

Nursing Intervention Program for Family Caregivers

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Abstract: Population aging leads to an increase of dependence, not only due to the loss of autonomy, but also associated with the increase of diseases. In this sense, family caregivers play a crucial role in the care of their love ones, to ensure the satisfaction of basic needs.

The aim of this study is to compile a set of nursing interventions in a structured program, providing emotional and instrumental support necessary to facilitate the transition to the role of family caregivers.

After the analysis of the scientific literature in the field of nursing interventions for caregivers in transition and their needs, we selected the most evidenced ones, which we submitted to the scrutiny of an expert group through the Delphi technique.

This work culminated in the 93 nursing interventions in the field of emotional support and instrumental needs, where all these interventions included achieved high reliability values.

This work presents a consensual and structured nursing intervention program, which intends to be a facilitator of the transition to the role of family caregiver, in order to meet the needs and provide better care to their dependents. Its application to different environments and contexts can lead to optimal results throughout the transition process.

Key words: nursing intervention, emotional support, instrumental support, Delphi technique

1. Introduction

The census of 2011 (INE, 2012) denoted a deterioration of an aging population, a result not only of the improvement of health care, which is reflected in increased life expectancy, but also of the increasing incidence of chronic and/or disabling diseases. The decrease in capacity, resulting from the natural aging process and the burden of chronic diseases leads to a loss of autonomy and the need of constant care (Sequeira, 2010).

The increasingly aged, dependent people have their own needs and, in many situations, besides the permanent care they need, they also need support in meeting the most basic activities of daily living in order to maintain a certain standard of quality of life. In this way, continuity of care is extremely important and, given the

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current socio-demographic change, it became important to establish a National Network for Continuing Care (Portugal, 2006). Continuing Care are “a set of sequential interventions or health and social support, due to the joint review, focusing on global recovery understood how the therapeutic process and social, active and continuous support, which aims to promote autonomy improving the functionality of the person in a situation of dependency, through rehabilitation, upgrading and family and social reintegration” (Portugal, 2006). This specific care comprises both a network of formal support and a network of informal support (Petronilho, 2007). The former brings together the services of the State, such as the National Health Service, and services organized by local authorities, such as nursing homes, day centers, home support services, among others. The latter relates mainly to family, but also to the surrounding support network, set up by neighbors and friends.

In this context, informal caregivers — be it family, friends or neighbors — play a key role to ensure the necessary continuity of care. It is usually a member of the family who is responsible for the organization, assistance and care of the dependent person (Marques, 2007), so it is understandable to designate them family caregivers.

Continuing care means that family caregivers face a new set of challenges in the transition to this new role, which usually leads to an increase in stress and burden in different levels. It is the decisive task of health professionals, particularly nurses, to make this transition as healthy as possible, in order to provide these families with the vital knowledge and skills to enable them to provide adequate care (Petronilho, 2007).

The task of caring for someone brings out a number of needs and challenges that must be overcome and to which caregivers must adapt in the best way without compromising their own self-care. This adaptation, which we designate the transition to the caregiver role, entails a number of consequences for the caregiver, such as wear, financial cost, emotional and physical burden and associated risks. Caregivers need to take care of themselves because providing care is a difficult and demanding task at different levels (Santos, 2008).

Nurses are often the primary caregivers of individuals and the families who experience this transition and play a key role in this process through the personalized support they provide (Meleis, 2010). Thus, it is the job of these health professionals to adequately prepare these caregivers for the performance of this role by transmitting a body of knowledge and ensuring that they acquire a set of skills and abilities and other support. In particular, economic, emotional and social (Petronilho, 2007).

Intervention programs formulated by researchers based on the scientific literature highlights such as the main needs of family caregivers have emerged as useful tools for working nurses. Our goal is to contextualize and structure a set of nursing interventions aimed to achieve a particular objective, namely satisfy the needs of family caregivers.

Thus, a program of nursing interventions directed at the family caregiver was developed with the aim to facilitate the transition and integration of this new role. This program is framed in a doctoral project of Science in Nursing and emerged from a review of current scientific evidence in the study area, with special emphasis on the contribution of two works previously developed, particularly in the area of emotional support by Cardoso (2011), and in the instrumental field, a doctoral program of a PhD student, Paulo Puga, not yet been defended, which resulted in an initial document. We have chosen to integrate these two domains because at an early stage of the transition family caregivers not only show a need to know “how to do” but also lack the emotional support, especially when this role becomes a long and continuous process.

