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Sheung-Tak Cheng, PhD, Emily P. M. Mak, BSocSc, Rosanna W. L. Lau, BSocSc, Natalie S. S. Ng, BSocSc, Linda C. W. Lam, MD
Research Article

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Sheung-Tak Cheng, PhD, *,1,2  Emily P. M. Mak, BSocSc,1  Rosanna W. L. Lau, BSocSc,1,2  Natalie S. S. Ng, BSocSc,1 and Linda C. W. Lam, MD3

1Department of Health and Physical Education, Hong Kong Institute of Education, Tai Po, Hong Kong. 2Department of Clinical Psychology, Norwich Medical School, University of East Anglia, Norwich, United Kingdom. 3Department of Psychiatry, Chinese University of Hong Kong, Tai Po, Hong Kong.

*Address correspondence to Sheung-Tak Cheng, PhD, Department of Health and Physical Education, Hong Kong Institute of Education, 10 Lo Ping Road, Tai Po, N.T., Hong Kong. E-mail: takcheng@ied.edu.hk

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Abstract

Purpose: To discover positive gains as constructed by family caregivers of relatives with Alzheimer’s disease.

Design and Methods: Fifty-seven Hong Kong Chinese primary caregivers provided 669 diary recordings over an 8-week period, describing daily events and experiences in which positive gains were achieved. The diaries were analyzed independently by two researchers using thematic analysis.

Results: Ten themes related to positive gains were identified: (a) insights about dementia and acceptance of the condition, (b) a sense of purpose and commitment to the caregiving role, (c) feelings of gratification when the care-recipient (CR) was functioning relatively well, (d) mastering skills to handle the CR, (e) increased patience and tolerance, (f) cultivating positive meanings and humor amidst difficult circumstances, (g) letting go of things, such as when the CR’s qualities had been lost or personal agenda had become unrealistic, (h) developing a closer relationship with the CR, (i) finding support, and (j) feeling useful helping other caregivers.

Implications: In addition to treating negative outcomes such as depression, practitioners and researchers should identify means to promote positive gains. Strategies mentioned in the caregivers’ diaries, such as reframing stressful situations in a more positive light, may provide input into the design of such interventions.

Keywords: Positive aspects of caregiving, Alzheimer’s disease, Qualitative methods, Hong Kong Chinese

It is well-recognized that caregivers experience uplifts as well as burden and frustrations (Kramer, 1997). Such uplifts may be crucial to keep a caregiver going despite the day-to-day challenges, and may even reduce feelings of burden (Cheng, Lam, Kwok, Ng, & Fung, 2013a). In one of the early studies of this topic, Kinney and Stephens (1989) described 110 events from 60 Alzheimer family caregivers in the United States and asked them to indicate whether they had experienced the events in the past week. They also rated each event according to the degree to which it had been a hassle or uplift for them. The authors found contrasting perceptions across caregivers for 93 (85%) of the 110 events—these events were considered as hassles by some but as uplifts by others, supporting the idea that the impact of caregiving depends on appraisal. Thus, a negative appraisal leads to burden and other negative outcomes whereas a positive appraisal results in benign perspectives and emotions that are now commonly referred to as positive gains or positive aspects of caregiving (Cheng et al., 2013a; Kramer, 1997). In Kinney and Stephens’ study, caregivers reported an average of 49 events in the past week, with 40% of these being rated as uplifts, suggesting that
they were rather frequent experiences despite the prevailing burdensome aspects of caregiving. Moreover, events that were most frequently rated as hassles or uplifts typically concerned the care-recipient’s (CR’s) behaviors or conditions, such as the CR being agitated (hassle) or responsive (uplift). Another common hassle was providing assistance for activities of daily living, whereas other uplifts that were frequently reported generally concerned relationship with the CR or other close persons, such as spending time with the CR or receiving support from family or friends.

Broadly speaking, positive gains are benefits or rewards, whether intrinsic (e.g., a sense of satisfaction) or extrinsic (e.g., appreciation from the CR), that the caregivers obtain from the caregiving experience. Whereas the word caregiving implies a one-way flow of benefits from the caregiver to the CR, the reality is that caregivers also experience rewards from caring for the CR. Such rewards can be emotional, cognitive, behavioral, or interpersonal, but they have one thing in common—they are personally meaningful and cannot be thoroughly described without due regard to the subjective nature of the interpretations. They also tend to be unexpected in the sense that caregivers generally do not foresee them coming when they take up the responsibilities and hence it is not uncommon to find a surprise element in their description of gains. While the rewards arise in the context of caregiving, they are not necessarily time-limited and role-dependent; in other words, some of the rewards (e.g., enhanced coping ability) may radiate to other situations and persist long after caregiving is over.

