

## REVIEW ARTICLE

# Educational Intervention for Informal Caregiver of Person with Dementia: A Systematic Review

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## ABSTRACT

The role of caregivers is very important in the management of person with dementia, where it is not uncommon for them to experience psychological distress. However, the level of distress can be managed and reduced through strategic educational intervention. A systematic review has been conducted through searching Medline, Science direct, Cochrane library and EMBASE databases to provide a narrative synthesis that elaborate on methods and outcomes of the educational intervention among informal caregiver of person with dementia. From a total of 5125 records, eight studies were selected and included in this review, where the results show that educational intervention can be implemented either as individual or group intervention. Group intervention methods mainly focus on training programs such as workshops and lectures, and also group-based discussions. While for individual intervention, most of the activities were implemented through self-learning using technology or computer-based systems. In conclusion, based on the outcome of the studies, both methods of implementations are found to be useful in reducing psychological distress of the informal caregiver.

**Keywords:** Educational, Intervention, Informal caregiver, Dementia

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## INTRODUCTION

Dementia is a syndrome associated with declining clinical cognitive function that interferes with patient's social and occupational functions because of reduced cognitive abilities that affect memory, language skills, visual perception, self-management, ability to focus and problem-solving (1). As dementia progresses, the patient will generally require a high level of care that is mostly provided by the informal caregiver such as family to perform daily activities (2). A caregiver is defined as a person who cares for peoples that require assistance in performing their daily activities (3). The role of caregiver is very important in managing a dementia patient. Studies have shown that caring for a person with dementia is a stressful task due to the needs of balancing the caregiving activities with other demands, which often leads to psychological distress such as caregiver burden which lead depressive symptoms to them (2).

There are several contextual factors that could contribute to psychological distress among caregivers of people with dementia. According to the Pearlin Stress Process Model, the process of stress can be seen by combining three major conceptual domains which are the sources

of stress, the mediator of stress and the outcome of the stress (4,5). The sources or the stressor can arise from the occurrence of discrete events and the presence of relatively continuous problem (5). The outcome of the stress is depending on the mediator of the stress, which is the social and personal resources of the individuals and to what extent the stress proliferate (4). The personal resources of the caregiver is important mediator of the stress as the diminishment of personal resources such as knowledge could affect self-efficacy, self-esteem and mastery, makes peoples vulnerable to the process that lead to stress (5). Caregivers without proper knowledge on dementia and its care process tend to overestimate the physical and mental capabilities of the in person with dementia under their care (6). As a consequence, caregiver may easily feel frustrated and angry, hence building up the stress. Knowledge on taking care of person with dementia will influence the caregiver's appraisal and irrational belief in managing them (7). Therefore, intervention that focuses in improving the caregiver's knowledge in dementia management and care is essential to alleviate caregiver burden.

One of the interventions that have been used in many previous studies is educational intervention, which is aimed to improve the caregiver's knowledge in dementia management and care. Educational intervention will also improve the caregiver's skill to cope with the person with dementia, thus reducing the psychological distress. One of the most important factors in determining coping skill

of caregivers is the ability to appraise a stressful event by identifying and utilizing resources at their disposal to assist of the situations (8). Educational intervention helps to enhance the knowledge of the caregiver to properly exploit all the resources available in coping with stress resulting from managing and caring of a person with dementia. Studies also have found that behavioural problem of a person with dementia plays a significant role to the caregiver's psychological distress (9). Hence, information on the behavioural management of a person with dementia through educational intervention can reduce the caregiver's psychological distress. Moreover, the availability of information in the stressful environment can reduce the caregiver's stress and anxiety level (8).

Based on the literature, there are three methods of how an educational intervention delivered to the caregiver of person with dementia. The first method which is one of the commonest and successful methods of an educational intervention delivery is through face-to-face intervention. Face-to-face method can be done individually or in a group and cover a number of different areas such as information about the disease, the organisation care, practical advice in coping with dementia, skill training to handle person with dementia behavioural problem, decision making skill, emotional repercussion of being a caregiver and self-care (10). The second mode of educational intervention delivery is through telephone-based support programmes which are one of the practical and low-cost types of intervention (10). The third method is through the computer-based support system and the least recommended mode of educational intervention delivery due to the wide variation of access to and actual used of the computerised intervention that may affect the outcome of the intervention (10). It is important to tailor the intervention to the individual situation when implementing the intervention so that it can bring a successful outcome. Whatever method of intervention implementation, it should aim to maintain the mental, physical and well-being of the caregiver.

