

EVALUATION OF THE IMPLEMENTATION OF THE FAMILY CAREGIVER PROMOTING MONITORING MODEL

Avaliação da implementação do modelo de acompanhamento aos familiares cuidadores

Evaluación de la implementación del modelo de seguimiento a cuidadores familiares

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ABSTRACT

Background: the support provided by nurses to family caregivers in the transition to the role causes challenges in preparing of mastery in care and in the documental process. Information systems should be an essential tool in the decision-making of the professionals, allowing the continuity and quality of care provided and the achievement of health gains. **Objective:** evaluate the changes in the nurse documentation regarding family caregivers after the intervention. **Methodology:** quasi-experimental study before and after intervention, using the consultation of documentation carried out by nurses in their activities with family caregivers. **Results:** the focus of the Caregiver Role reveals a significant increase in the final phase, as well as the diagnostic statements involving the Caregiver Role. The most documented interventions remain those of the Assess an Teach type, but this increase is not significant. Interventions of the Incentive type are marginally significant and those of the Train and Instruct type show a statistically significant decrease. **Conclusion:** the study revealed improvements in the Caregiver Role areas, however it still reveals areas of caregiver underreporting, with need for a higher investment.

Keywords: nursing; family nursing; family caregiver; information systems

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França, D., Festa, A., Santos, P., Peixoto, M.J., & Araújo, M.F. (2023). Avaliação da implementação do modelo de acompanhamento aos familiares cuidadores. *Revista de Investigação & Inovação em Saúde*, 6(2), 39-50. <https://doi:10.37914/riis.v6i2.264>

Recebido para publicação: 25/01/2022
Aceite para publicação: 12/07/2023

RESUMO

Enquadramento: o apoio prestado pelos enfermeiros aos familiares cuidadores na transição para o papel, acarreta desafios na preparação para a mestria no cuidar e no processo documental. Os sistemas de informação devem ser uma ferramenta imprescindível na tomada de decisão destes profissionais, permitindo a continuidade e qualidade dos cuidados prestados e a obtenção de ganhos em saúde. **Objetivo:** avaliar as mudanças na documentação dos enfermeiros relativa aos familiares cuidadores, após intervenção. **Metodologia:** estudo quase-experimental antes e após intervenção, com recurso à consulta da documentação realizada pelos enfermeiros nas suas atividades com os familiares cuidadores. **Resultados:** os focos do *Papel de Prestador de cuidados* revelam aumento significativo na fase final, bem como os enunciados de diagnóstico que envolvem o Papel de Prestador de Cuidados. As intervenções mais documentadas mantem-se as do tipo Avaliar e Ensinar, mas este aumento não é significativo. As intervenções do tipo Incentivar revelam-se marginalmente significativas e as do tipo Treinar e Instruir apresentam uma diminuição estatisticamente significativa. **Conclusão:** o estudo revelou melhorias nas áreas do Papel de Prestador de cuidados, no entanto ainda revela áreas de subnotificação do cuidador, com necessidade de um investimento superior.

Palavras-chave: enfermagem; enfermagem de família; familiar cuidador; sistemas de informação

RESUMEN

Marco contextual: el apoyo brindado por enfermeiros a los cuidadores familiares en la transición al rol provoca desafíos en la preparación para el dominio en el cuidado y en el proceso documental. Los sistemas de información deben ser una herramienta fundamental en la toma de decisiones de estos profesionales, permitiendo la continuidad y calidad de la atención brindada y la consecución de ganancias en la salud. **Objetivo:** evaluar los cambios en la documentación de las enfermeras con respecto a los cuidadores familiares después de la intervención. **Metodología:** estudio cuasi experimental antes y después de la intervención, utilizando la consulta de documentación realizada por enfermeros en sus actividades con cuidadores familiares. **Resultados:** el enfoque del Rol del Cuidador revela un aumento significativo en su fase final, así como los enunciados diagnósticos que involucran el Rol del Cuidador. Las intervenciones más documentadas siguen siendo las del tipo Evaluar y Enseñar, pero este incremento no es significativo. Las intervenciones del tipo Incentivo son marginalmente significativas y los del tipo Capacitar e Instruir muestran una disminución estadísticamente significativa. **Conclusión:** el estudio reveló mejoras en las áreas del Rol del Cuidador, sin embargo aún revela áreas de sub registro del cuidador, con necesidad de mayor inversión.

