Processes of enhanced self-understanding during a counselling programme for parents of children with disabilities

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Processes of enhanced self-understanding during a counselling programme for parents of children with disabilities

Background: The stress and burden on parents of children with disabilities are well documented, and the parents’ way of handling the situation is crucial to the health and well-being of all family members, including the child with special needs. We conducted a group-based counselling programme for parents, based mainly on Gestalt education and personal construct theories, aiming at increasing the parents’ ability to handle the situation.

Aims: To explore the parents’ experiences from processes of change after the counselling programme.

Method design: This qualitative study is based on modified grounded theory.

Method: The study conducted in Norway examines the experiences of 67 parents (of whom 29 fathers) of children with disabilities. Information was collected through focus group discussions after finishing their sessions of the counselling programme.

Findings: From the parents’ experiences, the following categories were developed: feeling motivated to communicate, describing oneself in new words, being inspired to experience one’s own emotions, being more present and in charge and making a difference by taking new steps. The core category in our analysis turned out to be Improved handling of the situation by enhanced self-understanding. The parents seemed to redevelop their self-understanding through new experiences of themselves. They emphasized the importance of a secure setting of peers with similar experiences and skilled counsellors to feel free to explore one’s own emotions with connecting thoughts and bodily reactions. Discussion of existential issues as one’s own values also contributed to enhanced self-understanding, which strengthened the parents to find new possibilities and priorities in handling the situation.

Conclusions: The parents described subjective processes of awareness and self-reflection as important for being able to start a process towards enhanced self-understanding, which helped to detect one’s own values and new ways of acting. These experiences may be relevant for the parents and for the conduction of future counselling.

Keywords: health promotion, rehabilitation, parents of children with disabilities, lived experience, quality of life, counselling, grounded theory, focus groups, qualitative approaches.

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Introduction

Parents of children with disabilities often experience a strained life situation in terms of physical, psychological, social and financial challenges (1–3). While the physical and financial demands in these families are often recognized, the psychological and social demands are not always given equal attention by health professionals (4). The parents run an increased risk of decreased health and well-being, especially studied in the mothers (5–7). In recent years, there has been a shift in rehabilitation services for these children from child-centred models towards a family-centred approach, with parents being increasingly involved in the child’s rehabilitation (8, 9). Although the active involvement of parents is essential for creating good solutions, this shift may accidentally increase their total responsibility and, thereby, also their burden (8, 10, 11). According to Klingberg et al. (12), the ability of parents to
participate is more closely linked to the family’s social support and family income than to the degree of the child’s disability.

The parents’ experience of the situation will depend on how they consider their own resources and abilities to cope with it and prioritize (13–16). Nevertheless, there is extensive knowledge about how people can live a good life in a stressful situation (17, 18). Self-efficacy, responsibility, empowerment and promotion of health have been described (15, 19). Graungaard et al. (20) present a model from the parents’ experiences of resource creation essentially based on cognitive appraisals and reappraisals for improved coping. The authors claim that health professionals can support such processes among parents. There are, however, few studies that aim to support parents’ well-being, and there is a lack of knowledge with respect to the parents’ experiences of processes of change for better handling their life. A 3-year health promotion project among parents of children with special needs provided us the opportunity to study the parents’ own experiences.

The counselling programme

The counselling programme was based on the theories of confluent education from Gestalt psychology (21, 22), phenomenology of the body (23) and psychology of personal constructs (24, 25). The content was in co-understanding with principles in mindfulness (26, 27) and salutogenesis (17). In all experiences, bodily reactions, emotions and thoughts are understood as one integrated unit. Through new experiences and the ability of awareness and self-reflection, man can change earlier meaningful units, including self-understanding (14, 15, 21, 22, 28).

Applying this theoretical basis, a group-model was designed and evaluated among patients with chronic pain for improved well-being and coping (29). An adjusted and shortened programme was tried out (30) and in this study further developed together with two parents to a total of four sessions. Each session lasted five hours during daytime and addressed a specific theme: self-identity, one’s own core values, own emotions and own qualities. The participants were invited to activities, such as mindfulness and body awareness training, writing, creative drawing and guided imagery, shared with the others in pairs, in small groups or in the whole group (21, 30–32). The group leaders accepted the participants’ narratives and encouraged awareness of available resources and their own solutions for participation and well-being. Based upon what became important to themselves during the sessions, each participant formulated specific challenges for themselves to practise in between the sessions.

