THE UNIVERSITY OF HULL

Exploring the experiences of Paediatric Diabetes Professionals: the Therapeutic Relationship, Compassion Fatigue and Compassion Satisfaction

Being a Thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Clinical Psychology

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By

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Overview

This portfolio thesis comprises of three parts: a systemic literature review, an empirical paper and the corresponding appendices.

Part one is a literature review exploring the literature surrounding the development and maintenance of the therapeutic relationship between patients, families and health care professionals in type 1 diabetes. The results suggest a variety of factors which affect the development and maintenance of the therapeutic relationship primarily from the parents and young adult’s perspectives.

Part two is an empirical paper which investigated compassion fatigue and compassion satisfaction in professionals who work with children with type 1 diabetes. Using an online survey and quantitative methodology, the following information was collected: profession, years working in diabetes, caseload size, percentage of caseload classed as complex, percentage of caseload with HbA1c above 69 mmol/mol and personal stressors. General linear regression models were completed with all work related factors not statistically significant apart from personal stressors.

Part three has the Appendices from part one and two.

Contents

<u>List of Tables and Figures</u>

Systematic Literature Review

Empirical

Table 5: Parameter Estimates – Compassion Fatigue

Table 6: Parameter Estimates – Compassion Satisfaction

Part One: Systematic Literature Review

Exploring factors which affect the development and maintenance of professional-patient therapeutic relationships for children with type 1 diabetes

This paper is written in the format ready for submission to the Journal of Clinical Nursing – Please see Appendix K for the Guideline for Authors.

Total Word Count: 8947

Abstract

Background

The therapeutic relationship has been found to improve outcomes and patient satisfaction. Therefore, it would be useful to know how to develop and maintain this relationship especially in long-term chronic health conditions. Children with type 1 diabetes have a long standing relationship with healthcare professionals from diagnosis until transition to adult services. The aim of this review is to explore factors relating to the development and maintenance of the therapeutic relationship in children and young adults with type 1 diabetes, as well as understanding the perceptions of patients, families and healthcare professionals.

Methods

A systematic search of literature was conducted using the following electronic databases: EBSCO Host with Academic Search Premier, CINAHL Complete, eBook Collection, MEDLINE, PsycARTICLES, PsycBOOKS and PsycINFO. Six qualitative papers, three mixed methods and three quantitative papers were included. They were synthesised using narrative synthesis, grouping the papers into perspectives from parent's, patients and healthcare professionals. Quality of the included papers was assessed using the Mixed Methods Appraisal Tool (Hong et al, 2018).

Results

The review found some differences and similarities in factors amongst parents and patients. It also highlighted a gap in literature; healthcare professional's experiences of the therapeutic relationship in type 1 diabetes. Multiple factors were found to be common between all groups of people including: being positive and strengths focussed, asking about emotional wellbeing, loss of security of paediatric relationships, importance and difficulty of building new relationships. Some common factors between parents and patients included: communication style, seeing an individual beyond diabetes and continuity of a relationship.

Conclusion

In summary, a plethora of different factors were found to be linked to the development and maintenance of the therapeutic relationship. This has many clinical implications for healthcare staff to consider, as well as further research opportunities to understand the healthcare professionals' experiences.

Relevance to clinical practice

There are many possible clinical implications from this literature review. Healthcare professionals who work with people with diabetes and other long term conditions could consider the factors which families and patients have described, to alter their practice if it appears difficult to develop a therapeutic relationship. One of the main clinical implications which is also relevant is the significance of continuity of care related to the reduction of early death (Gray, Sidaway-Lee, White, Thorne & Evans, 2018). There is also the potential impact on commissioning and services provided in long term conditions care in order to provide the continuity of care, being up to date on paediatric and adult knowledge bases, being available and providing effective, timely care, and different services (e.g. mentor system, a biopsychosocial approach, question and answer sessions). Finally, training in communication or consultation styles could be delivered for healthcare staff which may include the strengths based consultation style, humanistic and comforting care qualities.

Key Words: Therapeutic Relationship, Type 1 Diabetes, Development, Maintenance

Introduction

The therapeutic relationship is a key part of clinical care throughout health services. For a child with a long term condition, this relationship is unique. This literature review will explore the development and maintenance of the therapeutic relationship for children and young adults with type 1 diabetes.

A patient will usually develop a therapeutic relationship with their health care provider throughout their care, this could be continuous in longer term care or a brief relationship in one appointment. Gray et al (2018) conducted a review establishing whether continuity of care e.g. seeing the same doctor for your health needs has any impact on premature death. Overall, they found that increased continuity of care in 18 of 22 studies was associated with significantly reduced risk of early death. They conclude: "Despite substantial successive technical advances in medicine, interpersonal factors remain important" (Gray et al, 2018, p1). This is crucial to consider in the current National Health Service (NHS) in the United Kingdom. Although the review contains papers from around the world, it is thought this could provide a wider and deeper understanding of the therapeutic relationship in different contexts. It is important to consider the applicability of these factors linked to the therapeutic relationship in the context in which a healthcare professional works.

There are many definitions of therapeutic relationship in different professions and therapeutic models. Cole and McLean (2003) researched the therapeutic relationship in Occupational Therapists. They considered four hypotheses: therapeutic relationships are related to functional outcomes; definitions of therapeutic relationships come from literature and the experts; there are differences in perceptions of therapeutic relationships in different sub-specialities; and skills in the therapeutic relationship were learnt on the job not in education. They provided an updated definition: "A trusting connection and rapport established between therapist and client through collaboration, communication, therapist empathy and mutual understanding and respect" (Cole & McLean , 2003, p44).

A King's Fund paper by Greenhalgh and Heath (2010) investigated all professions within their therapeutic relationships and found that "a good therapeutic relationship is built over time, through continuity of care and that it flourishes when encounters are not excessively time constrained" (Greenhalgh & Heath, 2010, p31). This included a review of literature relating to different understandings of the therapeutic relationship including: psychodynamic, narrative and socio-technical analysis. The socio-technical analysis is the understanding that the patient/practitioner relationship is a part of a wider care network in an organisation. The authors link this to the current NHS economy whereby care is delegated to different professionals and a therapeutic relationship is not developed in the same way as in continuous care e.g. within a traditional general practice. This will be interesting to consider in the current review, given that in diabetes care, interventions are provided by different members of the system in a wider care network, but they do have continuous care from diagnosis to transition to adult services. It will be useful to consider what factors if any can be found to help develop and maintain a therapeutic relationship if care is provided by different professionals.

Ackerman and Hilsenroth (2003) considered the variables which contribute positively to the therapeutic alliance. This includes: the ability of the psychotherapist to instil confidence and trust, capacity to connect with the patient, responsiveness, being dependable, being benevolent and confident in their ability to help the patient. This understanding will help professionals to know how to begin to develop a therapeutic relationship. It is hypothesised that potentially similar qualities will be found in the current review.

Hall, Ferreira, Maher, Latimer and Ferreira (2010) found that in physical rehabilitation settings that a positive therapeutic alliance was related to improved outcomes in rehabilitation but also improved treatment satisfaction. This suggests that it would be important for outcomes and satisfaction to improve the therapeutic relationship and this review hopes to find out what helps to develop and maintain this.

Therefore, all of the above research suggests that the therapeutic relationship is important in improving health outcomes, reducing mortality and improving patient satisfaction. It would be useful to know what affects the development and maintenance of this relationship and for the current review this was considered in type 1 diabetes.

Type 1 diabetes

Diabetes UK describes type 1 diabetes as “a serious, lifelong condition where your blood glucose level is too high because your body cannot make a hormone called insulin” (Diabetes UK, n.d.). Daneman (2006) states that type 1 diabetes carries a high risk of complications especially when it is managed poorly. Atkinson, Eisenbarth and Michels (2014) describe complications arising from type 1 diabetes as: cardiovascular disease, retinopathy (visual problems), nephropathy (kidney disease) and neuropathy (damage to peripheral nerves in hands and feet). This management requires a multi-disciplinary team (MDT) approach. Some of the interventions a health team may need to undertake are listed below:

- Insulin administration
- Blood glucose monitoring
- Meal planning
- Screening for co morbid conditions
- Screening for diabetes-related complications.

Type 1 diabetes involves support and advice from a healthcare professional consistently from diagnosis; this means that a therapeutic relationship develops from diagnosis until roughly 19 years old when the patient transitions to adult services (Diabetes UK). This includes multiple different relationships including with a paediatrician, dietitian, nurse and psychologist. Viinamäki, Niskanen, Korhonen, and Tähkä (1993) found that patients who positively experienced the patient-doctor relationship this had a positive effect on metabolic control, meaning they had better control. This relationship changes throughout the child’s life, Wiebe, Helgeson and Berg (2016) explored the social context of managing diabetes across the life span. They suggested that the therapeutic relationship changes from a triadic relationship between healthcare professional, parent and child to a dyadic relationship between child and health care professional. The current review will explore these perceptions.

Carcone (2010) proposed a theoretical model of social support for an adolescent with type 1 diabetes (Figure 1).