Palabras clave: enfermería; enfermería familiar; cuidador familiar; sistemas de información

INTRODUCTION

In the organisation of health services, nurses are in a privileged position to be facilitators in the transition processes experienced by people with dependency (PD) and family caregivers (FC) (Meleis, 2010). To this end, clinical practice must be based on solid theoretical foundations that support decision-making.

In their professional activity, it is important for nurses to ensure and promote the continuity and quality of care by documenting their practice in nursing information systems, an essential process for ensuring professional valorisation and visibility (Ribeiro et al., 2018).

Analysing the documentation allows us to indirectly understand the monitoring model used in the praxis. As identified by França et al. (2022a), the registers in the information systems refer to an approach focussed essentially on the dependent person and the scarce information on the FC's data shows a view of the FC as a care partner rather than as a client. The matrix built with the nursing team is intended to be a guiding instrument for care conception that meets the actual needs of the FC, in the exercise of their role as client (França et al., 2022b).

In this setting of redefining nurses' practice in their approach to family caregivers, the aim of this research was to assess the changes in nurses' documentation of family caregivers after intervention. Nurses' documentation reflects their conception of FC care.

CONTEXT / THEORETICAL BACKGROUND

In today's societies, there are new challenges for health systems, professionals and families associated with the increase in longevity (Jakovljevic et al., 2021). These phenomena have led to a high financial impact on the health service, which, within the framework of

current and more restrictive policies aimed at the sustainability of health services, has led to the increasing of early hospital discharges and more responsibility for the continuity of care in the home context being placed on families (Petronilho et al., 2017).

The structural and functional changes that have taken place in families have revealed a growing shortage of people to take on the role of carer (Jakovljevic et al., 2021). However, it is still the family that PD's look to for their needs.

In order to fulfil the role of FC, it is necessary to acquire knowledge and skills (Meleis, 2010). However, evidence has shown that carers do not feel adequately prepared to meet the demands of this new role (Hagedoorn et al., 2020), increasingly performing tasks that were previously only carried out by health professionals (Ullgren et al., 2018). The increased demands, combined with a lack of knowledge and adequate preparation, leads to feelings of uncertainty that are part of a scenario of excessive workload resulting in overload, with negative effects on the FC's well-being (Frederick, 2018).

As part of a multidisciplinary team, nurses must take an active role in implementing nursing therapies that facilitate this transitional process (Meleis, 2010), using the Nursing process. This consists of five phases that develop in a reflective cycle: assessment, diagnosis, planning, implementation and evaluation (Huitzi-Egilegor, et al., 2018). It is identified as a structure that makes it possible to record the autonomous and collaborative activity of nurses, self-affirming the profession, leading to an improvement in the quality of care (Huitzi-Egilegor et al., 2018; Queirós et al., 2021), while nursing documentation leads to greater visibility of the professional activity (Queirós et al., 2021).

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In Portugal, the computer system used in primary healthcare (SCLínico) combines the support system for Medical practice and the support system for Nursing practice, allowing the standardisation of information and improving the performance of the multidisciplinary team (Serviços Partilhados do Ministério da Saúde, 2018).

Literature has shown that the use of information systems brings benefits to nursing practice (Tasew et al., 2019). However, professionals report difficulties in their implementation, pointing to a lack of knowledge and preparation (Huitzi-Egilegor et al., 2018, Silva et al., 2016), a shortage of material and human resources (Huitzi-Egilegor et al., 2018), resistance to change (Huitzi-Egilegor et al., 2018), shortage of time (Reis et al., 2016), the need for continuous training and the lack of technical support (Silva et al., 2016). These difficulties constitute barriers to nurses' adoption of the documentary procedure for the different stages of the Nursing process, with a consequent impact on the non-visibility of indicators that reflect the health gains that are sensitive to Nursing care.

Considering the above and taking into account the basic principles of Participatory Action Research in Health (PARH), which presupposes a reflective approach, leading to a constant questioning and necessary rethinking as it develops, including the involvement of people as active elements throughout the process in all its different phases (Brito & Mendes, 2018; Wright et al., 2018), the use of this approach was fundamental for working on this subject and for achieving changes in the clinical practice and in the professionals themselves.

METHODOLOGY

The article being presented here is a quasi-experimental study before and after intervention. It reflects the last stage of a more comprehensive study conducted on PARH assumptions.