Four group leaders, two in each group, were all health professionals with experience in group counselling.

Aim

The aim of this study was to gain increased knowledge of the participants’ experiences from the processes of change for a better life during and after a counselling programme for parents of children with disabilities. This knowledge may increase the understanding of families in such situations.

Method

Setting

The present study assesses the experiences of participating parents in nine groups (2006–2007) 2 months after the counselling programme. Parents were invited to an information meeting through a nongovernmental organization for parents of children with disabilities, a university hospital and the family doctors and public health nurses referring them to this hospital. After the information meetings, the participants signed a full-informed consent prior to enrolment in the programme. The participants were informed that the group sessions were part of a research programme and that their responses in the focus group discussions would be used for this study. The project group, who conducted the programme with the first author as the administrator, was not part of the families’ regular healthcare systems and did not know the participants before the project. The Norwegian Data Inspectorate approved the project.

The participants

In all, 76 parents (31 fathers) chose to participate after the information meetings and were assigned to the nine counselling groups. Most were couples participating together, 14 participated alone and four were single parents. Their age ranged from 23 to 49 years (mean, 38.4 years). The parents had a total of 47 children from 1 to 18 years of age (mean, 6.2 years), 41 of them had siblings. The parents’ educational level varied from 6 years at school to more than 4 years at the university. Five parents quit the programme prematurely: the three who had children of 18 years and two who got a changed work situation. Those who completed the programme attended 92% of the time and assessed the programme’s relevance to 8.6 (on a scale from zero to 10). Among these parents, 67 (29 fathers) were able to participate in the focus group discussions.

The qualitative study

Grounded theory. In the present study, we wanted to look deeper into the parents’ processes of change. When studying social processes, the inductive qualitative method of modified grounded theory is useful (33), particularly when the aim is to increase the understanding of the research area.
The theoretical roots of grounded theory originate from symbolic interactionism, which states that an individual’s meaning is constructed and changed through interactions with others (34). Therefore, meaning will be reconstructed as individuals’ perceptions of the world by their interactions are changing, as in new situations (35).

The basic principles of grounded theory include theoretical sampling and analysis, constant comparisons, theoretical sensitivity and saturation. Constant comparison includes a repeated comparison of raw data and emerging categories during the entire process of analysis. Theoretical sampling is used to reach saturation and is guided from the emerging categories (36). Saturation, although somewhat ‘elastic’, is reached when new focus groups do not seem to bring additional information into the emerging categories but fit into the categories already devised. (33). Theoretical sensitivity refers to the researcher’s reflexive way of developing research questions and performing analysis.

Data collection. Two months after the sessions ended, semi-structured focus group discussions lasting up to 90 minutes were conducted in all nine counselling groups, to get more detailed descriptions from the participants’ experiences of their own processes (37, 38). The two group leaders were moderators. The purpose of the discussions was to increase the knowledge about ‘what had happened’ and ‘what became important’ to the participants. The moderators also asked the participants to comment on opinions that had arisen during discussions preceding their group. The participants had the opportunity to raise subjectively important issues, and the moderators asked probing questions. In addition, they discussed their experiences and reflections with each other. All the discussions were tape-recorded.

Analysis according to grounded theory. The focus group discussions were verbatim-transcribed by the first author, also with nonlanguage utterances noted for bringing up the atmosphere and emotions that followed the words. The texts were read as a whole to obtain a general idea before read line by line in an open coding to define what was pronounced. The open coding process ended up by gathering units with similar contents into more abstract categories. In focused or selective coding, every category was further developed by abstraction and through constant comparisons where different parts of the data were continuously compared with other parts in terms of differences, similarities or links between the different categories (33). A specific category was compared with other categories, as well as information from different participants was compared with an emerging category (39). More than identifying topics, we looked for actions and processes of ‘What is happening here?’ In this coding, the different categories were finalized as earlier data were recorded, also searching for saturation. A ‘core category’ was developed from the data, which was central and could be related to all other categories. Through the whole process, the researchers’ ideas, suggestions and theoretical reflections were compiled in ‘memos’.

