ABSTRACT:
Introduction: Since the incorporation of women into the world of work, together with the progressive ageing of the population and the increase of chronic diseases, there is an alteration in the role of the caregiver, due to the physical, work and family burden it bears, emotional conflicts and with other family members. Mutual aid can be an effective alternative to promoting the well-being of caregivers, as well as their families and dependents.

Objective: To know the characteristics of self-help groups for family caregivers and their influence on caregivers, the dependent and family health.

Methodology: Systematic review. The search strategy included the Pubmed, Scopus, Psycinfo, Eric, Cochrane plus and CSIC databases; selecting scientific articles in either Spanish, Catalan, English, Portuguese or French, for the last 10 years.

Results: 12 articles related to the study topic were selected. All studies show that participation in these groups can improve the physical-psychological well-being, the health of caregivers and, at the same time, reinforce their sense of social support, although there is a lack of studies in our environment, with a size higher quality sample.

Conclusions: Caregivers benefit from participating in self-help groups. Therefore, they should become a routine component of the family caregiver.

Keywords: Family caregiver, self-help groups, family health, caregiver burden, dependents.
RESUMEN:
Introducción: Desde la incorporación de la mujer al mundo laboral, junto con el envejecimiento progresivo de la población y el aumento de las enfermedades crónicas, se produce una alteración en el rol del cuidador, debido a la carga física, laboral y familiar que soporta, generándose conflictos emocionales y con el resto de miembros de la familia. La ayuda mutua puede ser una alternativa eficaz para promover el bienestar de los cuidadores, así como el de sus familias y dependientes.

Objetivo: Conocer las características de los grupos de ayuda mutua (GAM) para cuidadores familiares y su influencia sobre los cuidadores, la persona dependiente y la salud familiar.

Metodología: Revisión sistemática. La estrategia de búsqueda incluyó las bases de datos Pubmed, Scopus, Psycinfo, Eric, Cochrane plus y CSIC. Se buscaron artículos escritos en español, catalán, inglés, portugués o francés, publicados en los últimos 10 años.

Resultados: Se seleccionaron 12 artículos relacionados con el tema de estudio. Todos los estudios muestran que la participación en estos grupos puede mejorar el bienestar físico-psicológico, el estado de salud de los cuidadores y, al mismo tiempo, reforzar su sentimiento de apoyo social, aunque faltan estudios en nuestro medio, con un tamaño muestral superior y de mayor calidad.

Conclusiones: Los cuidadores se benefician de participar en grupos de ayuda mutua. Por lo tanto, deben convertirse en un componente de rutina del cuidador familiar.

Palabras clave: Cuidador familiar, Grupos de ayuda mutua (GAM), salud familiar, sobrecarga del cuidador, personas dependientes.

INTRODUCTION

Illness or a family member’s dependency could take part in family life, causing structural, procedural and emotional problems. The 88% of the total time dedicated to health care is provided in the domestic environment, being part of the normality and the daily life of the families. Only one person generally assumes family care, most of the time, a woman. The caregiver is the person in charge of looking after these sick people, dedicating, in its majority, 24 hours to them. Little by little, they get careless of their own cares to totally look after the ill person. Caring of a dependent person might be annoying and stressing and it may negatively affect the caregivers’ social and family fields, as well as their professional lives. Besides, there is a danger in their physical life, a possible increment of social isolation, risk of anxiety and depressive disruption. Additionally, social discrimination and repudiation may be reached, causing emotional frustration as well as blame and auto-blame feelings in the process of care, which might end up their capacity of taking care. In addition, the caregivers’ stress is related to negative results to the attention recipient, that is, the dependent patient and the costs for the society, as the increased number of nursing homes and admissions in hospital. Besides, it can affect the family’s health, understanding this as its capacity of work and adapter to stressing vital events, like illness or any of its members’ incapacity.

It is estimated that there is about 130.000 sick and elder people caregivers in Andalusia (Spain). After approving the Support to Andalusian Families Decree, caregivers have become into an indispensable piece in our Sanitary Service, carrying out a huge labour in social and family field due to their attention to disabled relatives. That is why a specific programme to facilitate help to family caregivers has been provided, this the "Caregivers’ Attention Improvement in Andalusia Plan", with interventions as formal support, through "breathing" community services; psycho-educational programmes; mutual help groups; psychotherapeutic interventions (counselling); or a combination of the above.