The results of the study in the diagnostic phase pointed to a care model focused on the FC as a substitute for formal carers, where the most prevalent interventions were in the area of know-how. Records from the FC perspective as clients were almost absent (França, et al., 2022a).

In an effort to incorporate the evidence that allows nurses to become more meaningful to FC's in the different stages of transition to the role, a guiding matrix for the conception of care was co-constructed with the two nursing teams (n=16), and its consequent transposition into nursing information systems. The two units were selected for convenience due to their location and easy accessibility.

This article reflects the post-intervention evaluation stage, taking as its information source the nurses' records in the six months following the intervention. Both in the Initial Assessment (IA) phase and in the Final Assessment (FA) or post-intervention phase, the source of information was the family nurse's documentation and the data collection was centred on the two nursing focus areas integrated in the SCLínico: Caregiver Role and Caregiver Stress.

The clinical files used to collect the information were identified from the global list of people with dependency held by all the nurses in both family health units. The IA corresponded to the extraction of data from SCLínico regarding the six months prior to the research start and the FA was conducted six months after the intervention implementation. Inclusion

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criteria were: being enrolled in the dependents' programme and having FC. Exclusion criteria were being dependent but institutionalised, having been referred to an integrated continuing care team, or

living outside the geographical area of the family health unit. A total of 163 cases were analysed in the IA and 323 cases were analysed in the FA based on the same criteria (Fig.1).

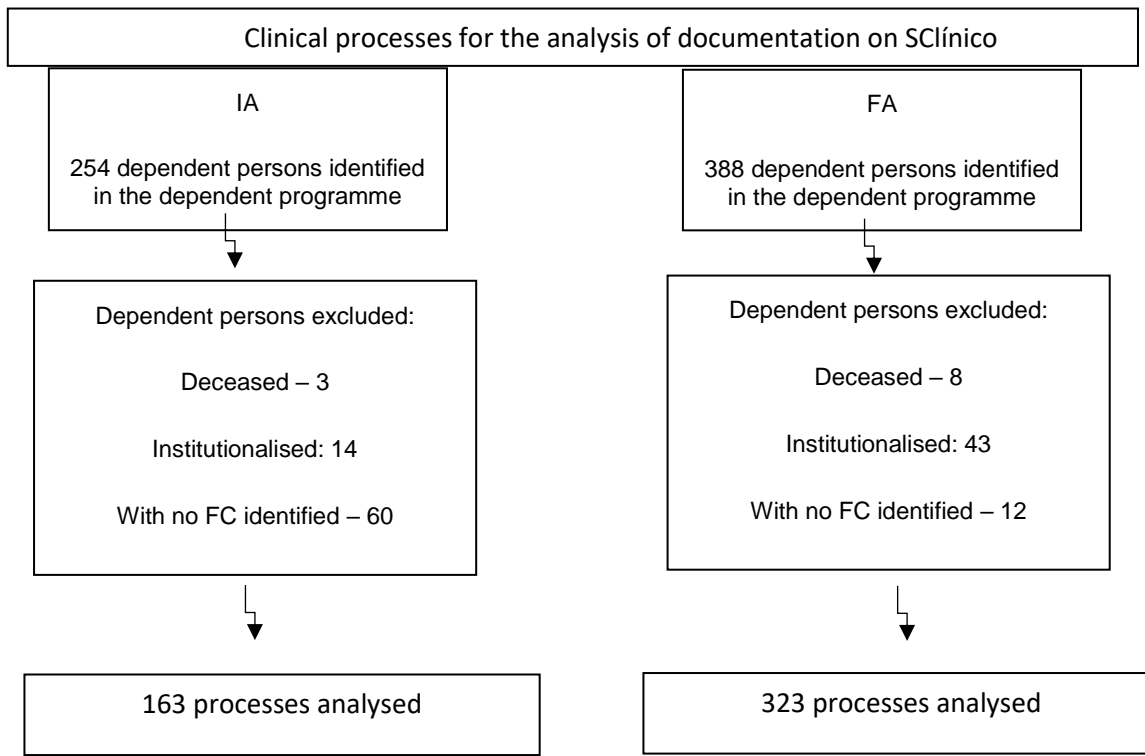


Figure 1 - Selection of clinical processes for data extraction

Once the 163 processes were selected, the data was collected. In compliance with the guidelines given by the ethics committee, the collection was carried out by two contact nurses, one from each unit. To extract the information from each clinical file, a document was previously prepared to systematise the data. Each contact anonymously sent this information to the main researcher. The same procedure was followed for the FA.