Findings
In the analysis, a core category ‘Improved handling of the situation by enhanced self-understanding’ emerged, related to five categories based on the parents’ descriptions of their experiences. These categories formed a model of personal processes of change including phases where some seemed prerequisite to the next, although they were also occurring simultaneously and reoccurring as the participants made new experiences, that is, feeling motivated to communicate, describing oneself in new words, being inspired to experience one’s own emotions, being more present and in charge and making a difference by taking new steps.

Feeling motivated to communicate
The parents stated that they had been surprised by how they had felt motivated and free to expose themselves in the groups and open up to their own thoughts, reactions and emotions. The experience of being understood by those they considered qualified for understanding was essential. They thought of their own situation as fundamentally different as they often experienced either being avoided or gaining too much attention compared with ‘normal family’ parents. Several parents felt like performers on a stage with health professionals, with regular parents and others as audience. They thought others would pity them without really understanding when hearing their story; ‘it would not be worth it’. They were also excluded from advice inexperienced ‘normal family’ parents often receive from the more experienced. They associated their motivating freedom in the groups with being able to express themselves without feeling inhibited; it was ‘worth it’ as the others were able to really listen and believe them. This preunderstanding was confirmed by responses such as eye contact, tears and relevant comments, all at the right moments. They described how they could take themselves more seriously, feel less alone and more normal. They also emphasized the group leaders’ nonjudgemental attitudes and appreciated the group leaders’ independence from their regular rehabilitation team. The participants experienced how it became meaningful and exiting to find out more about themselves and became more interested in the experiences and reflections of others.

If you’re talking to someone you know is in somewhat the same situation as yourself, you’ll express yourself in a completely different way than when you’re talking to someone you’re maybe hoping will understand you, but who most likely doesn’t stand a chance. It has something to do with – all those human things, that are understood by others, and feelings, – it
becomes intimate, I think (...) I think it was very special to be here — It was good to – open up.(P-51)

**Describing oneself in new words**

Feeling more free and motivated to communicate, most of the participants felt encouraged to consider new words and trying them out to find better descriptions, facilitating more relevant commenting on the participants’ narratives. They described the process of finding words to their experiences and thereby exploring themselves as new and rather hard, especially in the beginning and particularly regarding issues seldom addressed. Such issues were their own values, strong emotions and bodily reactions. Also, based on others’ comments, they experienced how new words could better describe themselves, for example, wanting to be in control or feeling isolated. Few of the parents had raised these experiences as an issue before, and fathers stated they had had very few occasions to practise how to describe themselves. Simultaneously, almost everybody told about their astonishment when some words, like ‘friends’ or ‘grief’, aroused their strong reactions. Some words, both others’ and their own, had even affected the parents’ understanding, for example, the word ‘joy’ had made many realize how happy their lives still were. New words had emerged and were discovered by their own writing, describing drawings or putting words to bodily reactions. They described their struggle to find the right words like ‘listening to myself in a new way’. What they had thought of as ‘anger’ could be closer to ‘grief’; irritating ‘concerns’ could also be useful ‘preparations’. A confirmation of changed self-understanding emerged from this exploration. Couple participants furthermore emphasized how they were now able to see their partner in a new way and underlined how active listening in the group differed from their usual conversations.

I listen to others and – I begin to write about something. And when I, in a way, begin to talk about it, perhaps something else comes out too — it’s like I’m saying something which raises my own awareness of what I’m saying! And when I have to ‘present’ it, or say it myself, maybe I’ll say something else than what I’ve really written.(P-20)

**Being inspired to experience one’s own emotions**

Many of the parents described how they at first had become amazed or chocked as they had realized their own unexpected and strong emotions. Some had been frightened by their own fear or anger, some ashamed by grief they considered unacceptable. These emotions were often connected with negative thoughts, like not wanting the child, and bodily reactions, like muscle tension. However, many parents had avoided the emotions because they had no time or room for them. They experienced how they needed to be challenged to recognize and realize emotions they thought were ‘gone a long time ago’ (grief) or emotions from ‘deep inside of me’ (hope, joy). By being challenged, most of them experienced how what they had considered an unpleasant emotion, such as impatience, actually was the acceptable emotion of being sad because their child could not understand. The acceptable emotions could be easier to address, like explaining more carefully or making better plans to not become impatient. The parents had also been surprised by their intense experience of joy, particularly from small details in life and their child’s satisfaction, and they had realized how important their child was to them. They experienced how they could be really sad and happy simultaneously, although some hurtful feelings and also some of happiness and hope seemed almost unacceptable. Still, everybody emphasized how important recognition of all emotions had been to their well-being. This increased their understanding of their own ways of taking control or denying their special situation. They agreed that these processes were hard work, but also described the value of living with the whole width of their emotions.

