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Jennifer Louise Cooper
Curtin University

Suhad Marjei
Sheikh Khalifa Medical City

Rachel Rossiter
University of Newcastle

Sharon Brownie
Aga Khan University, sharon.brownie@aku.edu

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Recommended Citation

Cooper, J. L., Marjei, S., Rossiter, R., Brownie, S. (2014). Qualitative Research: A pathway to gain an understanding of UAE mothers' experiences and perceptions of managing a child newly diagnosed with Type 1 diabetes. *International Journal of Diabetes and Clinical Research*, 1(2), 1-3.
Available at: https://ecommons.aku.edu/eastafrica_fhs_sonam/94



Qualitative Research: A pathway to Gain an Understanding of UAE Mothers' experiences and Perceptions of Managing a Child Newly Diagnosed with Type 1 Diabetes

Jennifer Louise Cooper^{1*}, Suhad Marjei², Rachel Rossiter³ and Sharon Brownie^{4,5}

¹Curtin University, Australia

²Sheikh Khalifa Medical City, UAE

³School of Nursing & Midwifery, University of Newcastle, Australia

⁴Workforce & Health Services, Griffith University, Australia

⁵Head of Nursing Fatima College of Health Sciences, UAE

*Corresponding author: Jennifer Louise Cooper, RN, BN, PG Dip Com Hlth, MN, Doctoral Candidate PhD Public Health, Curtin University, Australia, Tel: +971501417270; E-mail: jenniferlouisecooper@outlook.com

Abstract

A childhood diagnosis of Type 1 diabetes is a life changing event for both the child and his/her family. The impact is experienced strongly by mothers who most frequently fulfil the primary caregiver role for children 12 yrs old and younger. Studies which have sought to understand mothers' experiences and perceptions of managing a child newly diagnosed with Type 1 diabetes are mostly questionnaire-based and few, if any, explore the issues within the uniqueness of a Middle-Eastern context. The qualitative research methods described in this discussion have been designed to gain a better understanding of UAE mothers' experience in managing a child newly diagnosed with Type 1 diabetes. The intended research will provide the health service entity with the opportunity to review existing services and further enhance the service and nursing care provided to this growing clientele group.

Keywords

Type 1 diabetes, childhood diabetes, Qualitative research, Cross-cultural research

Introduction

The number of new cases of childhood onset Type 1 diabetes has increased substantially in recent years particularly in younger children [1]. Reducing the risk of long term complications requires a careful balance of a healthy diet, exercise, blood glucose monitoring and regular insulin injections [2]. The impact upon families and particularly the principal caregiver (usually mothers) is extensive.

In order to provide improved educational and support services, it is important to understand the mothers' experiences and perceptions of managing a child newly diagnosed with Type 1 Diabetes. The research project described in this discussion is designed to explore and better understand mothers' experiences, their perceptions, their coping strategies and how a service provider can improve health and nursing services to better support this clientele group.

The Study

In order to provide an improved service, it is important to understand the mothers' experiences and perceptions of managing a child newly diagnosed with Type 1 Diabetes. The research project described in this discussion is a health service improvement initiative. The research is a pilot study designed to explore the experiences, perceptions and coping strategies of mothers with a child who has been newly diagnosed with Type 1 Diabetes, and to analyze this information to:

- Identify and determine the key themes which should be explored in a larger study.
- Gather information to inform enhanced health and nursing service delivery to this clientele group.

Some existing studies

Most studies that have attempted to address parents' perceptions have been questionnaire based with very few using a qualitative methodology. Among existing studies, Hatton et al. (1995) [3] highlight the stress for parents of children with type 1 diabetes mellitus; including the seriousness of the disease, the demands of being expected to manage their child's long term care and the nature of the disease. Lowes et al. (2005) [4] showed that parents felt that they needed to move to a world view that 'accommodated the child with type 1 diabetes, rather than that of the world of how that should be'. Miller et al. (1999) [5] explored how children felt about their initial diagnosis, daily discipline, being normal along with good and bad things and how they felt they were supported or otherwise. These studies contribute to the body of knowledge on this topic but very few address the perceptions of the parents, particularly mothers, how they cope and how the diagnosis of childhood type 1 diabetes has impacted upon their lives and that of their child. More research is clearly needed and there is a paucity of research relating to the

Citation: Cooper JL, Marjei S, Rossiter R, Brownie S (2014) Qualitative Research: A pathway to Gain an Understanding of UAE Mothers' experiences and Perceptions of Managing a Child Newly Diagnosed with Type 1 Diabetes. Int J Diabetes Clin Res 1:012

Received: September 27, 2014; **Accepted:** November 20, 2014; **Published:** November 25, 2014

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experience of mothers with a newly diagnosed child, particularly mothers living and raising children within a Middle Eastern context.

