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Giving Voice to Caregivers: a game for family caregivers of dependent individuals*

Dar Voz aos Cuidadores: um jogo para o cuidador familiar de um doente dependente Dar Voz aos Cuidadores: un juego para el cuidador familiar de un enfermo dependiente

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ABSTRACT

Objective: To construct and assess a board game created to promote the effective transition of family members into caregivers of dependent individuals. **Method:** This was a qualitative exploratory and descriptive case study conducted with family caregivers of dependent individuals. **Results:** The study resulted in the conceptualization, construction, and assessment of the board game. The game proved to be an important family evaluation tool, enabling open communication and interventions in family dynamics. **Conclusion:** The results showed that the game can help build new family narratives, providing an opportunity for open communication, expression of problems and sharing, representing an important family evaluation and intervention strategy.

DESCRIPTORS

Caregivers; Family; Aged; Games, Experimental; Family Nursing.

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INTRODUCTION

The health-illness transition is a time of crisis for families, and according to general systems theory, a change in the health condition of one of the elements affects the entire family unit⁽¹⁾, especially the family member who takes on the new role of caregiver. According to Meleis, this transition is a concept associated with crisis theory, and can be a result of natural family developmental and health/illness transitions, for example⁽²⁾.

The experience of caring for sick individuals in the home has become a more common part of family routines. Family caregivers experience a situational transition, which includes situations of crises in which roles are redefined and new ones incorporated⁽²⁾. These new roles can be experienced with multiple needs and feelings, which tend to be contradictory and antagonistic due to associated tension, competencies and conflict⁽³⁾. Aware of the complex and unique nature of the experience of family care⁽⁴⁾, and of the presence of factors that facilitate or inhibit effective transitions⁽⁵⁾, the researchers sought to create a collaborative game as an effective strategy to facilitate this transition. The idea of the game emerged from the need to intervene in family crises triggered by acquisition of new roles associated with caring for a dependent individual. The new tasks are usually distributed unequally among family members, and caregivers are the only ones to receive additional roles to those they already had, causing imbalance in the family unit⁽³⁾.

More than an intervention, the game proposes co-participation, acting to provoke change⁽⁶⁾. Games have been used for years in the field of therapy and have been very successful in cases in which social skills and interactional behaviors are the target of the intervention⁽⁷⁾. The benefits of using games with families, as well as their application and effectiveness, have been observed and documented in a wide range of situations⁽⁸⁾.

Games allow space for reflection, the sharing of values and actions that guide feelings and emotions, diluting differences and mediating the negotiation of agreements. The use of games has been increasingly disseminated and established as an important strategy to awaken new possibilities for intervention⁽⁹⁾. The use of games in health care steers professionals away from a predominately paternalistic approach, with the goal of facilitating self-efficacy of individuals⁽¹⁰⁾ and families, which was the researchers' aim for the intervention.

Considering the above, the researchers investigated the validity of constructing a board game with the purpose of facilitating effective transition among family caregivers. Lack of resources and the scarcity of literature about the use of games in relation to this issue was the background of this journey. It is hoped that this collaborative game can bring out the playful side of families when addressing the problem-solving process associated with caregiving, in addition to serving as a nursing evaluation and intervention tool.

The objective of the present study was to construct and assess the board game *Giving Voice to Caregivers* (in portuguese, *Dar Voz aos Cuidadores*), created to promote an effective transition of family caregivers of dependent individuals.

METHOD

The process of conceptualizing a game requires careful methodology, especially to plan and establish its objectives, focusing on the actual needs of users. The results seem simple, but the development of an instrument of this nature requires the integration of numerous variables. Games must be carefully planned to reach the intended results, which involves rules, collaboration among members, competition, and also frequently require props or other objects⁽¹¹⁾. Figure 1 portrays the steps that composed the conception, construction, application and assessment of the game.

Type of study

This was a qualitative exploratory case study. Case studies are the most adequate method of investigation to describe and analyze relationships within a phenomenon⁽¹²⁾, allowing for intensive and in-depth study. To this end, this type of study must be conducted in the locations where the phenomena occur, in recognition of their complexity, with no attempt to control or limit the research to specific variables⁽¹³⁾. Case studies may be single or multiple⁽¹⁴⁾. Considering the above, the case study was considered appropriate to identify behaviors, perceptions, emotions, and opinions developed while applying the game.