Descriptive statistics were used to analyse the data, in particular the frequency measures (absolute and relative). In the analytical statistics, the association between nominal variables was analysed using the non-parametric Chi-squared (χ^2) test, comparing the frequencies observed at the two evaluation moments.

The *t-student test* was used to compare means between independent samples (IA and FA).

Data analysis was conducted using SPSS version 27. The significance level was defined as $p < 0.05$. The study began after a favourable opinion from the National Data Protection Commission (authorisation 10744/2016) and the Health Ethics Committee (authorisation 105/2016).

RESULTS

From the 163 IA processes analysed, one caregiver was identified (0.6%), and 12 (3.7%) caregivers were reported in the 323 FA processes. Concerning the focuses Caregiver Role and Caregiver Stress, two distinct types of documentation were found. One

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documentation type addressed the focus statement, with no other records associated with the different stages of the nursing process; the other enabled to identify records on the subsequent stages of the nursing process (diagnostic activities, diagnosis and interventions), in addition to the focuses statements.

Table 1 shows the results of the processes with an active recording of the foci without other associated records. Results show an exponential increase in the focus Care Provider Role in the FA [110 (34.4%)], compared to the IA [20 (13.3%)], with a statistical significance of ($p=0.001$).

Table 1

Processes with records with a focus on the Role and Stress of the Caregiver

	Inicial Assessment		Final Assessment		χ^2
	N (163)	%	N (323)	%	
Caregiver Role	20	13,3	110	34,4	$\chi^2 = 26,24; gl = 1; p < 0,001$
Caregiver Stress	28	17,2	56	17,3	$\chi^2 = 0,002; gl = 1; p = 1,000$

From the processes with an active recording of the foci and records in other phases of the nursing process, 19 foci were identified in the IA and 20 in the FA. In both assessment moments, two focuses (Caregiver Role and Caregiver Stress) were identified. The remaining foci were related to the dependent person, being that

some were listed in both assessments while others were cited only in one of the assessments.

Concerning the focuses Caregiver Role and Caregiver Stress and the records related to the other stages of the nursing process (Table 2), data showed a significant increase of records on the focus Caregiver Role in the final assessment ($p=0.002$).

Table 2

Processes with records with a focus on the Role and Stress of the Caregiver

Focus	Inicial Assessment		Final Assessment		χ^2
	N (163)	%	N (323)	%	
Caregiver Role	5	3,1	35	10,8	$\chi^2 = 8,656; gl = 1; p = 0,002$
Caregiver Stress	6	3,7	9	2,8	$\chi^2 = 0,290; gl = 1; p = 0,387$

In the focuses listed in the PD, some were only recorded in one of the assessments while others were recorded in both assessments. Also, some focuses included a single record in both phases. According to these results, we decided to group the focuses into the following dimensions: Self-care, Management of signs and symptoms, Management of therapeutic regimen and Adherence to vaccination (Table 3).

The creation of these dimensions was necessary to make it possible to use some statistical tests. While comparing both assessment periods, an increase of records was observed, except for Management of therapeutic regimen, which showed a slight decrease, although with no statistically significant differences.

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Table 3

Focus of the Dependent Person with records addressing the Caregiver

Focus	Inicial Assessment		Final Assessment		<i>t (p)</i>
	N (163)	%	N (323)	%	
Self-care	8	4,9	23	7,1	<i>t (484) = 0,534; p = 0,594</i>
Self-feeding	4	2,5	-	-	-----
Walking	1	0,6	3	0,9	-----
Walking using device	-	-	1	0,3	-----
Self-transferring	-	-	1	0,3	-----
Personal Hygiene	1	0,6	1	0,3	-----
Autonomy in self-care	1	0,6	12	3,7	-----
Self-vigilance	1	0,6	2	0,6	-----
Management of signs and symptoms	18	10,9	41	12,6	<i>t (484) = 0,354; p = 0,723</i>
Aspiration	2	1,2	1	0,3	
Confusion	1	0,6	-	-	
Dehydration	1	0,6	-	-	
Dyspnoea	1	0,6	-	-	
Overweight	-	-	2	0,6	
Hypertension	-	-	1	0,3	
Infection	-	-	1	0,3	
Maceration	2	1,2	4	1,2	
Energy metabolism	1	0,6	2	0,6	
Orientation	1	0,6	-	-	
Fall	5	3,1	12	3,7	
Sleep	1	0,6	-	-	
Ulcer	-	-	9	2,8	
Pressure ulcer	3	1,8	9	2,8	
Management of the therapeutic regimen	14	8,6	18	5,6	<i>t (484) = 1,225; p = 0,221</i>
Overall management of the therapeutic regimen	13	8,0%	15	4,6%	
Self-administration of drugs	1	0,6%	3	0,9%	
Adherence to vaccination	-	-	3	0,9	-----

