

DEVELOPMENT OF AN INTERDISCIPLINARY INTERVENTION PLAN FOR THE INFORMAL CAREGIVER: A PATH OF CO-CONSTRUCTION OF RECOGNITION

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Abstract: The demographic revolution of the last twenty years has made informal caregivers the invisible backbone of the long-term care delivery system. The necessary and fair request for social and political recognition of this agent was finally granted in 2019, the year in which the status of informal caregiver was regulated in Portugal for those who provide care at home to dependent people, without receiving any remuneration. The present study aims to develop an interdisciplinary intervention plan for the informal caregiver. An action research study that included three stages: *focus* group to analyze needs, interventions and indicators; Delphi panel to validate the content of the intervention plan; *focus* group with experimental application of the intervention plan on a computer platform. It integrated 82 health and social professionals from the Azores archipelago and 9 experts from different professional areas. At the end of each stage, the proposed changes were incorporated. The intervention plan is organized according to the needs of the informal caregiver, having been grouped into 5 domains: training for the role; material and structural resource needs; social support needs; family support and individual management needs; informal caregiver health support needs. In each domain, types of specific needs were established, for which standardized interventions were defined to respond to them. The indicators that emerged were organized according to the principles of structure, process and result, allowing a transversal monitoring of the needs, interventions and results obtained for the informal caregiver. The elaboration of an interdisciplinary intervention plan for the informal caregiver was a challenge in its construction process. However, it allows a comprehensive assessment of the informal caregiver, in order to support an articulated response and directed to the professional area

that is best able to meet their needs.

Keywords: Family caregiver; care plan; interdisciplinary practice; Community-Based Participatory Research.

INTRODUCTION

Informal caregivers, given the current global epidemiological and demographic situation, are considered the “backbone” of long-term care (Krieger, Specht, Errens, Hagen, & Dorant, 2020).

The rapid and profound societal change with regard to the composition and organization of the family, the role of women and the aging of the population along with low birth rates, left us with a dilemma: Who will take care?

Several studies point out that the majority of the population wants to age at home, and the concept of *aging in place* is pointed out as an ideal of aging for many of us. The *aging in place concept* requires an interdisciplinary approach led by gerontology, valuing interventions at different scales: national, regional, community and individual (Fonseca, 2018). Aging at home and in the community must not be a resource, but rather the first option, due to the advantages of social inclusion and associated emotional reward.

But is this ideal possible to achieve, without the figure of the informal caregiver?

Despite being widely described as someone who provides care at home without receiving remuneration and is a figure that has accompanied the human being throughout its evolution, in Portugal it took a while to be recognized, and after being the subject of this recognition, there are heterogeneities, with significant and nuclear differences in terms of the concept itself.

In 2019, the legislation that regulates this role was published and those who already played it, finally saw their role recognized politically and publicly.

The legislation was published in mainland Portugal, the Madeira Archipelago and the Azores Archipelago, and it is in the context of the application of the Legal Regime for Supporting Informal Caregivers in the Autonomous Region of the Azores (RJACIRAA), that this study was developed.

Regional Legislative Decree No. 22/2019/A of 5 November supported the entire dynamics of implementing the response to the informal caregiver, which was structured in a way that it can be considered a community intervention project, which simultaneously involved the areas of health and social. As it is a project of this nature, which covered the 19 municipalities of the Region and involved different *players* from public and private entities, it made sense to us that from the beginning everyone was involved in the process of construction and development of the intervention plan, in its implementation and evaluation, even during the pilot phase.

In this sequence, this article intends to demonstrate a part of this construction project, not only of the instruments and supporting documents, but also of the development of a work philosophy and the implementation of social policies. Thus, the aim of this study focuses on developing an interdisciplinary intervention plan for the informal caregiver.

The initial proposal of the intervention plan that was presented to the *players* and which served as the basis for the work developed, was built by the researchers based on a scope review carried out for this purpose. The proposal included different domains, in which the possible health and social needs and interventions were listed, culminating in indicators associated with the implementation of the intervention plan.

