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Learning to change: Transformative outcomes of programmes and activities for family caregivers of people with dementia in Taiwan

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Abstract

This study explored the transformative outcomes of programmes and activities for family caregivers of people with dementia in Taiwan. Transformative learning theory was used to examine the relationship between participation and positive outcomes. A group of nonparticipants was included to provide a complete picture of the transformative learning process. In this qualitative study, 18 participants were interviewed with audio recording, and the data were transcribed verbatim. A thematic analysis was performed to determine the themes and subthemes in the results. The results revealed that participation in programmes and activities was not the single factor leading to transformative outcomes; family support, self-adjustment, the ability to cope, and coordinated intervention in accordance with individual preferences and needs also facilitated transformative outcomes for nonparticipants. Further studies should focus on interventions modifying factors of perceived caregiver burden, for instance, by providing psychological support to informal caregivers, offering programmes and activities targeting the management of *neuropsychiatric symptoms in patients with dementia, and supporting quality of life.*

Keywords: programmes and family support groups, transformative outcomes, family caregivers of people with dementia

Introduction

Dementia affects approximately 50 million people worldwide, and this is projected to increase to 82 million by 2030 and 152 million by 2050 (World Health Organization, 2020). Most people with dementia live at home (50%–80% in various European countries; Valzolgher, 2018). In Taiwan, the estimated population of adults aged 65 years or older is 3,607,127 (Ministry of the Interior, 2019), and 280,783 persons have dementia. Specifically, the prevalence of dementia is 8% for those aged 65 years or older (Taiwan Alzheimer's Disease Association, 2020). Official statistics from Taiwan indicate that 94% of people with dementia live at home and 6% are institutionalised; furthermore, 55% of people with dementia are cared for by family members (Ministry of Health and Welfare, 2011, 2017). Confucian values may play a vital ideological role for people who care for their parents in Taiwan; such caregivers, especially sons, may consider caregiving to be their family obligation. However, these cultural values may reduce well-being when family caregivers struggle to fulfil high expectations with diminished resources (Funk, Chappell, & Liu, 2013).

In Taiwan, family caregivers may require the following types of informal and formal social support: (a) home-based care, including paid caregivers, home care nurses and physicians, residential rehabilitation, and nutritional consulting services; (b) community-based care, including day care centres, community care centres, and respite care, that provides a temporary 'vacation' for family caregivers; and (c) institutional care, including nursing homes and group homes, that provides 24-hour care for patients with physical or mental disabilities. Furthermore, numerous programmes and activities are provided for family caregivers, such as the School of Wisdom, Family of Wisdom, Family Support Group Services, and the Centre for Integrated Dementia Care. In 2017, the Taiwanese government issued the *2018–2025 Taiwan Dementia Plan*, which aims to support the needs of patients with dementia and their families and mitigate the negative impacts of dementia and caregiving.

Challenges and benefits encountered by family caregivers of people with dementia

Family caregivers face challenges such as a lack of knowledge about the disease and appropriate care, coping with problem behaviours and comorbidities, and managing medical treatment and daily activities (Chiu et al., 2010). Unlike other diseases, dementia leads to a progressive decline in memory and other cognitive functions, which results in increasing dependence on others for daily activities (Pinquart & Sörensen, 2003; Lethin et al., 2018). Families may have limited knowledge and few skills regarding caring for family members at home, and they are often unprepared to confront the complex emotions associated with such caregiving. As the disease progresses, patients with dementia begin to exhibit behavioural and neuropsychiatric symptoms, including delusions, aggression, wandering, and agitation (Sousa, Sequeira, Ferre-Grau, Neves, & Lleixa-Fortu, 2016), which can present family caregivers with barriers to effective communication and make it difficult to manage the changing levels of care and decision-making required. A recent study revealed that among family caregivers of people with dementia, almost 60% reported high or very high emotional stress, 34% experienced depression, 43% experienced anxiety, and nearly 28% received psychotropic medications (Zimmerman et al., 2018).

However, studies have also reported positive effects of caregiving among family caregivers; for example, some caregivers perceived themselves as uplifted because they actively promoted positive aspects of care (Donovan & Corcoran, 2010). Moreover, valuing positive aspects (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991), significant gratification (Pinquart & Sörensen, 2003), and reciprocal relationships (Huang, 2009) have been reported by caregivers and care recipients. These studies have suggested that some aspects of family caregiving may yield positive individual effects.

As mentioned, the burden of caring can negatively affect the physical and mental health of the caregivers of people with dementia. Therefore, providing resources and support to such caregivers should be a high priority for governments. The need to provide quality education and support programmes to help individuals living with dementia, family caregivers, and professionals is growing (Black et al., 2013). Studies have shown that the overall competency and preparedness, health-related quality of life (Kuo, Huang, Hsu, Wang, & Shyu, 2016), and depressive symptoms (Huang et al., 2013) of family caregivers of people with dementia improved after participation in programmes and activities that address the management of behavioural problems in patients with dementia.