One of the resources that family can get, in these situations, are support networks that
community offers, like mutual help groups, in which confrontation and finding suitable solutions strategies are shared, in a therapeutic environment. (7) Mutual group for caregivers is defined as a group of “equals” to help each other, to whom offer emotional support, facilitate abilities acquisition and management of tools to deal and sort out problems related to care, increase self- esteem and decrease co-dependency, help in social adaptation process needed in the situation of care, having the group as a network of social support, reduce pharmacologic drugs usage related to caregivers´ overburden. (8)

Regarding family groups modalities, three types of groups were differentiated: informative, self-help, and support groups. Informative groups’ principal objective is helping families in better looking after their ill members, having medical information and/or nursing assistance. Its duration is short (6-10 sessions). Mutual help groups are based on the support between their members, although they have progressed being guided by a professional and got defined as help groups, where all the above aspects and the support-orientation and learning strategies are combined. (9) The bigger and bigger impact that elder dependent people care has in the society is reflected in the number of publications about interventions for caregivers. Although, these interventions´ design and methods have gained quality, the reality is that, in the actual moment, the interventions´ effect size to reduce the caregivers´ discomfort is, in the best case, moderate. From the studies developed in the last twenty years, we can affirm that informal caregivers are exposed to a stressing situation that increases the risk of suffer from several physical and emotional problems, anxiety and depression mostly. So far, different types of interventions have been developed. However, application of support programmes and investigation about their efficiency is not enough, even more in our sociocultural environment. (10)

The empirical study of the interventions carried out to support elder dependent people’s caregivers started in the 80’s, and their advantages are not yet clarified. (5) Trying to establish the effectiveness of these groups in the improvement of caregivers´ emotional status, a few revisions have been carried out. However, all of them are focused only and exclusively on dementia people caregivers, (8) although in 2017, a meta-analysis collected very varied studies, on people dependent on different causes (chronic diseases, dependent diseases, old age...) or articles focused, in general, on family caregivers, but all mediated by SHGs Online. (11)

So these self-help groups (SHG) for family caregivers research tries to know the characteristics of these groups and their influence on caregivers, the dependent person and family health.

MATERIAL AND METHODS

A systematic review has been carried out. For this process, recommendations from PRISMA declaration have been followed. (12) Next databases were selected: Pubmed(13), SCOPUS(14), Cochrane Plus(15), ERIC(16), PsycInfo(17), National Library of Health Sciences (BNCS) of the Carlos III Institute of Health. (18)

Search strategy

First, for this search we have used key words related to our wished objectives, according to Mesh and Decs terms: (Caregiver) OR (home nursing) AND (self-help}
The search strategy used for each of the databases with their respective limiters and records obtained are shown in Table 1.

<table>
<thead>
<tr>
<th>Database</th>
<th>Search strategy</th>
<th>Records</th>
<th>Search date</th>
</tr>
</thead>
<tbody>
<tr>
<td>PUBMED</td>
<td>(caregiver OR home nursing) AND (self-help group OR Group Structure) AND Family Health</td>
<td>85</td>
<td>04/03/2019</td>
</tr>
<tr>
<td>SCOPUS</td>
<td></td>
<td>89</td>
<td>08/03/2019</td>
</tr>
<tr>
<td>PsycINFO</td>
<td></td>
<td>61</td>
<td>15/03/2019</td>
</tr>
<tr>
<td>ERIC</td>
<td></td>
<td>23</td>
<td>08/03/2019</td>
</tr>
<tr>
<td>Cochrane Plus</td>
<td></td>
<td>165</td>
<td>08/03/2019</td>
</tr>
<tr>
<td>National Library of Health Sciences</td>
<td>LIMITS: Abstract - Last 10 years - Language*</td>
<td>1</td>
<td>11/03/2019</td>
</tr>
</tbody>
</table>

**Selection process**

To select articles, we considered next inclusion and exclusion criterions:

- **Inclusion criterions:**
  - Original investigation article.
  - Quantitative or mixed studios.
  - Moderate or high article´s quality.
  - Direct relation with family health and dependent people caregivers´ individual health.
  - Language*: Spanish, Catalan, Portuguese or French.
  - Publication date within the last 5 years.