According to Table 4, the diagnostic domains (Knowledge, Ability, Potential, Caregiver Role, Stress, and Pressure ulcer) were identified in both assessments. Overall, there was an increase of records in the FA, except for Pressure ulcer, which was only

documented in the IA. Among these diagnostic domains, the most frequently documented in both assessments are the Potential (n=29; n=54) and Knowledge (n=15; n=50) domains, although with no statistical significance.

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Tabel 4

Domains and type of diagnostic statements in the Initial Assessment and Final Assessment

Diagnostic Domains	Inical Assessment		Final Assessment		<i>t (p)</i>
	No. of records	Type of statemen t	No. of records	Type of statemen t	
Knowledge	15	6	50	11	<i>t (484) = 1,874; p = 0,062</i>
Capacity	5	5	15	5	<i>t (483) = 0,756; p = 0,450</i>
Potencial	29	20	54	18	<i>t (484) = 0,113; p = 0,910</i>
Caregiver Role	1	1	31	3	<i>t (484) = 0,001; p = 0,001</i>
Stress	1	1	9	1	-----
Pressure Ulcer	1	1	-	-	-----

A significant increase was found in the final assessment ($p=0.001$) for the diagnostic domain of Caregiver Role. The documented interventions were analysed following the nursing process, being identified ten different

types of actions (Support, Assist, Assess, Encourage, Teach, Stimulate, Instruct, Negotiate, Guide, and Train), although some were only recorded in one of the assessments (Table 5).

Table 5

Types of actions/interventions documented in the Inical Assessment and Final Assessment

Action	Inical Assessment		Final Assessment		<i>t (p)</i>
	No. of records	Type of interventions	No. of records	Type of interventions	
Assist	-	-	1	1	_____
Support	1	1	6	1	_____
Encourage	-	-	4	3	
Stimulate	5	3	28	6	<i>t (484) = 1,598; p = 0,050</i>
Teach	53	27	102	33	<i>t (484) = 0,071; p = 0,943</i>
Guide	1	1	2	2	_____
Instruct	24	16	8	4	<i>t (484) = 3,299; p = 0,014</i>
Train	8	5	1	1	<i>t (484) = 3,233; p = 0,018</i>
Negotiate	-	-	1	1	_____
Assess	51	25	164	25	<i>t (484) = 1,535; p = 0,072</i>
TOTAL		78		77	

In the IA, the most documented actions were Teach (n=53), Assess (n=51), and Instruct (n=24). In the final

assessment, Assess (n=164) and Teach (n=102) were the most expressive actions, with no statistically

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significant differences. The Instruct and Train actions showed a significant decrease of records in the FA ($p=0.014$ and $p=0.018$, respectively). The Stimulate interventions showed a marginally significant increase of the records (Initial assessment-5; Final assessment-28) ($p=0.050$).

DISCUSSION

Despite the pandemic outbreak scenario in which the implementation of the Family Caregiver Monitoring Model took place, the results obtained show a positive perspective of the path developed with the nursing teams, aiming at improving the care provided to the family caregiver.

Given the unfavorable scenario in which the implementation of the intervention took place, the results indicate the use of PARH paradigma allowed nurses to become aware of the need to build a path conducive to change, with regard to FC care and its documentation in the Nursing Information System.

The substantially higher number of dependent persons listed in the FA is likely to be associated with the effects of COVID-19 disease in the more fragile population, consequently increasing dependence in activities of daily living (Fettes et al., 2021). However, this data may also be indicative of the nurses' greater sensitivity to the identification and signalling of the PD.

In addition, the increased awareness of nursing teams can partially explain the increase in the number of family caregivers identified in the final assessment. However, this increase is below the desirable because this information is missing in 97% of clinical records.

The identification of the caregiver is crucial for care planning (FC and PD) to meet the family caregiver and the dependent person's needs in a timely manner

(Hagedoorn et al., 2020). In these transition processes, nursing support and monitoring is essential to fill the gaps in the transition to the new role, which will positively impact the care provided to the PD (Meleis, 2010).