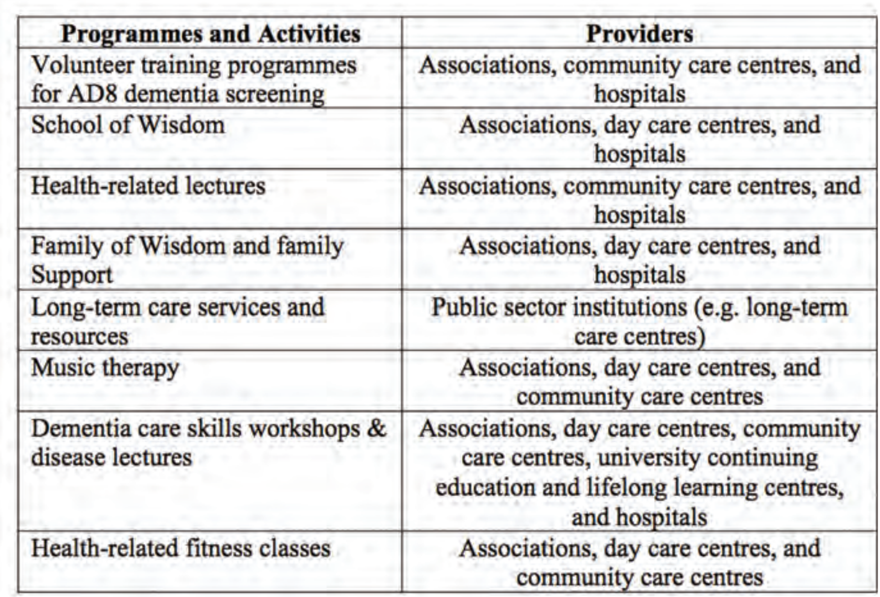
Types of programmes and activities

Various types of programmes and activities were investigated in this study (Table 1). These services were mostly individually tailored and provided by private and individual associations, hospitals, day care centres, and community care centres, although some were organised and delivered by public sector institutions or the continuing education and lifelong learning centres of universities. The lengths of programmes and activities also varied, with most lasting from a few hours to one or two days. The programmes and activities were led by various professionals (e.g. social workers, clinical psychologists, neurologists, geriatricians, nurses, and therapists) depending on content. Lectures, seminars, workshops, and group activities were typical teaching methods. Because the government is aware of the challenges faced by people with dementia and has endeavoured to promote dementia education to support such patients and their caregivers, the programmes and activities in this study were mostly funded or partly funded by the Ministry of Health and Welfare or the Taiwan Lottery Funds. Hence, the participants, in particular dementia patients and their family caregivers, were generally able to join the programmes and activities free of charge. A small number of programmes and activities had associated fees. Some of the programmes and activities were recognised by service providers.

The government's Long-Term Care 2.0 programme was extended in 2017 to include healthcare services for people 50 years or older diagnosed as having dementia, with these services targeted at communities and local areas. Twenty centres for integrated dementia care are presently in operation, and these are staffed with case managers and care consultants and provide clinical diagnoses and referrals. One hundred thirty-four community sites for dementia provide the following services: cognitive promotion, Family of Wisdom, family caregiver training, and support groups. Two hundred eighty-seven community service sites, including day care centres and small multifunctional group homes, are presently in operation (Ministry of Health and Welfare, 2017).

School of Wisdom was established in 2005 and has provided health promotion programmes and activities for patients with mild dementia (clinical dementia rating = 1) and their family caregivers. This organisation has provided nonpharmaceutical programmes and activities to 130,000 households to help dementia patients cope with their daily routines. According to the above report, for 80% of the participants with dementia, their speech and ability to interact with others have improved since their first participation (Public Television News Network, 2019).

Table 1 Types of programmes and activities and their providers



Programmes and Activities	Providers
Volunteer training programmes for AD8 dementia screening	Associations, community care centres, and hospitals
School of Wisdom	Associations, day care centres, and hospitals
Health-related lectures	Associations, community care centres, and hospitals
Family of Wisdom and family Support	Associations, day care centres, and hospitals
Long-term care services and resources	Public sector institutions (e.g. long-term care centres)
Music therapy	Associations, day care centres, and community care centres
Dementia care skills workshops & disease lectures	Associations, day care centres, community care centres, university continuing education and lifelong learning centres, and hospitals
Health-related fitness classes	Associations, day care centres, and community care centres

Family of Wisdom is an innovative project combining behavioural dementia therapy, family support, social therapy, and care skills training (Tang, Wu, & Lee, 2013). Family of Wisdom involves a homelike environment in which patients with dementia are encouraged to build connections with their caregivers. The purpose of Family of Wisdom is mainly to develop social activities that both patients with dementia and their families can benefit from. Programmes and activities such as the School of Wisdom and Family of Wisdom have provided alternative types of support and information for patients with dementia and their family caregivers.

Applications of transformative learning theory

Transformative learning theory has been applied in a number of theoretical studies of adult education as well as in empirical studies of social and community transformation, participation in group experiences, personal illness, intercultural learning and lifestyle, and career change (Vaughn, 2016). In the present study, we examined transformative learning theory through findings from a group of family caregivers of people with dementia who often reported negative caring experiences. We focused on aspects of the theory that have been critiqued and have raised questions about attempts to foster transformative learning in the context of negative experiences. Specifically, we paid attention to participation in programmes and activities and questioned the levels of transformation reached when family caregivers are constrained by negative caring experiences. Although this study was primarily based on data from participants in programmes and activities, data from nonparticipants were also included to compare the extent of transformative outcomes.

Transformative learning theory

Mezirow (1978) defined the process of going through a women's college reentry programme as a perspective transformation. He considered perspectives to comprise the beliefs, values, and assumptions that are developed through life experiences and proposed that a person interprets and constructs meaning from those experiences through the developed perspective. Mezirow (2003, pp. 58–59) defined transformative learning as 'learning that transforms problematic frames of reference to make them more inclusive, discriminating, reflective, open, and emotionally able to change'. Learning can be understood as the process of constructing a new or modified interpretation of the meaning of experiences in order to guide further action. Mezirow (1995) introduced a series of phases that constitute the transformative process. This process begins with a 'disorienting dilemma' or an 'alienation from prescribed social roles'. During the learning process, a learner moves through the subsequent phases towards the creation of a new perspective that is integrated into the learner's life. Mezirow (1995) stated that this transformative process is not completed until the learner engages in reflective discourse. Through dialogue with others, the learner comes to understand that their transformed perspective may be shared by others. Reflective discourse is a type of content-oriented dialogue that attempts to justify beliefs by defending reasons and examining evidence of contrary views. Finally, learners adopt encountered views and integrate them into new perspectives before taking rational action. In this sense, a type of social action results from the newly developed perspectives or revised interpretation of meaning that comes from prior experience. At this point, the individual's transformative process is considered complete.