Effective educational intervention for caregivers is a necessity so that their psychological distress can be reduced when caring for person with dementia. Educational intervention allows them to acquire skills that are needed to perform their caregiving tasks, which will often lead to better and successful outcomes (11). However, there are many methods to implement the educational intervention subject to the caregiver and patient conditions. The aim of this systematic review is to provide a narrative synthesis on the methods of educational intervention implementation and the outcomes of each intervention for informal caregivers to person with dementia.

## METHODS

This systematic review was performed according to a pre-specified protocol and is reported according to

Preferred Reporting Items for Systematic Review and Meta-Analysis: the PRISMA statement. A systematic literature search was conducted up to May 2019 on several main electronic databases, which are PubMed/Medline, Science Direct, Cochrane library, and EMBASE. Keywords that were used in the literature search were [(Education OR Educational) AND ("Randomized Control Trial" OR RCT) AND (Caregiver OR Carer OR Family)] AND Dementia. In addition to electronic database, manual search for additional published article or report from reviews and reports were also conducted.

For inclusion, this study tries to meet the following criteria: (a) target population must be informal caregiver, (b) English or Malay language article or report, (c) randomised control trial studies, (d) intervention group were compared with no intervention control or usual care control, (e) blinded studies and (f) published articles or reports. A study will be excluded if: (a) it is a duplicated article or report, (b) multicomponent or psychoeducation studies, and (c) multiple target population. One reviewer will first select an abstract from the search for full text review based on the inclusion and exclusion criteria. The extracted data from the reviewed full text were then put into data extraction forms. All the extracted data were checked independently by a second reviewer for accuracy against the data extraction form. Any discrepancies were then evaluated by second reviewer and conclusions were made based on discussion.

The chosen studies were sorted according to the publication year. There are six features, which are extracted from each study: (a) author/s, year of publication, and country (b) number and characteristics of participants of the study, (c) intervention implementation methods, (d) content of the intervention, (e) outcome measurement, and (f) study findings. The outcome measurement was then further classified either as primary or secondary outcome.

## RESULT

### Literature retrieval process

The search strategy has yielded 5125 records. From the 5125 records, 5064 records were excluded based on the title screenings. Through reviewing the abstract, 30 studies were found to be relevant for full text review. Out of 30 articles, only eight articles were included in the review, where the rest 22 articles were excluded based on inclusion and exclusion criteria. The reasons for exclusion are the intervention methods used are 1) multicomponent intervention or psychoeducation intervention, 2) not randomized controlled trial (RCT) and 3) unsuitable study participants. The study selection process is illustrated in Figure 1.

### Study characteristics

The data presented in Table I is the overview of educational intervention among informal caregivers of

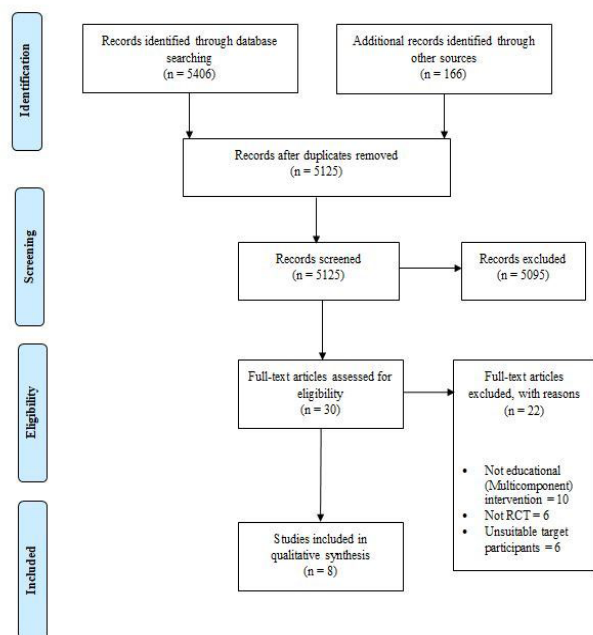


Figure 1: Flow chart of the study

person with dementia that are included in this review. The eight chosen studies were published between 1998 and 2018 (12-19). A total of 662 informal caregivers, family members or relatives to person with dementia were included in this reviewed study. Only one study was conducted as multi countries trial which is in Denmark, Poland and Spain (17). Other studies from the review were conducted in Italy, United State of America (USA), Germany, Iran, Australia, and Japan (12-16,18,19). All of the studies have focused only on adult caregiver to the person with dementia.