FRAMEWORK

The implementation process of the Informal Caregiver Support Scheme of the Autonomous Region of the Azores was perceived as an opportunity to carry out action-research, since the research subject is inserted and directly experiences the research context. And this is a necessary factor for knowledge to be constructed and for the research subject to participate equally in the knowledge generation process (de Melo, Maia Filho, & Chaves, 2016).

In action research, participants are involved in the project construction process from the outset. In this case, the technicians who would constitute each of the 19 Support Offices for Informal Caregivers in the Azores were the first to play an active role in the co-construction of the domains and indicators that would form part of the evaluation and intervention with the caregiver- cared person.

As we consider that this support for the informal caregiver and the person cared for as a complex intervention, to help these people to live safely and independently, interventions can be designed to respond to individual needs through a personalized assessment (Beswick, et al., 2008). In this sense, evaluation instruments were developed based on the assumptions described by (CRAIG, CHADBORN, SANDS, TUOMAINEN, & GLADMAN, 2015):

1. Comprehensive and covering a wide range of domains;
2. person-centered;
3. That they are reliable and fit for the clinic;
4. Acceptable for clients and professionals;
5. Information for the social and health area;
6. That support health resource planning.

For this intervention to be comprehensive and integrated, it has to be carried out by a multidisciplinary team (Ambugo, et al., 2021) where the health and social systems are in fact integrated. The model adopted for this construction, in addition to being person-centered, with a biopsychosocial approach, focused on the needs of informal caregivers. The legislative document is organized according to the rights of informal caregivers duly recognized. However, for each of these rights there may (or may not be) a need for the informal caregiver.

There are few studies that observe the caregiver based on their needs, and those that focus on the consequences of the role of informal caregiver, arising from not seeing their needs answered are very common (Silva, Teixeira, Teixeira, & Freitas, 2013). Descriptions are invariably negative and symptom-centered. There are still few studies that focus on biopsychosocial aspects of care and its positive aspects (Gil, 2010).

From the studies that analyzed the needs of informal caregivers, we can see that they seek information and training to take better care, professional support and financial and legal support (Silva, Teixeira, Teixeira, & Freitas, 2013).

In order to measure the results of the responses to the needs of caregivers, the creation of monitoring indicators becomes increasingly urgent. Pedrosa et al (2021) express this concern when mentioning that there is a gap in the production of knowledge about indicators of burden, associated factors, repercussions and clinical manifestations associated with care. Likewise, it is urgent to know the determinants related to the caregiver's health in order to define support strategies and public health policies that integrate services and home care with quality, effectiveness and safety.

In order to define indicators associated

with the health and social area in the context of the informal caregiver, we can have as support the proposal of Donabedian (2003) following an organization of structure, process and result. The structure indicators reflect the organizational reality through the existence of human and material resources, flows and protocols, information systems, service production, population coverage and implemented actions. Process indicators comprise aspects related to knowledge, supervision and quality assurance of care or service delivery processes. The third option focuses on the results of the interventions carried out, which must be expressed in measures that show the changes/impact on the client.

With regard specifically to the informal caregiver, Rodrigues, Ferreira, & Ferré-Grau (2016) reinforce the importance of monitoring indicators such as burden and quality of life, in order to guide interventions, inhibiting the factors that potentiate the burden and reinforce those that enhance the quality of life.

In addition to the aforementioned indicators, others may be produced that allow the monitoring of results, constituting a fundamental means of measurement to demonstrate the changes associated with the implemented interventions.

Following the scope review carried out, transposing the theoretical assumptions presented here to the initial proposal of an intervention plan for the informal caregiver, the following domains were defined: *Care to be provided to the person; Training for the role; Material and structural resources; Social Support; Health Support; Family Support; Individual management.*

In the Care to be provided to the dependent person domain, the care needs of the dependent person were identified and, inherently, the care that the caregiver will

be responsible for. In the domain related to *Capacity building for the role*, the needs associated with knowledge and technical capacity to provide the care identified in the previous domain were defined. Interventions to respond to these needs focus on investment in theoretical and practical training.