In order to assess the initial document and include areas still uncovered, we resorted to the Delphi Technique. This corresponds to a set of iterative procedures applied to a group of experts, not in person, in order to obtain

consensus opinion on a matter for which there is insufficient or contradictory data (Fair, 2005). It is structured in such a way as to collect and synthesize knowledge of an expert group through a series of process questionnaires, together with feedback organized views.

The first known application of the Delphi technique dates back to 1948, when it was used to predict the results of various types of horse racing. Although promising at first, some defects detected in its application led to it being used again only in 1953, this time to collect the opinions of seven experts on nuclear war as part of the scheme of the defense of the USA (Dalkey, 1969, pp. 1–5).

In general, the Delphi procedures have five characteristics: “Anonymity; Iteration with feedback; Statistical treatment of the group responses; More efficient use of time of experts; Convergence in the distribution of responses” (Fair, 2005). Similarly, Dalkey (1969, p. 16) lists three essential characteristics, in particular anonymity (the answers are obtained through formal questionnaires), iteration and controlled feedback (performed by an exercise of systematic analysis in several rounds) and response statistical group (the group’s opinion is mirrored in the final round, through individual reviews). Furthermore, the author refers to a set of features that should be taken into consideration when opting for this procedure, namely the reduced effort that is required from the participants, since it does not involve costs, travel or meetings; the rapidity because only the time required to complete the questionnaire is requested; and the relative efficiency in obtaining the knowledge of experts and their consensus, as it allows to summarize a set of knowledge, opinions and suggestions about the topic under review, which is very productive and beneficial.

About this technique, Delbeq, Van Come and Gustafson (1984, pp. 113–114 cit. por Justo, 2005) consider that, if the group is homogenous, between ten to fifteen participants are sufficient in the expert group for the necessary convergence.

According to Press (1978, pp. 526–535 cit. por Justo, 2005) and regarding the establishment of the expert panel, the following criteria should be met: personally know the region, community or institution under study; perform the functions or develop activities related to the object of study; actively participate in the life of the community or institution; and have participated in earlier work on problems related to the material under study.

According to Dalkey (1969, p. 20), the overall result of the contacts may be summarized as follows: in the first round, a wide range of individual responses usually comes with large dispersion; with iteration, analysis of responses and feedback, the distribution of individual responses progressively narrows (convergence); usually the group response (defined as the average of the final individual responses) becomes more accurate and convergent. This last result is the most significant.

Although the Delphi technique may be a time consuming procedure, depending on the need for sending and receiving the questionnaire to obtain the desired consensus and though it may require a detailed and statistical analysis of the responses, it is a procedure that allows the obtainment of a desired convergence of responses from various experts on a certain topic or project, providing access to different levels of knowledge and keeping the anonymity of the actors. Furthermore, it has very low cost and may even be performed virtually at the most appropriate moment within the stipulated deadlines.

With the use of this technique, we intend to obtain consensus on nursing activities that allow a concerted intervention in the instrumental emotional domain. This work is intended as a detailed description of the use of the Delphi technique, the way it was implemented, its different stages and main results, up to the attainment of a consensual program, which will be further tested in the care process.

2. Methodology

The initial program was supported by the scientific evidence in the field of family caregivers, specifically at the level of needs demonstrated by these when providing care to the dependent family member. Thus, based on the studies mentioned above, an initial document was developed with a set of nursing interventions in the field of emotional and instrumental support, consisting of several activities directed towards the family caregiver, which were submitted to the analysis of a set of previously selected experts.

This nursing program was developed taking into account the parameters of classified nursing language, based on the International Classification for Nursing Practice (ICN, 2010), with the goal of formulating interventions and nursing activities directed to the family caregivers. All interventions included in this program are directed towards meeting the needs of family caregivers during the process of providing care to the person who has expressed some kind of dependence in self-care.

In order to constitute the expert group certain criteria had to be fulfilled, namely being a nurse and work and/or do research on the subject of family caregivers. A group of 11 nurses was formed, five of which work in primary health care, five teach in nursing/health schools and one works in a hospital. Six members of this group of experts do research on the subject of family caregivers.

We have chosen to contact various experts via e-mail, given its practicality and convenience. We set a period of 15 days for the experts to evaluate the document and respond, followed by a period of 7 days of analysis of the collected data, after which a new document was sent for further analysis. We repeated this procedure for a total of four rounds, until a substantially reduced program of nursing interventions was obtained that brought together the general consensus, expressed by statistical analysis of the data obtained with the determination of several parameters: the average, the median, the mode and the standard deviation.