## Result of individual studies

### Intervention implementation methods

Two educational interventions methods were implemented, which are individual and group interventions. Five of the reviewed studies have used group educational intervention and another three of the reviewed studies were implemented as individual educational intervention. The five studies that used group intervention was implemented through group-based discussion or training program (12-15,18). Three studies that were using group-based discussion as educational intervention consist of eight to 15 group

Table I: Overview of studies included in the review

Source	Participants	Intervention Implementation Methods	Intervention Contents	Outcomes Measurement	Study Findings
Zanetti, Mettieri, Bianchetti & Trabucchi, 1998 (Italy)	23 families caregiver of dementia person	Six-session educational program on dementia behaviour management techniques. Consists of a didactic presentation, followed by one-hour group discussion for each session. Topics discussed by medical doctors, nurses, social workers and cognitive rehabilitation therapists.	Information on dementia process, personality and behavioural changes, strategies to manage behavioural disturbances, and suggestions for successful coping with functional disability.	<b>Primary Outcome:</b> Caregiver knowledge on dementia <b>Secondary Outcome:</b> Caregiver depression, perceived stress (behavioural disturbances and functional disturbances) and quality of life	Significant improvement on caregiver knowledge regarding dementia and significant reduction on level of stress associated with patient's behavioural disturbances.
Hepburn, Tornatore, Center & Ostwald, 2001 (USA)	94 relative's caregiver of dementia person.	Community-based 14 hours training workshop (Provided in seven weeks with two hours per session). Combined classroom instructions and exercises with assignment of additional read to be put into practices and strategies taught in the workshop.	5 main components: 1. Information provision: Information on dementia and effects of dementia to the dementia person abilities in daily life. 2. Concept development: Framework on understanding effect of dementia on dementia person cognitive function and development of strategies in managing daily life and behaviour of dementia person. 3. Role clarification 4. Belief clarification 5. Mastery-focused coaching.	<b>Primary Outcome:</b> Caregiver response to person with dementia behaviours. <b>Secondary Outcome:</b> Caregiver depression, burden, belief about caregiving	Significant improvement on caregiver measure of belief about caregiving and reaction to behaviour problem. Significant difference in the measure of stress mediator, belief, response to behaviour, depression, burden.
Kurz, Wagenfeil, Hallauer, Schneider-Schelte & Jansen, 2009 (Germany)	292 family caregivers of dementia person	Educational intervention in group format (eight caregivers per group) with therapists (experienced psychologists or social workers) with seven bi-weekly group sessions of 90 minutes duration each.	Information on Alzheimer's disease that is structured along the different stages of dementia severity.	<b>Primary Outcome:</b> Caregiver depression <b>Secondary Outcome:</b> Caregiver quality of life, time spent on caregiving, healthcare utilisation, satisfaction with the intervention, and dementia person nursing home admissions	Significant greater satisfaction in the intervention. Weak effect on caregivers' psychological quality of life. No difference in the caregiver level of depression.
Pahlavan-zadeh, Heidari, Maghsudi, Ghazavi & Samandari, 2010 (Iran)	50 family caregiver of dementia person	Family education program. Five weekly sessions using lectures, group discussions (10-15 members in groups), and question and answer with 90 minutes duration for each session. The program was conducted by first researcher.	Information on changes in the elderly, the definition, stages and symptoms, risk factors, diagnostic methods, and treatment of dementia, ways to improve communication with patients, feeding them, and ways to control and deal with their urine and faecal incontinence, methods to improve their sleep, bathing and personal hygiene, and dressing the patient, methods to control patients' unusual behaviour including repetitive behaviour, pursuing the caregiver, shouting, unreasonable laughing and crying, and disregarding social rules, methods to control patients' unusual behaviours including excessive walking and restlessness, hiding things, being suspicious and slandering, irrelevant resistance, and stubbornness methods to control patients' unusual behaviour including vagrancy and wandering and aggression, safety measures at home, how to entertain patients at home, and methods of reducing caregivers' burden.	<b>Primary Outcome:</b> Caregiver burden	Significant reduction in caregivers' burden.