Given these issues, the aim of the present study was to examine the transformative outcomes of participating in programmes and activities for the family caregivers of people with dementia in Taiwan. A control group of caregivers who did not participate in these programmes or activities was included to reflect the effects of nonparticipation. To our knowledge, transformative learning has not been studied in the context of family caregiving for people with dementia. Studies have rarely used transformative learning theory to compare the attitudes and experiences of participants and nonparticipants in programmes and activities. Consequently, the transformative outcomes of participation in such programmes and activities should be examined for the family caregivers of people with dementia to reveal knowledge gaps in evidence-based practices in this field. Thus, the present study examined the following research questions: With respect to family caregivers, what are their negative experiences caring for people with dementia? How does participation in programmes and activities help the family caregivers of people with dementia? Do family caregivers – participants and nonparticipants in programmes and activities – develop positive experiences?

Methods

In this qualitative study, 18 eligible participants who met the inclusion criteria were recruited to attend an in-depth interview after giving their consent to participate. The details of inclusion criteria are provided in the following section. The researcher used a list of open-ended questions to interview the participants; throughout the interviews, prompts and follow-up questions were employed to encourage responses of greater depth and breadth (Kitzinger & Willmoot, 2002).

In this study, the data analysed included answers to the following open-ended questions: (1) What types of negative experiences have you encountered when caring for a family member with dementia? (2) How has your participation in programmes and activities helped you as a primary caregiver? (3) Did any factors encourage you not to join the programmes and activities?

Interviews were conducted during February and March 2014. The interviews were recorded and then transcribed. This study was approved by the Institution of Review Board (IRB) of National Cheng Kung University. In accordance with the IRB's requirements, participation was informed and voluntary, and all possible effort was made to ensure data confidentiality.

Ethical and emotional issues

We recognised that interviews were potentially emotionally fraught experiences for participants because participants were asked to relive difficult experiences in their personal and caregiving lives. The interviewer thus conducted interviews appropriately and was sensitive to the needs of participants. The interviewer has family members with similar experiences of caring for people with dementia. This familiarity helped the interviewer to adopt an appropriate countenance and manner of address, employ appropriate interviewing techniques, and respond with empathy to the experiences and views of participants. The strategy of consulting with professionals and practitioners was also used effectively prior to the interviews. For example, the interviewer met with social workers and a neurologist who is familiar with family caregivers of people living with dementia before starting the interview. In all cases, this enhanced the interviewer's confidence and enabled a more sensitive approach to interviewing, which benefited the research participants and the interviewer. Dickson-Swift et al. (2006) noted that qualitative interviews share similarities with therapy because both are based on empathy, listening skills, and giving space for participants to discuss personal issues. However, therapists aim to help their patients, whereas an interviewer merely listens and perceives. The researcher in this study, who had conducted a similar study, was able to play the roles of listener and guide to help the interviewees obtain resources or professional advice.

Participants

Overall, 18 participants were recruited from two associations and one medical centre in central and southern Taiwan, respectively. Participant and patient characteristics are listed in Tables 2 and 3, respectively. The family caregivers met the following inclusion criteria: (a) self-identified as a primary caregiver in their residence; (b) living with the care recipient (parent, parent-in-law, grandparent, or spouse with dementia); and (c) self-identified as having experienced both negative and positive aspects of caregiving or having had a social worker or attending physician and the researcher perceive them as having had these experiences.

Table 2 Participant Demographics

The participants	Gender	Age	The relationship between caregiver/ care recipient	The length of caregiving time	Participation in programme/support group/clinical trial
A1	F	55	Daughter/Mother	6-7years	Programme/ support group
A2	F	37	Daughter-in-law/ Father-in-law	1 year	Programme/ support group
B1	M	49	Son/Mother	4-5 years	Programme/ support group
B2	M	68	Son/Mother	10 years	Programme/ support group
A3 (mother of B3)	F	71	Wife/Husband	24 years	Programme/ support group
B3 (son of A3)	M	40	Son/Mother		n/a
A4	F	65	Wife/Husband	1-2 years	Programme/ support group
A5	F	73	Wife/Husband	3-4 years	Programme/ support group(stop going later)/clinical trial
B4	M	50	Son/Mother	5-6 years	Clinical trial
B5	M	75	Husband/Wife	2-3 years	Clinical trial
B6	M	72	Husband/Wife	5-6 years	Clinical trial
A6	F	50	Daughter/Mother	7-8 years	Clinical trial
A7	F	50	Daughter/Mother	6-7 years	Clinical trial
A8	F	50	Wife/Husband	6-7 years	Clinical trial
A9	F	30	Granddaughter/ Grandmother	5-6 years	Programme/ support group
A10	F	55	Wife/Husband	5 years	Programme/ support group
A11	F	40	Daughter/Mother	2-3 years	Support group
A12	F	50	Wife/Husband	5-6 years	Programme/ support group