The high representativeness of clinical processes with identification of the focus Caregiver Role, but with no other information regarding the subsequent steps of the nursing process, depicts a gap between practice and the models presented by the scientific community, highlighting the invisible role of the family caregiver (Cloyes et al., 2020).

The results indicate the need for teams to carefully consider the family caregiver in the transition to the caregiver role (Ploeg et al., 2020), since the family caregiver preparedness is positively associated with better outcomes for the recipient of care (Hagedoorn et al., 2020).

In the clinical processes with the identification of the Caregiver Role that progressed to the different stages of the nursing process, data showed a significant increase in the number of family caregivers who were the target of a care conception process aimed at meeting their needs. These data are corroborated by the literature (Samadbeik, et al., 2017), highlighting the importance of nurses' involvement in care documentation.

The focus Caregiver Stress in the active phase (with no records in the other steps of the nursing process) maintained the documented focus pattern, although with records in the following steps of the nursing process, which indicated a non-significant decreasing trend. In line with existing literature, these results reveal a poorly integrative approach to the family

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caregiver as the target of care (Cloyes et al., 2020; Ploeg et al., 2020).

In the FA, the diagnostic statements reflect an increasing trend of the records. However, only those referring to the Caregiver Role showed a statistically significant increase, attesting to the importance attributed by professionals to the caregiver assessment (Cloyes et al., 2020).

Despite the higher number of records compared to the number of accessed processes, the documented interventions are still focused on the Assess and Teach types. Notably, according to a national study, the interventions that could significantly impact the management of emotions of the family caregiver are still poorly recorded, hindering the identification of health gains (Driel et al., 2021).

The literature demonstrates that empowering family caregivers in their caregiver role, without neglecting their self-care and well-being, should be a priority of the nursing professional as a facilitating element of this transition (Ploeg et al., 2020). These study results indicate a gap in the documentation of some interventions promoting a healthy transition. However, the Stimulate type interventions showed a marginally significant improvement ($p=0.05$), revealing a more comprehensive approach to the family caregiver.

The current pandemic scenario may explain the significant decrease in the Instruct and Train interventions observed in the final assessment ($p=0.014$; $p=0.018$). This unprecedented event has led to restructuring family health units, conditioning face-to-face consultations and prioritising urgent care (Borges et al., 2021).

Although some improvements in the FA were observed, these were not substantial, probably because of the specific pan pandemic context. In fact, primary health care underwent an unprecedented restructuring due to the COVID-19 pandemic, which has severely affected health services at national and international levels, namely concerning the context and timing of this research (implementation of the intervention/final assessment). This new reality led to the reorganisation of family health units, in compliance with the guidelines of the National Health Service, directing the nurses' practice towards the responses to COVID-19 (DGS, 2020). These unprecedented events produced significant changes in the nursing practice, mainly at the organisational level, work with teams, telework, among others, and continue to impact the delivery of nursing care (Borges et al., 2021).

These changes had repercussions on the results obtained. However, the Family Caregiver Monitoring Model developed with the praxis nurses may have contributed to raising awareness of the need to bring the model in use closer to the best evidence and has likely improved the nurses' knowledge of the real potential of the parameterisation of this information in the SClínico.

CONCLUSION

These study results suggest a significant improvement in the identification of the family caregiver and the focus Caregiver Role (with and without other records in the subsequent steps of the nursing process) and the diagnostic statements involving the Care Provider Role.

The interventions aimed at the management of the family caregiver's well-being maintained an

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underreporting pattern. Although not all the Stimulate interventions are targeted at the family caregiver, those referring to the dependent person reflect a greater concern of the caregiver with the promotion of the family member's autonomy.

In addition, the significant decrease in the recording of Instruct and Train interventions illustrates the pandemic scenario.

The use of PARH approach proved to be an asset for the positive transformation of the nursing team and potential impact on the continuous improvement of care.

This study confirms the importance of the family caregiver and the need for institutions/professionals to intervene in this area. Further research should include a more robust study to assess the Family Caregiver Monitoring Model, namely a randomized clinical trial, to be implemented in a period of normalized activity, to reassess the adoption of the matrix by the team and consequent assessment of the FC satisfaction. After the end of the study, the researcher validated with the interlocutors nurses the continued use of the matrix in conducting diagnostic activities, defining interventions and evaluation.

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