Parental Behaviour in Paediatric Chronic Pain: A Qualitative Observational Study

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Abstract

Objectives: Parental behaviour appears to influence the adjustment of children with chronic pain. However research in this area has failed to produce consistent evidence. Studies have tended to rely on self-report measures derived from adult pain populations. This qualitative, observational research provides descriptive data of parental behaviour in a clinical environment.

Design: Qualitative observational study of parents and adolescents in a physically stressful setting. Modified grounded theory analysis of verbal and non-verbal behaviours.

Methods: Eight parent-adolescent dyads seeking treatment for chronic pain were videoed during physical exercise sessions. Verbal and non-verbal behaviours were recorded and transcribed.

Results: Four overarching categories emerged: 'monitoring', 'protecting', 'encouraging' and 'instructing'. These often had both verbal and non-verbal aspects. Within these categories, more precise behavioural groups were also identified.

Conclusions: This research identifies categories of parental behaviour that were derived directly from observation, rather than imposed on the basis of results from different populations. Four categories of behaviour were derived, which clarify and extend dimensions used in existing self-report instruments. Careful description of parental behaviours showed features that past research has neglected, and highlighted potential drawbacks of apparently positive parental actions.

Keywords

Parental Behaviour; Adolescents; Chronic Pain; Qualitative; Observational; Grounded Theory

Introduction

Chronic pain can be distressing and can impact on many important areas of child and adolescent development (Gauntlett-Gilbert and Eccleston, 2007; Roth-Isigkeit, Thyen, Stöven, Schwarzenberger & Schmucker, 2005). Research suggests that there is a relationship between the functioning of children and adolescents with chronic pain and certain environmental and social factors. Specific examples include parental responses, maternal distress and the family environment (Logan & Scharff, 2005; Walker et al., 2006).

Early research into the role of parent behaviour focused on 'solicitous behaviour' (e.g. giving special treats, excusing the child from school; Walker & Zeman, 1992). More recently, measures have highlighted the role of other parental responses. The Adult Responses to Child Symptoms (ARCS; Van Slyke & Walker, 2006) measures parent behaviour on three dimensions; ‘Protect’, ‘Minimise’ and ‘Encourage and Monitor’, whilst the Pain-related Parent Behaviour Inventory (PPBI; Hermann, Zohsel, Hohmeister & Flor, 2008) records parent behaviour as Solicitous, Distracting and Discouraging / Ignoring. Whilst some research has found a link between parental behaviour and child outcomes using such measures (e.g. Claar, Guite, Kaczynski & Logan 2010; Logan & Scharff 2005; Peterson & Palermo 2004; Walker et al., 2006) the findings are not consistent. Other research has failed to find a link between parent behaviour and the functional outcomes of children and adolescents (e.g. Reid, McGrath & Lang, 2005; Logan, Guite, Sherry & Rose 2006; Peterson & Palermo 2004). Palermo and Chambers (2005) reviewed the existing research on parent behaviour and concluded that findings were inconsistent and failed to capture the complexity of the parent-child relationship.

One reason for this situation may be a weakness in current self-report measures. Some measures use categories of parent behaviour that are not derived from a paediatric pain population. Both the ARCS and PPBI, for example, include items based on spousal responses from the West Haven-Yale Multidimensional Pain Inventory (Kerns, Turk & Rudy, 1985). However, categories derived from spousal behaviour may not apply to parenting situations. These instruments also all rely on retrospective parental self-report, with its intrinsic issues of social desirability (e.g. Logan, Claar & Scharff, 2008) and accuracy of memory and self-monitoring (e.g. Cohen, Manimala & Blount, 2001).

Recognising these limitations, researchers have undertaken observational studies to clarify parent behaviour, often in acute paediatric pain settings (e.g. Blount et al., 1989). Studies in chronic pain populations have produced equivocal results. Two studies have identified a potential role for parental discouragement (Dunn-Geier, McGrath, Rourke, Latter & Dastous, 1986; Reid et al., 2005), and one found increased parental directiveness in more severely affected children with arthritis (Power, Dahlquist, Thompson & Warren, 2003). However these studies examined pre-existing categories of parent behaviour that were presumed to apply to the study population. In contrast, the current study examined parental behaviour in a pressured clinical setting; that is, in initial physical rehabilitation sessions. It aimed to provide a description of parental behaviour that emerged from observation, rather than imposing existing categories. It used a qualitative approach to analyse both verbal and non-verbal parental behaviour in a non-laboratory situation that is directly relevant to clinical intervention. We hypothesise that a more precise description of parent behaviours will allow clearer understanding of the nature of parental influence, and will allow the development of parent clinical interventions.