... then, in a way – you become aware of — I have perhaps felt a few of those — hurt (emotions), and so I tried thinking creatively instead of thinking about what hurts. But to perhaps — think – a little about what is sad instead of pushing it away – trying to come out with it, make yourself let go of it instead of just holding on to it — Yes, you have to – make yourself aware of it, dare to feel it. Dare to feel what hurts.(P-26)

**Being more present and in charge**

As the parents got to know themselves better, they spoke of how they became encouraged to explore the consequences of their increased awareness. Sometimes, the new experiences had instantly affected their acting, like focusing on one thing at a time or taking their emotions seriously. However, most of them described how they had become astonished by the unusual question ‘What now?’ Their examples illustrated a further process from new awareness to realizing the consequences. They emphasized how they needed to be challenged to face the consequences of the new experiences and to take their self-reflection more seriously. Their vivid descriptions were indicative of the astonishment and excitement caused by these challenges, for example, taking more time with siblings or having a ‘personal assistant’ care for the child at home. They were used to think they just had to ‘live with it’, to leave the decisions to ‘specialists’ or to ‘fight for their rights’. Considering the consequences, they spoke of how their awareness had become more interesting and inspiring, but also frightening and demanding. Essential to this process, the parents emphasized their awareness of what
was truly important to them, their values and priorities, indicating reflection of their former traditional ways of thinking, including their avoidance tendencies and restricted ideas on possibilities. Relying more on their own values and thereby their own decisions, they described how they could allow themselves to struggle less and relax more. Becoming clearer to themselves, they could be clearer to others. Some parents realized how they had organized, but not really participated, in their child’s life, while others could see how they had been too much in control.

…it can be that I instead of doing something about it – it’s easier to shy away than doing something. (…) I think that the group has strengthened this – because you expose yourself – and get as a response: “Well, what are you going to do about it?” (smiles a little). It raises awareness – that it’s said. (…) For me it came from the values we had set up for ourselves, “what is important to me” – the things that mean something – it was a connection to what you want: What I want to do, not only wish for (smiles again) – That was it, then: What is important to you – that’s a job in itself to find out!(P-44)

Making a difference by taking new steps

The parents underlined the importance of having taken the time to find and try out the specific, often practical, newly found solutions. Most of them expressed a need for support in terms of finding the small, feasible steps. They now analysed what being too much in control or denying and avoiding their situation looked like. They described how their enhanced consciousness changed their ability to see new possibilities for the moment and live more according to their own values, reactions and resources.

Thereby, the parents experienced how their self-understanding had been essential in influencing their situation. They gave examples of new steps taken both owing to being more present and taking new decisions, like taking a 30-minute walk every Tuesday and Friday. Within a short period of time, they had been amazed how much these changes meant. Moreover, steps that had seemed quite demanding but important, like making better plans or working less, had also been possible to achieve. In addition, they underlined how awareness of earlier coping had improved their handling of the situations. Experiences of satisfaction had opened up to new resources. Almost everybody had realized the importance of taking better care of themselves, which also had increased their self-respect. It had become easier for them to postpone some dreams and tolerate unpleasant choices as they thought it would be for the better in the long run. Many had thought their lives were not so far from “typical family life” after all. Living according to their own decisions, they experienced being more present, selective and optimistic, like ‘seeing a road always lightened up in the dark like an airplane landing-strip’, as one father described it.

To stop and say that: “No, I’m going to change things – I want things to be different now…” It has become a lot more clear that it’s possible – to affect things yourself, not just think that things can become different. It is a phrase I have never worked on before: that things can become different! And it’s very important psychologically, that you don’t get stuck in the wrong path or anything like that, but that you kind of take charge of things too.(P-44)

The core category: ‘Improved handling of the situation by enhanced self-understanding’

To get to know themselves better, the parents emphasized the value of being in a setting where they had become motivated and also challenged to increased self-awareness and self-reflection. They thereby had experienced and learned more about themselves. Through finding better words to describe their experiences, they could understand even more and found it interesting to explore their own emotions and the connections related to thoughts and bodily reactions. The parents emphasized how recognizing their own values and resources made it easier for them to choose what they wanted, separating what they could affect from what they could not. Based on this enhanced self-understanding, each one of them had been able to detect new possibilities, separating what was possible to achieve and in what way. The parents described improved coping and well-being as they chose to live more in accordance with their own values and resources in their situation.