Continue.....

**Table 1: Overview of studies included in the review (continued)**

Source	Participants	Intervention Implementation Methods	Intervention Contents	Outcomes Measurement	Study Findings
Stirling et al., 2012 (Australia)	31 relatives caregiver of dementia person	Caregivers were mailed with the Decision Aids (DA) that comes with instructions on how to read the contents over the following week.	Information about the common available community services (domestic help, gardening and maintenance, personal care), descriptive information about respite care, decision tools based on selecting a respite care option, vignettes describing carers' experiences, brief targeted information about the trajectory of decline in dementia, and phone numbers and links to facilitate gaining further information.	<b>Primary Outcome:</b> Caregiver burden <b>Secondary Outcome:</b> Caregiver decisional conflict, knowledge of the dementia trajectory, and decision participation preferences	Less increase in burden, a greater decrease in decisional conflict and a greater increase in knowledge of the dementia trajectory.
Núñez-Naveira et al., 2016 (Multi-centre: Denmark, Poland and Spain)	61 informal caregivers of dementia person	E-learning platform. The underAID application was developed to be accessible through any device with Internet connection: by using an application in any mobile devices (Smartphone or Tablet) or through a browser in a personal computer (PC). Consist of text information, videos, and images and references to the other websites.	5 modules with information about 15 different topics: <b>Module 1:</b> Cognitive Declines (Topics: Attention, Memory, and Orientation) <b>Module 2:</b> Daily Tasks (Topics: Bathing, Incontinence, Massage and Touch, and Physical Exercises) <b>Module 3:</b> Behavioural Changes (Topics: Anxiety and Agitated Behaviour, Depressive Mood, Manic Symptoms, and Emotional Control and Recognition) <b>Module 4:</b> Social Activities (Communication and Apathy and Loss of Motivation) <b>Module 5:</b> You as a Caregiver (Topics: Coping with Own Stress and Motivation)	<b>Primary Outcome:</b> Assessment of the UnderstAID feasibility <b>Secondary Outcome:</b> Caregiver depressive symptoms, competence, caregiving satisfaction with the care provided.	Majority of the caregivers assessed the underAID application as unacceptable. Significantly decreased in depressive symptomatology.
Seike et al., 2016 (Japan)	54 family caregiver of dementia person	Comprehensive education program. 12 classroom style lectures.	Information on dementia medical, care-related, psychological, and social welfare domains, plus interactive exercises.	<b>Primary Outcome:</b> Coping skills <b>Secondary Outcome:</b> Caregiving stressors, cognitive caregiving appraisal, caregiver depression scale, and burnout.	Significant changes to positive caregiver coping skills. Caregiver also showed less depression, burnout, and better caregiving appraisal.
Kales et al., 2018 (USA)	57 family caregiver of dementia person	Innovative web-based tool WeCareAdvisor. Caregiver received: 1. An iPad with the WeCareAdvisor website link 2. Optional email account setup (if no prior email access) 3. Approximately 15-min instruction in use of the tool. 4. Weakly "check-in" phone call from a study team member to trouble shoot problems with the tool and encourage tool use.	Three main components: 1. <b>A guided DICE approach:</b> WeCareAdvisor provides a set of strategies for possible medical/pain issues that include delirium for caregivers. Caregivers are instructed to try the strategies for one week and then evaluate the strategies effectiveness on them; if the strategies are helpful, they are encouraged to keep using them, if the strategies are not helpful, caregivers are encouraged to conduct another DICE session to get a new set of strategies. 2. <b>Caregiver Survival Guide:</b> Compendium of information for dementia caregivers located in one place for "one stop shopping". 3. <b>Daily messaging feature:</b> Provides an encouraging daily communication to caregivers for emotional support and motivation.	<b>Primary Outcome:</b> Caregiver confidence in managing behavioural and psychological symptoms of dementia (BPSD). <b>Secondary Outcome:</b> Caregiver stress, depression, burden, negative communication, relationship closeness	Improvement in caregiver confidence in managing BPSD. No difference was found in secondary outcome.

members (12,14,15). The discussions were conducted in five to eight sessions with each session ranging from 60 to 90 minutes. The discussions were facilitated either by occupational therapists, experienced psychologist, social worker, or nurses. Apart from group-based discussion, group intervention was also conducted using training program such as workshop (13) and comprehensive education program (18). The workshops were conducted in two hours session for seven weeks, which also included classroom instruction. The comprehensive education program was implemented through 12 classroom-style lectures (18).