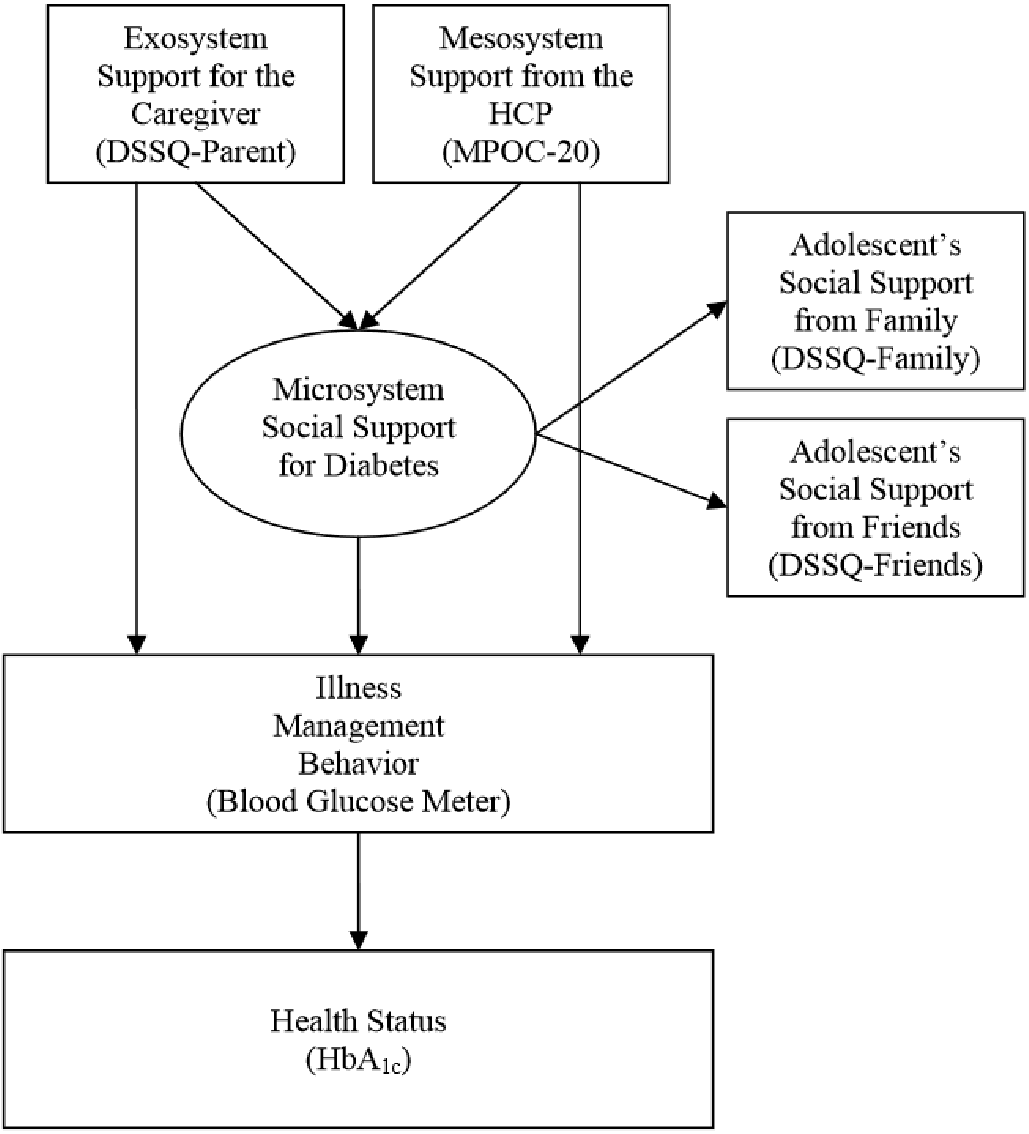

Figure 1*: Theoretical model of social support proposed by Carcone (2010). HCP is Health Care Provider.*

This model suggests that the impact of social support from family, friends, health care providers and support for the adolescent's caregiver can have an impact on management of diabetes and their control (HbA1c). Therefore, this suggests that it is important to consider these relationships that provide support to an adolescent with type 1 diabetes, and this review will look at the support and relationship between health care provider and adolescent.

There are a multitude of demands on a healthcare professional. Firstly the healthcare professional is responsible for the clinical elements of care for a patient with type 1 diabetes and they are responsible for educating a child and their family on how best to manage diabetes. They also have other demands for example supporting the child and family to adjust their lifestyle to better manage diabetes, managing interpersonal conflicts when supporting a child and their family, developing a therapeutic relationship, understanding a child's life apart from diabetes and considering external factors e.g. complex life circumstances, safeguarding concerns, mental health difficulties etc.

This multitude of demands could have an impact on the diabetes healthcare professional. Green, Albanese, Shapiro and Aarons (2014) studied the individual and organisational factors affecting burnout in community mental health providers, where a similar multitude of demands may occur. Surveys were completed by 285 providers and organisational factors accounted for most of the variance within reported burnout. These factors included role conflict (for example interests of clients are often replaced by bureaucratic concerns such as paperwork); role overload (for instance the amount of work I have to do keeps me from doing a good job); growth and advancement (for example numerous opportunities to advance in this agency); role clarity (my job responsibilities are clearly defined) and cooperation (for instance feeling of cooperation among co-workers). Furthermore, research in physical healthcare burnout has also been carried out, for example, Maytum, Heiman and Garwick (2004) considered compassion fatigue and burnout in nurses who work with children with chronic conditions and their families. Twenty nurses were interviewed about their experiences. Nurses were found to be able to recognise their own early indicators of compassion fatigue. The nurses identified different triggers for compassion fatigue and burnout, work related (caring for children with chronic conditions, professional role, work overload, broader system issues) and personal triggers (crossing professional boundaries, taking things personally, having unrealistic expectations of self, family crises/problems). These factors were more predictive of burnout, as they provide a stressful environment as well as individual factors. With these competing demands and individual factors it is possible that this will affect the time available to develop and maintain a therapeutic relationship.

To explore the importance of the therapeutic relationship and what helps to develop and maintain it could help the NHS to structure patient care and ensure it is beneficial and helpful. There have been huge developments in technology including delivering consultations over social media and Skype. Petrovski, Zivkovic and Stratrova (2015) found that patients preferred communicating with health care providers over social media, and it helped to improve health outcomes. This may be a different type of therapeutic relationship which has recently changed due to the use of technology. This was researched in children and adolescents in type 1 diabetes therefore it appears this was useful for the client group. Therefore this raises questions about whether we could move towards more online contact, with less face to face contact. Is the face to face therapeutic relationship important in improving patient outcomes or could the same be done online developing a different type of therapeutic relationship?

Review Aims

The main aim of this literature review was to determine which factors link to the development and maintenance of the therapeutic relationship between paediatric diabetes professionals, patients and families. The findings from this could be used to inform future service developments and to consider the importance of a therapeutic relationship in these settings.

It is important to complete a review within this area as the results could support those working in Type 1 Diabetes care. This is a unique relationship which develops over a long period of time, and as research above suggests that a good therapeutic relationship can affect patient outcome. Therefore, this is important to consider what helps to develop and maintain this relationship. Furthermore, given there are multiple demands for a professional working in this area it may be that this has an impact on the therapeutic relationship. The patient group explored is children and adolescents with Type 1 Diabetes. The review will also consider the perceptions of families and carers and health care professionals.

The following questions were asked:

1. What factors were related to the development and maintenance of the therapeutic relationship from the perspective of the patient (with type 1 diabetes), family and health care professional?
2. Are there any differences in perception of the therapeutic relationship between the different members of the system (patient, family, healthcare professional)?
3. What clinical implications does this research have for the practicing health care professional?

Method

Search Strategy

Databases

An electronic search was completed using EBSCO Host with Academic Search Premier, CINAHL Complete, eBook Collection, MEDLINE, PsycARTICLES, PsycBOOKS and PsycINFO.

Search Terms

The following search terms were applied to all text on EBSCO Host. Asterisks (*) were used to widen the results for differing endings. Hashtags (#) were used to find different spellings of words e.g. paediatrician and paediatrician. Quotation marks (“ “) were used when terms should appear together e.g. “working alliance”.

(Child* or youth* or teen* or adolescen* or juvenile* or infant* or toddler* or Paediatric* or Pediatric*) AND diabet* AND (nurse* or "healthcare professional*" or "health care professional*" or p#ediatrician* or "child* doctor*" or "child* medic*" or dietitian* or dietician* or psychologist* or therapist* or counsel#or* or "healthcare provider*" or "care provider*") AND (relationship* or "therapeutic alliance" or "working alliance")

Article selection process

The final search was carried out on the 20th January 2020 and returned 1001 results. It was limited to English Language, this returned 970 results. These were screened by title first to look for relevance to the current question, this returned 299 results. These were then screened by title and abstract, and full papers where necessary. The following inclusion and exclusion criteria were applied.

Inclusion Criteria:

- Papers which consider the therapeutic relationship from different perspectives – the patient, the family, carers, healthcare professionals
- English language papers, or where an English translation is available.
- Type 1 diabetes
- Papers which look at children or young adults (up to and within 5 years after the age of transition to adult care)

Exclusion Criteria

- Titles which were referring to the medical aspects of diabetes
- Titles and abstracts which appeared not to consider the relationship between professionals and patients or families
- Titles and abstracts which had impacts on the health care professional's role but did not directly consider the relationship in the aims or methods.
- Descriptive papers
- Papers which researched adults or older adults
- Papers which did not look at diabetes either type 1 or type 2

From each paper the methodology, country, participants, measures and key findings were extracted (Table 1). Figure 2 shows the article selection process. Papers were identified from database searching, screened by title and abstract and then full papers were read. 12 papers were included in the final synthesis. Each full paper was read and data extracted into Table 1, further data from each paper was extracted and placed in the results section.

Quality assessment

Quality was measured by using the Mixed Methods Appraisal Tool (MMAT; Hong et al, 2018). This tool assesses quality for papers using Quantitative, Qualitative and Mixed Methods which were included in the review. Each paper was given a quality percentage from 0-100% with 100% being the highest quality paper. This was also reviewed by an independent researcher to establish inter-rater reliability. The majority of the papers were rated the same, and those which were not, discussions were had to establish the same ratings. Appendix M details the quality scores for each paper, using the MMAT as above.

Data Analysis

The papers included in the review are of different methodologies, quantitative, qualitative and mixed methods. Therefore, it was decided that a narrative synthesis was best used to analyse and synthesise the results and to relate to clinical practice. This allowed common themes and factors to be collated by participant (patient, family member or health care professional). For the narrative synthesis all papers which were chosen were read and notes made about each paper within Table 1. Throughout this three main categories appeared to be the most common – which were the patient, family and health care professional. The author noticed common themes and also different themes between each group, this led to the development of Figure 3. The author did contemplate grouping by theme type e.g. communication etc., but it was decided that to answer the research questions it would be better to group by participant type.

