

THE PERINATAL LOSS CARE EDUCATIONAL PROGRAMME AND ITS EVALUATION

IZOBRAŽEVALNI PROGRAM ZDRAVSTVENE NEGE OB PERINATALNI IZGUBI IN NJEGOVA EVALVACIJA

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ABSTRACT

Keywords:

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Introduction: Working with bereaved parents is an immense challenge for professionals in the field of perinatal care and requires a high level of knowledge and skill. This article aims to evaluate the effectiveness of the Perinatal Loss Care blended educational programme.

Methods: An evaluative assessment was carried out using a scored questionnaire to gather pre- and post-programme data. Participants were medical and healthcare professionals (n=200) who participated in the programme voluntarily (the Medical Professional/Motivated group and the Others group) or were selected by their employer and for whom attendance was mandatory (the Medical Professional/Non/Motivated group).

Results: Participants' perception of their own knowledge and understanding of perinatal bereavement care was significantly higher on completion of the educational programme, proving its effectivity. There was a statistically significant effect on overall score in individual groups of respondents, as well as the whole set (p<0.001), with post-intervention scores higher than pre-intervention scores. No statistically significant differences in overall score were detected before participation in the educational programme in individual groups (p=0.204). Participants from the Medical Professional/Non/Motivated group achieved lower post-intervention scores to a significantly greater extent (p<0.05) and more often perceived the educational programme as being "very difficult" (x²=20.66, df=6, P<0.01) compared to other groups.

Conclusions: The educational programme was assessed as effective. Care of bereaved parents has its specifics and healthcare professionals should possess a basic knowledge of how to provide sensitive care during this time.

IZVLEČEK

Ključne besede:

nega ob perinatalni izgubi, izobraževanje, strokovnjaki s področja zdravstvene nege, kombinirano učenje, evalvacija programa

Uvod: Delo z žalujočimi starši predstavlja neverjeten izziv za strokovnjake na področju perinatalne nege in zahteva visoko raven znanja in sposobnosti. Prispevek ocenjuje učinkovitost izobraževalnega programa Nege ob perinatalni izgubi.

Metode: Z uporabo vprašalnika se je izvajalo ocenjevalno poročilo za zbiranje podatkov pred in po izvajanju programa. Sodelujoči so zdravstveni strokovnjaki in strokovnjaki s področja zdravstvene nege (n = 200), ki so v programu sodelovali prostovoljno (skupina zdravstvenih strokovnjakov/motiviranih in skupina ostalih) ali so jih izbrali njihovi nadrejeni, njihovo sodelovanje pa je bilo obvezno (skupina zdravstvenih strokovnjakov/nemotiviranih).

Rezultati: Dojemanje sodelujočih o svojem lastnem znanju in razumevanje nege ob perinatalni izgubi je bilo po končanem izobraževalnem programu značilno višje, kar dokazuje njegovo učinkovitost. Podan je tudi statistično značilen učinek na splošen izid posameznih skupin anketirancev ter na celoten set (p < 0,001) z višjimi rezultati po izvedbi od rezultatov pred izvedbo izobraževanja. Pri splošnem rezultatu ni zaznani statistično pomembnih razlik pred sodelovanjem v izobraževalnem programu v posameznih skupinah (p = 0,204). Sodelujoči iz skupine zdravstvenih strokovnjakov/nemotiviranih so dosegli nižje rezultate po izvedbi v statistično pomembnem obsegu (p < 0,05) ter so pogosto izrazili, da je izobraževalni program »zelo zahteven« (x² = 20,66, df = 6, P < 0,01) v primerjavi z drugimi skupinami.

Zaključek: Izobraževalni program je ocenjen kot učinkovit. Nega žalujočih staršev ima posebnosti in strokovnjaki s področja zdravstvene nege potrebujejo osnovna znanja, kako v tem času ponuditi občutljivo nego.

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1 INTRODUCTION

Perinatal loss (miscarriage, stillbirth, neonatal death) is a psychologically stressful event and parents endure agonising sorrow following the death of a baby. In the Czech Republic, around 450 women and their families experience perinatal loss every year. For most women experiencing perinatal loss, the quality of care from medical professionals has a direct effect on their psychological health and the grieving process (1-3).

Medical professionals refer to stillbirth as one of the most difficult experiences in the field of obstetrics (4) and describe the support and care of bereaved parents as demanding and complicated (5, 6).