Discussion

This study shows that the parents experienced important processes of change through increased understanding of themselves in their situation. This enhanced self-understanding described from new experiences is in line with the reconstructions of meaning in Gestalt theory (21, 22) and also in personal construct theories (24, 25). From awareness of their own values and accepting their own emotions, the parents could understand better how to take care of their resources and live according to the consequences of their new experiences. They emphasized the context of their experiences as important to the processes, like being in contact with others in the same situation and challenged by the counselling programme; they became motivated to open up, find new words and recognize their thoughts and reactions in a new way (28). The parents’ descriptions of active participation and handling their situations fit into the theories developed by Antonovsky (17), Nygard and Kunszenti (15) and Neimeyer (14). This flexibility based on the awareness of their own values was described as an important source of new energy and satisfaction.

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The participants seemed encouraged to uncover their earlier concepts of understanding, their ‘gestalts’, a necessity to become free to reflect on and find new possibilities of meanings and understanding (22, 41), a ‘reconstructed meaning’ (14). To these processes, the participants underlined the importance of contact with other group members’ qualifications based upon relevant experience, described as an expectation and experience of ‘being understood’. Also, others have documented aspects of the context as crucial to the participants’ ability to become aware of and express themselves (40–43). Some studies conclude that parents meeting each other are important, and different from meeting others (44, 45). As our participants experienced that their thoughts and emotions were understood and were common, it was worth the effort of communicating, and they felt more ‘normal’. Together with the trust and understanding of being together, the participants underlined the importance of being challenged, which is documented less. It was necessary to their enhanced self-understanding to become aware of, face and reflect on the hurting and limiting aspects of themselves (22). In contrast to self-help groups, the participants doubted they would have talked about unpleasant or existential issues without professionals challenging them (46).

The participants were amazed by their process of expressing themselves and how new words confirmed new experiences that changed their thoughts about themselves, also described by Ginger (22). Narrative theory and therapy emphasize the value of reformulating one’s own story to experience an enhanced awareness and self-understanding (47). Becoming willing to communicate, the parents took the risk of receiving hurtful responses. The activities in confluent education, like writing and reading it aloud, seemed to encourage further creative steps of the participants’ healing process of ‘owing’ their new experiences (21). The couples especially learned more about how to appreciate each other and their differences through these processes, found also by Reichenberg and Hallberg (48). The contact with others made them self-reflection more specific (22).

The participants told they had been amazed by the happiness they became aware of while simultaneously also recognizing their own hurtful emotions. Avoidance of their own emotions seemed to stem from either fear of being overwhelmed, feeling ashamed or looking at their own reactions as unimportant at the moment. The stress and pressure on parents of children with disabilities are well documented (2, 3, 8). Lately, also the parents’ happiness and deep love for their child are described (7, 49, 50). The participants also described their new experiences of facing their own emotions as important to their ability to new self-reflections and reactions, their self-understanding (13, 18, 51). Kearney and Griffin (52) visualize parents’ position in the ‘tension between joy and sorrow’; our participants described trying to find a balance between hurtful emotions and the gratefulness the child had brought to their lives. Their descriptions of ‘both – and’ were more like the ‘embrace of paradox’ as Larson (53) calls the parents’ reframing of meaning as they both love their child and still want the child to be ‘normal’. New theories of grieving describe two parallel coping processes: acceptance of the loss (here, the child’s disability) and reorientation towards a new life (the family’s reconstruction of meaning), called ‘The Dual Process Model of Coping with Bereavement’ in (54).