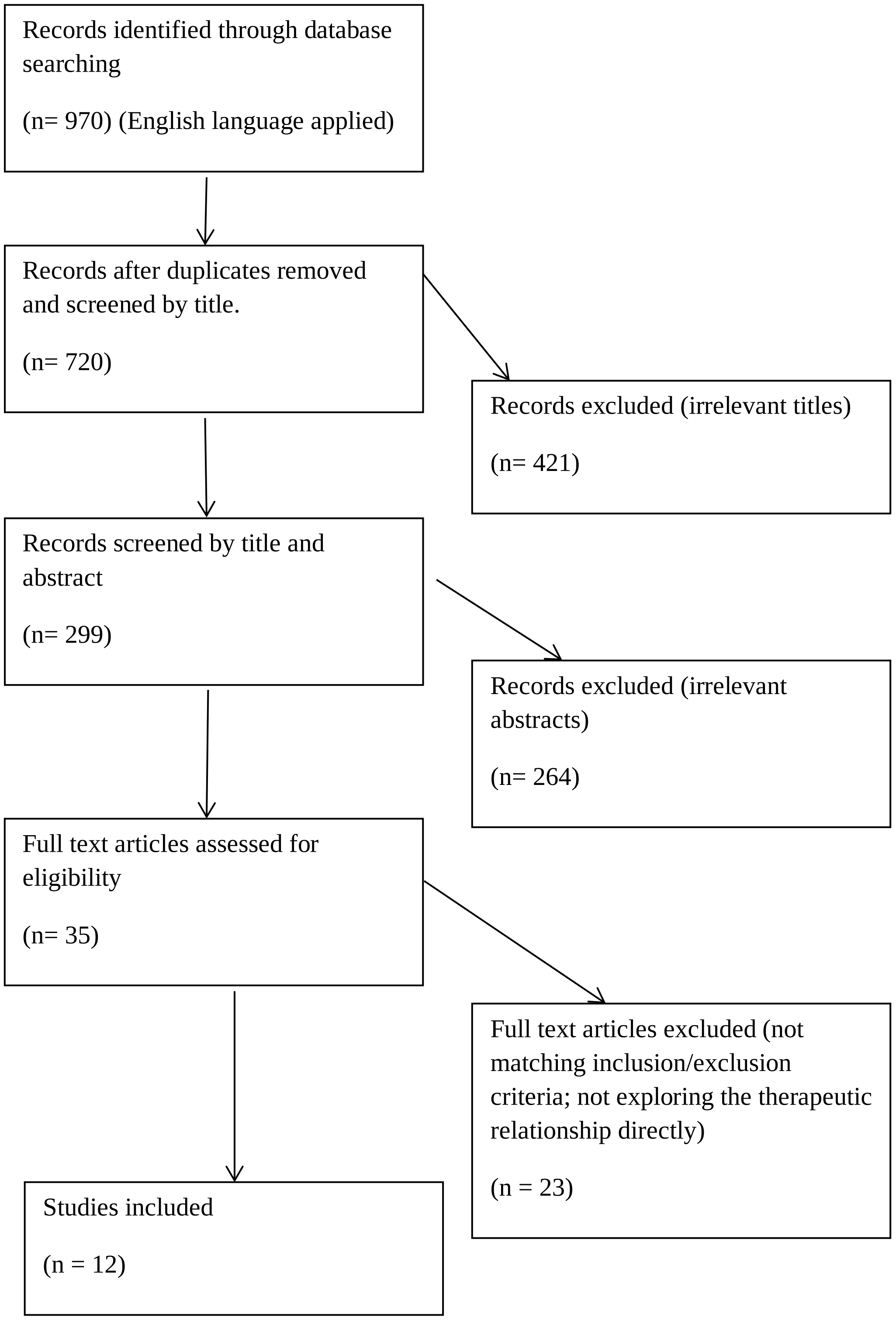

***Figure 2**: PRISMA flow diagram of the article selection process (From Moher, Liberati, Tetzlaff & Altman, 2009).*

Results

The results section will follow a narrative synthesis. Firstly, it will consider the methodology of papers and how the therapeutic relationship was measured throughout the literature. It will the explore studies asking patients perceptions, parents perceptions and studies with a mix of respondents (patients, parents and healthcare professionals). It will then integrate the themes/factors found in a Venn diagram.

Methodology

The papers are summarised in Table 1.

Methodology and measures used

Throughout the different papers different methodologies are used: quantitative, qualitative and mixed methods. There was no consistency over the papers which makes it difficult to compare and contrast them. Overall, qualitative interviews were used gaining perspectives from different people involved in the care. A variety of different scales were used including Likert scales and standardised scales to measure different aspects of diabetes management. This has some limitations especially considering the scales could have shown ceiling effects in their results and this was described in one of the papers (Hilliard et al, 2019). They explained that satisfaction was already rated highly, and struggled to show improvement during the study. Despite this, common factors were found across different papers including focus on communication, seeing the person beyond diabetes and transition. But varying factors were also found between each group of people who were studied. Figure 1 shows the accumulation of factors found. As one can see from the diagram, there is a gap within the research found which is looking at health professionals experiences of the factors related to the development and maintenance of the therapeutic relationship. This may be interesting to consider in the future as health care professionals will have an abundance of experience of different therapeutic relationships both successful and unsuccessful and perhaps have ideas of what affected these relationships.

There is not a consistent approach on how the therapeutic relationship is measured. Some papers used qualitative interviews generated from either the current literature or surveys with parents with children with Type 1 diabetes, which allowed for the generation of suitable questions. However, other papers asked broad questions in semi-structured interviews which may or may not generate information surrounding the therapeutic relationship. One paper used the Caring Nurse-Patient Interaction short scale (CNPI-23; Cossette, Cote, Popin, Ricard & D'Auoust, 2006); this directly measures the caring nature of a nurse's role, perhaps most directly linked to measuring the therapeutic relationship. This was found to be internally consistent, reliable and valid (alpha scores ranging from 0.61-0.94, Kaiser-Meyer-Olkin index score of 0.94 - exceptional; Cossette et al, 2006). Another paper directly created a positivity focussed intervention and asked about it, which may have influenced the results and factors they found which impact the therapeutic relationship.

Location

The majority of the papers included (7 papers) within the review are from the United States of America (USA), it is wise to consider the impact on the results as the USA have a different healthcare system to the United Kingdom and the implications that this healthcare system may have on the therapeutic relationship. It is hypothesised that having a long term condition and the impact of having private insurance could affect the quality or quantity of the therapeutic relationship, therefore this should be taken into account when concluding from the papers included if utilising this review in a country like the United Kingdom with a national health service. There were also different countries e.g. Turkey, where the paper investigated the introduction of a telehealth service; it may be that within parts of the UK this is already established therefore less relevant currently.

Participants

Throughout the literature generally similar age groups of children participated this was around the transition age from 15-25 years old. When parents were interviewed they sometimes had children who were younger, but it appears that younger children’s thoughts were not included within this research. This may be because of the ease at which research can be completed with younger children, or that younger children are less involved in their health care compared to older children who begin to take on more responsibility around teenage years.

Sample sizes ranged from 8 participants in qualitative studies to 799 participants in a survey generation as a part of another paper (Ginsburg, Howe, Jawad & Buzby, 2005). Throughout the qualitative literature sample sizes ranged from 8 to 116 (with the latter being a mixed sample of children and young adults, parents and healthcare professionals).

The majority of the papers were focussed on Type 1 diabetes, but three of the papers had other chronic health conditions included (cystic fibrosis, type 1 diabetes, congenital heart disease; specialists from different areas asthma, diabetes, sickle cell disease; and type 2 diabetes).

Methodological Quality

Table 1 shows the quality scores for each paper, Appendix C shows the quality assessment tool and Appendix M details the breakdown of quality scores for each paper. Papers scored between 60-100%. Papers generally rated lower within mixed methods papers – having not adequately described and interpreted both qualitative and quantitative information and explored any divergences between the data. Also papers did not always report their acknowledgement of potential confounders affecting their research e.g. looking at a variety of health conditions or other factors which may affect HbA1c levels changing. Papers rated highly on having suitable qualitative approaches and deriving findings from their data, they also interpreted results providing rich data from their interviews. The majority of the qualitative papers scored 100% because of their methodology and interpretation. Generating interview questions from surveys and current literature suggests that they may be valid for the current population researched.

As described above some papers included multiple chronic health conditions which could affect the validity and reliability of using the results to answer a question regarding Type 1 Diabetes, especially in the paper asking health care specialists about their relationship with patients given they work with different health conditions. It is hypothesised that similar results may be found across health conditions and therefore these papers were included with the hesitation that conclusions can be made from a mixed sample.

Patient perspectives

Pyatak, Florindez and Weigensberg (2013) asked eight young adults about their past and current approaches to diabetes management, challenges to diabetes care, interactions with clinicians, habits, routines and their environments. They aimed to see what factors related to adhering to diabetes treatment. Three out of eight of the study participants did not feel it was difficult to adhere to diabetes management recommendations. Those who found it difficult to adhere explained a range of factors including: efforts to mislead the care provider, treatment fatigue and burnout and social support problems. They explained that they lied to the health care provider because it may lead to a confrontation if they told them the truth regarding their health care decisions. They explained that when their health care provider acted in an authoritarian manner – especially “lecturing them about the consequences of their actions” (Pyatak et al, 2013, p712), this led them to lie about non adherence. The young adults welcomed a collaborative approach from their health care provider as well as the health care provider being aware of the daily realities of a young adult’s life, for example that they may drink alcohol whilst at college despite it being advised not to do so. They also found that open communication about what the young adult actually does to manage diabetes is important and the way this could be facilitated is through minimising the power imbalance.

One main quote from the paper which illustrates this is “It’s kind of insulting when you’re hearing that you should check 30 minutes before you eat. I know. But I’m doing something else at that time and choose not to. It’s not that I didn’t know” (Pyatak et al, 2013, p712) This highlights that health care providers should not lecture, should be collaborative and should be aware of the realities of patients’ lives to develop and maintain the therapeutic relationship.

Dovey-Pearce, Hurrell, May, Walker and Doherty (2005) studied the preferences of young adults for developmentally appropriate services. They did this by interviewing and holding focus groups for 19 young adults aged 16-25 years old. The main themes they found included: diagnosis, continuity of staff contact, influence of age upon care, interactions with staff, access and environment and suggestions for service development. This suggests that the relationship with staff is important for the young adults, in the form of continuity of staff contact. The young adults explained that sharing information with multiple different professionals felt like a burden, and clinic appointments were not always individually relevant demonstrated through the following quote “If there’s not a patient-doctor build up, then you think, ‘Well why should I bother coming?’” (Dovey-Pearce et al, 2005, p413). The authors suggest that this could lead to an improvement in trust, perceived usefulness of contact, rapport within the relationship and ease of communication between patient and staff. In terms of age, it is highlighted that it is important for professionals to be aware of paediatric and adult knowledge bases, to ensure they look at developmental and diabetes issues. Interactions with staff were also seen as important and for the current review the following factors were considered as useful for the development and maintenance of the therapeutic relationship including: “consistency of contact, civility and rapport, listening, involving the person in the consultation and giving them choices, a non-judgemental and encouraging approach, giving positive as well as negative feedback, facilitating coping skills and access to specialist information, whole-person care facilitated by multi-disciplinary teams, and age-appropriate shifts in consultation style” (Dovey-Pearce et al, 2005, p415). This communication style is similar to the previous findings above, where they wanted HCP’s to be collaborative, here they ask HCP’s to be non-judgemental and encouraging; suggesting that supportive communication is required within this therapeutic relationship. To improve services the young adults suggested a range of things including: staff knowing about a person’s life, asking what they want from the meeting, staff being interested in the person as well as the diabetes, question and answer sessions with staff, mentor system – young adults mentoring adolescents and age banded clinics. Finally, the authors suggest that the relationship between the health care professional and the patient can be an interface between the health care system and the patient supporting them to fulfil the required tasks through modelling appropriate relationships, acquire skills and knowledge and overcome barriers.

