

RESEARCH PROTOCOL

Tackling perinatal loss, a participatory action research approach: research protocol

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Abstract

Aim. The aim of this study was to promote changes to improve the care provided to parents who have experienced a perinatal loss through participatory action research.
Background. The birth of a child is a joyful event for most families, however, unfortunately some pregnancies end in loss. Perinatal loss creates a heavy emotional impact not only on parents but also on health professionals, where in most cases there is an evident lack of skills, strategies and resources to cope with these kinds of situations.

Design. Participatory action research is the methodology proposed to achieve the purpose of this study.

Methods. Participatory action research consists of five stages: outreach and awareness, induction, interaction, implementation and systematization. The working group will include professionals from the Mother and Child Unit for patients at a tertiary level public hospital in Spain. The duration of the study will be 3 years since the approval of the protocol in January 2011. The qualitative techniques used will include group dynamics such as the SWOT analysis the nominal group technique, focus groups and brainstorming, among others that will be recorded and transcribed, generating reports throughout the evolution of the group sessions and about the consensus reached. Content analysis will be conducted on the field diaries kept by the participants and researchers. This project has been funded by the Andalusian Regional Ministry of Health.

Discussion. Participatory action research is a methodological strategy that allows changes in clinical practice to conduct a comprehensive transformative action in the care process for perinatal loss.

Keywords: grief, midwifery, nursing, participatory action research, perinatal loss, professional practice change, research protocol

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Introduction

Background

The image of motherhood is advertised as being synonymous with achievement (Maroto Navarro *et al.* 2004). The birth of a child is considered a joyful event for families. Nobody thinks about the opportunity that there may not be a happy ending, but some pregnancies end in loss.

According to data from the World Health Organization (WHO) (Åhman & Zupan 2007), it is estimated that of 13,160,000 live births in 2004 in the most developed countries, 134,000 perinatal deaths were produced, of which 84,000 were stillbirths. Although these rates are statistically significant, the social, economic and technical improvements have led to a great reduction of said deaths over the last few decades (Freitas *et al.* 2008). However, the cultural changes and the incorporation of women into the workforce in the last third of the twentieth century has favoured that the number of children that a couple decides to have continually decreases. With this in mind, the greater repercussions felt by the parents are understood about the loss of an intensely desired child. The concept of perinatal loss includes those losses that take place at any moment during pregnancy up to

the first month of life of the baby and the transfer of a child for adoption (Gold 2007, Mathew *et al.* 2008).

The psychosocial impact of perinatal loss has been studied extensively over the last 25 years, showing that parents experience the same grieving reactions that are observed in other situations of mourning and even more intense in some cases due to the lack of social visibility of perinatal grieving (Gold 2007). Perinatal losses are events that change the lives of the parents, leaving them with feelings of inner emptiness, guilt, irritability, overwhelming grief, rage, apathy and fear of another pregnancy (Badenhorst & Hughes 2007, Barr & Cacciatore 2007, McCreight 2008, Bazotti *et al.* 2009). Different studies have shown that close to 20% of women present depressive symptoms and anxiety up to 1 year after the loss and, they may even develop psychiatric disorders that could affect later pregnancies and their relationship with the next baby (Hughes & Riches 2003, Lok & Neugebauer 2007).

Nonetheless, it must be emphasized that perinatal loss affects parents and those responsible for its management. The situations of perinatal loss produce a heavy emotional impact on health professionals, where, in most cases, there is an evident lack of skills, strategies and resources to cope with these kinds of situations (Pastor Montero *et al.* 2007). In fact, many health professionals recognize their level of knowledge and understanding of grief counselling to be insufficient and few have received specific training (Chan & Arthur 2009). The development of basic and advanced education would enable staff to better cope with their work (Laakso & Paunonen-Ilmonen 2001). However, at times, instead of a solid education base, personal beliefs guide the actions of health professionals more so than evidence (Fernández-de-Maya & Richard-Martínez 2010) or the parent's desires. There is also great ambiguity about the responsibilities among the different professionals involved, creating an obstacle to parents to acquire the appropriate information (Laakso & Paunonen-Ilmonen 2001).