With regard to *material and structural resources*, aspects related to support resources were integrated to facilitate the performance of the role as a caregiver, given the needs of the person cared for. This included the need for support devices, as well as the elimination of barriers at home.

Social support domain integrated needs associated with home support services: hygiene, food and cleaning. In addition, accessibility to health resources through transport for the person cared for, as well as existing and eligible financial support for the caregiver or person with dependency. Interventions aimed at these needs focused on direct contacts with social response entities or on speeding up the submission of requests for support.

Concerning the Caregiver's *health support domain*, needs oriented towards health surveillance, mental/emotional maladjustment of the informal caregiver and situations of physiological maladjustment were incorporated. For which intervention proposals emerged to promote individual surveillance of the caregiver, referral to primary health care or areas of medical specialty. As far as *Family Support is concerned*, this domain contemplates the needs related to direct support to the informal caregiver in the provision of care and in the management of domestic activities. The main intervention was aimed at identifying a secondary caregiver.

In the domain of *Individual Management*, the needs for daily/weekly organization of care delivery, household chores and self-care

activities, the organization and prioritization of care, culminating in the need for social and leisure activities, were highlighted.

The indicators were constructed in order to produce evidence on: the results of the identified needs (result indicators); monitoring of defined/carried out interventions (process indicators); the existence and use of support resources for the caregiver and for the person cared for - structure indicators.

METHODS

The study design follows the principles of action-research methodology, in its dynamic and collaborative way, where the cooperative, democratic and empowering commitment of the populations (Lewin, 1946) becomes the strategic tool to respond to the problem: elaboration of an intervention plan to the informal caregiver.

Due to the fact that it is an applied methodology and linked to the context, with researchers and participants involved in the action, the decision makers on the implementation process constitute themselves as the target population of the study, which resulted in a sample of 82 health professionals and in the social area that integrated the support offices for informal caregivers in the Autonomous region of the Azores - Portugal. These professionals are responsible for implementing the intervention plan in the field with caregivers.

Based on the results of a scope review whose objective was to identify the needs of informal caregivers of people with dependence, the researchers systematized the structuring areas for the elaboration of a proposal for an intervention plan. This proposal presented the needs of informal caregivers organized by domains, accompanied by the respective interventions that could respond to these needs.

Measurement indicators associated with the intervention plan were also defined.

Based on this preliminary work, 3 stages were developed until the final document was defined with the intervention plan for application in the field: Analysis of the plan proposal by the professionals; Delphi panel with experts for plan content validation; Experimental application of the intervention plan by the same professionals mentioned in the first stage. At each stage, changes and suggestions were introduced in order to be included in the next stage.

In the first stage, with the objective of carrying out an analysis of the needs, interventions and indicators, a meeting was held with 39 health and social professionals from 9 of the 19 support offices for informal caregivers. In multidisciplinary groups of 4 or 5 people, they were provided with a grid where for each item they would have to identify the needs and interventions that would remain, that could be removed, altered or new elements that they considered important to be incorporated.

The results of this process were analyzed by the researchers, and the initial proposal for the plan was restructured in order to be sent to the experts.

In the second stage, a Delphi panel was prepared that included 9 experts, with the objective of validating the content of the intervention plan and indicators. This technique is characterized by presenting a summary of the opinion of experts who constitute a panel of respondents and are geographically distant (Marques & de Freitas, 2018). The percentage needed to reach consensus can range from 50 to 80% (Vieira, 2008).

Experts who met the following criteria were selected: Professional experience in the area with a minimum of 5 years; professional activity developed with informal caregivers

or researchers in the area and at least one representative from each professional area that applies the instrument in the field.