Zoni et al (2018) aimed to look into patient self-management activities, patient perceptions of the therapeutic relationship, and satisfaction with the nurse led consultation. Twenty young adults participated, aged sixteen to 23 years old. Patients completed a self-care inventory (Lewin et al, 2009) and the Caring Nurse-Patient Interaction Short Scale (Cossette et al, 2006). This second scale looks at 4 domains of care; clinical, relational, humanistic and comforting care (See Appendix I, for the details of these scales). Overall patients rated caring behaviours as highly important. Humanistic and comforting caring was rated highest for importance. The most observed types of caring were comforting, clinical and humanistic caring. Patients explained that being considered an individual, beyond being a person with type 1 diabetes, was very important, this is also similar findings to other papers suggesting that holistic care is important. Relational items were rated as least important and least observed in clinical consultations (See Appendix I for further details about how they measured each type of caring).

Hilliard, Perlus, Clark, Haynie, Plotnick, Guttmann-Bauman and Iannotti (2014) examined two groups of young people (and their parents) a transition expectations group and a post transition group of before and after transition to adult diabetes care. They used a mixed methods approach using quantitative questionnaires and open ended qualitative questions. They used the self-efficacy for diabetes self-management measure (transition expectations), semi-structured interviews, and physician/health care team subscale of the chronic illness resources survey (post transition group). The following themes were found; timing of transfer, early transition preparation, developmentally appropriate interactions, social/family support, building a safety net and coordinating care. One of the main points was to consider the ending of the relationship with paediatric providers and the development of the new relationship with the new adult provider. They spoke about time to build relationship, trust and rapport, feeling that it was less personal and that the adult providers were disinterested in them. The transition expectations group hoped for a “personality “click”” (Hilliard et al, 2014, p349), being open minded and non-judgemental.

Jones, Hammersley and Shepherd (2003) aimed to explore participant’s personal experiences of diabetes, the relationships with healthcare professionals, and alternative models of care. Eight individuals between 16 and 18 years old participated in interviews. Three key themes were found in the data including: the changing impact of diabetes, the importance of “good” relationships with health care professionals and the need for continuing support as young adults. This paper echoed the themes similar to previous works including that the young adults found it difficult “moving from long-term familiar relationships with paediatric health care professionals to infrequent consultations in the adult clinics, which were initially perceived as impersonal…” (Jones et al, p347). They felt that adult consultations were focussed on diabetes and limited in time. The authors conclude that healthcare professionals may need training into adolescent specific behaviour and their context surrounding them aside from diabetes. It appears similar findings were discovered throughout the different papers surrounding transition, primarily that the adult relationships were different to paediatric relationships, were generally less personal and focussed on diabetes rather than the individual.

Parent Perspectives

Swedlund, Schumacher, Young and Cox (2012) researched parent’s perceptions of physician communication style. They asked parents to fill in four items assessing the relationship with the provider (including: ongoing relationship between child and physician and parent and physician, parent comfort asking questions and parent trust in physician) and the main outcome was “How satisfied were you with your child’s physician visit today?” To rate the communication, the visits were filmed and the physicians communication was rated on friendliness, interest, responsiveness and dominance. 47% percent of parents were extremely satisfied with the visit, 45% were very satisfied, 5% were satisfied and 3% were very dissatisfied. Only the friendliness component of communication style was associated with visit satisfaction ($p < .05$). They also found that satisfaction was related to the quality of ongoing relationships 31% of parents were extremely satisfied and strongly agreed they had an ongoing relationship with the physician, 12% strongly agreed and were less satisfied ($p < .001$). This paper suggests that friendliness communication and the ongoing relationship with the physician can affect the satisfaction with the relationship. Therefore this suggests that healthcare professionals should be aware of their communication style and the feasibility of an ongoing relationship to improve satisfaction of the therapeutic relationship for parents of children with chronic health conditions.

Howe, Ayala, Dumser, Buzby and Murphy (2012, 2014) presented two elements of a four stage study from the United States of America (USA). The main aim of the study was to find out what parents thought about their relationship with healthcare providers. They conducted four stages including two focus groups, survey and interviews. In 2012, they presented key themes from interviews this included: laying the foundation, providing clinical care and engaging families as partners. Laying the foundation was described as the therapeutic relationship, qualities which were important included warmth, caring, sincerity and kindness. It was reported that parents appreciated the fact that healthcare professionals could focus on them despite other demands, and that they personally knew the parent and the child and were aware of interests and passions. Appreciating the complexity of day to day life was also deemed as important for the parents. Parents asked for diabetes management plans which fit for the family’s day to day life, involving the adolescent in treatment plans, more in depth support about parenting a child with diabetes, care that is effective, timely, accessible and creative in meeting needs, and the ability to access the healthcare providers in times of crisis. They also valued the importance of continuity of care, which is similar to the paper above suggesting a continuous relationship is valuable to parents of children with Type 1 Diabetes. The final theme is engaging families as partners and they reflected on a “deepening trust between themselves and the provider and a growing sense of being known and understood” (Howe et al, 2012, p123). Empowerment was one of the main features of this theme, including teaching the parents/children skills to manage diabetes but recognising independence. Unhelpful behaviours were also explained including providers being judgemental or dismissive, inflexible or not adapting diabetes management to the family’s day to day life. One of the main conclusions from this paper which is really important for healthcare professionals to understand is that parents felt that the “quality and character of the relationship that they have with their clinicians is at the heart of what enables them to “live well” with diabetes” (Howe et al, 2012, p125). In 2014, the authors presented stage four of the study, themes from interviews with 63 parents and caregivers. The main themes were: understanding the journey, setting the tone, being captain of the ship and attending to affect. These themes are further described below:

1. Understanding the journey – this is the need for the healthcare providers to fully understand the changing nature of diabetes evolving over time. For example understanding that the parents were learning and staff should adapt their approach as time went on.
2. Setting the tone – this was described as the healthcare staff’s ability to be “focussed, attentive and responsive to establishing an open and collaborative relationship” (Howe et al, 2014, p1245). They wanted providers to know it was more than medical management. Further qualities that were seen as desirable were the ability to reassure, making the family feel comfortable, asking questions, and being caring and nurturing. Some of these qualities are similar to what the children and young adults reported were important suggesting that it is a common theme amongst both parents and their children.
3. Being captain of the ship – When the family felt they were in crisis or diabetes control was poor they wanted the healthcare provider to take charge and support the family.
4. Attending to affect – this theme explained the importance of the healthcare provider being able to “recognise, validate and respond to parent’s emotions and their challenges inherent to raising a child with diabetes” (Howe et al, 2014, p1247).

Ginsburg et al (2005) also presented a paper from the four stage study described above. They reported descriptive statistics regarding the respondents to the survey. Families that had one adult to manage diabetes care reported three items as being more important: good communication with family, diabetes professionals and insurance companies (p=.046), the diabetes team does not judge or blame the family for poor metabolic control (p = .002) and the diabetes team knows about the important issues in a family's life (p = .005). This may be important for health care professionals to understand the family structure and how this may impact the parent's view of how the child and family can live well with diabetes. The authors also conclude that it is important for health care professionals to understand the variety of factors linked to diabetes management but also that they understand the life experience and individual factors of a family living with a child with diabetes. One point had two polarised views which were both strongly supported - one side wanted the diabetes team to know their personal life issues and understand that they are not only dealing with diabetes, but the other side did not think their personal lives were of concern to the diabetes health professionals. Therefore, it would be important for health care professionals to ask what the family/individual would like from the health care team. Parents spoke of the importance of emotional and mental health of their child, they suggest this can be promoted by health care professionals including: equipping children with skills to explain their illness to other children perhaps to reduce the risk of isolation from their peers, having a biopsychosocial approach and referral networks to further support, support groups for the children/adolescents, knowledge of challenges during teenage years and understanding that families live with diabetes 24 hours a day, 7 days a week.

Health care professionals, parents and patients perspectives

Hilliard et al (2019) researched a new strengths based behavioural intervention for adolescents. This intervention included a discussion at the beginning of clinic appointments about adolescent rated diabetes strengths and parent rated diabetes management adherence. The structure of the intervention includes:

1. Review diabetes strengths profile items
2. Make positive reinforcing statements
3. Elicit discussion about strengths and adherence behaviours, focussing on what the adolescent is doing well.
4. Encourage the adolescent the identify ways to continue to build on the strengths and/or engage in adherence behaviours.

Outcomes which were measured include HbA1c and blood glucose monitoring adherence, adverse events (e.g. visits to emergency departments), problem areas in diabetes (PAID-T) (Weissberg-Benchell & Antisdel-Lomaglio, 2011), and the PAID-PR – for parents (Markowitz, Volkening, Butler, Antisdel-Lomaglio, Anderson & Laffel, 2012), diabetes family conflict scale – revised (Hood, Butler, Anderson & Laffel, 2007), three subscales of the paediatric quality of life inventory (Varni et al, 2004) – healthcare satisfaction generic module, providers rated the overall satisfaction with the patient/provider relationship on 1-10 scale, and a qualitative interview was carried out with the participants asking about their experiences of the intervention.

Feedback included that the intervention was comfortable and participants and providers would like it to be integrated into normal practice, they appreciated the shift from problems to strengths. A parent reflected that they talked about emotional wellbeing and physical health and this meant that her child was more positive throughout the interaction, suggesting the value of both mental and physical health in the clinic visits. Adolescents said that using the strengths and looking at adherence behaviours led them to feel motivated to further improve on adherence behaviours that they did well and that they did not do as well. Healthcare professionals reflected that the intervention reminded them to start on a positive note and to think about things they do not normally discuss, they said it was sometimes difficult to focus on strengths and not problems. Adolescents and providers ratings of the relationship increased, but the parent rated scores did not increase.