Method

Participants

Participants consisted of a consecutive sample of eight parents and their adolescent children who were attending a three week residential pain management programme at a national speciality service in XXXXXX. The participants were recruited from two different treatment programmes (each programme consisting of six parent-adolescent dyads). The original sample consisted of twelve dyads; however the data from four dyads needed to be excluded. This was as a result of their distance from the recording equipment which resulted in unusable data. No significant demographic differences were noted between those dyads who were and were not included in the study. Adolescents had been experiencing pain for a minimum duration of three months and were diagnosed with a range of chronic pain conditions. The demographic characteristics of both parents and adolescents are presented in Table 1

[insert Table1 about here please].

Adolescents had experienced pain for a long time (mean 4.2 yrs) and experienced substantial functional disability; for example, only two of eight were able to attend full time school.

Ethical approval for this research was obtained from the NHS Local Research Ethics Committee and the hospital's internal Research and Development committee. Parents and adolescents were approached on the first day of treatment and informed of the research. They were given 24 hours to decide if they wished to participate. It was emphasised that neither participating nor refusing to participate would affect treatment, that participation was voluntary and that dyads were free to withdraw at any time. Participants were told that the research was being conducted to increase understanding into chronic pain and how it affects adolescents and their families, specifically within an exercise setting. They were told that the session would follow the same format as normal and that they were not required to do anything differently.

Procedure

Parent behaviour was recorded during group based exercise sessions using two stationary video cameras. Sessions were recorded near to the beginning treatment, at a point where the families on the treatment programme had become familiar with each other but prior to any explicit clinical input about parenting or parent-child communication. Sessions were led by a physiotherapist, lasted one hour and included a group discussion about exercising with chronic pain followed by the dyads being asked to work through a number of upper and lower body exercises. One of the researchers (ED) was also in the room during the sessions as an additional member of the clinical team. In total four physiotherapy sessions were recorded; two from each programme.

Transcription and data analysis

Parent behaviour was analysed using a modified grounded theory approach that stopped after one cycle of data collection (Glaser & Strauss, 1967; Willig, 2001). In grounded theory it is possible to continue collecting more and more data until 'saturation' has been reached, i.e. until no more themes or categories emerge. However many contemporary examples of grounded theory research use a modified approach which stops after one or more cycles The validity of modified approaches has been acknowledged by a number of writers in this area (e.g. Charmaz, 2003; Pidgeon & Henwood, 1997; Willig, 2001). Grounded theory is an inductive method of analysis, where new information emerges directly from data through the progressive identification and refinement of codes and categories in the data (Charmaz, 2006). All session content was transcribed, including both group discussion and physical exercises. Each session was transcribed on multiple occasions, each occasion focusing on just one dyad.

Each transcript contained descriptions of verbal and non-verbal parent behaviour and parent-adolescent interactions. Each transcript was coded line by line and sections of text were given subjective descriptive labels that aimed to summarise the recorded behaviour or interaction. Categories developed as existing labels were re-used, or when labels describing similar behaviour were combined under one heading. A method of constant comparative analysis was adopted during this process which involved comparing the emerging categories, identifying similarities, differences and highlighting potential subcategories. The group of eight was split into two; the first group's data were transcribed and coded before the data from the second group was also transcribed and coded. This allowed the researchers to check the consistency of categories from the first group, to determine if similar categories emerged from the second group, and to checking for instances of behaviour which challenged existing categories. Coding continued until the existing category structure was perceived to adequately capture the observed data. Memos were used throughout as a way of exploring the emerging themes, documenting the analytic process and increasing awareness of the influences and assumptions of the researcher. The initial transcription and coding of the observational data was conducted by one researcher (ED). Two other researchers (MT and JGG) were also involved in the analysis by providing supervision and helping to determine the integrity of the emerging categories. These were experienced chronic pain clinicians who were not involved in the adolescents' treatment. The analysis was conducted using NVivo 8 software.