Working with bereaved parents is an immense challenge for professionals in the field of perinatal care and requires a high level of knowledge and skill. Positive attitudes in healthcare professionals toward care for parents who suffered perinatal loss are associated with previous education in the field of care for bereaved parents, support of a dedicated bereavement team, and hospital policy supporting the care for bereaved parents (7, 8).

Most professionals who deal with the experiences of parents after perinatal loss point out the need for evidence-based training in care after perinatal loss using a parent-centred integrated pathway to improve the experience of bereaved parents (3, 7, 9-11).

In the Czech Republic, however, education in this field of care is insufficient. This is why the Perinatal Loss Care (PLC) course was created. This article aims to evaluate the effectiveness of the PLC-blended educational programme in the Czech Republic.

2 METHODS

The PLC educational programme is intended for medical and healthcare professionals who are involved in the care of bereaved parents. It is designed to incorporate theory and practice and has a duration of 10 weeks. It is based on a holistic approach to perinatal bereavement care with an emphasis on bio-psycho-socio-spiritual elements. A blended learning approach was chosen, as is recommended by Kavanaugh et al. (12) in respect of sensitive and often emotional content associated with grieving and bereavement. The theoretical part of the programme is divided into 10 lectures available to participants in the form of e-learning. Medical professionals consider online learning opportunities as suitable for their working conditions and needs (13). Every week a new lesson of the educational programme is made available to participants. The educational goals of individual lessons are stated in Table 1.

Table 1. Learning objectives of the PLC educational programme.

1. To understand the bereavement process after perinatal loss.
2. To define the principles of communicating adverse news to parents.
3. To critically evaluate the plan for the care of women during stillbirth.
4. To critically evaluate the plan for the care of parents during the death of a premature or disabled child.
5. To plan an intervention during the hospitalisation of women after perinatal loss.
6. To describe the main areas of education for women before release from hospital.
7. To understand the prospects of coping with grief after perinatal loss.
8. To distinguish normal and complex bereavement.
9. To describe the prospects of professional and non-professional help for parents after perinatal loss.
10. To apply the principles of mental hygiene.

Training content is complemented with current research, audio-visual recordings on perinatal palliative care, references to literary resources, and the testimonies of parents who have experienced perinatal loss. During the course, participants are able to discuss individual topics with each other and with tutors. Participant involvement is supported with the allocation of tasks in an interactive online depository. At the end of the e-learning educational programme, participants take a theoretical test.

The educational programme is led by two tutors (professionals in the fields of midwifery and psychotherapy). They also participate in leading practical seminars (2x8h classroom activities), which are arranged after the 5th and 10th e-learning lessons. The seminar includes workshops, role plays to resolve model situations, communication skills training, the application of psycho-relaxing exercises, and meetings with parents who have experienced the death of a baby. During the seminars, instructors create a safe place in which participants are able to discuss sensitive topics. Participants voluntarily play various roles in model situations. Personal and professional vulnerabilities are acknowledged and, following the workshops, a clearer understanding of accessible support strategies is gained. The recommended number of participants in the programme is 20-30. Ten weeks for the educational programme was chosen intentionally, as longer educational programmes are known to have a greater chance of changing attitudes toward caring for dying patients than one-off lectures (14).

The goal of the PLC educational programme is to improve participant knowledge of PLC, therefore, an evaluation was carried out.

2.1 Study Design

The PLC educational programme was evaluated quantitatively using pre/post-test, three group design (divided according to occupation and motivation for participation in the educational programme; see Sample). Surveys were administered pre- and post-training to attendees in 2015-2017. These courses were always led by the two same instructors and saw a total of 242 participants. The surveys focused on the perceived level of knowledge in participants, their expectations, and perception of the difficulty of the PLC educational programme. The researchers were able to compare perceived knowledge before and after an intervention due to a baseline of target population established based on surveys (15).

2.2 Sample

The PLC educational programme was offered to hospitals in the Czech Republic via e-mail, and an offer of the course was available on the “Empty Cradle” website - that of a group of parents who have experienced perinatal loss. A total of two hundred participants were incorporated into the evaluation research, all of whom agreed to take part in the research and all of whom completed the pre- and post-intervention tests. For the purposes of data analysis,

participants were divided into three groups. The first group (Medical Professionals/Motivated) consisted of medical professionals who chose to participate in the educational programme as a part of their lifelong education and who wanted to actively deepen their knowledge in the field of the care of bereaved parents. The second group (Medical Professionals/Non/Motivated) consisted of employees from a gynaecology-obstetrics clinic in the Czech Republic whose employer paid for the educational programme and whose attendance on the course was compulsory. The goal was a blanket training of the staff of one workplace and the seminars took place at the gynaecology-obstetrics clinic. The third group (Others) consisted of participants in the educational programme from various occupations, who were in one way or another involved in the care of bereaved parents and who were interested in obtaining new knowledge and skills in this field. Seminars for the Medical Professionals/Motivated and Others groups were held collectively (in mixed groups) at an educational centre in Prague.