Coyne, Heery and While (2019) conducted semi-structured interviews with adolescents and young adults, parents and healthcare professionals. They aimed to explore the views surrounding transition to adult services from different perspectives. The interview explored current issues reported in transition literature including experiences of transition, transitional needs, the provision of information and support, decision making, barriers and facilitators to good transition experiences and recommendations to improve transition. The four main themes with 13 categories found include: transition process and preparation (transition practices, preparation, timing); expectations of adult services: acceptance and loss (a culturally different environment, acceptance of the need to move, loss of security and relationships, concerns over shift in responsibility); transition to adult services – A culture shock (“No Man’s Land”, culture shock, shift in responsibility); flourishing or floundering in new roles (facilitating the shift in roles, flourishing or floundering in new roles, challenges of “stepping-back” for parents). Some of the main themes that are relevant for the review including loss of security and relationships; the building of new relationships in adult services which some participants felt was like entering “no man’s land”, where it was a more impersonal environment. They did suggest that young adults appeared to make new relationships more easily than parents did. Adolescents and young adults suggested that it may be difficult to open up and discuss concerns with the adult providers. The authors conclude that the “lack of relationship with the adult team was associated with anxiety, reluctant to share concerns and fears about deterioration in healthcare provision" (Coyne, Heery & While, 2019, p4072-4073) and that efforts should be made to make this relationship. As described above we hesitate to conclude that these findings will wholly explain the experience of individuals with Type 1 Diabetes given they explore the experience of multiple health conditions, it would be important to factor this into one's understanding when considering the relationship for young adults in adult healthcare.

Döger et al (2019) conducted a study to look at the effects of a telehealth system on diabetes control as they explained that a close relationship is required for satisfactory metabolic control. They developed a telehealth system which included: counselling being carried out through the internet and smart phones. They considered outcomes including: frequency of calls to the team (via telehealth system), duration of diabetes, use of infusion pump or carbohydrate counting and HbA1c levels. They were grouped in terms of HbA1c levels (< 7.5%, 5-9% and >9%) and call frequency (daily, 5-6 times a week, 1-2 weekly, once every 15 days). Using a chi-square test, they analysed the HbA1c levels in the different caller groups. They found that HbA1c levels at baseline were lower after six months in patients calling frequently ($p < .001$). They found that WhatsApp was chosen more frequently by the patients (57.3%). The diabetes education nurse was the most frequently contacted (32.9%), and insulin dose and blood glucose regulation was most frequently asked about (42.7%). Those whose HbA1c was lower than 7.5% consulted frequently, however only 6/26 (23%) of patients who had higher HbA1c levels (>9%) consulted frequently. The authors concluded that increased frequency which was enabled online enabled continuity of contact and reduced HbA1c level. This suggests that the important part of the relationship between health care professionals and patients and their families is the increased communication and education. Therefore, for the development and maintenance of the relationship healthcare professionals should be attentive to their role in providing this education and communication.

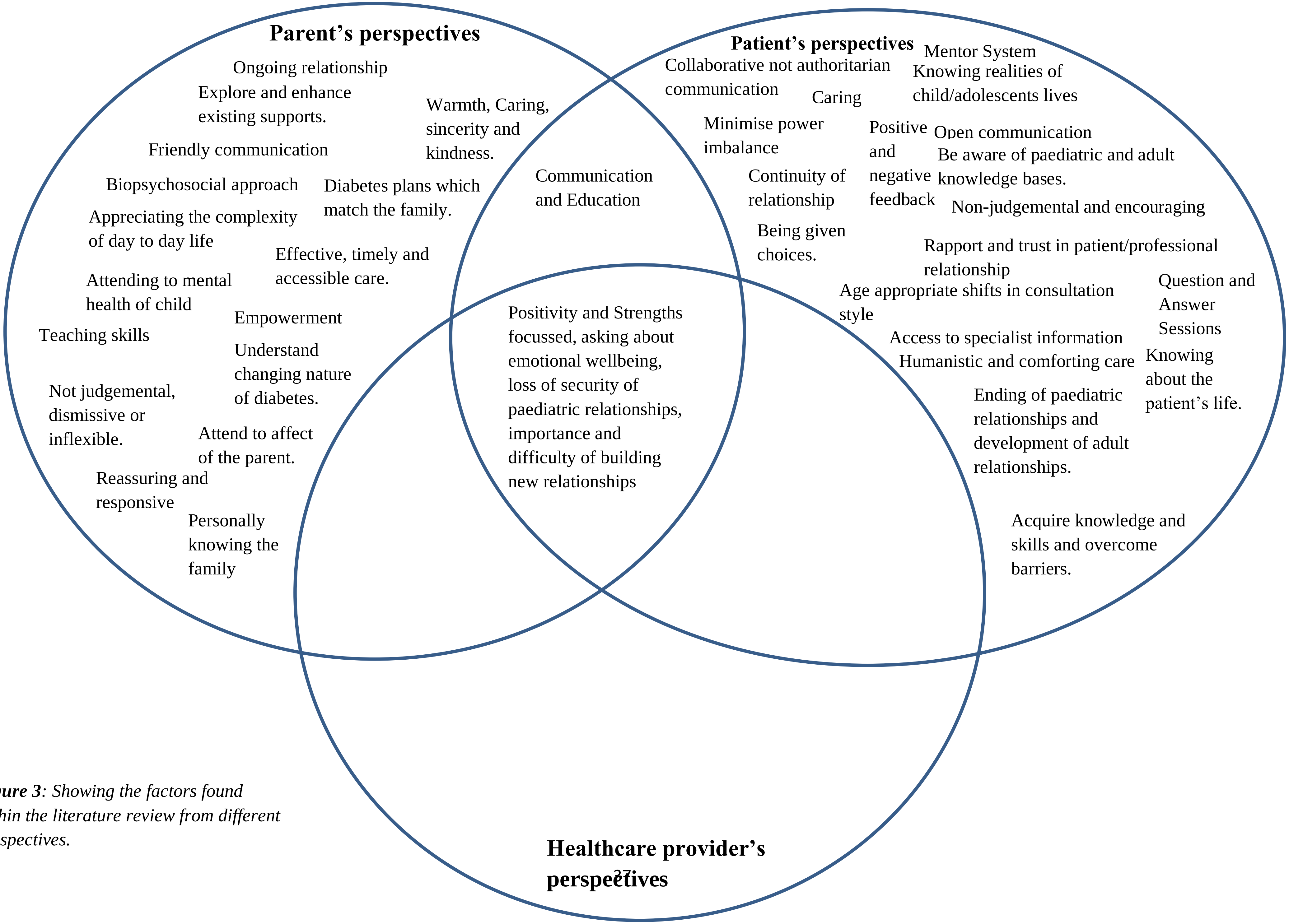

***Figure 3**: Showing the factors found within the literature review from different perspectives.*

Integration of findings

Figure 3 shows the factors found throughout all papers reviewed within the systematic literature review. It enables a comparison between the different participant groups as well as a recognition of similarities and differences between each group. Only two papers considered all participant groups. They investigated the use of a positivity focussed consultation style, which all participant groups found helpful within the diabetes consultation and they considered transition from paediatric to adult providers.

Similar themes were found within both patient and family participant groups for example: themes around communication style, understanding a patient beyond diabetes, healthcare professionals knowing the realities of day to day lives for patients, continuity of care and the changing relationships in the transition to adult services. Some differences included the suggestions that young people made regarding diabetes care including having question and answer sessions and a mentor system, which were not found within the parent participant data. This may be as the factors parent's suggested were focussed on learning about diabetes and their child's medical care compared to the social aspects of diabetes e.g. finding someone similar to you for support as a young person with Type 1 Diabetes.

Table 1: *Showing the papers included within the review, and quality analysis scores*

Authors	Country	Design	Participants	Measures	Key Findings	Quality Score
Coyne, Sheehan, Heery & While (2019)	Ireland	Qualitative	47 14-25 year olds (either Cystic Fibrosis, type 1 diabetes or Congenital Heart Disease) 37 parents 32 health care professionals	Semi Structured interviews	Key themes from adolescents: Transition process and preparation, Expectations of adult services: acceptance and loss, Transition to adult services: A culture shock, Flourishing or floundering in new roles.	100%
Hilliard et al (2019)	USA	Mixed methods	64 adolescents (with Type 1 diabetes) and parent (completed baseline) (mean age 15 years) 4 diabetes care providers (1 physician, 3 nurse practitioners)	Glycemic control (HbA1c), blood glucose monitoring adherence, adverse events e.g. hospital admissions, Diabetes Self-management profile self-report (DSMP-SR), Problem Areas in Diabetes (PAID-T and PAID-R parent rated) Diabetes Family Conflict Scale revised (DFCS-R). Paediatric Quality of Life inventory Healthcare Satisfaction Generic Module (three subscales). Provider rated satisfaction with patient relationship 1-10 scale, and documented whether they delivered the intervention, how long it took, how involved the family were and their comfort delivering the intervention. And a semi-structured qualitative interview with all participants.	Reported that the intervention took <10 minutes to deliver. Significant improvements in youth-rated diabetes strengths, adherence, burden and parent reported diabetes burden. The participants reported an improvement with relationship with provider and provider rated improvement in relationship with family ($p<.05$).	80%
Ginsburg, Howe, Jawad, Buzby, Ayala, Tuttle and Murphy	USA	Mixed methods	4 stage study exploring patients and their families with Type 1 Diabetes. Stage 1 – 44	Included open focus groups, Nominal group technique, parent-developed survey, semi-structured interviews, explanatory focus groups. All included the question "What makes the difference in whether a child and family will 'live well' with diabetes?"	Parents felt that clinicians can affect factors which help a child live well with diabetes including: sources of support from health care professionals, enhancing community support, looking for	100%

(2005)			parents (open focus groups) Stage 2 – 105 parents (nominal group technique) Stage 3 – 799 parents (parent developed survey) Stage 4 – 67 parents (semi structured interviews)		strength in families, accessible services.	
Swedlund, Schumacher, Young and Cox (2012)	USA	Quantitative	75 children 9-16 years old 8 paediatric specialists (in asthma, diabetes, sickle cell disease).	Parent pre-visit surveys including demographic information and 4 items assessing ongoing relationship with the physician. Post visit satisfaction measured on a 6 point Likert scale – "How satisfied were you with your child's physician visit today?"	47% of parents were extremely satisfied with the visit, 45% very satisfied, 5% satisfied, 3% dissatisfied. Friendliness communication style was significantly associated with visit satisfaction ($p<.05$). Overall found that communication style and having an ongoing relationship with the physician was associated with satisfaction of the visit.	60%
Howe, Ayala, Dumser, Buzby and Murphy	USA	Stage 4 of the Ginsburg et al (2005) Qualitative	63 parents of children with type 1 diabetes	12 question interview guide (questions informed from previous stages of the study)	Three main themes: Laying the foundation, providing clinical care and engaging families as partners.	100%

