ability and willingness to provide care was taken for granted by professionals involved in discharge planning. The significance of effective assessment and support planning in aiding the transition from hospital to home and supporting caregiving relationships should not be underestimated. An individual's ability and willingness to care should not be assumed at the point of hospital discharge, or beyond.

Strengths and limitations

The strength of the study lies in its multimethodological approach combining Photovoice and IPA, both of which contributed to the composite and complementary analysis enabling in-depth, inductive, participant-led exploration of caregiving motivations and the ways they relate to values, and to the challenges and gains (perceived and actual) of caregiving. Research and theoretical discourse on personal values in informal care is limited, and this qualitative study provides important evidence linking caregiver motivations with personal values. It highlights the need for fuller consideration of the nature of caregiving motives, encompassing phenomenological and existential perspectives in psychology, not solely the social and cognitive ones which are typically applied. All perspectives have been applied here. The study has provided insight into the situational factors and unique stories that influenced caregivers' motivations and this adds value to both theoretical and practical considerations as described above.

Motivations and willingness to care can change over time. The cross-sectional design of the current study restricts the extent to which the effect of changes in caregiving motivations over time can be examined, in that attributions of change are made retrospectively or are prospectively anticipated. Moreover, where caregiving motivations/willingness were inferred

based on caregivers' retrospective/prospective account, the assumption was noted (and referred to 'implicit motivation' or 'motivation hinted at' by the participant). This study aimed to differentiate, where possible, between initial and continued caregiving motivations (Zarzycki & Morrison, 2021), recognising that caregiving needs and experiences fluctuate over time. Whilst the cross-sectional design of this study meant that caregivers were interviewed on one occasion, this did not preclude exploration of initial and continued motives. For example, affectionate feelings such as love for the care recipient were discerned in caregiver accounts both as motivation to start providing care as well as motivation to continue providing it. Longitudinal prospective research could address such questions with more confidence.

Conclusions

This study identifies a broad range of contextual, psychological and social influences on caregiving motivations and demonstrates that caregiving motivations can be influenced by responses to specific caregiving challenges and gains. Caregiving motivations map to a varying extent onto different spectrums of existing theoretical frameworks, although intrinsic and extrinsic motivations, and a model of social exchange, appear less distinct in caregivers' lived experiences than previously suggested. In line with the phenomenological method of analysis applied in this study, existential phenomenological theory is considered to better understand the coexistence of different motivations and the nature of single complex motivations, which may be contradictory, mutually exclusive or ambiguous. The study has implications for theory and research: models of caregiver wellbeing and potential interventions to support caregiver wellbeing ought not to focus exclusively on reducing caregiver challenges but should also consider the caregiving motivations and experienced gains, and how these interact. Future research should also address the role perceived choice plays in caregiving motivations, willingness and caregiver outcomes over time. Explored interrelationships between motivations and values, and the challenges and gains (perceived and actual) of caregiving enable a better understanding of caregiver needs. The study highlights the importance of supporting caring relationships as a key focus for policy and underpinning health and social care practice, specifically, effective assessment and support planning at the point of hospital discharge and beyond, and regular breaks from caregiving.

Data Availability Statement: All relevant data are within the manuscript and its supporting online files. The participants' anonymised compiled raw data for each superordinate theme and subtheme, and an explanation of the enclosed material, are uploaded to the Figshare repository.