The process of implementing this method followed the assumptions defined by Marques & de Freitas (2018), but with only two rounds: 1) the constitution of the group of experts; 2) construction of the first questionnaire; 3) prior contact with the experts for participation; 4) sending the first questionnaire electronically; 5) reception of responses; 6) qualitative and quantitative analysis of responses; 7) elaboration and sending of the second questionnaire with *feedback* related to the first one; 8) reception of responses to the second questionnaire and analysis; 9) end of the process and writing of the final plan (Figure 2).

In each round, the experts were asked to rate their agreement with each item on a *Lickert scale* from 1 to 4 in which: 1 – *Strongly Disagree*; 2 – *Disagree (mostly)*; 3 – *Agree (mostly)*; 4- *Totally agree*. Subsequently, the agreement was calculated between all of them.

After the Delphi panel, the third stage included the experimental use of the intervention plan by 43 health and social professionals from the remaining 10 caregiver support offices. The plan was introduced on a computer platform, in order to test this functionality, and the professionals filled it out supported by a fictitious case of an informal caregiver. This way, it was possible to test the applicability of the content of the intervention plan and the need to make some adjustments in view of its integration into the platform.

Data analysis was essentially based on content analysis of the observations of professionals and experts, however, in the Delphi panel, a quantitative analysis was carried out regarding the agreement of the experts regarding each item evaluated.

All ethical precepts were safeguarded throughout the process, respecting the

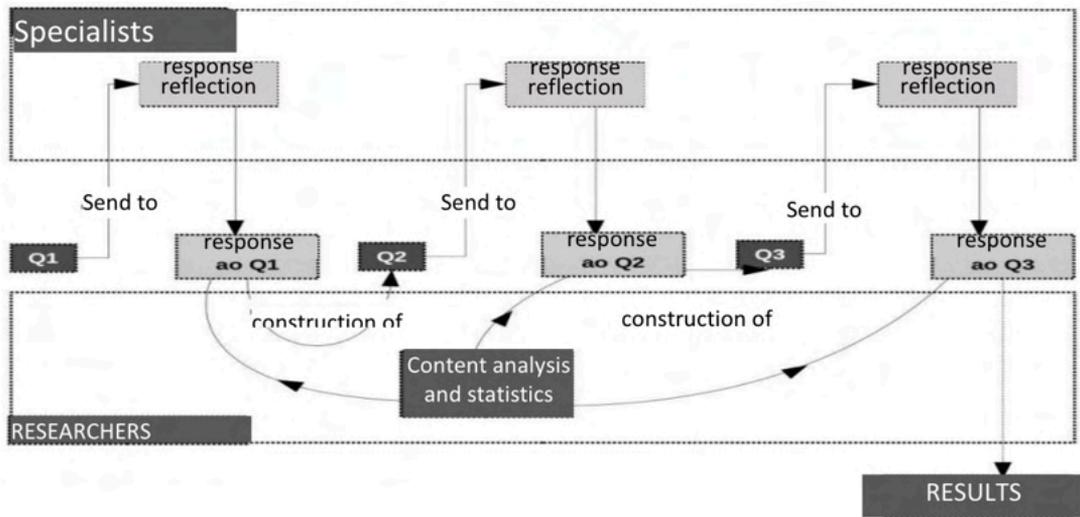


Figure 1: Generic schema of implementation of the Delphi method with three rounds ((Marques & de Freitas, 2018).

Declaration of Helsinki, and free and informed consent was applied to all professionals involved. Authorization was also obtained from the Regional Government to carry out this project.

RESULTS

The results of this study are in line with the work developed at each stage with the different actors in the process, until the implementation of the intervention plan. Therefore, the data presented are structured according to each stage.

In the first stage, of the 39 professionals, 33% were nurses and social workers with the same percentage, 10.5% were doctors and psychologists, 7.8% sociologists and 5.2 occupational therapists.

From the analysis carried out on the initial document, suggestions were made to increase, change or eliminate components in all domains.