Results

The results below detail the main categories and subcategories of parental behaviour to emerge, along with representative extracts from the transcripts. Throughout, the code ‘A’ refers to an adolescent participant and ‘P’ to a parent. These categories are intended to serve only as descriptions of behaviour. The study did not explore the reasons for the observed behaviours, or the consequences of behaviour. The intention was to remain close to the recorded data and to present descriptions of the categories that occurred most frequently within and across the dyads. Due to the qualitative nature of this research, no explicit quantitative data is available concerning the frequency of the categories of parental behaviour. However, the researchers were careful to highlight the behaviours which were recorded most frequently, within and across dyads.

1. Monitoring

The parent behaviour which occurred most frequently involved ‘monitoring’ of the adolescent. Here the parent demonstrated increased attentiveness to their child either visually or verbally (see Figure 1).

[insert Figure 1 about here please]

1.1. Visual monitoring. The most commonly recorded parent behaviour involved visual monitoring. In some cases this took place during exercise, where parents would either watch their child generally or would specifically focus on the area of their child’s body affected by pain. Visual monitoring took place when the parents were exercising alongside their child and also at other times when they appeared solely focused on monitoring their adolescent. In this latter circumstance, it would often be the case that once the adolescent had successfully completed one or two exercise repetitions, the parent would start to engage in the exercise themselves (see also ‘Modelling’, in 3.4 below).

Context: Group is doing a stand up exercise.

Extract: P3 stays seated and watches A3 as he does a full stand up from the chair and sits down again.

A3 starts to do the stand up for the second time, P3 turns and faces forward and starts to do the stand ups himself.

Visual monitoring did not only take place during exercise; for example, parents were recorded visually monitoring their child's facial reactions, the area of the body affected by pain, or the adolescent more generally during group discussions when no exercise was taking place.

1.2. Verbal monitoring. In this category the parent would tend to ask the adolescent how they were. Sometimes visual monitoring would lead to verbal monitoring; sometimes verbal monitoring appeared to occur without visual monitoring happening first.

Context: P2 and A2 are doing the stand up exercise side by side.

Extract: P2 looks across at A2.

P2: "Alright? Ok?"

A2 nods.

Like visual monitoring this verbal behaviour took place during exercises, group discussions, and at other points during the session.

2. Protecting

'Protecting' refers to behaviours where the parent appeared to act in a way that aimed to shield their adolescent from pain or distress.

Context: Group discussion about parents' aims and intentions during exercise.

Extract: P6: "Just try and stop them really [referring to physical exertion]. Prevent them from feeling worse the next day."

Protecting behaviour was observed in a number of different ways and has been organised into three subcategories (see Figure 2).

[insert Figure 2 about here please]

2.1. Instigating inactivity. Here parents may suggest that their adolescent reduce, stop or not start an exercise.

Context: A2 performing arm circles:

Extract: A2: "Mum it hurts"

P2: "Ok then don't do anything. It'll make it worse."

A2 stops exercise and rubs his arm.

2.2. Supporting inactivity. This related behaviour tended to occur after an adolescent had expressed concern or apprehension about doing an exercise or during the performance of one. Here the parent would support or justify the adolescent's decision to stop or not exercise.

Context: P6 is sitting beside A6. The rest of the group is standing and doing an arm raise exercise.

Extract: P6 (talking to physiotherapist): "It's hard for her because she can't do it....feels like she can't do it. She's pushing to do more than she can in a day. She's working so hard".

2.3. Unprompted assisting. Here parents would offer the adolescent help or get things for the adolescent e.g. reaching for folders, moving chairs. This was often done before the adolescent had asked for help verbally.

Context: Adolescent is putting a sheet on the floor.

Extract: A1 starts to reach down to put the sheet on the floor.

P1 takes the sheet from her and puts it on the floor.

3. Encouraging

Parents were observed encouraging their adolescents during sessions. This encouragement was observed in a number of different ways (see Figure 3).

[insert Figure 3 about here please]

3.1. Prompting exercise. Parents were observed verbally suggesting that the adolescent try or adapt exercises.

Context: Group is experimenting with getting down onto the floor

Extract: P1 stands ups: "Right, shall we go over [to the step]?"

A1 nods.

P1 and A1 walk over to the step.

P1: "Let's see if it's any easier getting down [onto the floor] this way. It might not work, let's just see what its like".