DATA COLLECTION

Data collection was carried out between January and June 2016, in three stages: focus group to conceptualize the game, pretesting the game, and a second focus group to assess the game.

The content present on the card games were a result of a literature review conducted about the needs of family caregivers of dependent individuals⁽³⁾, as well as the data resulting from two focus groups with caregivers of dependent individuals.

The focus groups were mediated by the researchers and lasted an average of 60 minutes. The sessions were audio recorded and took place in rooms made available by the institutions, following a previously established script. The aim of the questions was to explore the role of caregivers, gather elements to identify the difficulties inherent to the caregiving role and gather more in-depth data to identify the need of caregivers. Participants were randomly recruited for the focus groups, according to their availability and interest in the study, with the following inclusion criteria: caregivers of sick adult family members, older than 18 years, and absence of any cognitive and communicational impairments. The use of focus groups, which consisted of 12 caregivers, provided important findings at this stage.

2 Rev Esc Enferm USP · 2018;52:e03309 www.ee.usp.br/reeusp

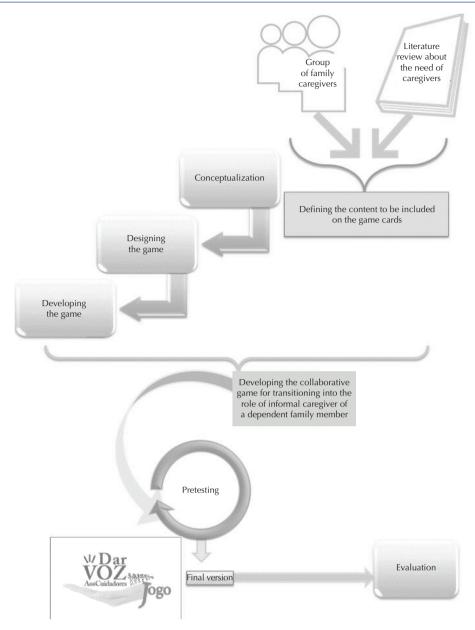


Figure 1 – Design of the game's development – Porto, Portugal, 2017.

DATA ANALYSIS

Games need to be tested to expose possible errors and conduct any necessary reformulations⁽¹⁵⁾. Pretesting was conducted with one family, which had one informal caregiver and was selected by convenience and volunteered their participation. The following inclusion criteria were established: absence of any cognitive or communication impairment, not having participated in any of the prior activities for this project, having a dependent family member over the age of 18 with a caregiver. The game was played for an hour.

The game was assessed post-facto, analysis was carried out after the variations occurred, according to the natural course of development⁽¹²⁾, in a new focus group. Focus groups are especially useful in evaluative studies, because they favor

the perception of practices, actions, and reactions to facts and events, emphasizing the need to consider the different perspective of subjects exposed to the studied phenomenon⁽¹⁶⁾. The focus group was conducted with the pretest participants and two family nursing experts, selected by convenience. The inclusion criterion for the experts was having advanced training in family nursing.

For the assessment, the following questions were made: Do you consider that the themes addressed in the game were useful for caregivers? Do you think that the themes in the game were clear and adequate? Was the duration of the activity adequate? Do you think the methodology is adequate for a group of caregivers? Can the game help and be useful to caregivers? Do you think the game had an impact by itself? Overall, how do you rate the game? Would you recommend it to anyone?

3

www.ee.usp.br/reeusp Rev Esc Enferm USP · 2018;52:e03309

DATA PROCESSING

The data that emerged from the focus groups were transcribed, including the researcher's notes and reflections. The corpus of analysis consisted of the data transcription accompanied by pre-analysis, followed by the codification of selected data, and data aggregation considering the inductive experience of the phenomenon, highlighting text excerpts from the interviews.

ETHICAL ASPECTS

This study abided by all the relevant ethical principles. Participants were given informed consent forms to sign and their anonymity was ensured. The study was approved by the Research Ethics Committee of the respective institutions through Resolution no. 1.553.398/2016, according to ordinance 466/2012.

RESULTS

The results are presented according to the phases of the study: game conception, construction, application, and assessment.

CONCEPTION

The findings provided the thematic areas to be included in the game, based on theoretical framework of various authors.