Along with that previously mentioned, few hospitals have protocols for cases of perinatal loss, leading to the existence of a wide variety of approaches and protocols from one institution to the next (Claramunt *et al.* 2009), although there are interventions and strategies that are known to help parents carry out a healthy grieving process (Chambers & Chan 2000). Among them, the following are considered as optimal: give emotional support (McCreight 2008), explain what interventions should be conducted (Geerinck-Vercammen & Duijvestijn 2004), encourage the mother to see and hold the baby, to give it a name, create memories and to celebrate farewell rituals (Capitulo 2005), validate the loss (Stratton & Lloyd 2008), offer guidance about the grieving

process (Gold 2007) and specialized psychotherapy (Aerde 2001), ensure the continuity of care (Claramunt *et al.* 2009) and keep in mind sociocultural considerations (Hsu *et al.* 2002, 2004).

Given that there are many couples that have not received adequate care and taking into account the need felt by professionals that want to modify these situations (Pastor Montero *et al.* 2007), the following questions arise: how can professional practice be changed? What working method would be used? How are care-related decisions made when professionals have varying points of view? How can research results be transferred to practice?

Overcoming the obstacles that impede the translation of enhanced scientific knowledge to decision-making in daily practice is a challenge for health professionals (Pearson *et al.* 2007, Forbes 2009, Wallin 2009, Fernández-de-Maya & Richard-Martínez 2010, Moreno-Casbas *et al.* 2010). In this context, participatory action research (PAR) is arising as a methodological strategy that enables a better transformation of specific situations, reduces the gap between research and practice and facilitates the implementation of new knowledge (Grol & Grimshaw 2003, Hall 2006, Booth *et al.* 2007, Williams *et al.* 2008, Abad-Corpa *et al.* 2010).

The term PAR was first coined by Lewin in the 1950s and later, the concept was further developed by Fals Borda, based on group dynamics and the resolution of social conflicts (Pérez Serrano 1990, Balcazar 2003). It has to do with a collective process of production and reproduction of knowledge needed to transform reality, inserted in a defined action strategy (Rodríguez Gabarrón 1999). It is more sociological than pedagogical although the paradigmatic perspective that is presented herein is the critical theory proposed by Guba and Lincoln (1994).

In PAR, a spiral reminiscent of the nursing process (Glasson *et al.* 2006) is set in motion that is very useful to health professionals due to its reflexive process throughout the action itself (Delgado Hito *et al.* 2001). It gives professionals the opportunity to see themselves actively involved and to work together with the design, direction and results of the research (Reid-Searl *et al.* 2009). They are able to reflect on their practice (Li *et al.* 2010), develop theories (Munten *et al.* 2010) and to select strategies adapted to the context (García Mozo *et al.* 2010). PAR is characterized by a humanistic design, ensuring the participation of all involved parties to share their knowledge and experience and to learn the process of problem-solving. They are given a sense of ownership and commitment to the actions implemented, as the professionals themselves are agents of change (Hall 2006).

The approach presented herein is a coercive instrument to empower professionals and to make the innovative attitude of professionals about their clinical practice visible by demonstrating the capacity to generate knowledge in an active, critical and reflexive manner. Cultivating the need felt for change about care in perinatal loss in professionals with a research-oriented culture increases the quality of healthcare services.

The study

Aim and objectives

The aim of this study was to promote change to improve the care given to parents that have experienced perinatal loss using PAR.

The specific objectives are to:

- Recognize the personal, institutional and organizational barriers that hinder change.
- Build awareness around the fact that the reflexive process is the essential motor to generate alternatives of change.
- Develop proposals that improve professional practice involving the entire healthcare team and ensuring a greater use of scientific evidence.
- Implement the strategies agreed on that drive change.
- Evaluate the change process of clinical practice.

Research hypothesis

The qualitative nature of the study and the fact that it is a PAR proposal, impedes the formulation of a true hypothesis. The study starts from the idea that PAR is intended to provide strategies for professionals to identify, reflect on, act, correct and to evaluate their own clinical practice to carry out a comprehensive transformative action in the area of perinatal loss.

Design

Some authors place PAR as a type of qualitative research, although its theoretic foundations are closer to critical sociology (García Mozo *et al.* 2010). Kemmis and McTaggart (1988) describe the process of action research as a spiral of cycles of planning, acting, observing and reflecting. The methodological model that will be used in this project is the one proposed by López Alonso *et al.* (2010), influenced by the proposals of Fals Borda (1981) and Park (1993). This methodological process has five stages: outreach and awareness, induction, interaction, implementation and systematization.

Study setting

The study was carried out in the Mother and Child Unit for patients at a tertiary level public hospital in Spain.