In the domain *Care to be provided to the person with dependence*, it was suggested to add new interventions related to physical and cognitive stimulation as well as monitoring in health surveillance.

In the *Training for the role*, needs associated with social and health responses were integrated, as well as the support of other caregivers.

Material and structural resources domain, training interventions were included regarding equipment and advice on bureaucratic processes for applying for social support.

Regarding the *Social Support domain*, several social responses were identified that support the provision of care and household chores. In terms of the *Health support* domain, the importance of having a referral intervention for home health care was reinforced.

In the indicators related to the plan, suggestions were given for the incorporation of some process indicators, in order to give visibility to the intervention of professionals. Result indicators aimed at the gains of the informal caregiver and the person cared for were also suggested. Indicators resulting from the measurement of burden, quality of life and socio-family situation

were also incorporated.

The group of experts that integrated the Delphi method in the second part of the study was composed of: 2 nurses, 2 occupational therapists, 2 psychologists, 1 doctor, 1 sociologist.

In the first round, the agreement obtained between experts, both for the needs and for the interventions included in each domain of the plan, ranged from 67% to 100%. In terms of indicators, there were some areas with less agreement, so values between 56% and 88.9% were obtained. From a structural organization perspective, it was suggested that the domain of *Care to be provided by the informal caregiver* be integrated into a separate section of the intervention plan itself, since it is a need-inducing support/diagnosis information.

In terms of needs, the experts indicated suggestions for changes in the areas: *Capacity building for the role*, *Human and material resources* and *Health support*. In the first two, terminology changes were suggested and in the last one, other needs were incorporated.

In the analysis of interventions, adjustments were suggested in the domains: *Social support* and *Family support* and *Individual management*. The suggestions indicated were aimed at clarifying the wording of some interventions, as it was concluded that the terminology used induced different types of interpretation.

With regard to indicators, the difficulty in establishing root indicators for an intervention plan of this nature aimed at the informal caregiver was notorious. Thus, the comments that accompanied the evaluations carried out were in the sense of some doubts about the feasibility of the proposed indicators.

After carrying out the aforementioned adjustments and a subsequent second round of consultation, we had a response rate of 88%, as one of the experts did not respond.

The results of the second round showed a percentage of agreement of 100% in the needs and interventions and 88% in the indicators, which showed security in the changes made.

In the last stage, during the experimental application of the intervention plan on a computer platform, of the 43 professionals involved, 42% were nurses, 37.2% were social workers, 11.6% were doctors, 4.6% were psychologists and occupational therapists.

During the transposition of the intervention plan to the computer platform (third stage), so that the calculation of the indicators was feasible, it was necessary to make adjustments, both in the way of assessing the needs and in the designation of certain interventions. After the experimental use by professionals in the health and social areas, it was possible to assess the need to incorporate some alternatives both in the identification of needs and in the definition of interventions. Considering that the application of the plan was carried out in a group perspective in a given context, the suggestions were recorded in a free text document and subsequently analyzed by the team. The contributions received were aimed at making small adjustments to the response options for the needs, as well as identifying some interventions that had not been constituted as an option for selection.

The path taken and the adjustments established throughout the process culminated in the needs and associated interventions that are detailed in table 1, and in the indicators that allow monitoring the intervention plan exposed in table 2.

DISCUSSION

The concept of «needs», namely «needs for care», has been explored by authors of the most diverse theoretical orientations for decades. Considering that “need” is a significant problem in the social or health