The literature review about the needs of family caregivers of a dependent individual resulted in five thematic areas: transition into care, being responsible for everything, the importance of support, access to formal support, and communication and information processes, which are addressed more in-depth in the cited paper⁽³⁾.

The focus groups consisted of 12 female caregivers, with ages between 30 and 67 years. Time of caregiving ranged between 1 to 21 years, and most cared for their mother or father. A systematic and focused analysis was conducted about the family caregivers, which resulted in themes similar and interconnected to the needs that emerged from the transcription of the focus groups, categorized as follows: the need to learn by oneself, time needed to maintain roles, the need for support networks, resilience to face family imbalances, and caregiving resources.

Based on these data and the integration of the contributions of various authors, the concepts and data behind the game emerged. The contributions of Walsh were especially significant, who has described some processes that favor family resilience and that can be stimulated by health teams⁽¹⁷⁾. These were also included in the game, namely: Making meaning of adversity, Positive outlook, Maintenance of transcendence and hope, and Flexibility of organizational patterns.

Sense of connection: capacity to commit, exercise leadership, and respect individual differences and limits; seeking to reconcile disturbed relationships.

Mobilizing social and economic resources: extended family, community support networks and safety.

Favoring communicational clarity: consistent messages, clarifying ambiguity.

Encouraging open emotional expression: sharing feelings, empathy, and recognizing the value of humor.

Collaborative resolution: shared decision making and focusing on objectives.

The authors based their proposal on the various family nursing contributions and intervention models, which can be cognitive, affective and behavioral, and help families discover new solutions to reduce their emotional, physical, and spiritual suffering⁽¹⁾. These interventions are: Pointing out the strong points of the family and of individuals, Providing information and opinions, Validating or normalizing emotional responses, Encouraging narratives of the disease, Helping to reduce isolation, Stimulating family support, Encouraging all family members to be caregivers, and supporting the official caregiver, Encouraging rest, and Planning rituals.

The integration of the data resulted in different thematic areas that were included in the game in the form of Caregiver cards, which allow them to express their emotional and physical needs through their own narratives, family cards, to intervene in family imbalance, health professional cards, which refer to the need for formal support, cards that reference the support network, and finally, task cards. The task cards allow for the intervention to go beyond the game itself, transferring the focus from the family's complaints into concrete objectives. This creates active involvement in meaningful rituals, which can help family dynamics flow better⁽¹⁷⁾.

CONSTRUCTING THE GAME GIVING VOICE TO CAREGIVERS

When creating a game, some issues must be defined, such as its objectives, the game format, how the challenge is developed, number of players, duration of the game, rules, and content⁽¹⁵⁾. The game developed in the present study was named *Giving Voice to Caregivers* (Figure 2), and its objectives were: Creating a favorable environment for expressing and experiencing feelings; Creating a space that allows for behavioral patterns within the family system to be better understood; Promoting better interaction and adaptation among members of the family system; Encouraging the competencies of the caregiver and family members to face adversity; Strengthening caregivers and the family, encouraging the active process of re-structuring and growth.



Figure 2 – Game logo – Porto, Portugal, 2017.

The board game path represents the four phases of transitioning into a family caregiver, namely: denial, lack of awareness of the problem; search for information and the emergence of negative feelings; reorganization; and resolution⁽¹⁸⁻¹⁹⁾.

taking the game format to a test audience to discover applicability problems) in order to validate it^(11,20). The game prototype was tested with a family of eight with one caregiver, as illustrated in the genogram in Figure 4.



Figure 3 – The game board – Porto, Portugal, 2017.

The objective of the game is to go from start to finish, passing through the different phases experienced by caregivers. The game was created to be played with one caregiver and their family members. However, one to four caregivers can be included, with their respective family members. All family members can participate in the game, but only one pawn is used per family. The game should be mediated by a trained nurse.

Caregivers are the main players, and the game begins by them rolling a dice, and then moving the number of spaces on the die. Next, they must follow the directions written on the respective square. The squares are colored the same as the question cards (purple, green, and blue). The player then takes the same-colored card, which will either be directed at the caregiver, the family, or the health professional, reads the question out loud, and after it is answered, puts the card aside. The game goes on like this successively, until someone reaches the end.

