

Student nurses supporting children with learning disabilities: The Family Placement Scheme

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Summary: At Glasgow Caledonian University, nursing students are given the opportunity to gain practice experience by providing care and support to children with learning disabilities within the individual child's home-setting during the summer holiday period. Three families of children with learning disabilities took part in a pilot study. The Study attempts to understand and explain the effects, if any, of such practice experiences for the families concerned. Hermeneutic analysis of interview texts utilising a Gadamerian approach reveals an initial understanding of the realities of life for the families concerned. The emergent picture is one of mothers being trapped within their own homes by and with their learning disabled children. Nursing student placements are viewed by families as liberating.

Keywords: learning disability; students; family; Gadamer; nursing

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Introduction

Family-centred working is a developing trend within healthcare (King, 1997; Case, 2000; Law et al, 2003), the concept of 'Family Nursing' being a good example of its emergent and positive nature within contemporary nursing practice (O'Sullivan Burchard, 2005). However, within the field of learning disabilities, collaborative working in partnership with families has been a long-standing aspect of caring practice (Cunningham and Davies, 1985).

Glasgow Caledonian University (GCU) provides a three year course leading to Registration with the Nursing and Midwifery Council as a Learning Disability Nurse.

During their course, students undertaking the learning disability branch programme have the opportunity to gain practice experience by providing care and support to children with learning disabilities and their families, within the home-setting. This placement is referred to as The Family Placement Scheme.

Background

Learning Disability Nursing students take part in the Family Placement Scheme towards the end of the second year of their course. The six week placement constitutes the practice element of a second year module and, through authentic first-hand experience, students learn of the contextual variations to socially normative patterns of living (Blacher & McIntyre, 2006) commonly experienced by families of learning disabled children. Furthermore, by this process, students learn how to provide insightful nursing support (King, et al., 2006) by being able to meaningfully relate to people demonstrating actual or perceived, relational, familial, or social background differences to their own (Doane & Varcoe, 2006). The timing of this placement correlates with the school summer holidays thereby giving families extra support whilst their children are at home for an extended period. There is growing evidence (Baldry et al, 2005) to support the contention that such time-limited and focussed additional support may actually avert family crisis and, in some instances, even avoid family breakdown. Although research has already been completed in relation to the perceptions of families of children with learning

disabilities, in terms of the nature of the ongoing support they receive (Dyke, et al., 2006; Goodley and Tregaskis 2006; King, et al, 1997; McGill et al, 2006), literature review suggests that no studies similar to that undertaken presently exist (Farasat & Hewlitt-Taylor, 2007). Furthermore, despite the Family Placement Scheme's existence at GCU for well over a decade, so far as the author is able to ascertain, it remains the only one of its kind certainly within the UK, possibly, worldwide. Perhaps not surprisingly, the effects upon families of having learning disability nursing students gaining practice experience within their homes remains largely unknown.

Pilot study

Aim

This pilot study attempts to understand the effect, if any, of such practice experiences for the families concerned, by interviewing parents of children with learning disabilities following placement completion.

Participants / method

The process whereby families and students are matched is multifaceted. The following two hypothetical examples are typical:

Example 1

During the semester prior to the Family Placement Scheme students explore the theoretical basis of contemporary educational provision for children with special needs and, thereafter, spend six weeks gaining related practice experience supported by a special needs teacher, in a classroom setting. Whilst in this setting, a significant number of students initially self-match themselves with specific children. A typical scenario would be a student who, as part of their classroom practice learning, works closely with a seven year old boy to try to improve his concentration on his school work. The boy has Down's Syndrome and the student's interest in the condition is heightened. The

classroom teacher recognises that the boy seems to relate particularly well with the student and mentions it to the child's parents. The prospect of the Family Placement Scheme is raised and the match is made.

Example 2

Parents separate. Husband departs the family home, leaving his wife to care for their eleven year old daughter who has autism. The mother evidences difficulty supporting her daughter alone due to the child's challenging behaviour. The social worker attached to the family recognises the additional strain that is likely to be placed upon the mother during the summer months, and informs the mother of the existence of the Family Placement Scheme. If the parent is interested, the social worker contacts the Family Placement Scheme coordinator and a student is then matched with the family concerned.