3.2. Prompting speaking. Parents would also prompt their child to engage in group discussions and speak about their experiences of exercising and how it has been affected by their chronic pain.

Context: Group discussion about exercising

Extract: Physiotherapist: "What sensations will you be getting in your body?"

P1 (to A1): "Your legs shake."

A1 nods.

A1 (to P1): "Shall I say that?"

P1 nods

Physiotherapist (to group): "Anything else that you feel?"

A1 (to group): "I get really, really shaky."

3.3. Praising. Parents were observed verbally praising the adolescent for the exercises they were doing.

Context: A1 and P1 are looking at the worksheet.

Extract: P1: “That’s far more you've done today on your first time than in a long time. It’s fantastic.”

3.4. Modelling. Parents promoted exercise by modelling the exercises themselves. This most frequently occurred when the adolescent had stopped or opted out of the exercise.

Context: Group are doing an arm circle exercise.

Extract: A4 stops doing the arm circle exercise. P4 stands in front of him and continues to do the arm circles.

P4: “Am I symmetrical?”

A4: “You're starting to drop [your arms] again”

P4 raises her arms and continues to do the arm circles.

A4 does an arm circle whilst seated.

4. Instructing

As well as protecting and encouraging, parents were also observed instructing adolescent behaviour. This often took place when an adolescent was already engaged in exercise. Here parents sought to further direct what an adolescent was doing. For example, they may provide further instructions about exercise quality and quantity. (see Figure 4).

[insert Figure 4 about here please]

4.1. Modifying quality. Parents were observed instructing the adolescent on how to exercise, including giving direct instructions of what to do. In some cases the parent would physically move parts of the adolescent's body to demonstrate how they thought the child should be exercising.

Context: Adolescent and parent start doing the side stretch exercise facing each other.

Extract: P2: "Keep your arm by your side. Legs straight. Legs straight. From the top, not stretching from the leg."

There were also instances of the parent correcting how the child was exercising:

Context: Group is doing an arm circle exercise.

Extract: P2: "Try and keep your arm straight. You're not doing it properly."

A2: "It's normal mam, I'm just doing the same as you."

4.2. Modifying quantity. Another form of instructing behaviour occurred when the adolescent had opted out or slowed down during exercising. Here the parent may instruct the adolescent to restart or increase exercising.

Context: Group are doing an arm circle exercise.

Extract: A4 sits down: "I'm done."

P4: "Come on, one more."

A4 sighs, then gets up and starts to do the arm circles again.

Discussion

The study involved a qualitative analysis of video recordings of parent behaviour within exercise sessions during an adolescent pain management programme. A wide variety of parent behaviours emerged from the data and were organised into four main categories (monitoring, protecting, encouraging and instructing). The methodology behind this research was unusual – that is, a qualitative analysis of verbal and non-verbal behaviour – but it allowed categories of behaviour to emerge from the full range of behaviours observed, rather than imposing categories from pre-existing frameworks. Although the categories presented above are unlikely to do justice to the full, reciprocal complexity of the parent-adolescent relationship, they may represent an advance on previous work and are supported by behavioural examples.

‘Monitoring’ behaviours were frequently observed in all parents and consisted of a notable increase in attentiveness to the adolescent, verbally and visually, both when the adolescent was exercising and during other moments in session. Current self-report instruments contain items on the verbal aspects of monitoring. However, the current results also emphasised non-verbal monitoring such as increased watching of the child generally, or their pain area specifically. Thus, future research can incorporate these behaviours, and can examine their consequences for the child. For example, if a child were closely attending to a painful body part in an exercise session, this might be taken as evidence of hypervigilance and pain-related fear. Our research has identified that parents also engage in such behaviours, raising the question of whether parents model or support such fearful attention.

Many protective parental behaviours were observed, including speaking for the adolescent and suggesting or instructing the adolescent to stop exercising. These behaviours were labelled as protective as it appeared that the parents were attempting to reduce physical overexertion or to prevent the adolescent from discussing upsetting topics. Previous research has documented parental protective behaviour within paediatric chronic pain populations (e.g. Sherry et al., 1991; Simons, Claar, and Logan, 2008). Parental protection is normative and understandable, but we observed parents initiating and socially supporting avoidance of physical and emotional demands in their children. Avoidant coping has been associated with poor outcomes in a range of different studies on children with chronic pain (Eccleston, Crombez, Scotford, Clinch & Connell 2004; Walker, Smith, Garber & Van Slyke, 1997). The identification of the 'Unprompted Assisting' category also highlights the need to discriminate whether parental 'help' has been requested by the child, or whether it has been initiated, unprompted, by the parent. Future observational and self-report research could examine the distinct impact of solicited and unsolicited help.