There are some special squares that direct players to move backwards, or that are "help" squares. Help squares give caregivers and the family the opportunity to obtain extra help, which if accepted, allows them to cross bridges to more advanced phases on the board. When the game is over, caregivers gather one task card and read it out loud so that everyone can hear the task they will have to carry out together.

APPLYING AND ASSESSING THE GAME

Games need to be tested and assessed for possible errors and, if necessary, reformulated^(11,15,20-21). It is important to test the game before it is made available for use (for example,

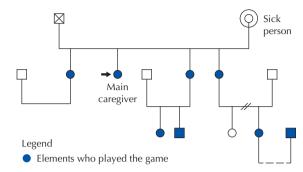


Figure 4 – Family genogram – Porto, Portugal, 2017.

Eight family members and two family nursing experts participated in the focus group to assess the game. The narratives of the participants resulted in the following thematic areas: open communication and expressing feelings, intervention in family dynamics, and a family evaluation tool.

The game integrated all those who wished to participate, as highlighted by this expert:

The game allows us to include family members of all ages, even the youngest ones can and should participate (Expert 1).

The players described the benefits of applying the game for caregivers, family members, and nurses, as shown in Figure 5.

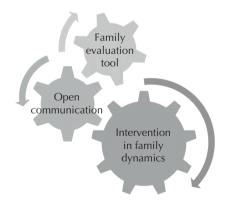


Figure 5 – Benefits of applying the game – Porto, Portugal, 2017.

The game allowed for open communication, enabling caregivers to express their feelings to their family.

The game allows caregivers to talk about what is really going on and how they really feel (Family 3).

Through the game, the family members do not focus only on themselves, they are focused on answering the questions (Expert 1).

5

www.ee.usp.br/reeusp Rev Esc Enferm USP · 2018;52:e03309

The game also allowed feelings and emotions to be shared, as it fosters open communication among the family. With the game, the family addresses themes that they probably haven't addressed before, and they begin to realize how each one thinks (Expert 2).

Participants also mentioned how the game intervened in family dynamics:

We are a family, not just one caregiver or one sick person, we are all in it together, and through the game we realized that each one of us can help, some more, some less, some in this way, others in that way (Family 2).

The game allows families to reflect about what each of its elements has done up to the present and what changes they can make from now on (Expert 2).

Last, the game was indicated as a possible family assessment tool.

Within a single session, nurses are able to gather several family members and observe how the family works, without having to ask questions. They can observe how the family organizes itself, how care is provided, and each member's role (Expert 1).

If nurses asked questions directly, many of us would probably not even answer, if it weren't for the game (Family 4).

DISCUSSION

Caregivers experience many challenges when caring for dependent family members, including unmet needs in several areas⁽²²⁻²⁴⁾. Caring for caregivers means promoting their health, that of dependent individuals and also that of the entire family. Clinicians and researchers need to shift their narrow focus away from individual caregiver, usually wives, sisters, daughters, or daughters-in-law, and encourage the involvement of all family members, working together as a team of caregivers⁽¹⁷⁾.

When approaching families, the focus must be on developing strategies that support family caregivers⁽²⁵⁻²⁶⁾, such as games. These tools have been increasingly applied in nursing; however, studies have shown that they are more directed at undergraduate nursing education^(11,15,21).

The *Giving Voice to Caregivers* game prioritizes the communicational aspects of families, promoting and facilitating change during the transition and crisis process they are experiencing⁽¹⁾. Family interventions must be analyzed holistically, as illness in one of its members alters the family equilibrium. Nursing care must consider the needs of the entire family, considering the impact of the illness on all family members⁽²⁶⁾. A systemic approach supports that the most effective form of working with individuals is within the family context⁽²⁷⁾.

New nursing initiatives in family health must consider that family health is an integral part of the practice and an interdisciplinary challenge with clinical implications. Nursing needs specific interventions with families, determining their effectiveness in practices, and that can be recommended in health-illness transitions⁽²⁸⁾.

Promoting and maintaining family health is an area of family nursing with considerable room to develop and test family interventions⁽¹⁾, as in the case of the board game.

Within the logic of systemic interventions, it is only valid that professionals work directly with the totality of forces that influence families⁽²⁷⁾. The aim of the game is to strengthen families, based on the understanding that all families, while still considering their diversity, can survive oppressive stress and regenerate themselves, affirming their potential for self-repair and growth from crises⁽¹⁷⁾. Developing nursing interventions that aim to promote or facilitate change in family systems is the most challenging and stimulating aspect of working with families. The role of nurses includes proposing family interventions, while not directing or demanding certain type of change or form of family functioning⁽¹⁾.