2.3 Data Collection Tool and Process

The construction of the evaluation questionnaire was inspired by the UBET tool (16). The evaluation questionnaire that was used comprised of questions focusing on the perceived level of knowledge of the respondents before and after the completion of the educational programme (see Table 2).

Table 2. Pre- and post-test and points rating.

| Questions | Possibilities/ Scales | Points |
|---|---|-------------|
| How much do you know about the psycho-social care of parents after perinatal loss? | 1-10 | 1-10 |
| I know the rules on communicating information about the death of a baby to parents. | No - more likely no - more likely yes - yes | 0-3 |
| How would you intervene in the physical contact of a woman with her stillborn baby? | a) I would recommend the woman see and hold the baby. b) I would provide information on how the woman could physically say goodbye to the baby. c) I would not recommend the woman physical contact with the stillborn baby. d) I would ask the woman if she wanted to see or hold her baby. | 0-3 |
| I am able to recognise cases in which the grieving process of a woman has become complex and she needs professional psychological help. | No - more likely no - more likely yes - yes | 0-3 |
| I know effective tools of mental-hygiene and I know how to use them in practice. | No - more likely no - more likely yes - yes | 0-3 |
| Total | | 1-22 |

The questionnaire was always completed before the start of the educational programme and, after its completion, respectively before the final practical seminar, in which further questions could be asked or further information added.

Within the framework of a mathematical-statistical analysis, the shift in the perceived level of respondent knowledge was measured using applied standard scales in a Paired T-Test. The degree of compliance was also tested using a Pearson Chi-Square test. Testing was performed using the SPSS and SASD programmes, version 1.5.6. The Medical Professionals/Motivated, Medical Professionals/Non/Motivated and Others groups were tested separately and, subsequently, the entire set together.

3 RESULTS

3.1 Demographic Data

A total of 200 participants met the criteria of the study. Their demographic characteristics are represented in Table 3. All categories were strongly dominated by women, who made up 93% in total. The first group (designated Medical Professionals/Motivated) consisted of 74 participants, of whom 53 were midwives, 9 neonatal nurses, 2 obstetricians, and 10 neonatologists. The second group (designated Medical Professionals/Non/Motivated) included 27 midwives, 51 neonatal nurses, and 9 neonatologists, with 87 participants in total. The third group (designated Others) contained 39 participants, including psychologists, social workers, doulas, counsellors, priests, crisis interveners etc.

Table 3. Descriptive statistics (mean and SD or relative frequency) by group.

| | Medical Professionals/ Motivated | Medical Professionals/ Non/Motivated | Others | Total |
|---------------------|-------------------------------------|---|-----------------|-----------------|
| Gender (women %) | 90.54 | 95.4 | 92.31 | 93 |
| Age | 37.84 (8.65) | 39.13 (7.7) | 36.95 (7.64) | 38.23 (8.06) |
| N | 74 | 87 | 39 | 200 |

3.2 Evaluation

A statistically significant effect in the total score was observed in individual groups of respondents, as well as in the whole set ($p < 0.001$) with post-intervention scores higher than pre-intervention scores (see Table 4).

Table 4. Results of pre and post-tests scores by category of attendants and in total.

| Group | Mean pre-test scores (SD) | Mean post-test scores (SD) |
|---|---------------------------|----------------------------|
| Medical Professionals/ Motivated | 9.76 (3.28) | 18.00 (1.90) |
| Medical Professionals/ Non/Motivated | 9.05 (3.20) | 17.32 (2.34) |
| Others | 10.05 (3.33) | 18.41 (1.81) |
| Total | 9.51 (3.28) | 17.79 (2.13) |

Min. 1 point, max.22 points

No statistically significant differences in total score before the completion of the educational programme in individual groups were identified ($p = 0.204$). However, significant differences in total score were identified in individual groups after the course. Participants from the Medical Professionals/Non/Motivated group achieved lower scores to a significantly greater extent, and participants from the Others group achieved higher scores to a significantly greater extent ($p < 0.05$).