In addition to practising mindfulness with an accepting attitude (26), the participants underlined the value of being challenged to self-reflection on targeted topics and possibilities. Their descriptions of being more ‘present’ and ‘in charge’ sounded like a process from passive escape–avoidance to active participation linked to well-being in coping theories (15, 55, 56). Other descriptions seemed to be a process from being in totally control to letting others in. Mostly, their processes seemed more like a ‘meaning-focused coping’ from ‘emotion-focused’ or ‘problem-focused’ (55). In the literature, different coping styles and the concept of ‘Sense of Coherence’ are commonly used as definitions and classifications of parents. Little is documented from the processes of reorientation or elements that contribute to such processes for well-being by living more in accordance with one’s own values (17, 20, 53). Furthermore, few interventions have had the aim of improving parents’ well-being (11, 57).

The participants emphasized how awareness of self-understanding coupled with knowing what was truly important to them provided their important motivation to changed behaviour. Their ways of acting varied greatly, as described by Glidden and Natcher (58). The parents also chose different solutions according to different situations and life periods in their life. The decision to choose the handling that corresponded to a living based on one’s own decisions from enhanced self-understanding made them active ‘agents’ different from passive ‘pawns’ (16). As the parents were able to change their behaviour, their existential self-reflections seemed to be a crucial basis to the practical reappraisals described by Graungaard et al. (20).

Strengths and limitations
Applying a qualitative focus group discussion method in a setting where the moderators knew the participants from the counselling group sessions provided an opportunity to obtain rich data. The group leaders’ double role as counsellors and researchers could be perceived as disadvantageous, however, not when considering the aim of being able to reflect on the participants’ processes through this study (36, 38). Important issue in our counselling programme also emerged in the core category from the
participants’ experienced processes of change. Possibly, their narratives in the focus group discussions could be influenced by wishes to be ‘clever pupils’, producing a social desirability bias in the information given (59). The same desirability problem exists on the researchers’ side by being limited by their own professional and theoretical background to discern what to be considered as important. On the other hand, the parents’ detailed descriptions illuminated many unexpected aspects, both from their specific changes in daily life and their processes as a result of awareness. We were also surprised by the participants’ downgrading of some of their emotions as unacceptable, like shame and depression. The result chapter was discussed with some of the parents who approved the content.

One may ask if this study is a kind of ‘quality assessment’ or evaluation of our counselling programme, as the parents often related their changing processes to what happened during the sessions. In our opinion, any type of evaluation should approach the planning and conduction details in a way that we did not. In contrast, our study aims to explore individual processes that might not be specific for our counselling method or the programme.

Other considerations
The parents who chose to participate in the counselling groups we assume were especially motivated, extra frustrated or had special resources. However, the participants described themselves differently in terms of resources and possibilities, yet everybody struggled. They represented a wide variation with respect to education and socioeconomic situation, as well as the children’s age and functional level, and their invitation acceptance could not have been foreseen. The amount of participants in this particular study is very high (n = 67) according to other qualitative studies, which speaks for that saturation is reached. Many fathers participated, which is unusual as few fathers have participated in earlier research (7), and few men participated in counselling groups (29). They especially emphasized their need to discuss their experiences and being challenged. From other studies, one might expect gender-specific findings in a study like ours (51), but the thoughts, emotions and reactions the parents described were represented both among the mothers and the fathers. Everybody highlighted the importance of freedom to ‘truly be themselves’. Differences by the parents’ gender may be smaller among volunteers for a counselling programme than among parents in general. We know little about those invited, who chose not to participate, or how many they were. Few attended the information meeting without participating. In our opinion, parents of children with disability should be offered attention to their processes of enhanced self-understanding related to their family situation. In our study, the support was offered independently of the usual rehabilitation, appreciated by the participants.

Conclusion and implications
The parents described new awareness, experiences and existential processes of self-reflection as important for being able to start their process towards enhanced self-understanding. Especially, they emphasized their need to explore their own values and accept strong emotions to detect new possibilities. Accordingly, they experienced new energy and more ways of living with their own reactions and the family’s special needs. To feel free and motivated, they underlined the importance of a secure setting together with challenges from interaction with qualified peers who had relevant experience and with skilled counsellors. These aspects of their own processes may be relevant for the parents of children with disabilities and for the conduction of future counselling.

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Authors’ contributions
The first, second and last authors provided the concept idea and research design. The first author gathered the data, made the transcript and together with the last author performed the analysis with contributions from the other authors. All authors participated in manuscript drafts and critical revisions and all read and approved the final manuscript.

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