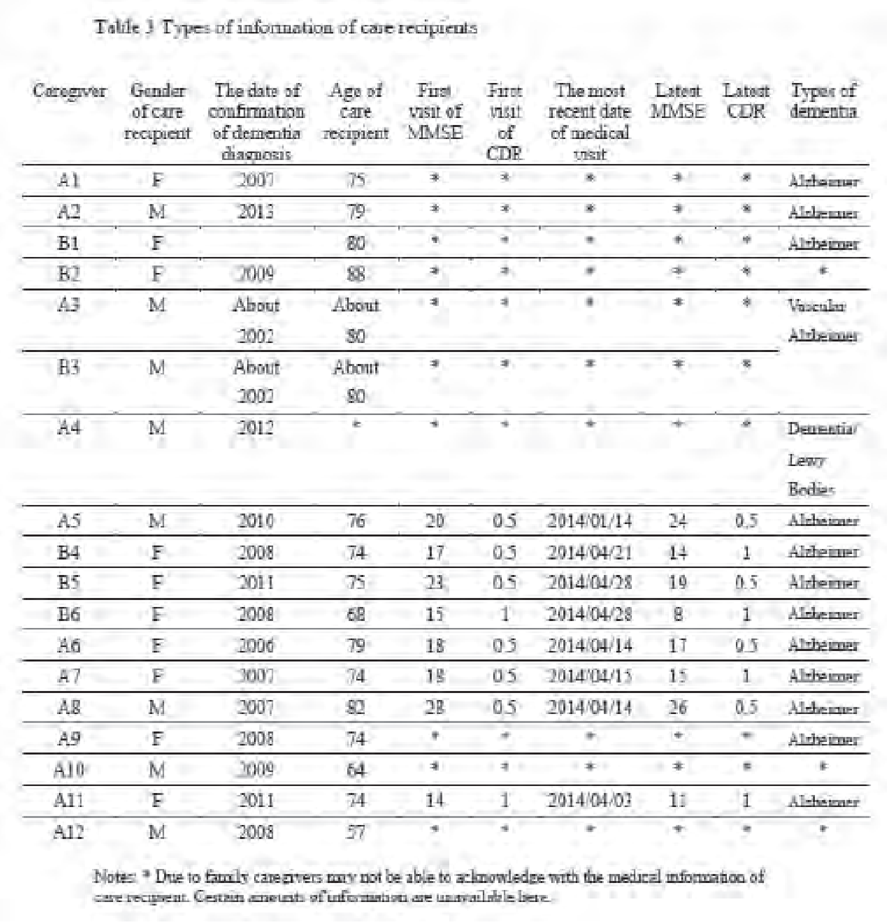


Table 3 Types of information of care recipients

Caregiver	Gender of care recipient	The date of confirmation of dementia diagnosis	Age of care recipient	First visit of MMSE	First visit of CDR	The most recent date of medical visit	Latest MMSE	Latest CDR	Types of dementia
A1	F	2007	75	*	*	*	*	*	Alzheimer
A2	M	2013	79	*	*	*	*	*	Alzheimer
B1	F		80	*	*	*	*	*	Alzheimer
B2	F	2009	88	*	*	*	*	*	*
A3	M	About 2002	About 80	*	*	*	*	*	Vascular Alzheimer
B3	M	About 2002	About 80	*	*	*	*	*	
A4	M	2012	*	*	*	*	*	*	Dementia/ Lewy Bodies
A5	M	2010	76	20	0.5	2014/01/14	24	0.5	Alzheimer
B4	F	2008	74	17	0.5	2014/04/21	14	1	Alzheimer
B5	F	2011	75	23	0.5	2014/04/28	19	0.5	Alzheimer
B6	F	2008	68	15	1	2014/04/28	8	1	Alzheimer
A6	F	2006	79	18	0.5	2014/04/14	17	0.5	Alzheimer
A7	F	2007	74	18	0.5	2014/04/15	15	1	Alzheimer
A8	M	2007	82	28	0.5	2014/04/14	26	0.5	Alzheimer
A9	F	2008	74	*	*	*	*	*	Alzheimer
A10	M	2009	64	*	*	*	*	*	*
A11	F	2011	74	14	1	2014/04/03	11	1	Alzheimer
A12	M	2008	57	*	*	*	*	*	*

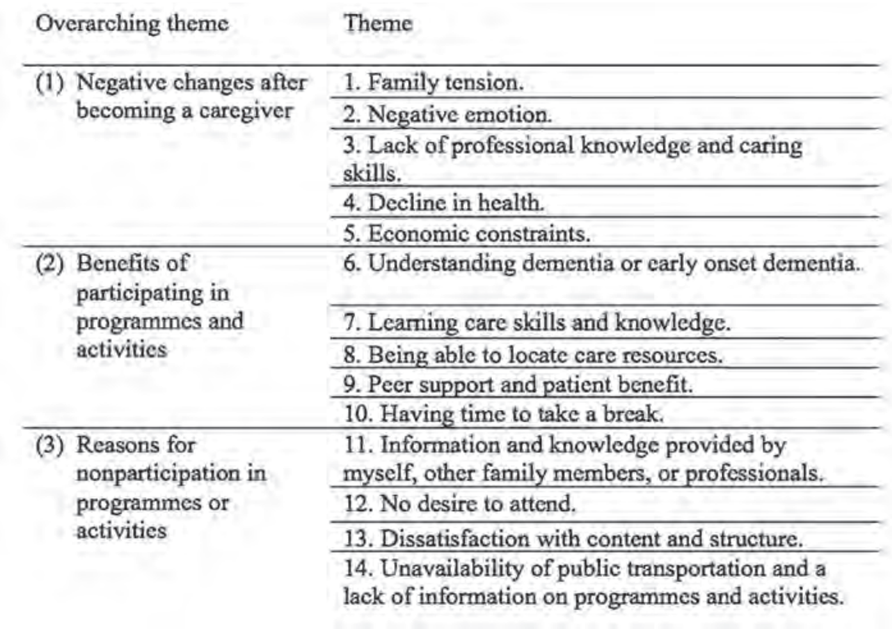
Notes: * Due to family caregivers may not be able to acknowledge with the medical information of care recipient. Certain amounts of information are unavailable here.