Although there are psychometric measures to assess positive gains (e.g., Tarlow et al., 2004 for review), qualitative studies have the advantage of allowing free expression of emotions and thoughts (hence going beyond themes preconceived by researchers) and a deeper probe of their personal experiences, especially how positive and negative emotions/thoughts are intertwined in the process of handling caregiving demands. However, only a few studies have attempted to explore the positive side of caring for someone with dementia. Sanders’ (2005) study of 85 dementia caregivers in the United States found 81% of them to report gains, which were grouped into three themes—growth in spirituality and faith, personal growth, and increased mastery. In a small sample of 12 Singaporean dementia caregivers, three overarching themes were described, namely personal growth, relationship enhancement, and higher-level gains such as changes in life philosophy (Netto, Goh, & Yap, 2009). Thus, two of their themes overlapped with those of Sanders, suggesting that the domains of positive gain may be similar across cultures.

In a study about home care, Peacock and colleagues (2010) found that some dementia caregivers talked spontaneously about positive gains. Five main themes emerged from six focus group discussions (N = 36) and three individual interviews. First, participants saw caregiving as the opportunity to reciprocate what the relative had done for them before, and this was especially common among children and husbands. Wives tended to feel that caregiving was a natural continuation of the marital relationship. Second, participants described personal growth in terms of resilience in continuously adapting to novel challenges in caregiving; they described that process as a journey of discovering one’s strengths and were grateful for having walked the journey together with the relative. Third, caregivers appreciated the assistance from certain family members and friends as well as from formal care providers, especially when there were fewer visits from other relatives and friends. Some also appreciated support from the CR who accepted the disease and validated the caregiver’s worries. Fourth, mastering the demands of caregiving and providing a safe environment gave them a sense of accomplishment and competence. This might involve reading and going to workshops to learn about the disease and becoming prepared for what might come next. Finally, a gain related to some of the points above was a closer bond with someone they loved. Some caregivers preferred to keep their relatives at home for as long as possible, while using respite or home care to support their continuous commitment to care provision. However, because the study was not specifically designed to tap positive gains, it might have left out some important themes.

On the whole, there is a dearth of qualitative research into positive gains by dementia caregivers. In the following, we report a study on positive gains as constructed by a sample of Alzheimer’s caregivers in Hong Kong as revealed in their diaries. Because the diaries were based on daily events, they reflected how positive gains were constructed “on the spot,” rather than merely summary and retrospective reflections as in one-shot interviews or focus group discussions. In that sense, aside from minimizing recall bias, they documented the process in which positive gains develop while coping with everyday events and revealed the caregivers’ mental and psychological journey in searching for positive gains.

**Methods**

Fifty-seven primary caregivers (8 wives, 2 husbands, 42 daughters, 2 sons, 1 daughter-in-law, 1 son-in-law, and 1 nephew) providing at least 14 hr of care per week to a relative with physician-diagnosed Alzheimer’s disease in the mild-to-moderate stage, were recruited from clinics, day hospitals, and social centers through referrals by staff. The sample had a mean age of 54.0 years (SD = 7.06), with 65% married, 77% having secondary education or above, and 72% living together with the CR. Mean care duration was 2.32 years (SD = 1.74). The caregivers provided informed consent to participate in a study on “caregiving benefits” and were each given a tape recorder. In the following 8 weeks, they were asked to voice-record positive gains as a result of providing care to the relative. Ethics approval was obtained from the Central Research Committee of the Hong Kong Institute of Education. Voice recordings rather than written diaries were used because some spouse caregivers were illiterate and because we wanted to standardize the data collection
method. Standardization is particularly important in the present context because the oral and the written form of the language (Cantonese being the main Chinese dialect in Hong Kong) are not the same.

To ensure that caregivers understood what to record, they were provided a description of what constituted a positive gain at either the clinic/center or their own home. They were told that a positive gain was something good that happened to them because of the caregiving responsibilities, and hypothetical examples were provided. Caregivers also practiced recording recent positive experiences in front of the research assistant before they were left to start the diary exercise. Because it was not possible to predict when a positive gain would arise and because it was not always possible to fit a diary recording into the caregiver’s routine, we did not specify which days of the week and what time of the day to do the diary. We only asked the caregivers to record any positive experiences in relation to caring for the relative in the same evening, up to three times a week. We also did not specify any format or structure for the diary to allow free expression by the caregivers. Research assistants collected the tapes back on a weekly basis when one or more recordings were made. Altogether, 669 diaries (mean = 11.74, SD = 6.84, range = 1–24) were returned by the participants and constituted the data for this study.