Along with monitoring and protecting, parents were observed encouraging their adolescent. This was seen through role-modelling, suggesting exercises and praising exercise when it was being engaged in. Parents were also recorded prompting the adolescent to speak for themselves. Existing self report measures include some items which focus on encouraging activity. The ARCS, for example, includes an item which describes ‘trying to involve child in some activity’. However, in this study we observed a wider range of 'encouraging' behaviours, seemingly aimed at prompting physical and interpersonal engagement in treatment. In particular, some parents were observed modelling an independent, unprompted engagement with exercise themselves, rather than prompting or cueing their children. It is possible that such a focus implicitly conveys a confidence in the adolescent's capacities for self-management, and that the parent is modelling a willingness to confront difficult physical tasks rather than monitoring their child’s performance. Future research can examine this behaviour. It may be possible to generate self-report items or observational codes that capture these other aspects of 'encouraging' (e.g. 'I believe in praising my child when they are making effort') and potentially negative features (e.g. 'I need to keep encouraging my child in order for them to do anything at all').

A fourth category of observed parent behaviour was labelled ‘instructing’. This included instances where the parent instructed the adolescent to start exercising, gave direct instructions on how to exercise and in some instances provided further feedback about how exercises should be done. This category may have some overlap with encouraging behaviours: for example modifying quantity (4.2) may blur with aspects of prompting exercise (3.1). However we felt that instructing behaviour involved more telling, directing, and in some instances more of a critical tone while encouraging behaviour had more of a supportive quality. Few behaviours of this kind are currently found in existing parental behaviour instruments; however they were identified in a recent observational study. Power et al. (2003) observed that mothers of children with severe juvenile idiopathic arthritis were more directive during a cognitive task than mothers of children with less severe arthritis. It may be that these behaviours foster helpful ongoing feedback for a child, or alternatively make them feel that their actions are constantly open to evaluation and judgement. Future research could attempt to distinguish parental feedback that is balanced, information-based and non-judgemental from that which is largely evaluative and corrective.

The four categories above lend support to some behavioural dimensions in existing self-report measures. For example, the ‘encourage and monitor’ sub-scale of the ARCS includes items such as: “ask your child questions about how they feel”, “reassure your child that she is going to be ok”, while the ‘protect’ subscale includes the item “pay more attention to your child than normal”. The results presented above both confirm the usefulness of these categories and provide an opportunity to expand them and to include new instances of parental behaviour. The collection of specific behavioural observations in this study has also raised questions about the positive or negative impact of specific behaviours on a child's autonomous functioning. For example, 'monitoring', 'encouraging' and 'instructing' behaviours seem to have potentially positive and negative aspects that might be explored in future studies.

Whilst the categories in this study may be useful, there are also limitations to the generalisability of these findings. First, although the context of observation had a number of advantages – it was treatment-related and in a genuine clinical environment – it was also quite unlike the contexts of everyday family functioning. Parents and adolescents knew that they were being observed, and it is impossible to know the effect of this factor on our results. Also, parents and adolescents were at the beginning of their treatment. Although this allowed us to examine behaviour before there was any intervention around parenting, we may have chosen a situation in which children were particularly fearful and uncertain, and in which parents felt under pressure to prompt and encourage them. The dyads in our study were also, by definition 'untreated'; this may have increased the emphasis on less functional parent behaviour and limited our ability to detect post-treatment, pro-functioning parental approaches. Our methodology also had limitations. Future studies could compare behaviour occurring in challenging, pressured clinical sessions to more routine, less evocative work; this would establish which parent behaviours are generic, and which are launched in response to perceived threat to the child. Whilst it was invaluable to attempt a bottom-up description of verbal and non-verbal behaviour, our qualitative approach meant that our sample was very small and that the categories were derived by the judgements of a single researcher who was immersed in these data. Whilst all of the appropriate reflective checks were performed as part of a rigorous qualitative approach, another observer may have categorised the data differently. Importantly, our research comes from a limited population. For example, our sample included only one father. Whilst this is common in the literature (McGrath, 2008), it limits the extent to which our results can be extended to normal home life. Also, our sample were all adolescents with relatively disabling pain conditions and high levels of distress, being drawn from a specialist national tertiary service. It is unclear whether our findings would apply to the parents of younger children, or to less disabled samples. Finally, our research focused only on overt parental behaviour rather than trying to examine the functions or cognitions that were driving it.