Upon receipt of feedback from each expert, the analysis was performed in two ways: statistically and by analyzing the contents of the various suggestions and opinions related to each item analyzed. For each item of the program a Likert scale was elaborated, according to which the experts were asked to express their level of agreement with the given item (Cunha, 2007, p. 24). Each item of the program refers to a nursing activity directed towards the family caregiver, which is included in a particular nursing intervention, and can be evaluated on a scale of 1 to 5 according to the agreement and feasibility assessment in the context of care, level 1 being the lowest and 5 corresponding to the highest level of agreement regarding the evaluated activity.

Although the median and interquartile range are the most used statistical measures and the ones usually cited, averages, modes and frequency can also be determined (Fair, 2005). Milholand and colleagues (1973, pp. 1272–1275 cit. Justo, 2005) replaced the variance and standard deviation for the “group rate of trust” to measure the accuracy of the Delphi panel. To obtain this rate, each member ranked their responses applying the Likert scale, thus indicating the degree of confidence of their response; the mean score was taken as the level of confidence the panel.

Thus, with regard to the criteria used in the selection of activities, we considered different parameters, in particular the level of agreement (average), median and standard deviation. In the first and second round we eliminated those that had averaged less than 4, had a standard deviation greater than 1 and a median of less than 4.5. In the following rounds, we chose to reduce the sieve and, in this way, select the items that obtained a mean equal or higher than 4.5, also taking into account the median (greater than 4.5) and standard deviation (lower or higher than 1).

3. Analysis

Statistical analysis of data was done using Microsoft Office Excel. Regarding the suggestions and opinions of each expert, they not only led to the reformulation of some of the interventions and respective nursing activities, but also added new ones considered relevant, which were subsequently subjected to expert analysis.

Suggestions of this kind were progressively reduced as the document came into a final stage of greater convergence and consensus.

The different opinions of experts have led to a better intervention program, integrating the reality of each unit of domiciliary care and caregivers that receive this kind of support. In this way, with the implementation of this intervention program at home, we expect to meet the main needs of family caregivers, overcome their difficulties and thus ensure a better transition to this role.

4. Results

In the first round, 240 nursing activities were put to analysis of the expert group, relating to different nursing interventions on emotional support (Promoting the Role of Family Caregiver and Family Caregiver Stress / Risk of Family Caregiver Stress) and instrumental support (assistance in self-care: Bathing, Dressing and Undressing, Feeding, Using the toilet and Transferring). After statistical analysis, we eliminated 82 items that had both averaged less than 4 and had median and standard deviation values of less than 4.5 and greater than 1, respectively.

At this stage, due to the need for clarification and simplification of the program, the various suggestions and opinions of the participants were taken into account and their integration and the reformulation of various activities according to the classified language resulted in a new document with 90 items, which was once again put to the analysis of the expert group. In this second round, keeping the previously stipulated criteria, 13 items were eliminated, leaving a total of 77 items.

When the program was sent to the third evaluation by the expert group, a number of nursing activities in the field of technical aids for each self-care activity was added, as suggested by one of the group members, making a total of 105 items to be assessed. Apart from this change, and also by suggestion, we decided to divide the emotional support in different nursing interventions, including “Promoting the Role of Family Caregiver”, “Promoting Social Support”, “Promoting Family Involvement” and “Stress/Risk Family Caregiver Stress”, keeping interventions within the different aforementioned self-care activities. We chose to include items with a mean equal or greater than 4.5 in terms of level of agreement, all with a median value of 5 (which means a high convergence in appraisals) and deviation lower than 1 (19 nursing activities with standard deviation values of less than 0.5 and 1 with standard deviation value of 0).

Regarding the technical aids for the “Promoting Social Support” intervention, we chose to submit a new document with a total of 94 nursing activities to assessment in a final round. Of these, 5 had a mean of 4.4, but we decided to keep them because the median was 5 and the standard deviation between 0.6 and 0.8, which shows high consensus of opinion with regard to these activities.