(2012)		interviews				
Ayala, Howe, Dumser, Buzby and Murphy (2014)	USA	Further exploring the third theme above – Engaging families as partners	63 parents of children with type 1 diabetes	Same interviews as above but analysed the third theme in more depth.	Found sub themes surrounding parents' wants and needs from providers including: understanding the journey, setting the tone, being captain of the ship and attending to affect.	100%
Jones, Hammersly and Shepherd (2003)	UK	Qualitative	8 Young adults (16-18 years old) with Type 1 Diabetes	Semi-structured interviews to explore issues related to their experiences of diabetes.	Three key themes including: the changing impact of diabetes, the importance of 'good' relationships with health care professionals, and the need for continuing support as young adults.	100%
Hilliard et al (2014)	USA	Mixed Methods	20 15-17 year olds with type 1 diabetes (and their parents) 2 groups: Transition expectations and Post Transition group	Quantitative questionnaires and qualitative responses to open ended questions, Transition expectations: completed a self-efficacy for diabetes self-management measure, parent reported transition preparation behaviours measured through three questions, and semi-structured interviews. Post Transition: questionnaire assessing feelings and experiences with adult care providers including the physician health care team subscale of the Chronic Illness Resources Survey – three items assessing supportive patient-provider interactions. Four open ended questions regarding transition were asked.	One main theme associated with the current review: relationship with and characteristics with adult care provider (from transition expectations: communication listening style, open minded, personality "click"; from post transition: time to build relationship, trust, rapport, less personal, disinterest in patient)	60%
Dovey-Pearce, Hurrell,	UK	Qualitative	19 young adults (16-25 years old) with diabetes (all	Interviews were based on themes in the current literature including: coping with diabetes, experiences of diabetes services and provision of developmentally appropriate	Key themes included Diagnosis, continuity of staff contact, influence of age upon care, Interactions with	100%

May, Walker and Doherty (2005)			types)	services. Later focus groups (8 participants) to consider two themes (experiences of diabetes services and suggestions for service development)	staff and access and environment. Participants suggestions for providing age appropriate diabetes services included improving clinic organisation, the consultation, informational care and providing extra services e.g. question and answer sessions with staff or a mentor system.	
Döğer et al (2019)	Turkey	Quantitative	82 children between 2-18 years old with Type 1 Diabetes	The diabetes team developed a telehealth system. Counselling was conducted by communication networks like the internet or smart phones. The following information was collected: Call frequency, duration of diabetes, use of infusion pump or carbohydrate counting, demographic information and patient history information and HbA1c levels at baseline and follow up.	Increase in frequency of counselling by the diabetes team led to improved HbA1c levels. Speedy communication and patient education are important features of the therapeutic relationship.	80%
Zoni et al (2018)	Switzerland	Quantitative	20 young adults (aged 16-25 years old) with Type 1 Diabetes	Evaluated patient outcomes including HbA1c, the Self-care Inventory (Lewin et al, 2009) and the Caring Nurse-Patient Interaction short scale (CNPI-23; Cossette, Cote, Popin, Ricard & D'Auoust, 2006).	Overall the therapeutic relationship was highly valued as important, with humanistic and comforting caring being rated the most important. It is important for the patients to feel they are seen as an individual beyond type 1 diabetes. This will be important in transition and continuity of care.	75%
Pyatak, Florindez and Weigensberg (2013)	USA	Qualitative	8 young adults (19-25 years old) with Type 1 Diabetes	Each participant participated in a series of 6 interviews. They were asked about their past and current approaches to diabetes management, challenges and dilemmas related to diabetes care, interactions with clinicians, everyday habits and routines and physical and social environments.	Key factors related to adherence to diabetes management included: health care providers who acted in a collaborative rather than authoritarian approach to support, friends and family who were supportive and not overbearing.	100%

Key themes found to be motivating nonadherence include: efforts to mislead health care providers, adherence to alternative standards, treatment fatigue and burnout, social support problems and emotional and self-efficacy problems. The authors conclude that non-judgemental communication may be important in providing positive health outcomes.

Discussion

This review aimed to investigate the development and maintenance of the therapeutic relationship between patients, families and healthcare professionals in type 1 diabetes care. The literature reviewed considers different perspectives and aims to understand what factors were important for each group of people. The following questions were considered:

1. What factors are related to the therapeutic relationship from the perspective of the patient (with type 1 diabetes), family and health care professional?
2. Are there any differences in perception of the therapeutic relationship between the different members of the system (patient, family, healthcare professional)?
3. What clinical implications does this research have for the practicing health care professional?

What factors are related to the therapeutic relationship from the perspective of the patient (with type 1 diabetes), family and health care professional?

From the patient literature, it was mainly adolescents and young adults that were asked about their relationship with healthcare professionals. Much of this research was around transition between paediatric and adult services, as this is a main time when relationships will change for the young people. The main factors that were found in the literature include: being collaborative, continuity of relationship, knowing about the patient's life, rapport and trust, giving positive and negative feedback, being aware of paediatric and adult knowledge bases.

During a child's diabetes trajectory parents are, at first, the main people who manage the diabetes, as the child becomes more independent this responsibility becomes their own. Therefore, much of the research focussed on parent's perceptions of their relationship with healthcare staff. Some of the main factors for the development and maintenance of the therapeutic relationship include: having an ongoing relationship, which is warm, caring, sincere and kind, using a biopsychosocial approach, matching diabetes plans to the family being aware of the day to day realities of life and not being judgemental, dismissive or inflexible in their approach. This links to the paper in the introduction from Wiebe et al (2016) who explored the social context of managing diabetes across the life span and suggested that this relationship changes from triadic (healthcare professional, parent and child) to dyadic (child and healthcare professional); therefore it is understandable that much of the research focuses on parental perceptions.

Overall, this review found papers that investigated the therapeutic relationship between healthcare professionals, the patients and their families. Multiple factors were found to be common between these groups of people including: positivity and strengths focussed, asking about emotional wellbeing, loss of security of paediatric relationships, importance and difficulty of building new relationships. These factors came from a paper which considered a strengths based consultation style, in which health care professionals found the intervention to be different to their normal consultation style, and sometimes found it difficult to focus on strengths not problems. However, once health care professionals had incorporated it into their practice they felt it was easy to administer and it received positive satisfaction ratings from the patient and their families. This paper was one of the only papers which collected information from health care professionals. It would be useful for research into health care professionals experiences of working with patient's with type 1 diabetes and what factors they think develop and maintain a therapeutic relationship. Much of the review and the factors described support Cole and McLean (2003)'s definition provided, which focusses on collaboration and communication. This is important as this appears inconsistent within the literature but it appears that this definition fits for patients with type 1 diabetes and their families.

Are there any differences in perception of the therapeutic relationship between the different members of the system (patient, family, healthcare professional)?

Between families and patients, similar factors were found to develop and maintain the therapeutic relationship with the main similarities being around communication style and knowing the realities of the patient and families lives. Another main factor is that healthcare professionals know the person and family beyond diabetes, and provide care related to this, including creating individualistic plans and appreciating the changing nature of diabetes. It is difficult to know if similar factors would be found within healthcare professional's perceptions. One of the main factors that were appreciated by all members of the system is the positivity in consultations. This focus on strengths as well as difficulties within the consultation room improved the emotional wellbeing of the patient, motivation of the patient and family to engage in adherence behaviours and patient and healthcare professional ratings of the therapeutic relationship. There does not appear to be any major differences in perceptions but there is a gap in research that was found in this review considering the healthcare professionals' perceptions of the therapeutic relationship.

What clinical implications does this research have for the practicing health care professional?

There are many possible clinical implications from this literature review. Healthcare professionals who work with people with diabetes and other long term conditions could consider the factors which families and patients have described, to alter their practice if it appears difficult to develop a therapeutic relationship. It would be important to consider individual differences in patients and families perceptions but this review could give a starting point to some of the conversations had between healthcare professional and patient and families. One of the main clinical implications which is also relevant is the significance of continuity of care related to the reduction of early death (Gray et al, 2018). This may be useful to consider if patients or families are disengaging from the continuous care within a paediatric diabetes team. The therapeutic relationship is especially important given the complications that can arise from diabetes management when not managed correctly.

Another clinical implication for the United Kingdom could be the impact on commissioning and services provided in long term conditions care. Obviously the most important things are clinical care and patient satisfaction, if the factors described in this review are what parents and patients need and want from long term healthcare professionals, then this will require resources and support from commissioners and organisations to support healthcare professionals to provide this care. To provide the continuity of care, being up to date on paediatric and adult knowledge bases, to be available and provide effective, timely care, and different services (e.g. mentor system, a biopsychosocial approach, question and answer sessions), further funding and resources will be required to support staff to provide these services.

In addition, it was hoped that the review could look at the socio-technical analysis considering the therapeutic relationship as part of a wider care network (Greenhalgh & Heath, 2010). There may be different elements amongst a multi-disciplinary team (MDT) whereby different types of therapeutic relationships are formed. Much of the research included did not distinguish between these different roles in the MDT, and consider the factors appropriate for the development and maintenance in the therapeutic relationship with different professions. It is assumed that these relationships may be slightly different, given the differences in care provided.

Finally, the review raises the question that perhaps training in communication or consultation styles could be delivered for healthcare staff to provide the caring nature that both parents and patients felt was necessary for a positive therapeutic relationship. This may include the strengths based consultation style, humanistic care qualities (considering individuals as more than their health problem, encouraging hope, emphasising efforts and not having an attitude of disapproval) and comforting care (respecting privacy, taking basic needs into account and giving medications/treatment at scheduled time).

Implication of quality/design issues

Overall, the papers were mainly qualitative (6) or mixed methods (3), this allowed for an in depth understanding of the perspectives of parents and patients. These studies were of relatively high quality because they were exploratory and written up well to include information from their results. It may be difficult to establish whether these perspectives are representative of the whole population of patients and families, but it provides a starting point to conversations around factors which may help with the development and maintenance of the therapeutic relationship.

Amongst the quantitative research, there is a multitude of standardised scales and Likert scales which have been developed for the research. This suggests that it is difficult to measure the therapeutic relationship and this could be a weakness with the research involved as there is no standardised way to measure it. As there is no consistency throughout the research it is difficult to conclude the factors which are and are not linked to development of the therapeutic relationship.