During the analysis of individual answers from the evaluation questionnaire, some significant differences between individual groups of respondents were identified. To the question "How would you intervene in the physical contact of a woman with her stillborn baby?" a statistically significant shift in the choice of possible answer was unequivocally proven (see Table 5).

Table 5. The evaluation of the question “How would you intervene in the physical contact of a woman with her stillborn baby?” in pre- and post-test.

| “How would you intervene in the physical contact of a woman with her stillborn baby?” | Medical Professionals/ Motivated | | Medical Professionals/Non/ Motivated | | Others | |
|---|-------------------------------------|----------------|---|----------------|---------------|----------------|
| | pre-test % | post-test % | pre-test % | post-test % | pre-test % | post-test % |
| a) I would recommend the woman see and hold the baby. | 23.0 | 36.5 | 24.1 | 48.3 | 23.1 | 17.9 |
| b) I would provide information on how the woman could physically say goodbye to the baby. | 44.6 | 60.8 | 46.0 | 46.0 | 53.8 | 82.1 |
| c) I would not recommend the woman physical contact with the stillborn baby. | 0 | 0 | 0 | 0 | 0 | 0 |
| d) I would ask the woman if she wanted to see or hold her baby. | 32.4 | 2.7 | 29.9 | 5.7 | 23.1 | 0 |

In the whole set, and in the groups of medical professionals (Motivated and Non/Motivated), the shift was proven at the level of $p < 0.001$, in the group of Others at the level of $p < 0.05$. After completion of the course, in all cases, a statistically significant decrease was observed in the choice of answer d) “I would ask the woman if she wanted to see or hold her baby,” and a statistically significant increase was observed in the choice of answer b) “I would provide information on how the woman could physically say goodbye to the baby,” (with the exception of the Medical Professionals/Non/Motivated group, where the choice of answer b) did not change). The choice of answer a) “I would recommend the woman see and hold the baby,” also saw a statistically significant increase, with the exception of the Others group.

Before the completion of the PLC educational programme, respondents anticipated that during the programme they would improve their knowledge and secure more assurance in the psycho-social care of bereaved parents, meaning they would, therefore, be better able to cope with the situation of perinatal loss.

Participants’ expectations of the PLC educational programme were 83.8% fully met in the Medical Professionals/Motivated group, 52.9% in the Medical Professionals/Non/Motivated group, and 84.6% in the Others group. Participants mostly perceived the programme as being “moderately challenging” (58.1%). Participants from the Medical Professionals/Non/Motivated group assessed the course as statistically significantly more often as “very challenging” ($\chi^2=20.66$, $df=6$, $P < 0.01$).

4 DISCUSSION

Participants’ perception of their own knowledge and understanding of perinatal bereavement care was significantly higher after the completion of the PLC educational programme, proving its effectiveness. The effectiveness of the course could be affected by the combination of extremely efficient teaching methods. The blended learning method was chosen for the course, with online asynchronous e-learning on the one hand and personal meetings on the other, where elements of psycho-social training were used for the development of communication skills and the use of therapeutic techniques in the care of bereaved families. Positive effects of the course manifested in all three groups of participants (Motivated and Non/Motivated Medical professionals and Others). Each group, however, exhibited their own specific features. The Medical Professionals/Non/Motivated group received the lowest scores in the post-test. These participants attended the course at their employer’s behest; some exhibited an interest in education in this field, while others felt coerced into participating and felt that they had never encountered the situation of the death of a baby in practice. Their need for competence and autonomy, therefore, remained unfulfilled, which probably led to a negative impact on their learning experience and the satisfaction they obtained.

One question that remained unanswered in this research was whether the various medical professions benefitted from the course to the same extent. Participants in the PLC educational programme were predominantly midwives and neonatal nurses; only 2 male obstetricians were present, with no female obstetricians at all.

Therefore, they cannot be statistically compared. It can, however, be assumed that the attitude of the obstetricians toward bereavement care will differ. A qualitative study by Montero et al. (17, p. 1409) includes a statement by one of the obstetricians: "I don't believe that education is necessary, because we know intuitively how to manage these situations." In general, very little is known about obstetricians' reactions to perinatal death. Feelings of guilt and failure in obstetricians who care for women after perinatal loss (10, 17), sorrow and high emotional tension, which can lead to considerations of leaving the profession (11), are primarily mentioned. Withdrawal from the situation, "a conspiracy of silence" and denial, attention to the physical aspects of care, and immersion in administrative tasks were common reactions among healthcare personnel to perinatal death (9, 18, 19). These reactions may lead to a lower quality of care for the bereaved parents and the possibility of an avoidance of education in the field of the care of bereaved parents, or to resistance to compulsory attendance of the course. Therefore, it can be assumed that a higher attendance of obstetricians of the course could help to improve the quality of care, as well as their own well-being.