Data Analysis

The audiotapes of the diaries were transcribed to facilitate thematic analysis. Data analysis proceeded in several steps, namely, familiarizing with data, generating initial codes, identifying recurrent patterns, defining and naming themes, and reviewing themes (Patton, 1990). Specifically, two members of the research team who are native Chinese speakers and were experienced working with dementia caregivers read the scripts independently several times to familiarize themselves with the entire transcript before coding the scripts using an inductive approach (Braun & Clarke, 2006). The unit of analysis was each individual event or incident as described in the diary, which was open-coded to identify meanings denoting gain, reward, or benefit in the context of caregiving. Because of the nature of positive gain, meanings were assigned contextually and holistically. For example, a caregiver who simply said that “I felt calm today” would not be coded as a gain, but the same thing said after describing being hit by the CR and the strategies used to contain his or her anger would be coded as such.

Following independent coding, the researchers compared notes and resolved differences through discussion. Next, codes that were similar or related were grouped together and formed thematic categories in an iterative and reflective process. This was again done independently by the two coders who then compared and discussed their groupings. Through this process, the researchers clarified the meanings of each thematic category until a consensus was reached. For instance, humor and cognitive restructuring were grouped together (see below) because humor often involves some degree of reframing.

Subsequently, the senior author, also a native Chinese speaker, read the scripts and reviewed the coding to ensure that the themes represented the data well. Any difference in opinion was discussed with the two coders and the coding process was repeated until a final consensus was reached. Exemplary passages were then identified from among the scripts to illustrate each thematic category below. Note that the same diary might contain multiple gains that were mapped onto more than one category; thus it may not be possible to select scripts that speak to only one theme but not the others. Because the diaries were all in Chinese, we translated the selected passages for the sake of presentation.

Results

Insights About Dementia and Acceptance of Disease

This was one of the most common themes identified by the caregivers. Through various sources, caregivers learned more about dementia and what to expect as the disease progressed. More importantly, understanding and acknowledging the CR’s problems as manifestations of an underlying disease helped caregivers appreciate the uncontrollability of the CR’s symptoms and to refrain from making unrealistic demands on the CR. In summary, they were more inclined to consider how the CR might be experiencing the situation, rather than assuming that the problematic behaviors were intentional.

Like not eating, if it was before, I would be very upset. I had done the cooking and she refused to eat. But now I would think, perhaps she’s not hungry…. I can give the food to her later…. I feel a lot better this way. (Daughter taking care of her mother)

Other than reading or attending workshops, insights could come directly from dealing with the CR that was valued as personally relevant, given the genetic basis of Alzheimer’s disease.

At first, I thought I was the one doing the sacrifice, spending time to take care of my dad. But slowly, I realize how much I have learned from him in terms of what I might face when I get old. It helps me confront the issue early. (Daughter caregiver)

One of the direct consequences of accepting the disease was a reduction in self-stigma due to association.

Before I learned about the disease, I suffered a lot and could not adjust to [the caregiving role]. Now I feel less embarrassed and much more comfortable doing it. Initially, I wasn’t used to the looks people gave me when I took mom out. Now, I feel more relaxed and less stressed. (Daughter caring for her mother)
A Sense of Purpose and Role Commitment

Finding a reason for doing it would help caregivers get through the day and sustain their motivation in the long term. Perhaps the most common sentiment was, “It's my (mom/dad/spouse). I have to take good care of him or her, no matter what. It's the right thing to do.” For children, taking care of the parent was a fulfillment of filial obligations.

People who get this disease cannot recover. We can only slow down the rate of deterioration. So as children, we should treat her well when she is alive. (Daughter caring for her mother)

For spouses, taking care of their other half was considered part of the marital relationship, whether husband or wife.

Every morning, he gets up and goes to toilet a few times. You need to wait till he finishes before you can go.... And asking the same questions every day, so annoying. But thinking he's my dearest love, in sickness and in health, I would cheer up. (Wife caregiver)

A sense of purpose helped caregivers identify with the role and commit to it, and was strengthened with increased knowledge of things that can be done to improve management of the CR.

Knowing what dementia can do to a person forewarns me about the things to come.... But I know I cannot feel discouraged. I will continue to take care of, console, and support him. (Wife caregiver)

Before, I did not know why my mom acted this way. After I understood that her behaviors were due to the disease.... there were fewer misunderstandings and less miserable feelings. Instead, I would put more effort into finding ways to help her.... give her better quality of life. I won't be 'pig-headed.' (Daughter caregiver)

Perhaps the simplest, yet compelling reason to keep doing the job is “if not me, who else?”