Dimension	Need	interventions
Training for Paper	support in food	<ul style="list-style-type: none"> • Teaching • Training • group training • Physical/virtual information support • Psychoeducational group information
	support mobility	
	Support in hygiene care	
	support in the elimination	
	Support dressing/undressing	
	Support in placements	
	Support in transfers	
	Support medication management	
	Promote participation in socialization activities	
	Follow up in health surveillance (consultations/exams/vaccination)	
	promote autonomy	
<i>Material Resources: Need for assistive devices to provide care</i>	comfort and positioning	<ul style="list-style-type: none"> • Contact entity that provides resource • Inform about entities that sell/lease resources • Inform about the Support Product Assignment System (SAPA) • Teachings/information on the use of resources • Training on using the resource
	Hygiene and personal care	
	mobility and transfer	
	Food and household activities	
	Information and communication technologies	
<i>Structural Resources Elimination of architectural barriers in the home</i>	room accessibility	<ul style="list-style-type: none"> • Forward to another entity to support the elimination of the barrier Support for resolution at own expense
	Accessibility to the kitchen	
	Accessibility to sanitary facilities	
	Accessibility to external areas	
	Accessibility to another division	
<i>Social Support</i>	Home Support Service: Hygiene Care	<ul style="list-style-type: none"> • Inform about support entity • Contact the entity that provides support • Support the submission of a support request
	Home Support Service: food	
	Home Support Service: cleaning	
	Home Support Service: Clothes treatment	
	Home Support Service: Support for Informal Caregivers	
	Psychological Support	
	Transport for the person cared for	
	day center	
	Social supplement for seniors	
	Add-on by dependency	
	Third person assistance allowance	
	Social Benefit for Inclusion	
	Financial support to the caregiver	
	caregiver rest	
	Neighborhood/family network	
	Volunteering	
tele-assistance		

<i>Family and Individual Management Support</i>	Need for support in providing care	<ul style="list-style-type: none"> • Support in prioritizing care • Define a daily/weekly caregiver organization plan • Support in the redefinition of roles • Encourage participation in activities of personal interest
	Difficulty in organizing care	
	Difficulty managing household activities	
	Difficulty setting time for yourself	
	Need to redefine family roles	
	Need to participate in activities of personal interest	
<i>Informal caregiver health support</i>	Health promotion: introduces healthy lifestyles	<ul style="list-style-type: none"> • Forward to specialized follow-up • Diligence resources from the informal support network • Diligence Caregiver Scholarship
	Health surveillance: adhere to monitoring	<ul style="list-style-type: none"> • Forward to specialized follow-up • arrange transport • Diligence resources from the informal support network • Diligence Caregiver Scholarship
	Health problems	<ul style="list-style-type: none"> • Forward to specialized follow-up • Diligence resources from the informal support network • Diligence Caregiver Scholarship • Diligent formal support network resources

Table 1. Interdisciplinary intervention plan for the informal caregiver.

STRUCTURE INDICATORS
Percentage of CI with available resources compared to those required
Percentage of CI with architectural barriers intervened compared to the ones marked
Percentage of CI with social responses granted compared to those requested
Percentage of CI with identified secondary caregivers
PROCESS INDICATORS
Percentage of CI with identified training needs.
Percentage of CI that does not use the granted resources
Average waiting time for support resources
Average waiting time for social responses
Average hours used by CI for time off system
Percentage of CI in need of support to provide care and manage daily activities
Percentage of CI with referrals for specialized follow-up
RESULT INDICATORS
Percentage of CI that improved at least one level of mastery in each type of care
Percentage of CI with healthy lifestyle habits
IC's quality of life
IC overload
Socio-family situation

Table 2. Indicators associated with the intervention plan for the informal caregiver (CI).

area, for which there are potential solutions or interventions (GONÇALVES-PEREIRA & al, 2007), in the context of the informal caregiver this concept fits perfectly, since all those listed in this intervention plan are transversal to these two areas. As mentioned above, these interventions must be considered in an interdisciplinary team, and the answer must be given by the most competent professional for this purpose.

The caregiver's training must meet the basic human needs of the person being cared for, (Martins,, Faria, & Ribeiro, 2021) as it will be based on these needs that the caregiver will have to feel capable of providing adequate care.