One of the main weaknesses of the current review is that the papers included are from a variety of different countries with different health care systems. It would be important to consider this in application of the information within the clinical setting a healthcare professional is in. However, there are some factors which may not be affected by the health care system and private insurance for example communication style, being knowledgeable about paediatric and adult knowledge bases and seeing an individual as well as their health condition.

Suggestions for future research

As mentioned above a critique of the review is the omission of the perception of healthcare professionals. This would be important to consider as they have a wealth of experience in working with a variety of different patients and families which may not always be captured in the research. In some of the papers they reflected that those who were involved in research were those who were more likely to attend consultations and be involved in research activity. Therefore, by asking healthcare professionals this may give us an insight into the hard to reach group of who do not attend consultations as regularly and do not participate in research activity. The health care professionals may have some idea as to what affected this therapeutic relationship.

Furthermore, as most of the research is focussed on parents or adolescents/young adults it may be useful to ask children under this age what their opinions are for the development and maintenance of the therapeutic relationship. This also appears to be a gap within the literature found.

By using qualitative analysis to capture these two perspectives (healthcare professionals and younger children), a researcher could devise a questionnaire to capture a larger participant pool asking them about the factors found which help to develop and maintain a therapeutic relationship, investigating whether this is the case for a wider population. In this way this could account for the small sample sizes and therefore perhaps representativeness of samples included within qualitative research. Furthermore, it could help to support the development of a therapeutic relationship measure within Type 1 Diabetes care. This would allow a more consistent approach across research papers, ensuring that factors found are representative for children and young people with Type 1 Diabetes.

Conclusions

In conclusion, this review has found the perspectives of healthcare professionals, patients and families. Although there is room for further research in this area, it provides us with a starting point for factors to consider in healthcare professionals therapeutic relationships. The review indicates that there are multiple factors that families and patients find useful for the development and maintenance of the therapeutic relationship but it has also indicated a gap in the literature to directly consider the factors that healthcare professionals feel are important. Similar factors found between patients and families include: communication style, healthcare professionals knowing the realities of day to day lives for patients and families and knowing the patient beyond diabetes. Two factors overlapped all participant groups and this was around positivity in the consultations and transition. As there were not many papers focussing on healthcare professionals it is not known if their perspective would differ or be similar to patients and their families.

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Part Two: Empirical Paper

Compassion Fatigue and Compassion Satisfaction in Paediatric Diabetes Professionals

This paper is written in the format ready for submission to the journal Paediatric Diabetes.

Please see Appendix L for the Guideline for Authors.

Word count: 5592

Abstract

Background

Diabetes UK describes type 1 diabetes as “a serious, lifelong condition where your blood glucose level is too high because your body cannot make a hormone called insulin”.[1] Daneman[2] states that type 1 diabetes carries a high risk of complications especially when it is not managed correctly. This therefore requires close monitoring of a high-risk patient group which could cause difficulties for professionals working in the area, such as stress and compassion fatigue. Some examples of this include: having to monitor diabetes closely given small changes can have major health impacts especially hypoglycaemia and diabetic ketoacidosis; supporting a child/teenager who are going through changes in early adolescence as well as supporting the system around them including family members and schools and finally the frequency of contact that is required is relatively high to manage frequent changes in insulin needs.

Compassion fatigue and compassion satisfaction have been researched in many different groups of professionals including intensive care nurses[3]; cancer care providers[4] and psychosocial rehabilitation teams.[5] This paper will explore compassion fatigue and compassion satisfaction in paediatric diabetes professionals; investigating the following research questions:

1. Is compassion fatigue prevalent in paediatric diabetes teams?
2. What factors are associated with the development of compassion fatigue and compassion satisfaction?
3. Do personal stressors moderate the effects of work factors (e.g. profession, caseload size, HbA1c level, complexity, years experience) on compassion satisfaction and compassion fatigue?

Methods

An online survey was sent across the diabetes network in the United Kingdom. This survey asked questions including: profession, time worked with diabetes in a professional capacity, size of caseload, percentage of caseload classed as complex (safeguarding, engagement issues, learning difficulties, CAMHS involvement, parent mental health difficulties etc.), percentage of caseload with HbA1c levels over 69mmol/mol and whether they have any personal stressors currently (the following question was used: Do you currently have any personal stressors in your life such as: bereavement, mental health difficulties, financial stressors, parenting stress, marital stress etc.?) and the Professional Quality of Life Scale (ProQol Version 5). [6]

Results

It was found that 48.5% of participants were in the low range for compassion fatigue, and 51.5% of participants were in the moderate range for compassion fatigue.

A general linear regression model found that personal stressors were the only statistically significant predictors of compassion fatigue. A general linear regression model found that personal stressors were the only statistically significant predictors of compassion satisfaction. Personal stressors did not moderate the effects of work factors on compassion satisfaction and compassion fatigue. If a participant did not report a personal stressor their CF scores were -5.492 points lower and their CS scores were 2.746 points higher than those who did report a personal stressor.

Conclusion

To conclude, no statistically significant effects were found between the work factors and the outcomes measured on the Professional Quality of Life Scale. Personal stressors were

statistically significant, which provides some opportunity for future research into the specific effects for paediatric diabetes professionals. Furthermore, roughly half of the participants were in the moderate range for compassion fatigue, suggesting that this is prevalent in paediatric diabetes professionals. Potential clinical implications include: having time to discuss and recognise the impact of personal stressors on the development of compassion fatigue and compassion satisfaction may be helpful for individual members of staff.

Keywords: *Compassion Fatigue, Paediatric Diabetes professionals.*

Introduction

Diabetes UK describes type 1 diabetes as "a serious, lifelong condition where your blood glucose level is too high because your body cannot make a hormone called insulin".[1] Daneman[2] states that type 1 diabetes carries a high risk of complications especially when it is not managed correctly. Atkinson, Eisenbarth and Michels[7] describe complications arising from type 1 diabetes as, cardiovascular disease, retinopathy (visual problems), nephropathy (kidney disease) and neuropathy (damage to peripheral nerves in hands and feet).

This management requires a multi-disciplinary team (MDT) approach. Some of the interventions a health team may need to undertake are listed below:

- Insulin administration
- Blood glucose monitoring
- Meal planning
- Screening for co morbid conditions and complications.

Diabetes UK[1] state that 4.7 million people in the UK have diabetes, and 8% of these have type 1 diabetes (376,000 people). Children will be supported by a paediatric diabetes team from diagnosis to transition to adult care. This is because NICE Guidance[8] suggest that the decision for transition to adult services should be based on the "young person's physical development and emotional maturity, and local circumstances" (point 1.5.11). A paediatric diabetes team should contain a nurse, dietitian, clinical psychologist and a paediatrician. In addition to the roles above; they can also help to support the child at school for example by providing training to teachers/school staff. NICE Guidance[8] states that children and young people should attend four MDT clinic appointments annually, of which one should be an annual review. Blood glucose control is measured by HbA1c (average blood glucose for the last 12 weeks) and blood glucose levels. NICE Guidance[8] describes optimum control as being below 48 mmol/mol. The national diabetes audit by The Health and Social Care Information Centre[9] describes the following categories: less than 48, 48-53, 54-57, 58-69, 70-75, 76-80 and 80+. These categories describe how a person's diabetes is controlled, poorer control would lead to higher levels of input from the team (e.g. more frequent appointments, educating about diet or diabetes control). The higher the HbA1c levels, the more likely the young person is at risk of long-term complications due to sub-optimal diabetes management. This highlights why a MDT team approach is crucial in the care of diabetes, the complexities of the illness and the risks associated with poor control indicate a need for professionals to be closely linked to each patient. This close monitoring added to a high-risk patient group could cause difficulties for professionals working in the area, such as stress and compassion fatigue. Some examples of this include: having to monitor diabetes closely given small changes can have major health impacts especially hypoglycaemia and diabetic ketoacidosis; supporting a child/teenager who are going through changes in early adolescence as well as supporting the system around them including family members and schools and finally the frequency of contact that is required is relatively high to manage frequent changes in insulin needs. This is linked to the models below which suggest a multitude of difficulties and complexities leading to an increased risk of burnout, compassion fatigue (CF) and affecting compassion satisfaction (CS).

Theoretical concepts of Compassion Fatigue and Compassion Satisfaction

Within the literature three terms are used to explain similar concepts, these are Burnout, CF and secondary traumatic stress. Maslach, Jackson and Leiter[10] describe burnout as a syndrome containing three factors:

1. Emotional exhaustion- feeling emotionally overextended and exhausted by work
2. Depersonalisation- unfeeling/impersonal responses to patients/clients

3. Reduced personal accomplishment- described as a tendency to describe yourself negatively; this is primarily related to professional skills but also personal attributes

Figley[11] states that "CF, like any other kind of fatigue, reduces our capacity or our interest in bearing the suffering of others". Showalter[12] describes the symptoms of CF including: fatigue, depression, withdrawal, loss of interest in things you enjoy, having persistent thoughts related to the problems of others and physical symptoms (headache, muscle tightness, sleep disturbance). Figley[11] offers a theoretical model for CF (see Figure 1). This model includes 11 different factors which can contribute to the causes of CF. Figley[11] proposes that from this model we can establish how to prevent or treat CF. He proposes 4 different interventions:

1. Education on CF
2. Desensitisation to traumatic stressors.
3. Exposure dosage – including relaxation in the desensitisation process.
4. Social support

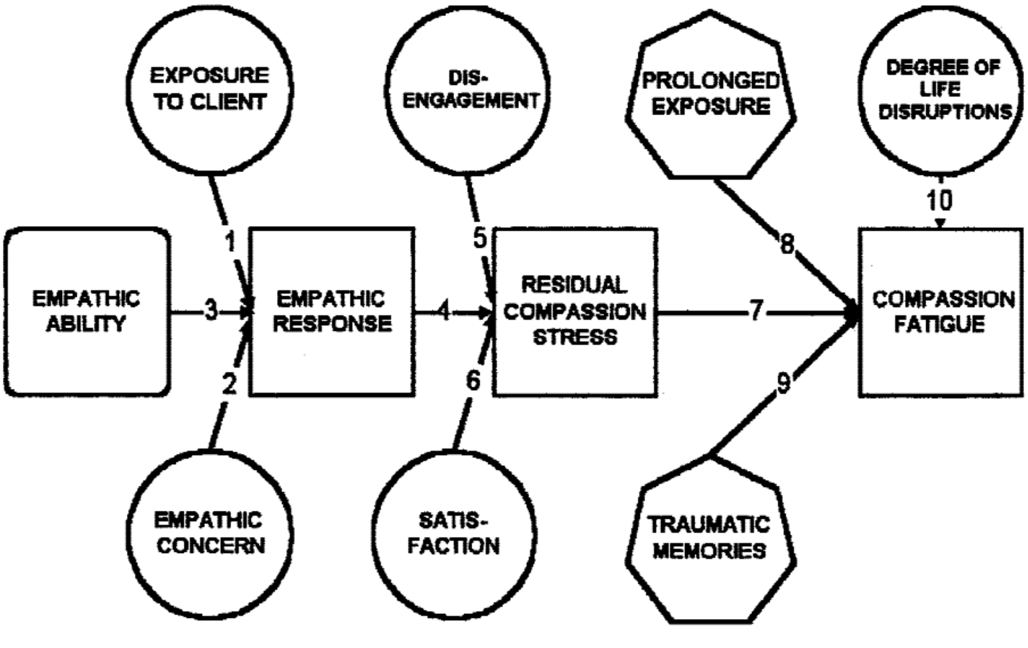

***Figure 1**: Figley (2002) model of CF.*

CS is defined by Stamm[13] in Li, Early, Mahrer, Klaristenfeld and Gold[14] (p90) as "an individual's satisfaction with his or her role as a professional caregiver".