How pitiful it is for an older person to be without someone caring for her. Unfortunately, my brothers would not take care of my mom. She is so lucky [italics added] to have me and her granddaughter…. [We made her] very happy. We are so pleased to see her well. (Daughter caregiver)

Feelings of Gratification and Gratitude

When the CR was seen to be doing relatively well, caregivers expressed happiness, satisfaction, and even gratitude. This was another common theme expressed in the diaries. Seeing that the CR’s condition was stabilized or improved validated their hard work and sacrifices. In the Chinese cultural context that emphasizes eating well, a good appetite can mean a lot to the caregiver.

We were having dinner. She refilled her bowl a bit after having a big bowl of rice. She seemed to have a better appetite [i.e., liked the food I cooked].... I was so, so happy. (Daughter caregiver and her mother)

Seeing mom getting better and better [being more responsive and less demanding], all the work I do, no matter how hard it seems, is worth it. (Daughter caregiver)

Often, the CR gave the caregiver pleasant surprises with performances beyond the latter's expectation.

We [daughter and her mom] were chatting after dinner. All of a sudden, mom called my name.... I was so happy, cause she hadn’t called my name for many years. She even couldn’t recognize me.... I was really happy. I hugged her so tightly.

Caregivers reported satisfaction, regardless of whether the CR’s stability or progress was directly related to what the caregiver did. And when the CRs were working hard themselves, engaging in activities believed to be beneficial, attempting self care, or helping with daily chores, caregivers expressed appreciation or gratitude.

Today, mom saw me occupied with other things when it’s almost time to cook. She took the initiative to ask whether I needed help to prepare the vegetables. I was so pleased she asked and found things to do herself. Although I had to separate the bad vegetables from the good ones after she washed them, but to her, it’s a contribution made. (Daughter caregiver)

Mom did not receive education and is illiterate. She only knew how to write the numerals 1–100.... She’s not interested in learning how to write words but is still willing to practice writing the numerals. It would be nice if she can keep doing it. (Daughter caregiver)

Importantly, a deep sense of satisfaction was expressed when the caregiver felt that the CR appreciated what the caregiver was doing for him or her, whether or not the CR was able to express it.

Although mom would not say “thank you” ... I know she’s happy inside.... I can feel she knows how we treat her. I know how she thinks.... I can feel it. (Daughter caregiver)

A Sense of Mastery

When caregivers were committed to the role, they wanted to do it well. When the CR responded well to something they did, they felt a sense of mastery and a confirmation that they were serving their purpose well. Caregivers talked a lot about how they put the relative on a schedule of activities and dealt with various issues confronted on a day-to-day basis including behavioral problems and impaired abilities. For instance, caregivers learned to speak more slowly and gently, use simple sentences, and repeat or rephrase instructions if necessary.

[This afternoon] my husband went out ... and got lost again. I was very angry ... and scolded him a bit. He...
hanged up on me.... What to do? ... I called him again and talked to him gently, in a low voice, “... I don’t know where you are. I have been out looking for you for a long time. Why don’t you ask someone how to get back home? ...” He said, “OK.” Half an hour later, I called him again.... He found someone to take him home.... I realized I shouldn’t be mad with him. He listens only when I am gentle.... He got back home safely. I’m so happy.

They also discovered strategies such as taking a break, ignoring, distraction, or diversion to handle repetitive questioning or unreasonable demands.

[My husband] had tantrums.... I was annoyed. So I ignored him and did not talk to him. After he finished tantrums, he came to me and said, “let’s go to have Chinese tea [dim sum lunch].” Then I smiled at him and pretended nothing happened.

After the bath [and after dinner], he [husband] asked why there was no dinner.... I thought: Don’t argue with him.... I thought about how to talk to him.... “Cooking dinner now. If you are hungry, why not drink milk or eat a piece of cake?” After he ate, he went to bed himself.... I really have to learn how to divert his attention [instead of arguing]. I get to sleep tonight!

Of course, caregivers talked about other skills they had developed over time. The following are just a couple of examples:

The purpose of today’s gathering was to let my husband meet with friends that he hasn’t seen a lot, to see if he could remember more things in the past.... He did quite well, and remembered many things because of the gathering. It turned out my arrangement today was very successful. I am quite happy about it. (Wife caregiver feeling proud)

I would try to prevent him [husband] from going out as much as possible.... I took out all the old movie discs.... Turned off the lights.... I sat in the couch and watched the movies with him.... We were both mentally absorbed ... like in a movie theater. And I also learned how to coax him.... It kept him from demanding to go out. I had a peaceful night in the end.