Considering the integrated needs in the field of *Training for the role*, the interventions presented for the interdisciplinary team's response focus on the provision of theoretical and practical information in an individual or group context, through physical or virtual tools. As mentioned (Jiang, , Sereika, Lingler, Tamres, & Erlen, 2018), all these interventions associated with the literacy of the informal caregiver must be adapted according to the specific needs of each person being cared for, taking into account the cognitive and physical capacity and the resources available to the caregiver.

The performance of informal caregivers will be all the more effective the better their abilities are to ensure the provision of care, as well as the availability of material support resources so that they can complement their action. The same thought process must be established if there are architectural barriers in the home if the action of the caregiver and the autonomy of the person cared for are compromised.

Thus, if health professionals need to be awake to identify the material resources to support the provision of care or the barriers that have a direct implication in their action, it

is equally important to liaise with professionals in the social area so that the responses inside and outside the family context to make these resources available or in the referral of the caregiver to find solutions to solve the problem (Hengelaar , Wittenberg , & van Hartingsveldt M., 2017).

Social support is essential in supporting informal caregivers. The community where the caregiver and the person being cared for becomes the support structure external to the family, where the social responses of proximity are usually installed that complement the care provided at home (José, 2012).

Social support can be provided financially or in the form of physical support resources. When the informal caregiver is not aware of the existing resources in this support network, the interventions of professionals must be directed to the information regarding their existence and to direct contacts, in case the caregiver or support is incapable of requesting support.

Individual management, family management and the management of priorities between the provision of care and household chores are a challenge and one of the main needs of informal caregivers (Rodrigues , Ferré-Grau C, & Ferreira, 2015). The caregiver is confronted with this reality, whether he suddenly becomes a caregiver or performs this role over several years, as there is a common denominator between both situations, which is to focus on the needs of the person being cared for and not focus on yes (Pereira, 2013).

Faced with this problem, together with the informal caregiver, a prioritization of care must be established, supported by a daily or weekly organization of activities, in a way that guarantees time and space for the caregiver himself. Within the family network, roles can be redefined and a secondary caregiver can be assigned in order to balance functions and

work overload (Melo, Rua, & Santos, 2014).

Following the above, protecting the health of informal caregivers must be an imperative and a concern of professionals who interact with them. This desideratum must be worked on from the moment he becomes a caregiver and accompanied throughout the process (Rodrigues, Ferré-Grau C, & Ferreira, 2015), in order to avoid that, in addition to the person cared for, there are two people who are the target of care.

For this reason, it is important to ensure health surveillance by the informal caregiver, referral to areas of expertise when changes are identified that can potentiate health deviations, as well as the availability of support resources from the family or social network to prevent situations overload and that enhance their quality of life.

CONCLUSION

With the involvement of an interdisciplinary team, an intervention plan was built for the informal caregiver, which initially was based on seven domains of needs and was systematized in five: *Training for the role; Material and structural resource needs; Social support needs; Family support and individual management needs; Informal caregiver health support needs.*

The specific needs and interventions proposed for each domain allow them to be adapted to the individual reality of each caregiver, so that any of the professionals in the team has the possibility to identify them and intervene based on their area of competence, or refer them to the professional who is most qualified to answer you.

The defined indicators are instruments that guide practices and the results achieved with them, so they allow monitoring of both, making it possible to systematically assess which aspects must be maintained, changed or removed.

Throughout this co-construction process, disparities and difficulties in “alignment” are common in this project typology, where action research is used and where the team that will implement the project is multidisciplinary.

If, on the one hand, it was possible to observe some differences in the conceptualization of need and indicator among the participants, it was also possible to understand that they did not start from the same theoretical basis of reference on which we based our assumptions for the initial plan presented, which was the centered approach in the person. This approach privileges process indicators and result indicators.

So when we have groups of participants who do not share frames of reference and who, although this is not desirable, work separately in their day-to-day lives, it is necessary to build a common language that is inclusive and global so that everyone understands it and nobody feel like you're not part of it.

This construction was a very important part of the process of developing the intervention plan for the informal caregiver and the defined indicators.

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