In the end a program of activities was achieved with nursing interventions in the field of emotional support and instrumental support, which aims to be a facilitating factor in the transition to the role of family caregiver facing a dependent family member. All activities included obtained a value of median and mode of 5, 2 achieved a

standard deviation equal to 0 (in the field of the “Promoting the Role of the Family Caregiver” intervention) and 59 achieved a standard deviation value lower than 0.5. Two activities obtained maximum concordance (also in the field of the “Promoting the Role of the Family Caregiver” intervention), thereby resulting in a program with 93 nursing activities in the field of emotional and instrumental support.

Regarding the emotional support, it consists of the following nursing interventions:

- Promoting the Role of the Family Caregiver (7 activities);
- Promoting Social Support (9 activities);
- Promoting Family Involvement (6 activities);
- Prevent Family Caregiver Stress (18 activities).

With respect to the instrumental support, it consists of the following nursing interventions:

- Assist in Self-care: Hygiene (13 activities);
- Assist in Self-Care: Tidying oneself (5 activities);
- Assist in Self-Care: Dressing and Undressing (5 activities);
- Assist in Self-Care: Nourishment (9 activities);
- Assist in Self-Care: Urinary/Intestinal Elimination (9 activities);
- Assist in Self-Care: Mobility (14 activities).

The implementation of this program began in April 2013, having already been applied to 62 family caregivers of the Integrated Continuous Care Teams from three counties: Oliveira de Azeméis, São João da Madeira and Vale de Cambra, of ACES Entre Douro e Vouga II – Aveiro Norte.

Whenever new patients were referenced, their caregivers were integrated in the study (Transition to the Role of Family Caregivers — Intervention Program), after reading, clarification and signature of the informed consent.

From a total of 62 family caregivers, 6 of the patients cared for died, so that the intervention could not be analyzed at the end and one caregiver was physically disabled to adequately perform his role. An average of six home visits was carried out to each of the other family caregivers. The intervention program was completed and evaluated in 50 of those.

From the preliminary analysis of the data obtained, we may conclude that some interventions are absent from the program but were nonetheless performed on several occasions, which shows their importance in the context of transition and integration of the role of family caregiver. In this way we can enumerate the following interventions:

- Promotion of mobility exercises, rehabilitation or gait (in 30 cases);
- Teaching about pressure ulcers and how to prevent them (25 cases);
- Teaching about positioning in bed and how to perform it (20 cases);
- Promotion of fluid intake and skin hydration (14 cases);
- Teaching about the prevention of the risk of aspiration (5 cases).

In addition to these interventions, others were performed, though on a smaller number of occasions, including:

- Teaching about the structural changes and adjustments to make in the house, the bathroom and bedroom (4 cases);
- Teaching about the diet, both diabetic, and anticonstipating or hypoproteic (4 cases);
- Management of the therapeutic regimen, such as elucidation on drugs and their mode of administration (3 cases);

- Teaching about the prevention of the risk of infection (2 cases).

5. Discussion

The formulation of intervention programs emerges as a means to structure and contextualize certain work interventions, in order to standardize the way to perform our tasks.

These are being increasingly developed, duly substantiated in the existing scientific evidence and when their application in different environments and contexts translates into benefits for the health of users, they can become standards of action or guidelines, if proven their effectiveness. There are standards of action for different areas of nursing, especially in terms of technical procedures, such as those for the circulatory system (catheterization, cardiac monitoring, among others), the gastrointestinal system (nasogastric intubation, parenteral and enteral nutrition, ...), the integumentary system (treatment of wounds), skeletal and muscle system (positioning in bed), the respiratory system (aspiration of secretions), as well as standards of action for self-care activities.

This work comes as part of a doctoral program, of which the main objective is to develop a set of nursing interventions, properly contextualized and adapted to the professional reality and the field of continuing care. It is expected that this intervention program meets the main needs and difficulties experienced by family caregivers while providing care in different domains.

This intervention program comes forth in a very specific and subjective context, aspiring to achieve a reduction in the burden experienced by family caregivers by changing certain coping strategies adopted by them. In this way it hopes to achieve an improvement in the general health of these people who provide daily uninterrupted care and deal with constant challenges and difficulties and, on numerous occasions, with the degrading overall condition of their loved one who becomes increasingly more dependent. This is a stimulating challenge because all small gains and achievements translate into gains in the quality of life of the caregiver and the quality of care provided.