Although effective methods to deal with the CR’s issues might not be apparent at times, caregivers maintained a sense of hope that some solutions would be found and kept searching for alternatives. Such an attitude was backed up by positive thinking to be discussed later.

I changed my way of thinking ... There are always more solutions than problems. Although problems keep coming, I would not stop finding solutions ... and support.... There is no point to keep worrying and be troubled by those problems. (Daughter caring for her mother)

While having a skill repertoire was important, successful skill application required a good degree of calmness and so the caregivers needed to manage their emotions as well.

My dad was not willing to take a bath or wipe clean his body. I had tantrums.... After my tantrums were over, I listened to a song.... Sat down for a while. And then I went back to dad again and coax him to get cleaned. He complied! After the bath I gave him jelly and other things as reward for behaving well. (Daughter caregiver)

Increased Patience and Tolerance

Whether dealing with behavioral problems, uncooperativeness, or simple tasks that now required supervision or assistance because of dementia, it was easy for the caregiver to become agitated, as in the preceding example. As time went on, most caregivers learned to become more tolerant and patient. A better “emotional intelligence,” so to speak, was identified by many caregivers as constructive personal growth as a result of providing care to the CR.

Just now, I chatted with mom on the phone. Aside from asking me the same questions over and over again, the sequence of her expressions or the sequence of happenings were all mixed up. I needed to have a lot of patience to guide her to describe the whole thing. (Daughter caregiver)

Mom has repetitive behaviors a lot. They have inadvertently made me a more patient person. I used to be short-tempered but now I learn to savor every moment. (Daughter caregiver)

Tolerance did not arise from improved knowledge about dementia alone, because change was typically gradual. Tolerance and patience appeared to come with the awareness that confrontation and coercion would not work. Some caregivers saw stretching their patience and tolerance, no matter how difficult the situation was, as a validation of their love for the CR.

Mom repeats the same words and the same annoying behaviors everyday. Neither did I take her words to heart nor did I reprimand her for her behaviors. I would only tell myself: Mom can still talk and do things. And I still have the ability to take care of her! (Daughter caregiver)

Cultivating a Positive Mindset

Increased patience and tolerance could reduce a good deal of negative emotions but the challenges of caregiving could still be overwhelming. A positive mindset helps to decrease negative caregiver appraisal and increase the likelihood of positive appraisal and the ensuing positive emotions. To do so, being able to shift attention away from fixation on frustrations, worries, and dysfunctional
thoughts in general to something positive and uplifting is essential (Hollon & Beck, 1994). Caregivers found cognitive shifting and a refocus on positive meanings to be helpful.

In fact, I had always been an optimistic and cheerful person. But facing a mom with dementia, how could I be happy? Her illness would not get better; not a thing was inspirational. Since taking care of my mom, everything looked so dark... But... since mom’s illness and my caregiving role are realities; nothing will change. Why not think about it more positively then? As long as I can give mom some instant happiness, like letting her eat what she likes to and giving her compliments generously, we’ll find happiness again! (Daughter caregiver)

For dementia caregivers, positive and negative emotions were often intertwined; in fact, part of the basis for feeling good came from the awareness that positive and negative emotions often go hand in hand.

Often, the source of happiness was my mom. The source of unhappiness was also my mom. But in fact, she did not give me too much hard time. There were many things that made me happy at the same time. (Daughter caregiver)

The most unforgettable experience is over meal—every day, he keeps asking for food in a way that really makes me annoyed. But he would say he’s worried you don’t have enough to eat! You feel the warmth. You want to cry and laugh at the same time. (Wife caregiver)

I went to a nearby neighborhood to buy food and went back home after about an hour. As soon as I entered the door, my husband said to me angrily, “Where have you been? You’ve been gone for half a day. I’ve been watching TV for several hours. I tried to look for you from over the balcony. I didn’t know where you were...” I was so worried about you! ... I was worried something happened to you...” [Sigh] I told him already before I went out... I don’t know whether I should feel angry or funny.... But I discovered that my husband was thinking about me all the time. I’m so happy.

The understanding that emotions are based partly on one’s thoughts gave caregivers a sense of efficacy in terms of control over their emotions.

After taking care of my husband, I understand that happiness is in your mind. Whether happy or not, it’s just a matter of choice. I choose to be happy.

Through cognitive restructuring, caregivers framed memory deficits and certain behavioral and psychological symptoms in alternative, positive ways. They sometimes referred to themselves as “Ah Q,” a fictional character created by the famous Chinese writer Lu (2009). In the novella, Ah Q was a rural peasant who was exceptionally skilled at self-deceptive “mind victories” when encountering humiliation or defeat.