A formal risk appraisal is carried out, prior to the commencement of each placement, to ensure the maximum safety of all concerned (Hewitt-Taylor & Farasat, 2007).

Students usually gain experience between two families and manage their own diaries in this respect. Students and families are appropriately supported throughout the placement by a specified link Lecturer; this well established tripartite supportive mechanism has proved (over time) to be highly effective.

Data collection

Once matched, but prior to the student placement commencing, families were made aware of the study and provided with detailed information. They were thereafter invited to participate, however the placement of the student was not conditional upon such participation. Parents opting into the study took part in a semi-structured face to face interview with the researcher, shortly after completion of the student's placement (Munroe, 2007). Interviews were audio-recorded. Audio-recorded interviews were transcribed, verbatim, by the researcher and thereafter hermeneutically analysed to identify any emergent patterns (Diekelmann, 2001). The researcher was the sole agent in this study, the roles of interviewer and analyst *not* being delegated to others (Fleming et al, 2003). Ethical approval for the study was obtained from the University's Departmental Research Ethics Committee.

Data analysis

Hermeneutic analysis utilising a Gadamerian approach (Gadamer, 1975) was considered most appropriate; subsequent literature review highlighting the five-stage approach proposed by Fleming et al (2003) as being congruent with the study in question.

Stage 1: Deciding upon a research question

Clearly there should be compatibility between the research question and the adopted method. Indeed Fleming et al (2003) strengthen this position by positing that the research question, at the outset, influences the whole research process and the researcher must return to it, and thereby remain consciously aware of it, throughout the research process.

Stage 2: Identification of pre-understandings

Identification and recording of the researcher's pre-understandings (Elliott, 1999), begins *prior* to any form of encounter with the research participants. Pre-understandings, in the Gadamerian sense, are not considered negative (Rasmussen, 2002) as is the case with Husserl's concept of 'bracketing' (Koch, 1995); quite the opposite. They are considered as being essential to the eventual achievement of authentic understanding of the phenomenon in question (Gadamer, 1975) and, in this instance, practical demonstration of such pre-understandings to the research subjects appeared vital to enable the researcher to more readily access, and thereby understand, the life experiences of the parent(s) in question. Or, to put it more plainly, the Researcher was able to demonstrate genuine empathy with the parent. Gadamer (1975) refers to the establishment of such shared understanding as the *fusion of horizons*. The horizon of the researcher is initially made present to the researcher by careful exploration and recording of their own knowledge, prejudices, and any other background beliefs associated with the phenomenon being investigated (Fleming, et al 2003); the horizon of the research subject being incrementally made known to the researcher as the researcher is immersed in the ongoing process of data gathering and analysis.

Stage 3: Gaining understanding through dialogue with participants

If one adopts a Gadamerian research method, then Fleming et al (2003) clearly suggest dismissing the notions of 'data collection' and 'gaining

information' preferring instead the concept of 'gaining understanding'. Understanding the other, can, however, never be totally achieved (Fleming et al 2003) and indeed in the final analysis individuals must always remain, in some way, invisible to each other (Laing, 1967). It is therefore important that the researcher does not attempt to gain understanding by trying to *experience the experience* of the other (Laing, 1967) or by attempting to see through their eyes (Fleming et al, 2003): it is only through *dialogue* that understanding is achieved by the fusion of the horizon of the researcher with the horizon of the participant (Rasmussen, 2002). It is perhaps important to make clear that *dialogue*, in a Gadamarian sense, means not only personal conversation, but includes the active contemplation of written texts (Fleming et al, 2003; Gadamer, 1975). Thus the interlinked facets of dialogue in this study were: the actual conversations with participants; the subsequent listened-to audio-recordings of conversations; the personal transcription of the audio-recordings by the researcher (*not* delegated to an assistant); and the subsequent analysis of the individual written texts.

Stage 4: Gaining understanding through dialogue with text

It is *within* this background of emergent, ongoing, incremental understanding through dialogue (Rasmussen 2002) that interview transcripts were eventually meditatively contemplated and analysed.