References

- Adams, J. S., Berkowitz, L., & Hatfield, E. (1976). *Equity theory: Toward a general theory of social interaction*. Academic Press.
- Al-Janabi, H., Carmichael, F., Oyeboode, J., Al-Janabi, H., Carmichael, F., & Oyeboode, J. (2018). Informal care: choice or constraint? *Scandinavian Journal of Caring Sciences*, 32(1), 157–167. <https://doi.org/10.1111/scs.12441>
- Allen, A. P., Curran, E. A., Duggan, Á., Cryan, J. F., Chorcóráin, A. N., Dinan, T. G., Molloy, D. W., Kearney, P. M., & Clarke, G. (2017). A systematic review of the psychobiological burden of informal caregiving for patients with dementia: Focus on cognitive and biological markers of chronic stress. *Neuroscience & Biobehavioral Reviews*, 73, 123–164.
- Aristotle. (1985). *Nicomachean ethics*. (T. Irwin, Trans.). Hackett.
- Australian Government. (2019). *The Integrated Carer Support Service*. Australian Government.
- Barber, N. (2010). *Kindness in a cruel world: The evolution of altruism*. Prometheus Books.
- Börsch-Supan, A. (2019). Survey of Health, Ageing and Retirement in Europe (SHARE) Wave 7. Release Version: 7.0.0. *SHARE-ERIC*. <https://doi.org/10.6103/SHARE.w7.700>
- Brunsdon, V., & Goatcher, J. (2007). Reconfiguring photovoice for psychological research. *Irish Journal of Psychology*, 28(1–2), 43–52. <https://doi.org/10.1080/03033910.2007.10446247>
- Camus, A. (1965). *The myth of Sisyphus, and other essays*. H. Hamilton.
- Carers UK. (2021). *Breaks or breakdown*. <https://www.carersuk.org/for-professionals/policy/policy-library/breaks-or-breakdown-carers-week-2021-report>
- Faucher, M. A., & Garner, S. L. (2015). A method comparison of photovoice and content analysis: Research examining challenges and supports of family caregivers. *Applied Nursing Research*, 28(4), 262–267. <https://doi.org/10.1016/j.apnr.2015.02.005>
- Frankl, V. E. (1988). *The will to meaning: Foundations and applications of logotherapy*. Penguin.
- Greenwood, N., & Smith, R. (2019). Motivations for being informal carers of people living with dementia: A systematic review of qualitative literature. *BMC Geriatrics*, 19(1). <https://doi.org/10.1186/s12877-019-1185-0>
- Haidt, J. (2006). *The happiness hypothesis: Putting ancient wisdom and philosophy to the test of modern science*. Random House.
- Humphrey, N. (1997). Varieties of altruism—and the common ground between them. *Social Research*, 64(2), 199–209.
- Khalaila, R., & Litwin, H. (2012). Modernisation and filial piety among traditional family care-givers: A study of Arab-Israelis in cultural transition. *Ageing and Society*, 32(5), 769–789. <https://doi.org/10.1017/S0144686X11000572>
- Losada, A., Marquez-Gonzalez, M., Knight, B. G., Yanguas, J., Sayegh, P., & Romero-Moreno, R. (2010). Psychosocial factors and caregivers' distress: Effects of familism and dysfunctional thoughts. *Aging and Mental Health*, 14(2), 193–202. <https://doi.org/10.1080/13607860903167838>
- Lu, Q., Mårtensson, J., Zhao, Y., & Johansson, L. (2019). Living on the edge: Family caregivers' experiences of caring for post-stroke family members in China: A qualitative study. *International Journal of Nursing Studies*, 94(22), 1–8. <https://doi.org/10.1016/j.ijnurstu.2019.02.016>
- Marquez-Gonzalez, M., Romero-Moreno, R., & Losada, A. (2010). Caregiving issues in a therapeutic context: New insights from the acceptance and commitment therapy approach. In N. Pachana, K. Laidlaw, & B. Knight (Eds.), *Casebook of clinical geropsychology: International perspectives on practice* (p. 3353). Oxford University Press.
- Morrison, V., & Williams, K. (2020). Gaining Longitudinal Accounts of Carers' Experiences Using IPA and Photograph Elicitation. *Frontiers in Psychology*, 11, 2429. <https://doi.org/10.3389/fpsyg.2020.521382>
- Quinn, C., Clare, L., & Woods, R. T. (2010). The impact of motivations and meanings on the wellbeing of caregivers of people with dementia: A systematic review. *International Psychogeriatrics*, 22(1), 43–55. <https://doi.org/10.1017/S1041610209990810>
- Quinn, C., & Toms, G. (2019). Influence of Positive Aspects of Dementia Caregiving on Caregivers'