A qualitative methodology

A qualitative methodology has been used to inform the research design. The use of a qualitative research methodologies is relatively new in the UAE and wider GCC but where used it is yielding a great deal of very valuable information. In gaining ethics approval of the study, the researchers found that they needed to provide significant information to defend their choice of a qualitative research design.

The rationale for the research design was defended on the basis that rigorous, systematic well-designed qualitative research processes assist in our understanding of many areas of health care about which we have unanswered questions and where there is uncertainty. Qualitative research has done much to reduce uncertainty in many areas of health service delivery and to answer the questions not previously posed. Qualitative research is especially useful in enhancing our understanding of patient needs and expectations; there is limited published research that can guide further development of patient-centred care. Sofaer (1999) [6] described the role of qualitative research as providing the beginning point when it is not yet clear what the right questions to ask are. '...initial questions are very open-ended; often the researcher asks...relevant individuals to describe, in their own way, their experiences and responses concerning a given situation or issue' (p. 1103). More recently, Paley and Lilford (2009) [7] described quantitative and qualitative research as alternative tools used for different tasks, enabling informative descriptions or perspectives on research questions. Where there is an absence or limited research qualitative methods are particularly useful in providing guiding data from which later more wide-scale studies can be constructed.

Research participants

The participant inclusion criteria for the approved study represents:

- Arabic mothers who live within the UAE and whose primary country of residence is within the Middle Eastern region.
- Arabic mothers with children newly diagnosed with Type 1 diabetes (within the last 12 months).
- Mothers of patients registered at the health service where the research is being undertaken.

The study is a purposively sampled exploratory study (pilot) and the sample size is not fixed. The sample size will be determined on the basis of theoretical saturation. According to Silverman [8] "*purposive sampling allows us to choose a case/s because it illustrates some feature or process in which we are interested*". Many qualitative researchers employ purposive and not random sampling methods. They seek out groups, settings and individuals where the processes being studied are more likely to occur [9].

The research pilot will begin with four participants. The initial participant size is limited because there is very little research in this field and if the researchers were to launch directly into a larger study important themes might be missed and not enquired about. Subsequently, a pilot study which gathers information and insights direct from participants is important to help ensure that the researchers are on track in respect to a later more large scale project design.

An approved interview sheet will be given to all attendees of the mothers' support group with which the researchers are associated. The information sheet has been made available one month prior to the study commencing. The researchers will endeavor to identify and purposively select mothers to participate with the most recent experience of a newly diagnosed child and who are likely to provide information rich examples and input to the study.

If similar themes emerge across the four participants then that probably is a sufficient number for the pilot study. If the themes

from each participant are completely different the usual approach is to interview some further participants until no new themes are appearing.

If more interviews are required to reach saturation, the researchers will continue with more interviews. Again, the mothers will be contacted via the Type 1 diabetes mothers' support group in the health facility with whom the researchers are associated.

Cultural considerations

Cultural sensitivity has been uppermost in the researchers' thoughts during the planning of this research. It is for this reason that the research team reside within or have experience working in the Middle East and include an Arabic speaking researcher who is culturally aware of the ethical imperatives plus the local culture and custom associated with conducting sensitive research such as this.

The investigating team have also been constructed to include locally resident English and Arabic speakers who can provide advice and review accuracy of translation and interpretation. Summaries and themes from transcribed versions can also be re-checked with participants. Ensuring accurate translation and interpretation of data in cross-cultural studies has been examined at length in qualitative research literature and the researchers in this team are utilizing Squires' (2008) [10] criteria and additional information published by Croot, Lees & Grant (2011) [11] and Li (2011) [12] to ensure that this research meets best-practice standards for cross-cultural research. The project is further strengthened by ensuring that the interviewers are active members of the research team and will be active in the translation and cross-checking of the accuracy of the transcripts such that the actual intention and meaning of the participants is fully captured. The researchers are informed by literature such as that of Larkin and colleagues (2007) [13] describing the importance of the team comprising members who speak the language of the participants and emphasize the invaluable contributions of team members who could legitimately speak the language and understand the fine nuances of expression. This helped the researchers feel much more secure in validation of the tools used in the research process and in gathering and interpretation of data.