Data analysis

Recorded data were transcribed in a Word file. Then, two research fellows independently conducted thematic analysis by following an inductive approach that entailed coding themes and subthemes (Kvale, 1996). Common themes were identified in the answers to the interview questions, such as negative experiences and participation in programmes and activities. Data were categorised into overarching themes and subthemes. All overarching themes and subthemes were compiled into tables to ensure the cohesiveness and distinctions of the responses; thus, the researchers were able to interpret the data in terms of transformative outcomes. The analysis was conducted on an explicit or semantic level (Braun & Clarke, 2006); nevertheless, we considered all possible readings of the responses to explore variations and contradictions. After the initial coding, a group of themes was identified and collated into a broad thematic map. Then, the main ideas and concepts of each theme guided the creation of the overarching themes. A final version of themes and overarching themes was agreed upon through discussions and reaching a consensus between the two researchers.

This analysis aimed to acknowledge, understand and appreciate the similarities and differences of the participants' experiences. Hence, we avoided making generalisations about family caregivers, and their experiences tended to be heterogeneous. Member checking was used for quality review and verification. The participants were asked to review the transcripts for accuracy, including the preliminary analysis of their responses that emphasised the aspects that were interpreted as being part of transformative learning. The data were considered reliable and valid both descriptively and interpretatively.

Table 4 Overarching themes and subthemes



Overarching theme	Theme
(1) Negative changes after becoming a caregiver	1. Family tension.
	2. Negative emotion.
	3. Lack of professional knowledge and caring skills.
	4. Decline in health.
	5. Economic constraints.
(2) Benefits of participating in programmes and activities	6. Understanding dementia or early onset dementia.
	7. Learning care skills and knowledge.
	8. Being able to locate care resources.
	9. Peer support and patient benefit.
	10. Having time to take a break.
(3) Reasons for nonparticipation in programmes or activities	11. Information and knowledge provided by myself, other family members, or professionals.
	12. No desire to attend.
	13. Dissatisfaction with content and structure.
	14. Unavailability of public transportation and a lack of information on programmes and activities.

Results

Data were clustered around three overarching themes: (1) Negative changes after becoming a caregiver; (2) benefits of participating in programmes and activities; and (3) reasons for nonparticipation in programmes and activities (see Table 4). The first overarching theme represents the negative experiences that family caregivers experience when caring for people with dementia and includes five subthemes: family tension, negative emotion, lack of professional knowledge and caring skills, a decline in health, and economic constraints. The second overarching theme represents the important benefits of participating in programmes and activities and the changes required to face and cope with dementia. The third overarching theme represents the reasons for nonparticipation in programmes and activities, some of which may be regarded as barriers to participation for family caregivers.

Negative changes after becoming a caregiver

According to the responses, negative experiences were mainly the result of family tension, negative emotion, lack of professional knowledge and caring skills, decline in health, and economic constraints. These themes are detailed as follows.

Family tension. A8 (aged 50; wife caregiver) admitted experiencing family tension. She reported, 'I have no idea. I just feel... we had an argument not so long ago. I said to him, "You like arguing with me". We have been frequently quarrelling lately. I find I have a bad temper now. I think this change is related to my husband's condition'. B4 (aged 50; son caregiver), recalled his mother's symptoms, 'She could repeat the same complaint about my wife that treated her badly, the same complaint again and again. This is very hard for my family and I to tolerate'.

Negative emotion. A1 (aged 55; daughter caregiver) recalled experiencing emotional stress.

> *Sometimes I feel mentally tired. Mom does not need to be cared for. I told myself to understand her health condition now and not to blame her if she gave me troubles and to treat her as an old nut. Sometimes I cannot put myself in her shoes. I just wonder, 'Why do you say these words that hurt?' or 'Why do you suddenly lose your temper?' I really feel hurt from what she sometimes tells me.*

A12 (aged 50; wife caregiver) reported the following:

> *For me, the psychological burden is greater than the physical burden. He does not need me like an old man does. Before the (confirmation of diagnosis) onset of dementia, he had a bad temper. Now he has become even worse. He noticed that his memory is not as good as it used to be. He has very low self-esteem. No matter what I say to him, he replies, 'Oh, you look down on me because I cannot make money now, because my memory is not as good as it used to be'.*

A2 (aged 37; daughter-in-law caregiver) did not live with her father-in-law until he recently moved into their house. She felt very stressed and isolated as her father-in-law's primary caregiver. A6 (aged 50; daughter caregiver) mentioned that 'Mom asked me the same thing more than 20 or 30 times. I held my temper. I know she is ill, but I am a human being; I have my own emotions too'.

Lack of professional knowledge and caring skills/economic constraints. B1 (aged 49; son caregiver) mentioned that after they had moved into their current flat, his mom frequently suspected that the paid carer had stolen her personal belongings. He suspected her cognitive condition was deteriorating. A1 (aged 55; daughter caregiver) confessed that at the beginning she did not know her mom was ill. She had learned about dementia during her previous experience as a volunteer, but she did not completely understand the disease and the problem behaviours caused by dementia. Moreover, vascular dementia was rarely seen 25 years ago, and even medical doctors had difficulty confirming its diagnosis. A3 (aged 71; wife caregiver) recalled that her husband had a stroke, after which he started to manifest problem behaviours:

> *Twenty-five years ago, my husband was working too hard—I think it was the fatigue that caused his high blood pressure. He then had a stroke. At that time, none of us realised he had dementia; that he had dementia was not confirmed until 12 years later. However, by then, his dementia was already in the moderate stage.*

Decline in health

Several participants reported that their health had been detrimentally affected since becoming a primary caregiver, but this was often ascribed to neurotic disorders. A1 (aged 55; daughter caregiver) recalled that in the early stage of caregiving, she experienced a dysfunction of her autonomic nervous system—she realised it was caused by pressure. In recent years, A3 (aged 71; wife caregiver) had developed a spinal problem because she needed to move her husband from time to time, which hurt her back. A3 advised the other caregivers, 'I would suggest family caregivers adjust themselves. This is your life, and you have to learn how to lean in and make your life progress'. However, B2 (aged 68; son caregiver) mentioned, 'although I have many health problems, they are not related to my caregiving. I used to be an athlete, and I was strong enough to carry heavy stuff without any problems'.