This afternoon, my mom was nervous about not getting cooking done in time for dinner... She took out all the different food ingredients. But she did not remember I had done the preparation already. It kind of bothered me. But when I thought about it from a different angle, I began to appreciate what she had done. She wanted to prepare food because she cared for us... When I think about things in a positive way, my feelings are calmer. (Son caregiver)

We were walking here and there [CR wandering].... I told people we were having a romantic stroll. (Wife caregiver)

Mom used to eat a lot in restaurants. But she ate very little [lately]. I treated it as if she’s on diet, to lose weight. Actually, the doctor said she’s overweight. (Daughter caregiver)

Perhaps the power of cognitive restructuring was most cogently demonstrated by this daughter caregiver and her siblings:

Mom wanted to have ‘tea’ (dim sum lunch).... But on the car, perhaps because she was hungry, she was very agitated and scolded us fiercely. Normally, we would be very upset when scolded. But seeing that she could yell so loudly, her lung had to be good and her mind had to be clear. So we ended up quite happy to see her scolding us like this.

The preceding example also illustrates the use of humor in coping with stressful situations and releasing tension. Humor is particularly helpful when positive reframing is not possible or achievable. Here is another example.

The phone rang this afternoon. My husband went to pick it up. But he did not pick up the phone. Rather, he picked up a water bottle. I did not get upset; instead, I laughed and laughed.

**Learning to Let Go**

Burden comes not only from objective demands, but also from subjective pressures on self. Such pressures may come from rigid expectations on one’s performance as a caregiver or inability to accept that a certain part of the CR is lost. Though not a common theme, being able to let go could be an important aspect of caregiver adjustment and growth.

Before, I couldn’t control my emotions. But looking back, I started to realize ways to deal with this illness, helping me release my tension. Gradually I enhanced his life and recharged myself. Little by little, I let go of him...
and I let go of myself too. I comforted him as well as myself, and we walk hand in hand into the future. (Wife caregiver)

A Closer Bonding With the CR

This was also another common theme. Despite the difficulties of taking care of relatives with dementia, caregivers felt that they were part and parcel of their commitment to a lifelong relationship. They treasured spending more time with the CR, reminiscing together and getting to know them more, especially when the remaining time was counting. They felt that such support exchanges were important and helpful to the CR too, especially at the early stages when the CR was pretty much conscious of their situations.

If not for my wife’s illness, I would not have spent so much time taking care of her personally. We have known each other a lot more.

Enhanced understanding of the CR might help to redeem negative experiences with the CR in the past.

I asked my mom why she said I was “nuts” [when I was young] but treated my son so much better…. She said, “I had four kids then; could not afford spending much time with each of you. But I have only one grandson….“ If I could have understood her situation then, I would have had a happier childhood. (Daughter caregiver)

Despite the decline and loss of ability, caregivers, especially spouses, often found the CR to be a valuable source of companionship, a confidant, and even practical support, although the CR might not be able to engage in meaningful conversations. Support exchange was not necessarily perceived to be a one-way flow; anything, however elementary, that gave meaning to the ongoing relationship was valued.

My illness has gotten a little better. Mom helped me take the [Chinese] herbal medicine back and boiled it right away. She did not forget how to boil herbal medicine. But there was one thing that made me so touched: She was afraid that she could not remember things well and so she sat in the kitchen until the decoction was over. And she was very careful with the medicine too. She hoped to do her best…. and to do more things for me while she could. (Daughter caregiver)

[Wife caregiver and husband were looking at past photos together. Husband could not recognize the places and the faces.] But if those were my portraits, he could recognize almost every one of them, all the way from young to old ages. This was a special moment…. He still remembered me. I feel so happy and content.

I would talk to him more. I don’t mind whether he understands or not. (Wife caregiver)

Often, feelings of intimacy became stronger through positive reminiscence. By revisiting enjoyable moments in the past, caregivers rekindled affection for the CR.

[Granddaughter visited.] He was very happy. He called her QQ (granddaughter’s nickname) and played with her…. Seeing him so happy reminded me of the moments when we went to pick granddaughter up from school. Sometimes we walked hand in hand; three of us together. Sometimes he carried granddaughter on his back and smiled on the way. These have become my pleasant memories forever. I wish these images will stay in my mind forever, and also stay in his hers forever. (Wife caregiver)

Earlier, we mentioned caregivers expressing appreciation for the CR’s efforts in self-maintenance, housework, and so on. Besides, caregivers felt appreciative when the CR seemed to be showing consideration and concern, and touched the caregiver’s heart (Monin, Schulz, & Feeney, in press). For instance, one daughter caregiver was grateful for the lack of pain complaint by her mother during a medical consultation for treating deep bed sores, which eased her worry:

Even the doctor was shocked. How come the wound was so deep? I was heartbroken to see it. But I really appreciate mom, for even though it looked painful … she did not whine.