Fleming et al (2003) propose a cycle of four separate steps to this stage:

Step 1: Fundamental meaning

All interview texts should be examined to find an expression that reflects the fundamental meaning of the text as a whole. (Fleming et al., 2003).

All texts were carefully contemplated with possible expressions highlighted. Texts were then further reviewed with each expression being considered in relation to other 'likely candidates', and the global text of each paper, until the expression judged to best reflect the fundamental composite meaning of the text emerged.

Three texts comprised the study; three *converging* fundamental meanings emerged:

I cannot cope another summer. I ... I can't cope being ... being stuck in this house ... the whole time ... (Family 1)

Only one word to say and that's chaos ... she's emm ... we're just house-bound and that's it! (Family 2)

I found having another person here that meant that I wasn't ... I wasn't stuck in this room ... (Family 3)

The overwhelming sense pervading all three texts was the sense of mothers being trapped in their own homes, with, and by, their own children.

Having such an understanding of the whole is considered the essential starting point influencing the subsequent detailed analysis of the text and understanding derived from it.

Step 2: Identification of themes

This stage of the process requires that:

...every single sentence or section should be investigated to expose its meaning for understanding of the subject matter. (Fleming et al, 2003)

The first interview text was read over, carefully, line by line, to identify emergent themes. Individual sentences were considered in relation to the fundamental meaning of the text as a whole, as well as the author's pre-understandings (Gadamer, 1975), to identify the significance, or not, of the meaning of a given sentence. Reading of the subsequent text continued with each sentence being considered, as before, until each and every line of the text of the first interview had been scrutinised and a collection of themes emerged (Ryde et al., 2008).

Step 3: Expansion of understanding

Every sentence or section is then related to the meaning of the whole text and with it the sense of the text as a whole is expanded. (Fleming et al, 2003)

Each theme was then individually, meditatively contemplated in relation to the initial interview text as a whole, as well as the author's pre-understandings, and each of the other themes comprising the list. Again, this iterative process (Morse et al., 2002) demonstrates close adherence to the Gadamerian principle of reciprocal dialogue between the individual parts and the whole (Gadamer, 1975; Jankowski, 2002). Thereafter the text of the second interview was approached and dealt with in the same manner as the first with sections of significant text being highlighted and coded in relation to the continually developing

collection of themes. At the end of this process the collection of themes were then, once more, individually, meditatively contemplated in relation to the first *and* second interview transcripts together. The cycle, again, ended. Finally, the text of the third interview was dealt with in the same manner as the first and second had been.

In pursuit of maximal trustworthiness of emergent understanding, the themes were once more meditatively contemplated in the presence of each individual interview text. On this occasion, individual texts were read whilst simultaneously listening to their corresponding original audio-recording (Fleming et al, 2003). This process provided an enhanced hermeneutic experience whereby the researcher may once more 'revisit' the original interview 'event' by experiencing auditory paralinguistic properties of speech and other non-verbal environmental cues from which a superior understanding may be derived. (Fleming et al, 2003; Rasmussen, 2002).

Step 4: Representations of shared understandings

... the identification of passages that seem to be representative of the shared understandings between the researcher and participants. (Fleming et al, 2003)

Identification of such shared understandings should provide the reader with significant insight into the phenomenon being investigated. They are significant, informative statements emerging from detailed attentive cyclical analysis. At this point a decision to cease the quest for further enhancement of understanding was made (based on limits to both time and resources) although the cycle could go on indefinitely (Fleming et al, 2003) including subsequent re-interviewing of participants as well as participants' scrutiny of texts with consequential further revisions.