Economic constraints

A9 (aged 35; granddaughter caregiver) mentioned that economic constraints had arisen after she became a caregiver. She noted that 'We are not doing well financially. I rely on my husband's income. I told my father and aunt about our family's financial strain, so they give me some money every month. Grandma applied for a pension, which is NT$7,000 [equivalent to US$230] every month. That is all we have for living. '

Benefits of participating in programmes and activities

Several participants reported that participating in programmes and activities resulted in benefits, including improved dementia knowledge and caring skills, enjoyment sharing experiences with others, peer support and patient benefit, and having time to take a break. These subthemes are detailed as follows.

Improved dementia knowledge and caring skills. B2 (aged 68; son caregiver) and A3 (aged 71; wife caregiver), who had rich experiences of caregiving, reported the benefits of participating in classes and activities. They had attended various courses and activities related to dementia caregiving skills. B2 reported the following:

> *I started to participate regularly [in courses and activities] in 2000. They have been a great help. As a family caregiver, you understand the problem behaviours of dementia patients, such as delusions, depression, and agitation, but I didn't have a thorough understanding of dementia until I attended those programmes.*

A3 recalled the following:

> *These classes are useful and helpful. They help you to understand the different stages of the disease. The classes help you to become more capable as a caregiver. There are many people attending these classes and activities. There are various choices too.*

B1 (aged 49; son caregiver) learned the methods he could apply in the process of caring for his mother. He said, ‘I realised the importance of physical fitness after Mom fell down and broke her bones. Attending classes is helpful to me. I can use the knowledge and skills in the process of caring for my mother’.

Enjoyment from sharing experiences with others. B2 also mentioned that he learned where to access caring resources. ‘Exchanging caring experiences with other caregivers was important to me. I could exchange experiences with other caregivers in the courses and activities. I now know where to apply for assistive devices’. A1 (aged 55; daughter caregiver) enjoyed sharing her caring experiences with others:

> *I expected to gain experience from others. The more we understand ourselves, the more effective we can be in our roles as caregivers. I hope my experiences benefit other families too.*

A9 (aged 36; granddaughter caregiver) showed considerable motivation. She continued attending courses despite being discouraged by her family members. She said, ‘At least I learned more about grandma’s problems from the lectures and from other family caregivers. I wanted to attend the classes and activities, but my family disapproved of the idea’.

Peer support and patient benefit. A1 (aged 55; daughter caregiver) continued, ‘I’ve gained much from the experiences of others. There are many individual cases (about caring for dementia patients). The more we understand ourselves the more we can do adjust ourselves…’ A10 (aged 55; spouse caregiver) mentioned that she thought the greatest benefit came from the support she had received from others in similar situations. She reported the following:

> *I was not alone. I had support from peers. We chatted and exchanged ideas. It was good for me to get close to people in a similar situation to us. He [her husband] didn’t speak much. The courses and activities we participated in were good for him, I think.*

A4 (aged 65; wife caregiver) stated the following:

> *He has been severely senile since 2012. I am suffering more from taking care of him. I am truly stressed. I cannot let go of these stressful feelings. Oh, whenever I see him like this I am upset. Friends tell me, 'Do not lock yourself in the house'. I went to learn Chi-Gong with my husband. Now we go to classes together and we even go to the open market. Without him next to me I feel anxious.*

Having time to take a break. The School of Wisdom was highly recommended by some of the participants because, unlike other programmes, it separates patients with dementia and their family caregivers. This provides the caregivers with an opportunity to take a break from caregiving. A4 continued,

> *My husband and I went to a series of programmes from the School of Wisdom. There were eight courses in total. I feel I can rest a bit when he is taken care of by the staff there. But there are limited seats for applicants.*

A12 (aged 50; wife caregiver) reported the following:

> *The School of Wisdom gave us a 2-hour break. I am glad that I went to the association and joined their programmes and activities. The staff there take care of the patients with dementia while the caregivers attend the programmes. I had no worries when I went, so I could adjust my mood during this period. If the care recipients were not separated from caregivers, it wouldn't be very helpful.*

A12 had visited numerous places in search of suitable courses and activities for her husband, who has mild dementia. She said, 'My husband is still young compared with other patients who attend dementia courses. I went to a course at the Evergreen Learning Centre, but it was not suitable for my husband. The School of Wisdom classes suit us the most'.

Reasons for nonparticipation in programs or activities

A small number of participants reported they never attend programmes and groups or have ceased participation. Their reasons were as follows.

Information and knowledge are provided by family or

healthcare professionals. B5 (aged 75; husband caregiver) said, 'I have participated in none of the classes or activities. My daughter-in-law passed on to me some materials she downloaded from websites'. A group of participants joined a clinical trial led by an attending physician in the hospital. Patients and family caregivers were cared for by a medical team from the hospital. B4 (aged 50; son caregiver) mentioned that he had joined a clinical trial in a hospital.