The results of its applicability and effectiveness will be subsequently determined, with the application of different scales, such as for the general health status (MOS Short Form Health Survey - Item 36 - version 2) (Ferreira, 2000), strategies of coping adopted (Brief Cope) (Ribeiro & Rodrigues, 2004) and the burden experienced by family caregivers (QUASCI — Assessment Questionnaire Informal Caregiver overload - short version) (Rodrigues, 2011). These assessment tools are being applied both in a first contact with family caregivers and in a last contact after the application of the program and completion of the intervention at the end of approximately 3 months. We expect to be able to monitor the variables which can then be translated into specific numbers and thus provide important information that will allow us to evaluate the efficacy of the intervention program.

The application of this group of structured nursing interventions has the strong support of the nurses of home care teams who provide care to dependent people and family caregivers and therefore potentiate the success expected at the end of the intervention.

When putting the intervention program in practice, it became evident that some aspects could be improved, in particular some interventions that being absent from this work proved to be important throughout the home visits because family caregivers expressed the need to acquire skills and knowledge. These same interventions were highlighted previously.

The promotion of both mobility or recovery exercises and the march of the dependent person proved to be

important in the sense that in a considerable number of situations the dependence of the person cared for comes from disability. The performance of simple repetitive mobility and walking exercises results in muscle toning, increased agility and flexibility and increased range of motion, which reflects in an increase in safety and independence.

In the case of family caregivers providing care to a bedridden relative, it is important to impart knowledge related to pressure ulcers and how these can be prevented. In the same sense, and associated with this condition, the teaching about positioning in bed also turned out to be very useful, in order to empower caregivers with the skills necessary to avoid the appearance of pressure ulcers that among other things are associated with high costs.

Finally, as we dealt mainly with elderly people, whose need for liquids is greater and sensation of thirst is lower, other interventions added to the intervention program were in the field of skin care and promotion of hydration, associated with the prevention of the risk of aspiration. It represents a decisive intervention with gains in the prevention of urinary and respiratory infections and skin problems.

In addition to these more frequent interventions, others were performed in order to provide the caregiver with the broadest knowledge. Thus, teaching about the need to undertake structural changes at home, the diet of the dependent relative according to his/her health problems, on the management of therapeutic regimen and the prevention of infection risk health problems.

This intervention program can and should be subject to new uses in professional practice, and if appropriate in other contexts as well, in order to improve it and thereby meet the needs of family caregivers. The replication of this work in the future should consider new suggestions and new interventions and pursue the improvement of this type of structured and contextualized intervention, allowing a certain standardization and normalization of nursing interventions for family caregivers in the domiciliary context.

6. Conclusion

This intervention program should now be applied in the context of nursing practice to caregivers of dependent relatives, in order to assess its applicability. Its main objective is to constitute itself as a simple, useful and concise working tool, enabling nurses to obtain positive results and thus help family caregivers in providing care.

It was obtained through the use of the Delphi technique which in a simple, convenient and almost cost-free way allowed not only to integrate the knowledge of several specialist nurses in the area of informal care, but also to get a program that converged to a widespread consensus around all interventions and nursing activities.

The application of this intervention program in a professional context revealed some aspects that could be analyzed, modified and improved, including the absence of certain interventions which have proved important in achieving the objectives of the study.

Thus, for subsequent applications of this intervention program, we suggest the addition of the interventions mentioned above, which should be the facilitating factors in the transition to the role of family caregiver and the proper performance of its functions.

In the final phase of the implementation of this intervention program, we can have a sense of meaning for family caregivers of the work undertaken and the results obtained. Although no concrete and objective data, we can say that the support provided to these caregivers, in the different areas that make up this working tool, provided significant support in the acquisition of skills and knowledge to better care. Equally important were the

moments of psychological and emotional support available at each home visit, with the establishment of a relationship of empathy with caregivers and attentive listening moments of the main difficulties and needs aroused by the care of a loved one.

The perception of these positive aspects stems from the completion of the documents and scales previously mentioned, for evaluation of the results obtained, but also the answer to questions that aim to determine the level of satisfaction of family caregivers. In this short questionnaire, it is intended that the family caregivers relate these positive and negative aspects of the intervention program, which are the main benefits obtained and the caregiver have any suggestions for the further improvement of the intervention performed.

The effectiveness of the intervention program will be subsequently analyzed, as soon as the intervention is completed in 60 Family Caregivers.

At the end of this work, we hope to get a tool to facilitate the important work done by nurses in home that can, somehow, guide specific interventions with family caregivers. The success of these interventions allows to obtain a better care, as well as minimize the harm to the caregiver's health and, consequently, to his family member.

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