- **Exclusion criterions:**
  - Impossibility in getting the complete article.
  - Same article found in a previous search.
  - Receptors of care are not dependent people.

For the selection of articles, we have carried out different strategies to filter the total number of articles found after searching, and this one has been divided in two periods. In the first filter, articles have been discarded by their title and their abstract. From 424 records found, 69 articles were selected.

Regarding the excluding criterions in this first selection phase, according to the title
and abstract, they can be divided in:
- German or Chinese language.
- Title not related to caregiver, SHG or family health.
- It doesn’t include an abstract.
- Duplicated articles from previous search.

In the second phase, filter was carried out by reading the complete text, getting 12 selected articles finally (from the 69 articles in the previous phase).

The exclusion criterions in this second period were:
- It is not an original investigation article.
- The article’s methodology is not the one we look for.
- It is not directly related to family health, SHG and caregiver.
- Impossibility to get the complete article.
- Poor article quality.
- Care receptors are not dependent people.

The whole selection process is resumed in the next flow chart, figure 1.

Figure 1: Summary of the item selection process.

The variables of interest used in data extraction in these articles were the characteristics of SHG, the advantages of SHG on caregivers, the impact of SHG on family health, and the benefits of SHG for the dependent. The country was also taken into account, to know if it is developed in a western (individualist) and eastern (group) society. Once the articles that were finally included in the review were selected, they were analyzed using the CASPe (Critical Appraisal Skills Programme) method. It is a tool structured in: validity, results and applicability. The higher the score, the higher the quality of the study. \(^{(19)}\) Therefore, only two failures of the total item on the quality of the article were taken as a limit.

**RESULTS**

Regarding articles’ quality, it is detailed in next table (table 2).
Table 2: Analysis of the quality of articles.

<table>
<thead>
<tr>
<th>Article</th>
<th>Quality</th>
<th>Detailed description of the analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>1(20)</td>
<td>Strong (9/10)</td>
<td>Its weakness is point number 8, given that studies were carried out in different populations but similar to each other, so we are not sure if results can be applied in our environment.</td>
</tr>
<tr>
<td>2(21)</td>
<td>Strong (10/11)</td>
<td>Its weakness is point number 9, given that we don´t know if we could apply the results in our environment, due to study is carried out in China.</td>
</tr>
<tr>
<td>3(22)</td>
<td>High (9/11-9/10)</td>
<td>27/27 between good and very good.</td>
</tr>
<tr>
<td>4(23)</td>
<td>Strong (10/11)</td>
<td>Blind method was not apply to the clinical staff, patients and study staff, or at least, it is not reflected.</td>
</tr>
<tr>
<td>5(24)</td>
<td>Strong (10/11)</td>
<td>The weakness is that clinical and study staff were not blind, or it is not said.</td>
</tr>
<tr>
<td>6(25)</td>
<td>High (9/11-9/10)</td>
<td>High quality in quantitative methodology (9/11), but regarding qualitative aspect, quality is high (9/10), but the chosen method is not explicit.</td>
</tr>
<tr>
<td>7(26)</td>
<td>Strong (10/11)</td>
<td>Limit in this case is the clinics, patients and study staff, given that they were not blind, or at least, it is not reflected.</td>
</tr>
<tr>
<td>8(27)</td>
<td>Good (8/10)</td>
<td>By the other hand, the quality of the quantitative part (as a descriptive observational transversal study) is good.</td>
</tr>
<tr>
<td>9(28)</td>
<td>High (9/10)</td>
<td>The chosen method is not explicit (phenomenology, grounded theory, ethnology...).</td>
</tr>
<tr>
<td>10(29)</td>
<td>Strong (10/11)</td>
<td>High quality. Because it is referred to a Chinese population, it cannot be extrapolated to our community.</td>
</tr>
<tr>
<td>11(30)</td>
<td>Very good (10/11)</td>
<td>Because it is referred to a Chinese population, we have the same problem as above.</td>
</tr>
<tr>
<td>12(11)</td>
<td>Very strong (10/10)</td>
<td>It clearly complies with all sections, even revealing the lack of high quality studies.</td>
</tr>
</tbody>
</table>

According to the classification made using the CASPe method, the selected articles have a high level of quality, but are heterogeneous because of a few reasons. SHGs have been studied and used in a huge variety of countries all over the world, in different years and databases, and applying different methodology.