> *We went to a family support group once. Mom didn't show any changes, good or bad, after attending the group. As for myself, I initially felt that I had no time to go, and Mom is timid. We've been participating in a clinical trial in a hospital. We go to the hospital and meet other patients and their families regularly. We've been going for 4 years now. We exchange information and feelings with other patients and family caregivers.*

No desire to attend. A8 (aged 50; wife caregiver) reported no need to attend dementia courses or activities because her husband only has mild dementia. She said, 'No. I never thought about going to [dementia] classes or family support groups. He still only has mild dementia. There is no need for me to go right now'. A5 (aged 73; wife caregiver) attended a family support group on two occasions but ceased to go because her husband was unwilling to return. She said, 'My husband and I went to two classes. It helped somewhat; however, we stopped going because he didn't want to attend anymore. I followed his wishes'.

Dissatisfaction with content and structure. B4 (aged 50; son caregiver) explained his negative experiences and impressions from attending programmes and activities:

> *I felt like it was just an occasion to collect negative feelings and emotions. I didn't know if there were any positive approaches or resources that were more effective; the seminar was just one-way communication. Lectures might not be what I need.*

B5 (aged 75; husband caregiver) stated that he had never attended any dementia courses or activities. He considered such courses and activities useless and said they did not help him practically with caring for his wife:

> *I haven't attended any [dementia] classes and activities. I do not think that they fit my needs. It seems like there is nothing I can*

> *do to keep her calm. I occasionally receive course information from family support groups. I think that unless you change yourself, you cannot manage things as you wish. I am the one who faces her all the time. I try to figure out problems bit by bit when they arise. I don't think lectures or activities could help solve my problems.*

Unavailability of public transportation and a lack of information on programmes and activities. B6 (aged 72; husband caregiver) and his wife live in a remote area in southern Taiwan. He said, 'I have never attended any classes or activities. We live in Fung Liao, a rural area in southern Taiwan. We need to take several forms of transport to get to the hospital in Kaohsiung. Besides, I have no idea where the courses are. What are these courses like?'

Discussion

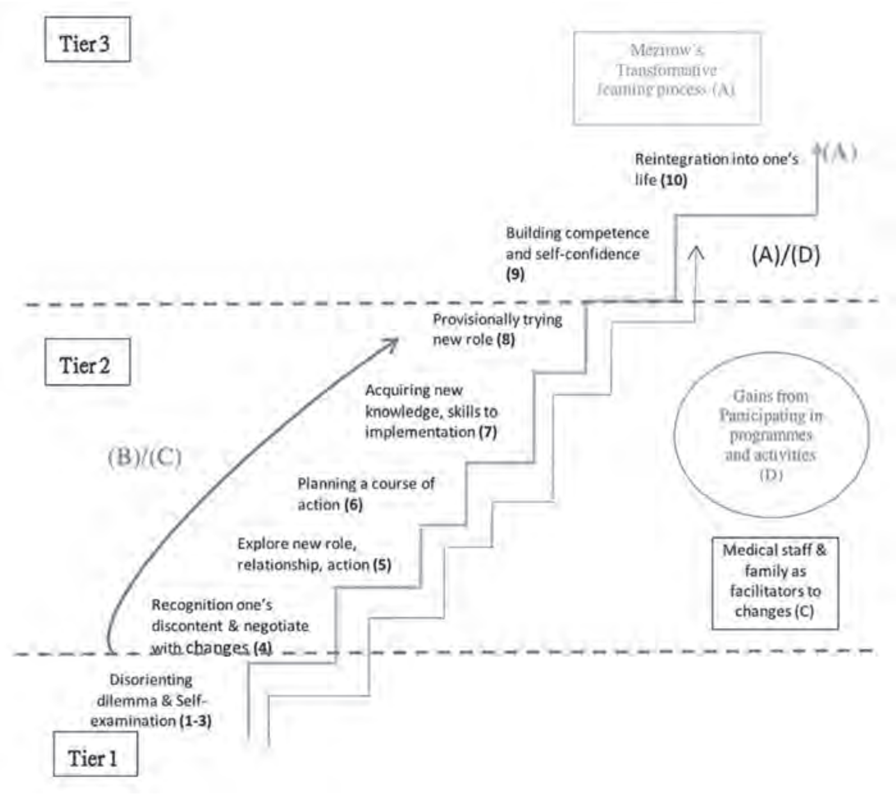
The primary objective of this study was to investigate whether family caregivers experienced transformative outcomes through attending programmes and activities. To our knowledge, this is the first study to adopt transformative learning theory to examine the relationship of participation in programmes and activities with transformative outcomes for family caregivers of people with dementia.

Our findings revealed that negative experiences after becoming a caregiver mainly involved family tension, psychological burden, health declines, and financial constraints. Other studies have provided similar evidence regarding psychological, mental, and emotional burdens (Pinquart & Sörensen, 2003), health decline (Corey & McCurry, 2018), and economic constraints (Wang et al., 2018). The participants in this study had been confronted by many disorienting problems, which can trigger changes in attitudes, beliefs, and values. Attitudes, beliefs, and views that had been internalised as habits were shaken, questioned, and rejected when exposed to transformative learning practices (Christie et al., 2015). For example, A1 asked, 'Why do you say these words that hurt?' and 'Why do you suddenly lose your temper?' A3, who had been a wife caregiver for more than two decades recalled, 'For about 12 years we could not confirm whether he was ill because of dementia'. Early onset dementia is dementia that first occurs at an age of <65 years. Healthcare providers generally do not monitor for the disease in younger patients, and months or years may pass before the correct diagnosis is made and proper treatment can begin (Alzheimer's Association, 2020). In this study, A12, the spouse caregiver of a patient with early onset dementia, recalled the misery from her early stage of caregiving.