The interview process

The research will commence with the involvement of four participants. Following interview, the interview tapes will be transcribed and a thematic analysis will be undertaken of their responses. To ensure all participants are fully aware of what they are consenting to prior to participating in the audio-taped interviews, an information sheet is provided to the participants in the participants' own language and where there are difficulties with literacy, this information will be read aloud to the potential participant.

Recording interviews is a well-established practice in qualitative research where semi-structured interviews are utilized as the means of data collection. Audio-recording of interviews is undertaken in order to '*preserve the spoken words*' and to enable accurate analysis of the participants' views and experiences. If interviews are not recorded and the interviewer is also responsible for taking notes then there are significant risks that the 'authenticity' of the participants' voice is lost in the process of responses being summarized by an interview scribe. Therefore, recording of interviews provides credibility to the research process.

A small digital recorder specifically designed for recording research interviews and other interviews and with the capacity to upload a record directly to a computer for transcribing purposes will be utilized. Participants are advised of the method and use of recording technique when invited to participate and this information is stated clearly on the consent form and is re-stated again prior to the interview commencing.

When the interview is ready to commence, the digital recorder is put on a table where all can see it and participants are always informed when it is turned on and when it is turned off. Participants are also advised that they can request that the recorder be turned off

Table 1: Conversational questions to guide the semi-structured interview process.

<p>Diagnosis: I am going to talk with you about the time when your child was first diagnosed</p> <ol style="list-style-type: none">1. Can you tell me what it was like when you found out your child was diagnosed with Type 1 Diabetes Mellitus (T1DM)2. Can you describe to me the things that worried/concerned you the most <p>Family, Community and Cultural Response: Now I'm going to talk with you about how your family and community responded. Family, cultural and religious view points and family support</p> <ol style="list-style-type: none">3. What support did you receive from your extended family4. Can you tell me how your religion plays a part in the management of your child's diabetes5. Can you describe the impact your culture has on managing your child's T1DM <p>Education and Support from your healthcare team</p> <ol style="list-style-type: none">6. What support did you feel you received from SKMC7. What do you feel helped you the most8. How do you feel we could improve our service to mothers with children newly diagnosed with T1DM <p>Day to day management issues</p> <ol style="list-style-type: none">9. Can you describe a typical day10. What helps you to cope11. If your child is at nursery or school, how do you manage this <p>Impact on parenting other children and home relationships</p> <ol style="list-style-type: none">12. Can you explain to me the impact having a child with T1 Diabetes has on your family, other children and your parenting styles
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at any point during the interview. The participants will also have the opportunity to review a copy of the transcribed tape so that they can read the transcription and view what has been recorded.

The quality and reliability of the data would be lessened if audio-taping is not possible, however, but if some mothers do not wish to consent to the recording process the researchers would take hand written notes at the time of interview. In such instances one researcher would conduct the interview, while the other undertook to take notes. If this occurs, training will be accessed to ensure that interviewers were competent in recording the content of the interviews accurately. Once again, participants would be offered the opportunity to review a copy of the notes taken.

A semi-structured interview technique has been designed to guide the interview process with the benefits of the semi-structured technique being to provide a framework which will steer the conversation on topic but provide flexible opportunity for unforeseen themes to emerge [14]. Table 1 includes the questions that will be used during the interview process.

Ethics approval

The study has been approved by the IREC (Institutional Research and Ethics Committee) at Sheikh Khalifa Medical City which is a major health service provider within the Abu Dhabi SEHA Government Health Services network.

Conclusion

The research process provides opportunity for health service providers and nursing staff to engage in an ongoing process of analysis and evaluation of current practice. Further research provides significant opportunity for ongoing quality improvement and 'innovates new practices' through the process of enquiry and experiential learning [14]. The intention of this research is to provide insights that will enhance the services and support available to mothers' managing a child newly diagnosed with Type 1 diabetes.

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