Stage 5: Establishing trustworthiness

As well as dealing with the trustworthiness of the research process, this stage addresses the equally important dimension, truthfulness – especially in relation to the researcher's analysis and consequent findings. Fleming et al (2003) propose that Gadamerian methods are, and should be, subjected to the same criteria as other qualitative research methods (Lincoln & Guba, 1985; Lincoln & Guba, 1994). Whereas in quantitative research a study's credibility depends largely upon the construction of the instrument, in qualitative studies the *researcher* must

be carefully calibrated as the instrument (Golafshani, 2003). The method guiding this study was transparent throughout and an audit trail was developed from the study's inception. Work began with the Researcher's meticulous self-deliberation to elucidate and then record existing pre-understandings (Gadamer, 1975). These initial pre-understandings were then revisited, challenged and developed periodically during the study especially throughout the data gathering and analysis process. The active adoption of a *not knowing stance* (Jankowski et al., 2002) assisted in the avoidance of 'accidentally' fitting the text into the Researcher's pre-existing sub-conscious constructions or categories. Two colleagues not directly involved in the study functioned as critical companions as the study proceeded. At the end, findings were shared with the parents who had participated in the study (Christensen & Turner, 2008; Ryde et al, 2008). Such verification of findings is essential and, depending upon the degree of variance between the researcher's understanding of the findings and those of the subjects, subsequent *conversational rounds* (Cole & Avison, 2007) may be required. This process was not considered necessary as the parents *enthusiastically* confirmed the credibility of the findings in relation to their own life circumstances and experiences. The study's main weakness however was the number of participants. Of the original six families agreeing to take part in the Pilot; one did not take part due to ill health; one family unexpectedly moved house with no forwarding address; and one family simply did not open the door to the Researcher nor reply to subsequent telephone voicemail messages.

Findings

The main findings were that, for all three families concerned:

1. The summer holiday period has a negative impact upon family life.
2. The learning disabled child has a negative impact upon normative family living because of the child's socially negatively valued behaviours.
3. A student nurse's presence within the family home during the summer holiday period has a positive effect upon the family by providing additional support in dealing with the child's socially negatively valued behaviours.

The horizons that are shared below provide a greater understanding of each of the above.

The summer holiday period has a negative impact upon family life

The previously stated 'fundamental meaning' (Fleming et al, 2003) identified the convergent finding of mothers being, in effect, trapped with their children in their own homes. The liberating effect of having a student on placement with the family is described in the following two examples. The mother explains her usual difficulties and the positive impact of the student's presence:

That's the hardest time. If there's ever a time that's the worst time...that's the school holidays. You get seven days at a play-scheme and the rest of the time you're on your own...you're with him (child) all the time during the week...you're not going to get a break...it's dead hard! 'Let's go to the seaside for the day'...well we can't go to the seaside 'cos he knows where Woolies is and he spends the whole time as we are walking along the front trying to get away to Woolies...and he's too big for me now...when he was younger you could just kinda hold him really tight and say 'no Woolies...' or 'going on the beach – no Woolies' but now he can get away from me so something like...having (student's name) here...he knows that he can't get by two people...quite a lot of the time I'm trapped in this house! (Mother 3)

This difficulty does not relate only to distant excursions – even playing in the back garden can be problematic:

... having somebody with me to take him out the back-door to play...maybe just put the paddling pool up and then...before what I'd be doing was I'd be saying...come on in if I wanted to go to the toilet or make a cup of tea...I couldn't...because he thought I was bringing him in...he doesn't have the communication skills...So what I end up having to do, like last summer was like put him in the car, take him to my mum's house... go to the toilet, get a cup of tea, put him back in the car and bring him home and then bring him in the back door. With (student's name) there I could say right you watch him and I'll get us a cup of tea. (Mother 3)

All three families evidenced little support from either family or friends and likewise considered that organised events (for example,

clubs and play-schemes) over the summer months were insufficient or inaccessible.

The learning disabled child has a negative impact upon normative family living because of the child's socially negatively valued behaviours

During the summer months, all three fathers go out to work; all three mothers stay at home with the children. This is a common occurrence (Truesdale-Kennedy et al, 2006). All three mothers expressed significant difficulties coping with their children; the difficulties being greater during the summer months. Of the three families taking part in this study, this fact was perhaps most movingly and extensively put by Mother 1 as she describes one particular incident:

'... she screeches ... it's that high pitched screeching because it just goes constantly...and it just goes right through ye so that was from ten o'clock until four o'clock...screeching and screeching I couldn't even go to the toilet but she was kicking at the door...I went upstairs to go for a shower and she was banging at the door...I went downstairs to get a cup of tea and she's grabbing my arm ... then I went to the toilet and she was kicking the door again and I thought...I can't take this any longer!...I broke down I thought I can't cope with this any longer - everywhere I went she was following me. I couldn't even sit down to watch what was happening on the news, read a paper, there were letters I'd had since Saturday I needed to read - just constantly tugging at me all of the time...she's wanting my attention all of the time...her sister's friend was in and they were getting pissed off with her too so they barricaded themselves in the living-room...and I thought I'll just go into the toilet and she was kicking and kicking and screaming and screaming and I thought ..I think ...I just thought ... if I go out and smack her! ... I just didn't know who to turn to - I couldn't get a hold of my husband - I phoned but couldn't get a signal ...I thought I'm gonnae batter her...if I smack her I just won't know when tae stop...and ehhe...she wiz ehhe the door ye could see the door shaking and the glass. I thought the glass is going to break ...and I wiz like that ...STOP IT! STOP IT! I ended up shouting at her through the door...and the more I was shouting the more she was kicking. I just phoned 999 and I just said to them I said listen...I need help here...cos if I don't I'm going to get up for murder of a child because I am just ready to snap here! ... so they turned up...and...they were really supportive.

All parents interviewed felt that they had been forced to *sacrifice a normal life* due to the presence of the learning disabled child within their family unit; however unlike Mother 1, the expression of positive articulations (Goodley & Tregaskis, 2006) were common - Mothers 2 and 3 describing their children most positively:

He is a lovely child! He's great! He's actually great but he does like a lot of attention...obviously...that's really (name)...he's just a great wee soul! (Mother 2)

Ach...he's a lovely wee boy...he's a good wee boy and he's coming on really, really well! (Mother 3)

There was little evidence of any of the learning disabled children playing outdoors with others. Only Mother 1 allowed her daughter out to play:

The wee boys that are about the same age as (name) are like ... putting her in the special needs buggy and pushing her up and down the street – ye know what I mean? I'm thinking, good-grief, ye know (name) is taller than them sort of thing ... but I think that's a good thing for them...in future so that when they ... leave ... leave the house they're gonna meet people like her and not be scared cos they've been brought up with it.

3. A student nurse's presence within the family home during the summer holiday period has a positive effect upon the family by providing additional support in dealing with the child's socially negatively valued behaviours

The multifaceted and positive impact of having a student on placement with the family is well demonstrated by Family 2. This section of text identifies some of the benefits occasioned by the presence of the student and suggests a high level of trust and integration of the student within the family nexus:

Mother: *We don't want him tied into a wheelchair when he is happy not to be in a wheelchair but because of that (risk of self-injury) he does need constant*

supervision so ... over the summer when (student's name) was here – one, it was another adult to speak to and that was fantastic it was also ... she had some ideas ... she got lots of information for us ... I don't know everything ... I don't know a lot of the support I might be able to get ... (student's name) had a few ideas I hadn't thought of whereas I had some ideas that may have helped (student's name) ... I hope ... but it was great just having somebody else there ... that had patience with a child like (child's name) because not everybody has patience with a child with disabilities; they kid-on that they do – but they don't. (Student's name) was just wonderful – she was lovely. Wasn't she?. (Question directed at child with learning disability).

Child: Yes!

Mother: 'She played Doctors with you and all sorts?

Child: Ohh-yes!

Mother: For my birthday ... for my birthday. I never have gone anywhere for my birthday but we went to see a film ... don't get me wrong ... we didn't abuse it ... we came straight back because that's ... she's (student) not a baby-sitter ... it is a placement for her to learn about ... you know? ... but ... what a great it was ... I ENJOYED THAT! (Child's mother looks at father and laughs!) It was ...

Father: We walked into town ...

Mother: It was so good, from our point of view ... you'd think someone had given us a million pounds in the Lottery ... just to get that wee bit of time because we don't ... ehmmm ... (voice falls off)

Mother: The fact that she was a nurse was a good plus-point because if anything had gone wrong with (child's name) I would have expected her to be level-headed; and I think that she would have been ... and if I asked her a question, you know, there was never any uncomfortableness ... you know? Some people are maybe a wee bit closed about somethings ... but she was so open and honest feeling and ... I don't know ... she's just lovely!