Participants

Participatory action research can be considered as a systematic process carried out by a specific community to reach a deeper understanding of their problems and work to solve them, while trying to implicate the entire community in the process (Pérez Serrano 1990). The working group (co-researchers) will be formed by professionals that work in the Mother and Child Unit of the hospital where the study will be conducted. The staff includes nurses, midwives, nursing assistants, care coordinators and physicians specialized in paediatrics, gynaecology and obstetrics and anaesthesiology. The possible number of participants is 30. The inclusion criteria include voluntary participation, having assisted in some case of perinatal loss and that the participant's work situation is not temporary.

Data collection

- The study duration will be approximately 3 years from the moment the protocol was approved in January 2011.
- Refinement of the study, recruitment of participants, preparation of group sessions, 2 months.
- Realization of group dynamics, 8 months.
- Implementation and systematization of the proposed strategies, 12 months.
- Data analysis, 10 months.
- Report writing and dissemination, 4 months.

The five stages of the proposed PAR will be carried out using techniques provided in the literature on participatory methodologies (Kemmis & McTaggart 1988, Pérez Serrano 1990, Park 1993, Alberich 2000, Martí 2000). Of those mentioned, the ones that allow for a reflexive learning process such as the Strengths, Weaknesses/Limitations, Opportunities and Threats (SWOT) technique, nominal groups, relationship maps, focus groups and role-playing are preferred. Approximately three group meetings will be organized for each stage, with a maximum duration of 2 hours. All group meetings will be recorded and transcribed in full.

In the fourth stage, the collection of data will be carried out using the participant observation technique, by the researchers and co-researchers. The co-researchers will write their reflective process in their field diaries. The design is flexible, in progress, that is, constructed throughout the process by the working group (Alberich 2000). Therefore, the dimensions of

the study will emerge from the praxis itself that will be generated in the working group. The phases that are presented below give a basic scheme, as when working with an active and participatory methodology, no definitions can be made beforehand (Martí 2000).

Outreach and awareness

The objective of this stage is to create awareness among the participants by conducting a conceptual and contextual outreach about perinatal losses, discussing the viability of the project, introducing the research team and identifying the participants of the working group.

Strategies of the research group:

- Conceptual and contextual outreach about perinatal losses and grieving.
- Discussion about the study proposal.

Group dynamics to guide the working group:

- Group session: reflexive reading of documentation, literature search.
- Joint discussion.

Induction

In this stage, the participants are encouraged to reflect on their own healthcare reality and to agree on how to intervene, designing the strategies for change.

Strategies of the research group:

- Joint discussion about perinatal losses and grieving and the importance of management.
- Analysis about the qualities that professionals should possess to provide care that is more human, satisfactory and of higher quality when dealing with perinatal loss.
- Discussion about the barriers and threats, strengths and opportunities when carrying out the best clinical care for perinatal losses.
- Joint strategy planning.

Group dynamics to guide the working group:

- Nominal group.
- SWOT technique.
- Focus groups.
- Relationship map.
- Brainstorming.

Interaction

The participants become aware that they themselves possess a transformative capacity based on their own experiences. The interaction of experiences serves as a base to identify the strategy map that will later be implemented.

Strategies of the research group:

- The participants describe their experiences related to perinatal loss and grieving to the group.

- Joint reflection about the strategies that they have adopted and that have been key to the successful resolution, or failure, of the case.

Group dynamics to guide the working group:

- Presentation of cases.
- Role-playing.
- Group sessions: problem-based learning.
- Joint discussion.

Implementation

This is the empirical stage of the process. The participants implement the strategies and experiment with the effects of their own interventions in clinical practice.

Strategies of the research group:

- Discussion about the implementation strategies.
- Contrast the implemented strategies with other strategies found in literature.
- Discussion about the evaluation indicators.

Group dynamics to guide the working group:

- Group sessions: literature search, fieldwork.
- Relationship maps.
- Joint discussion.
- Presentation of cases.

Systematization

The impact of the interventions, the degree of implementation and the objectives met will be evaluated while reflecting and creating awareness of the transformative capacity in the healthcare context.

Strategies of the research group:

- The results of the implementation are presented to the group to be discussed.
- Discussion about the positive and negative aspects of the interventions, difficulties found in the implementation, refinement of the interventions and/or planning of new strategies.

Group dynamics to guide the working group:

- Focus groups.

Ethical considerations

The Clinical Research Ethics Committee of the hospital has approved this project. All participants will sign an informed consent form where the characteristics and objectives of the project will be indicated along with information on the confidentiality of data. Anonymity will be respected at all times. Study participation will be voluntary and the opportunity to abandon the project at any time without any explanations will be clarified. To guarantee confidentiality,

the working group will be encouraged to identify themselves with a fictitious name.