The game assessment showed numerous benefits, especially those relative to communication within family systems. This is a key factor that needs to be structured within families, because formative, relational, education, interactional, and social integration practices are based on communication. Family relationships that are grounded in effective communication allow for the equilibrium of the family system⁽²⁹⁾.

The game cards with circular questions enabled the researchers to gather more in-depth data. Circular questions allow for the investigation of the relationships, or the connections between individuals, events, ideas or beliefs, with the aim of facilitating change⁽¹⁾. They also serve as assessment strategies and help families understand themselves as a system, spontaneously generating significant change⁽³⁰⁾. Furthermore, they allow family members to renew the ideas they have about each other and their relationships, defining them based on something beyond the illness⁽¹⁷⁾, helping family members to cure strained relationships and begin to work together as a team⁽¹⁷⁾.

The creation and application of the game achieved its objective, namely, to help family members discover new solutions and reduce or alleviate emotional, physical, and spiritual suffering⁽¹⁾. The game created a space for the players to express their feelings, allowing families to emerge from this transition stronger, with communication as the central theme of this recreational experience. The game helps families construct new narratives, fostering moments of openness and humor.

Limitations of the present study include the shortage of research of this nature, in addition to the limitations associated with the methodological options regarding case studies. Thus, the researchers suggest this strategy be replicated with different participants.

CONCLUSION

With the expansion of the family life cycle, inevitably, a greater percentage of family members are likely to become caregivers. At some point, families experience situations of illness and one of its members will be needed to provide care.

Caregivers experience pressure on taking on this new role; and if the associated demands and needs are not considered, many different feelings emerge, which are usually contradictory and antagonistic because of the tension, the need to develop new skills, and the associated conflict, generating suffering for individuals and their families.

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The evaluation of the game highlighted its benefits, namely the broad range of application. The game can be played by entire families, representing an important family assessment tool, and fosters open communication, intervening in family dynamics.

The game was developed as a mean for nurses to help caregivers transition into the new role associated with the illness of a family member, with communication at the core of this recreational experience. The game allows people to talk about serious things while playing.

The results show that the game helped construct new family narratives, providing the opportunity for players to openly express and share their problems and feelings. Thus, it can serve as an important family assessment and intervention strategy.

RESUMO

Objetivo: Construir e avaliar um jogo de tabuleiro criado com a finalidade de promover uma transição eficaz para o papel de cuidador familiar de doentes dependentes. Método: Pesquisa exploratória e descritiva, com uma abordagem qualitativa do tipo estudo de caso, com cuidadores familiares de doentes dependentes. Resultados: Permitiram a conceitualização, a construção e a avaliação do jogo de tabuleiro. O jogo foi uma ferramenta importante de avaliação familiar, permitindo uma comunicação aberta, com intervenção nas forças da família. Conclusão: Os resultados demonstram que o jogo ajuda a construir novas histórias de família, com momentos de abertura, exteriorização de problemas e partilha, constituindo uma importante estratégia de avaliação e intervenção familiar.

DESCRITORES

Cuidadores; Família; Idoso; Jogos Experimentais; Enfermagem Familiar.

RESUMEN

Objetivo: Construir y evaluar un juego de tablero creado con la finalidad de promocionar una transición eficaz al papel de cuidador familiar de enfermos dependientes. **Método:** Investigación exploratoria y descriptiva, con un abordaje cualitativo del tipo estudio de caso, con cuidadores familiares de enfermos dependientes. **Resultados:** Permitieron la conceptualización, la construcción y la evaluación del juego de tablero. El juego fue una herramienta importante de evaluación familiar, permitiendo una comunicación abierta, con intervención en las fuerzas de la familia. **Conclusión:** Los resultados demuestran que el juego ayuda a construir nuevas historias de familia, compartiendo momentos de apertura y exteriorización de problemas, a la vez que se construye una importante estrategia de evaluación e intervención familiar.

DESCRIPTORES

Cuidadores; Familia; Ancianos; Juegos Experimentales; Enfermería de la Familia.

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