Father: And she liked your home cooking!

Mother: ... she was comfortable enough eating with us!

Unexpectedly, upon reflection, all three families felt that there were no negative effects of having a 'stranger' within the family home. Mothers 1 and 3 did have reservations prior to the student's arrival; Mother 3 even considered cancelling due to the thought of a stranger in her home. Mother 2 had previously met the student at her child's school.

Discussion

Particular common themes emerged during this study. Families typically expressed difficulty meeting their child's needs and described their personal sacrifice of a 'normal' life. Other than the child's attendance at school, all three families received little support of any kind from either formal services or extended families. This finding is not uncommon for the families of children with learning disabilities and challenging behaviour (McGill et al., 2006). It was clear that the presence of the learning disabled child within the family unit generally had a negative impact upon siblings; a well established finding (Dyson, 1996). Sibling rivalry although a normative and perhaps even adaptive feature of family life (Berge et al, 2006) seemed magnified due to the perceived disproportionate amount of time parents spent with the learning disabled child; one child stating *hatred* of her sister. There appears to be a need for a greater level of organised sibling support (Truesdale-Kennedy et al, 2006). In families with other children (Families 1 and 2) the student's presence was additionally described as having a positive impact upon the lives of the learning disabled child's siblings. Similarly, the common experience of an increased level of parental stress (Dyson, 1996) was acknowledged by all families during the summer holiday period. Reasons given were due to a lack and consequentially a greater appreciation of (King et al., 2006) one or more of the small and simple, commonly taken for granted, components of everyday living. Hence, the most common benefits of having a student present were understood to be:

Simple companionship

Mothers regularly portrayed themselves as being left alone at home with their child unable to leave the house. Although the child was present, the parent's sense of aloneness with no one to talk to was evident in all cases. In this sense Parent 3 specifically stated how emotionally supportive the student had been.

Having someone to talk to who understands and is interested

Parents referred to having encounters with significant others including: grandparents, uncles, aunts, close friends and even professionals all of

whom demonstrated no authentic understanding of, or even real interest in, their child. However, parents felt that the students asked questions, understood and were genuinely interested in their child; furthermore they felt that they didn't have to *accommodate* students in the same way as they did other people and could therefore simply *be* themselves.

Physically helping to manage the child

This was a benefit repeatedly expressed by all parents. A common feature was the increasing physical size and strength of the child and the corresponding decrease in the mother's ability to physically deal with their child's behaviour / needs in a public setting.

Facilitating outings

By simply having another person present parents felt more confident and consequentially *liberated* allowing them to go out with their children, for example, for meals, shopping, trips to the seaside or even just playing in the park.

Entertaining / playing with the child.

The student merely taking part in whatever the child was doing allowed the parent to safely do something else - for example, spend time with their other children, do housework, make meals or just have a cup of tea and relax.

Suggesting alternative ways of doing things.

Once more this was a benefit expressed by all families. The fact that the person was a student nurse undertaking a course of study focussing upon the needs of people with learning disabilities gave parents the confidence to raise commonly difficult to discuss issues - for example, the management of their child's incontinence – and have such issues both understood and competently opined upon.

Conclusions

It is important that professionals involved in both the determination and provision of support services, for families of children with learning disabilities, have a *true* understanding of the realities of life for those concerned. The Gadamerian research method adopted, although arguably cyclical and protracted has, nonetheless, yielded trustworthy and defensible findings. Although the number of families participating in this pilot study was small, the venture has provided a useful initial understanding of the phenomenon in question. A key feature emerges; one of mothers being effectively trapped within their own homes by and with their own children: data analysis clearly suggests that the additional support provided by student nurses during the summer holiday period had a liberating effect upon the lives of the families concerned. Despite the fact that Glasgow Caledonian University's Family Placement Scheme has been in existence for many years, it may still be the only one of its kind. Similar placements with other students - not only learning disability (for example, children's nursing) and not only nursing (for example, social work) might be of comparable *additional* benefit to many families. Thus the drive to formulate this paper and thereby facilitate the early dissemination of these initial findings proved, irresistible.

A full study is planned in the very near future.

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