These data can be used to inform future research. Both self-report items, and behavioural codes for observational studies, can be generated and modified on the basis of the categories from this study. Future research using new or adapted quantitative instruments will be able to determine the associations between parent behaviours and adolescent functioning and distress, which is not achievable in descriptive research. Also, such an instrument could allow tracking of the parent-child relationship throughout treatment. There is also a need for more qualitative / descriptive work; it would be useful to contrast parent behaviour before and after treatment, or in treatment 'responders' versus 'non-responders'. Research of this kind would be required to ascertain clinically positive parent actions. The work on overt parent behaviour could also be combined, or contrasted, with research on parental psychological states. For example, parental catastrophising is a powerful predictor of child functioning (Goubert et al., 2006) ; however, it is unclear which overt parent behaviours mediate this effect. A parent's tendency to deny or avoid distress, and to struggle with thoughts and feelings around their child's pain is also associated with the child's functioning and distress (McCracken and Gauntlett-Gilbert, 2011). It would be useful to examine the role of overt parental behaviours as mediators of these effects. However, it is also possible that parents' psychological states may impact their children via relatively subtle cues (e.g. increased tension, implicit disapproval) that are hard to observe as overt behaviours. Future research can establish whether to focus on observable parent actions, or more directly on the parent's 'private' psychological variables; the answer to this question will affect choices for clinical intervention.

In summary, a qualitative and descriptive approach to parent behaviour in a clinical treatment environment has suggested behavioural categories that both support and extend dimensions already in use in current self-report instruments. Further quantitative work can examine the functional impact of these behaviours, and further qualitative work can focus on parental behaviour in 'recovered' adolescents who have benefited from treatment.