That is why, in order to develop the main results, they will be grouped following the next categories:

1. SHGs’ characteristics.
2. Advantages of SHGs for caregivers.
3. Impact of SHGs in family´s health.
4. Benefits of SHGs on dependent person.

In the table number 3, main author and publication year, the type of study and the sample, aim to get with each one along with the categories mentioned and results obtained for a posterior analysis are shown.

The gradation scheme of the Medical Technology Assessment Agency of the Catalunya´s Generalitat (AATM, Agència d’Avaluació de Tecnologia Mèdica in Catalan) was used to determine the level of evidence of the articles.
Table 3: Selected articles for review with their main results.

<table>
<thead>
<tr>
<th>Author, Year, Evidence</th>
<th>Type of study, Subjects, Country</th>
<th>Objective, Category, Analysis</th>
<th>Main results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Candy, Jones, Drake, Leurent, King (2011)</td>
<td>Systematic review. 11 trials with 1836 caregivers of a friend or family member with a terminally ill disease. UK</td>
<td>Evaluate the effects of SHG on the psychological and physical health of patient caregivers in the terminal phase of their disease. 2 Standardized Mean Difference [SMD]; 95% confidence interval [CI].</td>
<td>SHG can help them cope with their role as a caregiver and improve their quality of life. 7 trials: SMD -0.05; CI: -0.24 a 0.14; 6 trials: SMD 0.08; CI: -0.11 a 0.26</td>
</tr>
<tr>
<td>Chien, Chan (2013)</td>
<td>Randomized controlled clinical trial. 135 caregivers of members with schizophrenia. Two-thirds were men, and father or spouse. China</td>
<td>Assess the effects of SHG led by family members of people with schizophrenia on family functioning and social support. 3, 4 ANOVA.</td>
<td>Significantly increased improvement in the functioning of the family [F=5.40, p=.005] and patient [F=6.88, p=.001], reducing the severity of patients' symptoms [F=4.65, p=.01] and the number of hospitalizations [F=4.78, p=0].</td>
</tr>
<tr>
<td>Gräbel, Trilling, Donath, Luttenberger (2010)</td>
<td>Cross-sectional study. 404 caregivers for dementia patients. Germany</td>
<td>Determine what motivates caregivers in the use of SHG. Determine the characteristics of SHG. 1 Content analysis and binary logistic regression.</td>
<td>SHGs that offer an exchange of open experiences and discussions meet the requirements of caregivers. The degree of &quot;necessity&quot; (p&lt;.001) and the accessibility of SHG is a significant predictor for use (p.005).</td>
</tr>
<tr>
<td>Hemamalini, Judie (2014)</td>
<td>Clinical trial, with pre-test and post-test. 240 caregivers of people who suffered a stroke, 120 from the control group and 120 from the randomized experimental group. India</td>
<td>Assess the effect of SHG on family system strengths among stroke survivors' caregivers. 3 T-test and analysis of variance.</td>
<td>After 3 months, there was a significant difference (t=37.58; p=.001) in the strengths of the family system between the experimental group [44.73 (SD 5.83)] and the control group [22.08 (SD 3.07)]. SHG is an effective nursing intervention for stroke survivors' caregivers to strengthen the family system.</td>
</tr>
<tr>
<td>Study Authors</td>
<td>Study Type</td>
<td>Study Design</td>
<td>Participants</td>
</tr>
<tr>
<td>----------------------------------</td>
<td>-------------------------------------</td>
<td>-------------------------------------</td>
<td>--------------------------------------------------</td>
</tr>
<tr>
<td>Laakkonen, et al. (2013)</td>
<td>II</td>
<td>Randomized controlled clinical trial.</td>
<td>136 dementia patients and their spouses. Finland</td>
</tr>
<tr>
<td>McKechnie, Barker, Stott (2014)</td>
<td>IV</td>
<td>Mixed study: qualitative and quasi-experimental study. 61 caregivers of people with dementia, who participate in an online SHG. UK</td>
<td>Examine the impact of an online SHG for caregivers of people with dementia. T-test and thematic analysis interviews.</td>
</tr>
<tr>
<td>Rodriguez-Sanchez, et al. (2013)</td>
<td>II</td>
<td>Randomized controlled clinical trial.</td>
<td>125 caregivers of people with dementia or any other disability. Spain</td>
</tr>
<tr>
<td>Secanilla, Bonjoch, Galindo, Gros (2011)</td>
<td>VIII</td>
<td>Mixed: Descriptive transversal and qualitative observational. 30 caregivers of people with Alzheimer's disease. Spain</td>
<td>Analyze the level of satisfaction with respect to SHG and the overload of caregivers of people with Alzheimer's disease who participate in them. Descriptive analysis and participating observation.</td>
</tr>
<tr>
<td>Theurer, et al. (2014)</td>
<td>IX</td>
<td>Qualitative.</td>
<td>65 caregivers for people with dementia, or other disorders, such as heart disease, mental illness or musculoskeletal</td>
</tr>
</tbody>
</table>
### DISCUSSION