Data analysis

The data collection techniques that are proposed are varied. The criteria taken into account to determine the technique to be used include the nature of the information needed in each phase and the capacity to achieve the proposed objectives.

The focus of the analysis varies depending on the technique used in each phase. Therefore, in phase 1, 2, 3 and 5 the analysis strategy used will be content analysis (Krippendorff 2004) for all group techniques. After each group meeting, a report will be created that includes notes on the group session with the interpretations and observations of the meeting, the consensus reached and the codification and categorization of the primary aspects of highlighted significance in the data; the research group will draft the said report and deliver it to the co-researchers for the/of the analysis and interpretation for discussion and verification.

Two analysis strategies will be combined in phase 4: content analysis for the group techniques and discourse analysis using the methodology proposed by Taylor and Bogdan (1984) for observation, interviews and field journals. Both the analysis strategies will be carried out using NVivo software (QSR 2000).

Rigour

Scientific rigour is ensured by reliability, credibility, security, transferability and confirmability (Lincoln & Guba 1985). In this case, triangulation will be used to compare the data by the different members of the research group, and for the coding of the categories and for the consensus reached. The data will be returned to the co-researchers for verification about the feedback of the participants.

Discussion

The PAR is expected to improve professional practice in the healthcare field, especially in the attention that is given when a perinatal loss takes place. The research-action cycles are a self-reflexive spiral which serves as the base to carry out the changes in clinical practice. Through PAR, professionals will be able to review their professional practice and to identify areas that need improvement. They will create strategies based on research that they will carry out while recording what happens, the effects caused by the changes made in the

What is already known about this topic

- Perinatal loss produces a heavy emotional impact not only on parents but also on health professionals, where, in most cases, there is an evident lack of skills, strategies and resources to cope with these kinds of situations.
- Few hospitals have protocols for cases of perinatal loss, leading to the existence of a wide variety of approaches and protocols from one institution to the next.
- Modifying clinical practice is no easy task even when dealing with the implementation of recommendations that arise from evidence.

What this paper adds

- This article presents a research protocol using a participatory action research design.
- Participatory action research launches a spiral that is similar to the nursing process and favours the reflexive process of health professionals during the action.
- Participatory action research gives professionals the opportunity to see themselves actively involved and to collaborate in the design, planning and direction of strategies adapted to their context that improve their clinical practice.

Implications for practice and/or policy

- The study is intended to promote a change that improves the care that is given when a perinatal loss takes place.
- Participatory action research is a tool for the change process that ensures the quality of care that is given, humanizing the entire healthcare process for situations of perinatal loss and grieving and facilitating a healthy grieving process for parents.
- This methodology has the added value of favouring the participation and consensus of the decision-making professionals, along with contributing to improve personal self-esteem and to increase the degree of cohesion and interaction of the multidisciplinary team.

situation and evaluating the results. Critical reflexion on the results will give meaning to the effects and the consequences of the strategies carried out making it possible to modify practice depending on the objectives reached. New consideration and action proposals will be made to ensure that the quality of care given can be guaranteed, that the entire care process for perinatal loss and grieving is humanized and that parents are helped to go through a healthy grieving process.

This methodology has the added value of favouring the participation and consensus of the decision-making professionals, along with contributing to improve personal self-esteem and increase the degree of cohesion and interaction of the multidisciplinary team. The action strategies agreed on, once their usefulness is demonstrated in the centre, can serve as a reference for professionals from other institutions to manage perinatal loss in their own healthcare contexts.

Limitations

The following are considered as possible limitations for this study:

- The change process is a slow process. Changing specific practices requires the multidisciplinary team to become aware of the importance of the issue and perceive that the action and change in the clinical practice are necessary for the benefit of the parents;
- The characteristics of the healthcare team: the professionals have different levels of motivation or disposition to change, which may generate discrepancies and important opposition or resistance, even threatening to impede any changes by all the healthcare professionals of the team;
- Considering the qualitative nature of the study, the conclusions cannot be generalized, but they can guide and bring light to similar contexts and situations.

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Conflict of interest

No conflict of interest has been declared by the authors.

Author contributions

All authors meet at least one of the following criteria (recommended by the ICMJE: http://www.icmje.org/ethical_1author.html) and have agreed on the final version:

- substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;

- drafting the article or revising it critically for important intellectual content.

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