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Figure Legends

Figure 1: Monitoring behaviour and related subcategories

Figure 2: Protecting behaviour and related subcategories

Figure 3: Encouraging behaviour and related subcategories

Figure 4: Instructing behaviour and related subcategories

Figure 1. Monitoring behaviour and related subcategories

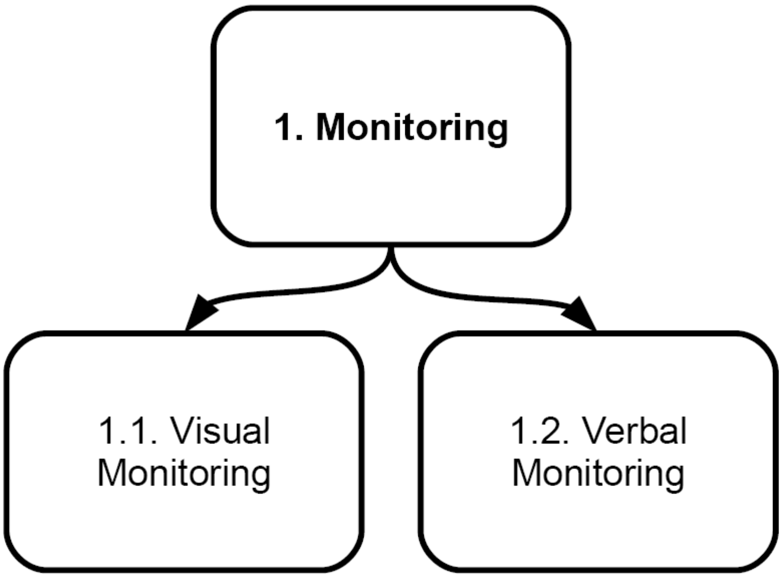

Figure 2. Protecting behaviour and related subcategories

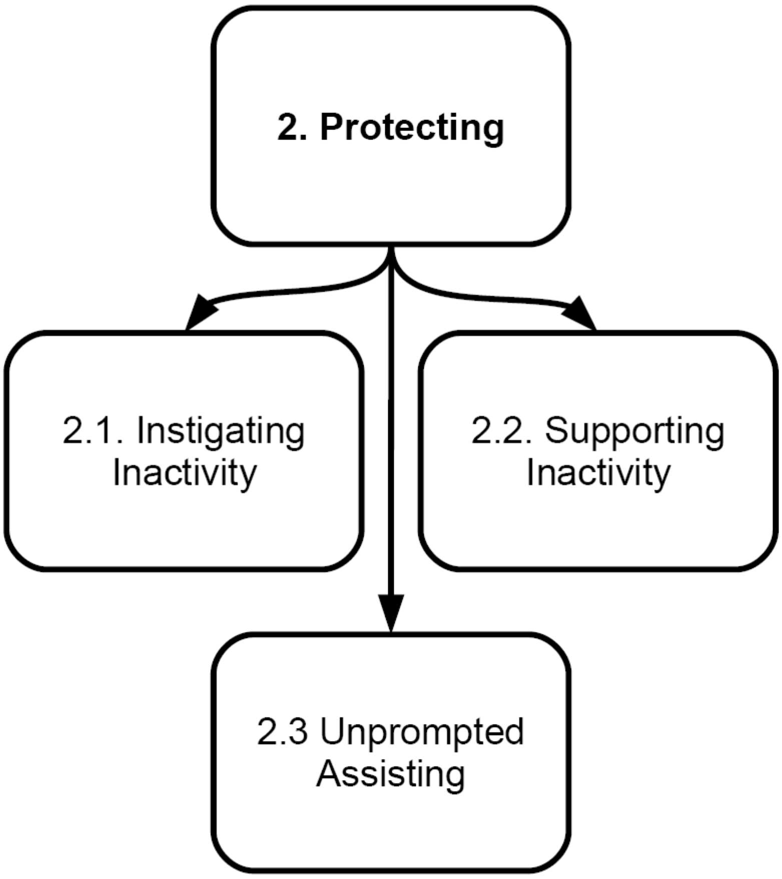

Figure 3. Encouraging behaviour and related subcategories

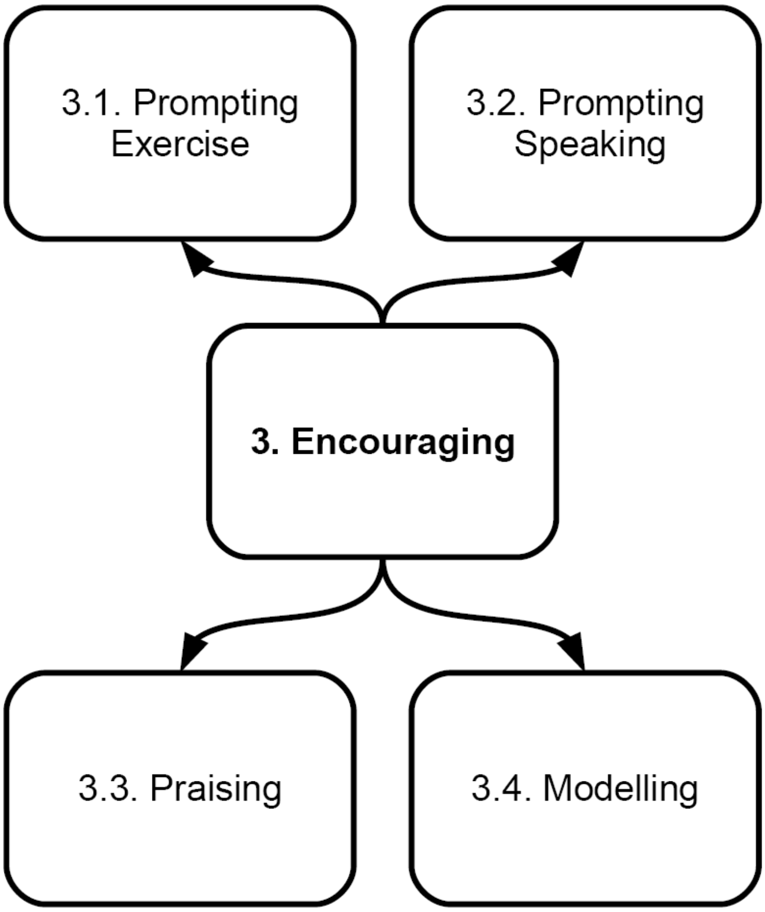

Figure 4. Instructing behaviour and related subcategories