- Well-Being: A Systematic Review. *Gerontologist*, 59(5), 584–596.
<https://doi.org/10.1093/geront/gny168>
- Revenson, T., Griva, K., Luszczynska, A., Morrison, V., Panagopoulou, E., Vilchinsky, N., & Hagedoorn, M. (2016). *Caregiving in the illness context*. Springer.
- Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, 55(1), 68–78.
<https://doi.org/10.1037/0003-066X.55.1.68>
- Ryff, C. D. (1989). Happiness is everything, or is it? Explorations on the meaning of psychological well-being. *Journal of Personality and Social Psychology*, 57(6), 1069–1081.
<https://doi.org/10.1037/0022-3514.57.6.1069>
- Ryff, C. D., & Singer, B. H. (2008). Know thyself and become what you are: A eudaimonic approach to psychological well-being. *Journal of Happiness Studies*, 9(1), 13–39.
<https://doi.org/10.1007/s10902-006-9019-0>
- Sartre, J.-P. (1948). *Existentialism and Humanism*. Methuen.
- Schulz, R., Biegel, D., Morycz, R., & Visintainer, P. (1989). Psychological paradigms for understanding caregiving. In E. Light & B. D. Lebowitz (Eds.), *Alzheimer's Disease Treatment and Family Stress: Directions for Research* (pp. 106–121). U.S. Department of Health and Human Services, National Institute of Mental Health.
- Seddon, D., & Prendergast, L. (2019). Short Breaks for carers: a scoping review. *Wales Centre for Ageing and Dementia Research, School of Health Sciences, Bangor University*.
- Shared Care Scotland. (2020). *Promoting Variety. Shaping markets and facilitating choice in short breaks*. <https://www.sharedcarescotland.org.uk/wp-content/uploads/2020/09/SCS-Promoting-Variety-2020-WEB.pdf>
- Smith, J. A., Flower, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. Sage.
- Swedish Government. (2010). *Social Services Act*.
- Van Deurzen, E. (2009). *Everyday mysteries: A handbook of existential psychotherapy*. Routledge.
- Wang, C., & Burris, M. A. (1994). Empowerment through photo novella: Portraits of participation. *Health Education Quarterly*, 21(2), 171–186.
- Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior*, 24(3), 369–387.
- Welsh Government. (2015). *Social Services and Well-being (Wales) Act 2014 Part 3 Code of Practice (assessing the needs of individuals)*.
- Williams, K. L., Morrison, V., & Robinson, C. A. (2014). Exploring caregiving experiences: caregiver coping and making sense of illness. *Aging & Mental Health*, 18(5), 600–609.
<https://doi.org/10.1080/13607863.2013.860425>
- Winston, C. N., Maher, H., & Easvaradoss, V. (2017). Needs and values: An exploration. *The Humanistic Psychologist*, 45(3), 295–311. <https://doi.org/10.1037/hum0000054>
- Yu, D. S. F., Cheng, S. T., & Wang, J. (2018). Unravelling positive aspects of caregiving in dementia: An integrative review of research literature. *International Journal of Nursing Studies*, 79, 1–26.
<https://doi.org/10.1016/j.ijnurstu.2017.10.008>
- Yu, H., Wu, L., Chen, S., Wu, Q., Yang, Y., & Edwards, H. (2016). Caregiving burden and gain among adult-child caregivers caring for parents with dementia in China: The partial mediating role of reciprocal filial piety. *International Psychogeriatrics*, 28(11), 1845–1855.
<https://doi.org/10.1017/S1041610216000685>
- Zarzycki, M., & Morrison, V. (2021). Getting back or giving back: understanding caregiver motivations and willingness to provide informal care. *Health Psychology & Behavioral Medicine*, 9(1), 636–661.
- Zarzycki, M., Seddon, D., Bei, E., Dekel, R., & Morrison, V. (2022). How culture shapes informal caregiver motivations: A meta-ethnographic review. *Qualitative Health Research*, 1–16.
<https://doi.org/10.1177/10497323221110356>
- Zarzycki, M., Seddon, D., Bei, E., & Morrison, V. (2022). Why do they care? A qualitative systematic review and meta-synthesis of personal and relational motivations for providing informal care. *Health Psychology Review*, 1–33. <https://doi.org/10.1080/17437199.2022.2058581>