Transformation rarely occurs unless the individual is convinced that it is necessary (Christie et al., 2015). Participants who reported negative caring experiences may have interpreted their conditions as a disorienting dilemma, self-examination, and sense of alienation (Stages 1–3; Mezirow, 1995; Figure 1). Participation in programmes and activities or support from medical staff and family members may play crucial roles in changing caregivers negative experiences and allowing them to move to the subsequent transformative stages of recognition of one's discontent and negotiation with changes (Stage 4), exploring new roles, relationships, and actions (Stage 5), and planning a course of action (Stage 6).

Moreover, participants in dementia programmes and activities reported numerous positive benefits for the family caregivers. For example, participants B1, B2, and A3 reported 'my dementia knowledge and caring skills improved', participants A1, A9, and B2 described that they 'enjoyed sharing experiences with others', participants A1, A4, and A10 reported 'peer support and patient benefit from the courses', and participants A4 and A12 stated that attending programmes and activities gave them 'time to take a break'. These results are in agreement with other studies that have demonstrated positive changes including better caregiving (Donovan & Corcoran, 2010), improved health-related quality of life (Kuo et al., 2016), and mitigated depressive symptoms (Huang et al., 2013) in the family caregivers of people with dementia after participation in programmes and activities focused on the management of behavioural problems. Our findings showed the prior negative experiences of participants were mitigated through their participation in programmes and activities, which helped them to gain an understanding of the disease and caring skills (Stage 7). Some of the participants may have been able to establish new personal roles (Stage 8) and possibly move into the stage of increased happiness and self-confidence (Stage 9).

Figure 1 Phases of the transformative learning process (Mezirow, 1995), and the incentives approach to transformative outcomes in our participants.



This study also examined the reasons for nonparticipation in dementia programmes and activities. A8, B4, B5, and B6 reported they did not participate in programmes and activities for the following reasons: 'information and knowledge provided by family and professionals', 'no desire to attend', 'dissatisfaction with content and structure', and 'unavailability of transportation and information'. Although A8, B4, B5, and B6 did not participate in programmes and activities, they were attending a clinical trial, which offered leadership and support from the patient's attending physician. Thus, they received considerable support from a group of professionals who helped them to cope with their negative caring experiences. Furthermore, A8 noted that she constantly argued with her husband; she thought her husband was ill, but he was still in a mild stage of dementia, and she considered there to be no need to join any programmes and activities. The family caregiver or patient may not yet be alert to the negative changes caused by the progression of dementia. In the case of A8, the condition of the patient could deteriorate rapidly, and caring could become more stressful for the family caregiver. Taylor (2009) claimed that individual experiences, critical reflection, dialogue, a holistic orientation, an awareness of context, and authentic relationships are the core elements of transformative learning and that the core elements and the theoretical orientation of transformative practice have interdependent and reciprocal relationships.

Conclusion and Limitations

A perspective transformation often occurs either through a cumulative series of transformed meaning schemes or from an acute personal or social crisis. This study investigated the transformative learning that occurs for the family caregivers of people with dementia as a result of negative caring experiences. The process of transformative learning can be broadly categorised into three tiers as shown in Figure 1. Both A1 and A3 had lacked knowledge on dementia and had experienced impaired health (e.g. negative emotions and back pain) since becoming caregivers. However, participating in programmes had helped them to improve their dementia knowledge and caring skills. A1 and A3 also enjoyed sharing their caring experiences with others and had gained much from hearing the experiences of others. A3 has even become a facilitator, sharing her dementia caring experiences and skills with others. A1, A3, and A12 appeared to have overcome their negative caring experiences and moved from the lower stages (Tier 1) to the upper stages (Tier 3). Although participation in programmes and activities may not be the only trigger for this change, these positive gains can be interpreted as a significant factor.

Moreover, transformative outcomes may have occurred for the nonparticipants in programmes and activities in this study. Support from medical staff and family members may have been other essential triggers contributing to transformative outcomes among nonparticipants. Therefore, the nonparticipants, who received support from family and medical staff, were considered to be in Tier 2. However, family and medical staff may have limited time, given their other duties, and they may not be able to provide holistic information and support to family caregivers. Furthermore, moral and financial support from inside and outside of the family, information about social resources, improvement in coping skills for problem behaviours related to dementia, and a coordinated intervention may also play crucial roles. Finally, motivation is considered essential for the family caregiver of people with dementia to participate in programmes and activities. The effectiveness of the programmes for individual preferences and needs may enhance the motivation of family caregivers. Family caregivers and patients should increase their awareness of dementia and dementia care at the diagnosis stage. However, family caregivers and patients with dementia vary widely, and one-size-fits-all programmes and activities may be unsuitable for all caregivers and patients. To improve self-adjustment, coordinated dementia interventions including continual supervision and feedback with cross-disciplinary healthcare and educational professionals (e.g. attending physicians, care managers, nurses, social workers, and educators) are recommended.

Some limitations of this study could be addressed through future research. For example, the views of caregivers may differ according to age (e.g. young old or oldest old), role (e.g. spouse or child), residential location (e.g. urban or rural), and life history of the patient. In addition, the progression of dementia varies between individuals. Longitudinal studies could follow up patients/caregivers for up to 2 years to address this limitation.

Further Directions

The population of Taiwan is ageing rapidly, and the number of patients with dementia is increasing. The transformative outcomes described in this study may assist family caregivers who are stressed and pessimistic. The present results provide long-term care policymakers, healthcare professionals, educators, practitioners, and family caregivers with a better understanding of the challenges faced by and the needs of people caring for patients with dementia. Future studies should focus on the effects of dementia interventions on the modifiable factors that predict perceived caregiver burdens, such as the provision of psychological support to informal caregivers, the availability of programmes and activities targeting the management of neuropsychiatric symptoms, and the provision of support for quality care.

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