The analysis of the 12 selected articles has been accomplished to determine what SHGs´ characteristics are, the benefits for family caregivers, dependent people and the impact of these groups into the family´s health, in addition to the society or...
environment in which they develop.

**Mutual groups’ characteristics**

SHGs are based on the colleagues support, the group dynamics’ usage and the encouragement for participants to deal with their active life. Principally, they try to motivate participants to identify their strengths and improve their abilities to resolve problems.Besides, SHGs that offer an experience exchange, open discussion, information and advice achieve family caregivers’ requirements. \(^{(22, 26)}\)

Together with SHGs, they support families to be physical, mental and socially active, and promote knowledge to understand and manage the illness, which includes dimensions as helping patients and their caregivers to identify problems, their own abilities development and their self-efficiency to sort out problems and dominate their daily lives. By the other hand, they provide a sensation of having something in common with other caregivers, experiences validation and opportunities, that is, giving and receiving help. \(^{(29)}\)

Besides, another way of SHG exists, as McKechnie V et al \(^{(25)}\), indicate, in his study, that is, caregivers support mediated on a computer.

This type of SHG offers a range of possible advantages in comparison with other traditional support groups, including the accessibility and the possibility of adapting the individual needs. It is specifically focused on online mutual support to caregivers looking after people with dementia, and it is used to ask for advice, share information, participate in discussions and feel supported.

These online self-help group’s participants referred an improvement in the relationship’s quality with the people with dementia. There was no change in users’ depression or anxiety during the study, but interviewed people informed about experiences and positive forum’s usage, in comparison with the traditional SHG.

In general, a significant improvement is observed, in comfort, obtaining a possible anonymity, anxiety and embarrassing produced by direct contact with other people reduction and exchange of ideas and feelings, much bigger than in traditional SHG.

Nevertheless, these online groups need much more investigation and time to obtain the same benefits than the face-to-face ones, as for example, the opportunity to offer health education by sanitary professionals. \(^{(11)}\)

In conclusion, SHGs for caregivers must focus mainly in moderate care experiences discussion. They must integrate psych-educational elements, in particular, information about illness and available treatment, in order to know how to deal with patients’ situation. To increase help groups’ usage, all the family caregivers not only must been informed about the existence and accessibility to these offers, but also about the advantages to themselves. \(^{(29)}\)

**Family caregivers**

In Wei Y-S study, et al \(^{(30)}\), it is been observed that a SHG for the dependent family caregivers is an efficient intervention to promote the physical and psychological health of caregivers, as well as their social support, to provide that network of social
relationships that caregivers have been losing over time.