It was not clear whether the CR’s ability to perceive and express pain was compromised by Alzheimer’s pathology (Monroe, Gore, Chen, Mion, & Cowan, 2012). Regardless, such experiences, whether intended or unintended by the CR, tended to engender positive feelings, including feelings of indebtedness, toward the CR and brought the caregiver subjectively closer to him or her. In addition, a better understanding of the CR and positive thoughts about him or her also helped to sustain or revive warm feelings for the CR, amidst the daily burden.

Finding People Who Care

Caregivers are not only stressed, but are often isolated, with few socializing activities (Haley et al., 1995). Tension within the family may increase as a result of negotiating responsibilities and disagreements over various arrangements (e.g., Suitor, Gilligan, Johnson, & Pillemer, 2014), while visits from other relatives and friends may be cut back. Caregivers may also feel that taking care of the CR is their sole responsibility for the sake of the family’s harmony and collective welfare (Cheng, Lam, Kwok, Ng, & Fung, 2013b). Nevertheless, some caregivers found comfort in family, friends, neighbors, or service providers.

I started to realize that I should get someone to talk to when feeling helpless sometimes. I felt better after letting everything out from within. (A daughter taking care of her mother)

My relationships with my siblings seem to have improved, because we now have common topics to talk about. That is, they would all ask about how mom is...
doing lately…. Everyone seems to show more concern. (Daughter caregiver)

For adult child caregivers who had their own families, perhaps the most indispensable support was the display of understanding and consideration from family members that their caregiving responsibilities would compete significantly with family time.

My kid phoned me and asked when I would go home to have dinner. I explained that because daddy hadn’t finished … they should have dinner first as I would be home late…. I promised a family vacation during summer school holiday and my child said “OK” right away. I felt the understanding from my young child; it made me very pleased. (A son caring for his mother)

Caregivers might receive assistance from neighbors or service providers for the care of their relative and felt a sense of warmth and gratitude, especially when the assistance was unexpected.

My husband went out … to buy bread…. Half an hour was gone and he’s not back yet. So I phoned him. He said, “I got lost.” Luckily, a woman was nearby and grabbed the phone…. “Your husband just asked me how to get back…. I remember him. He’s your husband…. We are at [a place]. Come pick him up.” … So pleased to have such warm-hearted neighbors.

Today, mom went to the clinic for follow-up consultation…. then the center…. Everywhere she went, the staff were very nice to her. All the way, we met many people who loved my mom. (Daughter caregiver)

Participating in intervention groups and being able to share issues and experiences with one another also enhanced feelings of support and connectedness with others.

[From sharing by another caregiver] … I discovered that many people made a lot more sacrifice than I do…. It inspired me to continue. (Daughter caring for father)

A Sense of Usefulness From Helping Other Caregivers

Being able to use their experiences to comfort and help other caregivers engendered feelings of empowerment and usefulness. When caregivers could help others this way, they sensed a larger purpose to what they had gone through.

I have mastered these issues when the other [caregivers] had not. So I tried to comfort them. They were upset because their relatives accused them of stealing or kept saying the same things over and over again…. I told them [people with this disease] don’t remember what they said moments ago…. She said, “Yes!” I said, “That’s why you shouldn’t be bothered by these things; don’t feel bad.” They felt less stressed afterwards. I don’t know if I’m becoming a teacher myself but it feels good to be able to relieve them of their tension. At least, I helped someone! (Daughter caregiver)

Discussion

The narratives revealed the scope of positive gains among Alzheimer caregivers and provided rich descriptions of such experiences. This study contributes to the literature in three ways. First, the narratives provided by our caregivers were grounded in daily events rather than simply overall commentaries typical in interviews or focus group discussions, and because of this, they provided richer illustrations of the intricacies in which positive gains arose from, or existed side by side with, hardship.

Second, although positive gains have been described in the literature, a more comprehensive scope of benefits were found in the caregivers’ diaries in this study. For instance, whereas the existing literature underscores feelings of appreciation by the CR as a common positive gain (e.g., Tarlow et al., 2004), our findings revealed how much appreciation caregivers have for the CR’s affection and efforts as well. Moreover, although the importance of finding positive strength and meanings amidst adversity has long been recognized (Folkman, 1997; Kramer, 1997), no study has documented the underlying thought processes and strategies when dealing with a relative with dementia. We also note that certain themes or sub-themes, including letting go, reduced stigma, and enhanced usefulness through helping others in the same situation, are not necessarily novel in the broader caregiving literature but have not been framed as positive gains as such before.