Apart from group intervention, educational intervention was also implemented as individual intervention, which is through self-learning. Among the three studies that used individual intervention, two studies have used technology-based method to implement the educational intervention through online applications that can be accessed through mobile devices (17) and web-based tools (19). Only one study has used booklet as a method to educational intervention (16). Although the intervention was implemented through booklet, the intervention information was delivered through e-mail,

which is also a computer-based intervention.

### Intervention contents

The content of the intervention is one of the important factors of educational intervention. All of the reviewed studies have included basic information on dementia and its process. Basic information on dementia include information on definition of dementia, stages and symptoms of dementia, diagnostic methods, treatment of dementia, personality and behavioural changes, effects of dementia to the person with dementia abilities, and personal care for person with dementia and their caregivers. They have also included information on the social support group that are available for dementia caregivers in their respective area. Five of the studies also shared the information on practices and management strategies of behavioural problem of demented person (12,13,15,17,18). Only two studies have included advices on best communication practice with demented person as educational intervention (15,17).

### Outcome measurement and findings

All of these studies have measured caregiver psychological distress as their primary (14-16) or secondary outcome

(12,13,17,19,20). Psychological distress was measured through caregiver burden or depression symptoms. Two of the studies measure caregiver burden as their primary outcome (15,16), while three studies have measured them as the secondary outcome (13,18,19). The caregiver burden was measured by using the short and full version of Zarit Burden Interview (ZBI) and Modified Caregiver Strain Index (MCSI). Two of the study's findings showed that there is a significant reduction in caregiver burden after educational intervention have been implemented (13,15). Two study findings also showed that there is reduction in caregiver burden after the intervention, however it is not a significant finding (16,18). Only one study's finding showed that there is no difference in the caregiver burden after the intervention was given (19).

In term of caregiver depression symptoms, five studies have measured them as secondary outcome (12,13,17-19) and only one study have measured the symptoms as primary outcome (14). The caregiver depression symptoms were measured by using Center for Epidemiologic Studies Depression Scale (CES-D), Montgomery-Asberg Depression Rating Scale (MADRS) or 6-item depression subscale of the Brief Symptom Inventory (BSI). From the review, three of the studies have found significant difference in the caregiver's depressive symptoms on the intervention group (12,13,17). Two studies have showed that there is reduction in the depression symptoms, however it is not significant (14,18). Only one study findings have showed that there is no difference in the caregiver's depressive symptoms before and after the intervention implementation (19). Apart from the caregiver psychological distress, two of the reviewed studies have also measured caregiver response to demented person behavioural problems as outcome of the studies (13,19). The caregiver response was measured by using Revised Memory and Behaviour Problem Checklist. Both of the study's findings show that there is significant improvement on caregiver reaction to demented person behavioural problems after the implementation of educational intervention.

## DISCUSSION

This review assesses published literatures on educational intervention methods and their outcomes among informal caregiver of person with dementia. There are two important aspects in ensuring effectiveness of an educational intervention, which are the form of implemented intervention and the content of intervention (20). This review have identified eight studies that cover a total of 662 informal caregivers from multiple countries such as USA, Demark, Germany, Japan, Italy, Iran and Australia. Several methods of educational intervention that have been implemented successfully have been identified. The two major methods of intervention are group and individual interventions, where majority of the studies have implemented the group-based educational intervention for both small and large group participants.

Group intervention is the most preferred method for educational intervention. Studies with different target population also have found that group teaching is a more effective approach compared to individual teaching (15). Most of the group intervention methods were conducted in a small group of participants, mainly through discussion. All of the group-based interventions were conducted in multiple sessions, with at least five sessions of 60 minutes discussion. Majority of the group-based intervention methods have a series of follow up discussions in each session. The studies have found that caregivers are able to maintain good management of dementia person at home for substantially longer period of time because of group-based educational intervention, which is also followed by individual support (21). Several group-based educational interventions were also implemented through training programs such as workshop and lecture. These training programs were conducted in multiple sessions followed with group discussion activities.