During discussions and personal meetings, participants supported each other and shared common painful stories, which in itself could have had an effect on the general sense of belonging and group support. Discussion and innovative methods during teaching tend to support the creation of opinions, attitudes and skills in the care of bereaved parents (20) and have a positive impact on the nurses' attitudes toward death by helping them better understand the significance of the experience of suffering (21). Meetings of individuals from various support and health professions also lead to an understanding of the role, as well as an appreciation of the roles of other professionals in the care of parents after perinatal loss (22).

A patriarchal approach in the field of healthcare, including care during childbirth, is still prevalent among medical professionals in the Czech Republic (23). This manifested itself in answers to the question "How would you intervene in the physical contact of a woman with her stillborn child?" Many studies state that the approach of carers and their communication with parents can have a significant effect on whether or not parents see or hold their deceased baby. Therefore, during the educational programme, great attention was paid to the rituals of bidding farewell to a deceased baby. Among other things, participants learnt that it is not recommended to ask bereaved parents the question, "Do you want to see your child?" but parents' natural compulsion to see and hold their deceased baby should be reflected (24, 25). Therefore, after the completion of the PLC course, the

preference of the answer, "I would ask the woman if she wanted to see or hold her baby," significantly decreased (29.5% of respondents chose this answer in the pre-test, with only 3.5% in the post-test). The positive attitude of the respondents toward the rituals of bidding farewell to a stillborn baby (none of the respondents preferred the answer, "I would not recommend the woman physical contact with her stillborn child," in pre- nor post-test) was one positive outcome of the research. Holding and seeing a deceased baby is valuable for most but not all women (26). Who should decide what would be best for a particular woman/parent? Can the healthcare professionals recommend physical contact with a deceased baby to all women? It is currently preferred to allow the parents to decide for themselves as to which solution is the best for them. Healthcare professionals should, therefore, inform the parents verbally and in written form of the opportunities available to them to bid farewell to their deceased baby, discuss their feelings, and give them time to decide before the birth. The answer, "I would provide information on how the woman could physically say goodbye to the child," was chosen by 47% of respondents in the pre-test and 58.5% of respondents in the post-test. In our research, in the group of Medical Professionals (Motivated and Non/Motivated), the preference for the answer "I would recommend the woman see and hold the baby," increased in the post-test (compared to the pre-test). In the Others group, on the other hand, preference for this answer decreased in the post-test (compared to the pre-test). Even though some parents need increased guidance in making difficult decisions after a diagnosis of stillbirth (27), medical professionals should not take a dominant position and make the decision on the parents' behalf. It is important for them to use their communication skills to maximum effect and to further educate themselves in the field of communication with patients, principally in emotionally demanding situations.

Limitations of the study include the fact that data was only collected immediately after the educational programme. Only a brief evaluation tool was used and one which was not validated.

5 CONCLUSION

The PLC educational programme was evaluated as effective. Training using blended learning proved to be successful and can be recommended primarily for the education of working medical professionals who are fully experienced in practice. E-learning can be constantly updated and fine-tuned to the expectations of course participants. Workshops during personal meetings enable the development of communication skills in the care of bereaved parents, as well as self-care and mental hygiene.

These are the two areas in which participants in the PLC educational programme required the most improvement. The care of bereaved parents has its own specifics and medical professionals should possess a basic knowledge of how to provide sensitive care during this period. Not all medical professionals, however, are motivated to educate themselves further in this field. In the Czech Republic, the creation of perinatal bereavement teams, in which professionals with an empathy and deep understanding of palliative care would work, is deemed to be essential.

CONFLICTS OF INTEREST

The authors have no conflict of interest to declare.

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ETHICAL APPROVAL

All of the respondents of the research completed the questionnaire voluntarily, were acquainted with the goals and the method of processing the questionnaire and agreed to participate in the evaluation of the educational programme. Since this study was viewed as evaluation and not specifically research, ethical approval was not formally sought nor required.

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