Wang L-Q, et al (29), affirm that participants in mutual support groups had significant improvements in the anxiety and quality of life levels. These discoveries support the efficiency of the mutual support groups to offer psychosocial support to family caregivers. Therefore, it must be converted into a habitual component of people with dementia caregivers within the nursing cares. Besides, the results indicate the need of nurses (as care agent) to evaluate caregivers’ health later on in the process of caring and to be conscious of their relation with emotional support. Results also highlight the importance of caregivers establishing an appropriate self-care system that provides emotional support and physical help.

Rodriguez-Sanchez E, et al (26), suggest that the implementation of a new psychological intervention improves mental health of family caregivers in charge, so, the fact that emotional discomfort doesn't increase and, even so it decreases significantly, can be consider as an important progress.

Laakkonen M-L, et al’s study (24), focused on disease management and saw how intervention helps accept the role of caregiver.

Finally, Candy B, et al (20), affirm that the interventions that directly support family or friends can help them cope with their role as a caregiver and improve their quality of life.

Family health

The article written by Hemamalini M, et al (23), talk about it. This article refers that SHGs have a deep impact into the family system, especially in its structure of roles and family functions. Family interventions’ main objectives are reduce the immediate negative stress effects that members of the family feel, as well as mobilizing their confrontational skills adaptively. Family caregivers informed that the intervention met their support needs, reducing some of their care demands, increasing their confidence and capacity to face the dependent family situation. Therefore, the study concludes that SHG is an effective nursing intervention, recommended to caregivers taking care of dependent people to strengthen the family system.

In conclusion, as Chien WY, et al (21), affirm SHGs’ participants indicated a significantly better improvement in family, in patient’s functioning and in social support for families. Therefore, mutual support groups are an effective community intervention for caregivers looking after dependent people and their families.

Dependent people

According to different studies, named previously, we can affirm that stress and anxiety reduction in caregivers, feelings exchange, adding the information about this care, that SHGs offer to caregivers, has a direct repercussion into the patients looked after by them, having more capacity to improve the dependent patients’ health status. Besides, a reduction in the number of relapses and symptoms is added, as well as a reduction in the sanitary services, thanks to the autonomy that caregivers gain by attending to SHGs. (20, 21, 30)

In other place, Theurer K, et al (28), describe groups that target caregivers along with the dependents themselves that revealed, after evaluating structured interviews and
observations, various topics, such as self-determination, giving and receiving help to other patients, discussions of their strengths and beliefs, and the expression of the challenges they face and how to better deal with them.

In addition, as if Secanilla E, et al (27), describe the decision of taking dependent people into a residential centre is taken in a reflexive and more distant way, without that many negative emotions, thanks to the attendance of caregivers to SHGs. In addition, the group helps to exchange useful information about sick people’s care and self-care matters, which allows the dependent patients’ improvement.

Society

One third of the articles (four of the twelve) are developed in an eastern society, three of them in China and one in India. Cultural differences between an eastern and a western society have an impact on extrapolating the results. For example, the study of Chien WT, et al (21) is carried out in China with male caregivers (2/3), against our environment where the caregiver role in women predominates. However, in Wang L-Q, et al’s (29), it was an advanced practice nurse who designed the protocol to guide the SHG process and the training of the facilitator and caregiver-moderator, based on evidence from the literature on family SHG in the western countries.

Limits and strengths

The above is one of the limitations of the study, although one of them is based on a western SHG. On the other hand, we only have included complete articles available, which implicates we may have not considered other important articles about this matter.

Three of the twelve selected articles are observational descriptive transversal and/or qualitative studies, which provides important and relevant information, but at the same time, they have a lower level of evidence than experimental studies or systematic revisions. Even so, in more than the half of them a high level of evidence methodology is used. In addition, this literature review has been conducted in pairs.

CONCLUSIONS

SHGs can help to reduce the physical and psychological discomfort of the caregivers, strengthening the family system. In addition, the attending of caregivers to SHGs provides benefits to dependent people, with a reduction in relapses. The SHGs’ characteristics are based on the support between their members. Besides, other types of SHGs have been found, as online groups, which offer other advantages, such as the accessibility. However, only a few studies exist in our environment. In order to get that, they must develop more studies in our environment, with high level of evidence, to be able to extrapolate the results to our population, promoting the SHG in our society.

REFERENCES