Although based on the studies reviewed, group intervention is the most preferred method of educational intervention; a few researches have also explored educational intervention through individual effort. Despite the fact that group intervention is a more effective method, their studies have also shown that individually delivered intervention are effective in reducing caregiver's psychological distress (22). Caregivers are able to personalize the required information to manage the person with dementia (17). Individual intervention is a more convenient method for the caregivers as they can individually select the time and location of learning the intervention method. All of the individual intervention studies in this review have used technology or computer-based system to implement the intervention rather than the conventional method of face to face group discussion. Individual educational interventions were implemented by using a mobile application or a web-based tool. Technology or computer-based systems provide convenient to the caregivers as they allow the caregivers to tailor the content and level of information according to their individual needs and circumstances (17). This method of educational intervention also allows the caregivers to prepare themselves for the following stages of dementia as person with dementia becomes more dependent and hence, requires higher level of care and management (23).

Nonetheless, despite being handy to the caregivers, previous studies performed on various target populations have found that computer-based system is the least recommended mode of educational intervention due to inconsistency in accessing the right information (10). This method of intervention requires the caregivers to participate the intervention process actively. The caregivers must have self-desire and effort to search and apply the learned information from the intervention (24). However, in reality, most of the caregivers are burdened



with various responsibilities. It is a difficult process to balance the needs of work, private life and caregiving, which restrict their time to read and comprehend the given online information (24). Computer-based intervention may not result in benefit to all caregivers because some of them are already old and may encounter difficulties in using the computer as well as limited access to the internet (25).

Based on the reviewed studies, both individual and group educational interventions have their own advantages and disadvantages. Individual intervention might be a more convenient approach for the caregiver compared to the group intervention. However, an individual intervention method requires the caregiver to be more active during the intervention process. Although the method of educational intervention is an important factor to predict a successful outcome, the content of the intervention itself also plays an equally important role. The studies show that the intervention contents can be similar for both individual and group-based interventions. The content that include focus area and emphasized information of the educational intervention can be implemented in variety of ways (13).

The content of the educational intervention in all reviewed studies was geared to improve the personal resources of the caregivers. Caregiver with better personal resources such as high level of self-efficacy and esteem in dementia person management is less vulnerable to stress (26). An effective educational intervention for the caregiver needs to include provision of disease information such as signs and symptoms, care planning, advice on managing dementia person and the importance of self-care, skill training, stress management, problem solving and decision making guidance (10). Every studies included in this review have included information on dementia process and its stages inside the educational module. Majority of the studies have also provided information on the behavioural problem among person with dementia and strategies to manage them.

Most of the studies outcomes measured the effect of educational intervention on the psychological distress of the caregivers and their coping skills to the behaviour problem of dementia person. Most of the study's findings, either an individual or group-based intervention, found that there is improvement in the psychological distress of the caregivers and they are better at coping with managing behavioural problem of the dementia person. Educational intervention helps to improve their knowledge in caring and managing person with dementia thus allows them to adjust and correct their belief and appraisal in caregiving. Caregivers feel less emotionally enmesh that allow them to think strategically on appropriate management and care process of person with dementia (13). Caregivers are more likely to realize the limitations of a person with dementia and they are

able to adjust their expectations, thus reducing the psychological distress (13). Caregivers also are able to provide better care through distinctiveness information of dementia process as it would help to increase caregiver empathy towards the patient (22). Through educational intervention, caregivers were also equipped with more information on solutions and tactics to help them manage their stress because of day-to-day demand of caring activities of a person with dementia (17).

## CONCLUSION

Educational intervention for informal caregivers of person with dementia can be implemented through various methods. Every method can be used to deliver various information targeting different outcomes. Educational intervention is also found to be helpful in easing the psychological distress of the caregiver of for a person with dementia.

## ACKNOWLEDGEMENTS

The evidence synthesis upon which this article was funded by the Geran Putra (GP) (funding project number: -GP/2018/9656800) from Universiti Putra Malaysia. The funder played no role in study design, collection, analysis, interpretation of data, writing of the report, or in the decision to submit the paper for publication. They accept no responsibility for the contents.

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