Third, the study provides data about the construals of positive gains in a non-Western sample. We saw at times culturally specific constructions, but we were also careful not to exaggerate cultural differences. For instance, whereas accomplishing filial piety may be a construction based on Confucius teachings, Western adult children may be more likely to talk about it as an obligation to reciprocate parental love and care—similar feelings under different labels. Thus, although specific constructions, such as Ah Q and those around appetite, might be culturally specific, the positive gains expressed are mostly similar to those reported in Western studies. Nevertheless, more cross-cultural research will help enlighten similarities and differences in positive gains across cultures.

Although the narratives were grouped under the themes to which they were most related, it was not unusual to find examples that spoke to more than one theme. In fact, it seems likely that the development of one gain fosters another, so that caregivers tend to report multiple gains over time. Accepting the disease appears to be the basis for several key aspects of gain, whether directly or indirectly, including identifying with the caregiving role, enhanced tolerance of the CR’s problems, and closeness with the CR. Without acceptance, one would be questioning the CR’s intent and why the responsibilities would be necessary, leading to blaming the victim and adverse relationship with the CR. With role
identification and commitment, caregivers are motivated to acquire the necessary skills and to do the “right thing” for the CR. When the CR responds, there is gratification and validation of the sacrifice made. Helping others in the same situation also contributes to a sense of satisfaction.

However, issues are not easily or permanently resolved when caring for someone with dementia. The chronic stress, occasionally exacerbated by unpredictable events, gives rise to recurrently elevated negative affect such as fatigue, anxiety, and depression, affecting health and the ability to carry out the caregiving duty. In fact, caregivers who are committed to their role, hence having high performance expectations on themselves, are likely to strain themselves and to feel sorry for not doing as much and as well as they would like (Cheng, Kwok, & Lam, 2014). Thus, caregivers have to learn how to regulate their emotions and are grateful for any assistance they get. This helps them appreciate people who show that they care, and their situation may draw further support from them.

Nevertheless, echoing two earlier studies of Hong Kong Chinese caregivers (Cheng et al., 2013a, 2013b), caregivers mentioned mostly emotional support from family and friends, but not other forms of support. Other than obtaining emotional support, caregivers need to develop ways to manage their own emotions, remain calm and enhancing positive emotions. Many caregivers reported increased patience and tolerance as a response, whether passive or active, to dealing with repetitive questions and behaviors day after day. Besides, the unrelenting challenges may force caregivers to change their mindset, actively constructing positive meanings and humor to deal with various situations. The narratives revealed some very creative constructions and reframing of adverse situations. When caregivers can see the CR’s problems in a more positive light, it is easier to feel closer to the CR, aside from other conducive conditions such as the time spent together. Letting go of bygones is also important for staying calm.

Although the diaries could not provide a direct test of our ideas above, we present this hypothetical model in Figure 1 in the hope of guiding future research. Studies are needed to test the directional relationships as specified in the model. It should be noted that not every caregiver experienced the full range of gains, or the same kinds of gain to the same extent. Thus, although Figure 1 attempts to outline a map of the interrelationships among the different gains, it does not define the journey for everyone. The search for positive meanings is an idiosyncratic journey, depending on each person’s unique circumstances. Nevertheless, given the fact that positive gains can help sustain the motivation to provide care (Folkman, 1997) and may improve caregiver emotional well-being (Cheng et al., 2013a), practitioners working with caregivers should, in addition to treating negative outcomes such as anxiety and depression, identify means to promote positive gains. The cognitive restructuring techniques reported in this article suggest a viable approach to help caregivers improve positive gains and well-being that needs to be investigated in future intervention research (see Cheng, Lau, Mak, Ng, & Lam, 2014).

A limitation of the present study is that most of the caregiver–CR pairs consisted of daughters and mothers. Although this was quite normal, we did not have enough combinations of other relationship kinds to permit an investigation of whether the positive gains experienced depended on the dyadic relationship. This could be achieved by oversampling other relationship categories for study. In particular, it will be interesting to find out whether there are generational (spouse vs child) and gender (daughter vs son and wife vs husband) differences. Moreover, it will be worthwhile to include the emerging population of unrelated informal caregivers (e.g., neighbors); their motivation to provide care is likely different which may have an effect on the positive gains they experience.

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