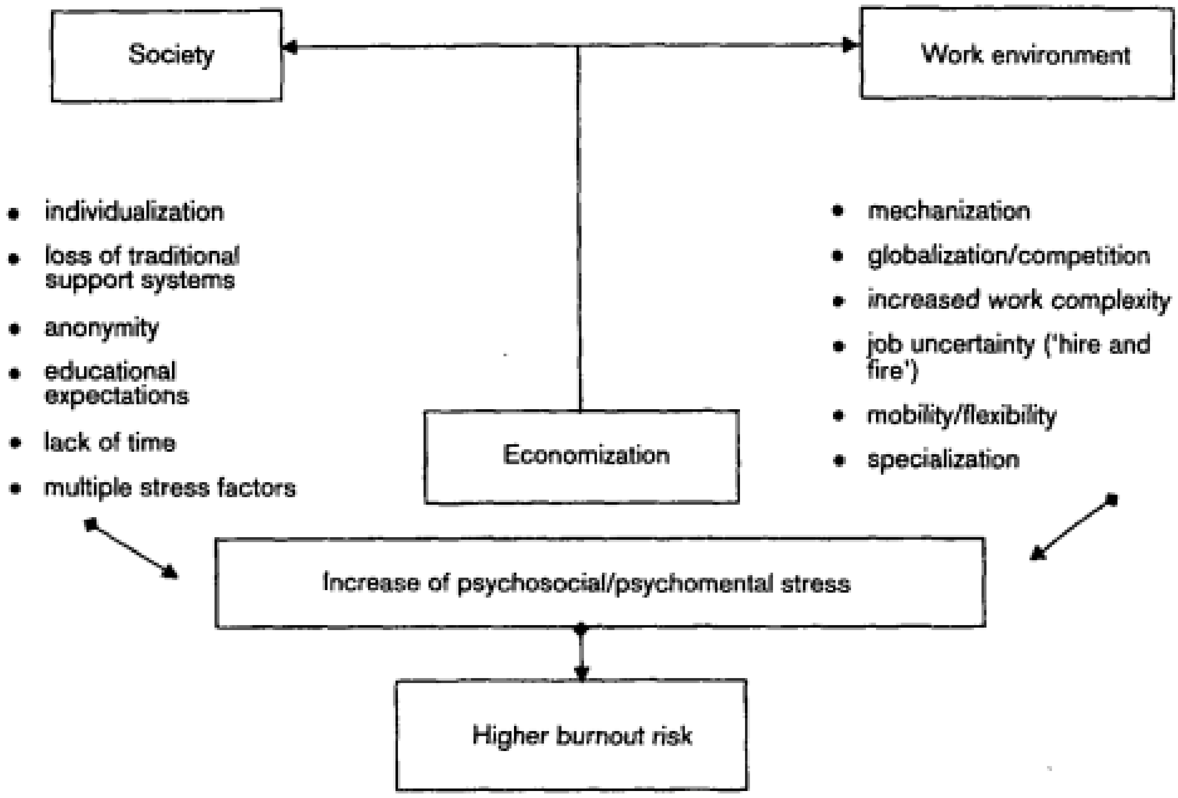

***Figure 2:** A model showing the interaction between societal factors and work environment in the development of burnout. Accessed from: Weber and Jaekel-Reinhard[15]*

Weber and Jaekel-Reinhard[15] consider a model of burnout which encompasses both societal factors and work environment. Figure 2 shows the model they have proposed which could be considered in terms of the current research. Throughout different pieces of literature these terms are used interchangeably, therefore it was decided to use CF within the current research in order to be consistent with the measure of CF and CS. Some papers below investigated the effects of burnout or secondary traumatic stress, and these findings will be taken into account given they are similar constructs to CF.

Ray, Wong, White and Heaslip[16] considered the relationship between CS, CF, work life conditions and burnout among front line mental health professionals. Different measures were used to see how these factors related to each other; the Professional Quality of Life scale [17], the Areas of Work Life survey[18], Maslach Burnout Inventory[10], and a demographic data sheet. They found that: higher levels of CS, lower CF and higher degree of fit in areas of work life would be predictive of lower burnout. The areas of work life explored include: workload, control, reward, community, values and fairness.[18]

Previous Research in Compassion Fatigue and Compassion Satisfaction

Further research considered external factors which may affect the risk of developing burnout. Green, Albanese, Shapiro and Aarons[19] studied the individual and organisational factors affecting burnout in community mental health providers. Surveys were completed by 285 providers, organisational factors accounted for most of the variance within reported burnout. These factors included role conflict (for example interests of clients are often replaced by bureaucratic concerns such as paperwork); role overload (for instance the amount of work I have to do keeps me from doing a good job); growth and advancement (for example numerous opportunities to advance in this agency); role clarity (my job responsibilities are clearly defined) and cooperation (for instance feeling of cooperation among co-workers). These factors were more predictive of burnout, as they provide a stressful environment. Interestingly, caseload size, level of education and number of years at an agency were not predictive of burnout. On the other hand, Acker and Lawrence[20] report a positive correlation between case load size and role stress for American social workers. This suggests that there are mixed results on the effects of case load size and its associated factors on stress and potential burnout. Therefore, in the current research case load size and associated factors will be examined.

Cancer care providers are faced with difficult circumstances every day. Najjar, Davis, Beck-Coon and Carney Doebbeling[4] completed a review of research into CF in cancer care providers. They reviewed 57 studies to identify prevalence of CF. They concluded that within the research there were mixed definitions on CF and how it differentiates from burnout, vicarious trauma and psychological distress. However they concluded that CF has an impact on health care providers causing decreased productivity.

Barr[3] observed the risk of CF in neonatal intensive care unit nurses in Australia. He examined many different relationships between work stress, social support, CF and CS. The conclusions from this paper suggest that CS and CF co-exist, whilst the nurses feel satisfied with their work they may be suffering from effects of CF/burnout. The author suggests that intensive care unit managers need to be aware of this. Although there may be relationships between the CF/CS and the demographics there may however be other factors mediating the results. Finally, this paper is from Australia, which may affect the results when translating to United Kingdom health care systems. Therefore, it is important to consider the differences in the way the factors may affect professionals in the UK.

Maytum, Heiman and Garwick[21] considered CF and burnout in nurses who work with children with chronic conditions and their families. Twenty nurses were interviewed about their experiences. Nurses were found to be able to recognise their own early indicators of CF. The nurses identified different triggers for CF and burnout, work related (caring for children with chronic conditions, professional role, work overload, broader system issues) and personal triggers (crossing professional boundaries, taking things personally, having unrealistic expectations of self, family crises/problems). This paper also considers coping strategies for the triggers including:

- Taking time away from work
- Being self-assertive at work
- Debriefing informally and formally at work

- Supportive professional relationships
- Awareness of personal triggers

This research considered both triggers and coping strategies for CF and burnout. The current research will consider personal stressors that may moderate the effects of work on the development of burnout and CF. Many of the coping strategies listed above can protect against burnout and CF. It was decided that for the current survey personal stressors would be considered by asking the participants whether they have any current personal stressors which may be affecting their work at the current time. This will allow us to see whether having personal stressors moderates the effects of work factors on the development of burnout and CF.

Effects of Compassion Fatigue

Poncet, Toullic, Papazian, Kentish-Barnes, Timsit, Pochard, Chevret, Schlemmer and Azoulay[22] consider the individual symptoms of burnout and CF including: tiredness, headaches, eating problems and insomnia. Reader, Cuthbertson and Decruyenaere[23] considered the effects of burnout for the organisation which includes: absenteeism, staff turnover, poor organisational commitment and low job satisfaction. It is important to consider the effects of burnout and CF on professionals but also by consequence the clients. Vahey, Aiken, Sloane, Clarke and Vargas[24] researched the effects of burnout in nurses to the patients. They explained that emotional exhaustion and lack of personal accomplishment affect patient satisfaction. Therefore, this indicates that if burnout was an issue for professionals it affects patient satisfaction of the care they receive.

In addition to this Garman, Corrigan and Morris[5] examined group level burnout in psychosocial rehabilitation teams. 333 staff completed the Maslach Burnout Inventory[25] from 21 teams. 405 clients completed the Consumer satisfaction scale (a modified version of the patient satisfaction inventory).[26] They found that between emotional exhaustion of staff and client satisfaction with the treatment there was a significant negative correlation of -.43. This suggests that as burnout increases within staff teams, patient satisfaction decreases. Care Quality Commission[27] state that their purpose is to ensure “health and social care services provide people with safe, effective, compassionate, high quality care and we encourage care services to improve”. This highlights the requirement for care to be of a high standard; and all aspects of care should be considered including staff wellbeing.

The current research

To date there has been little research that has investigated compassion phenomena in this professional group before. Weber and Jaekel-Reinhard’s[15] model of burnout encompasses both societal and work factors. Therefore the following factors were chosen to be explored in the current research: profession, time worked with diabetes, caseload size, complex cases (systemic factors affecting the caseload e.g. safeguarding, CAMHS involvement, learning difficulties, parental mental health, engagement issues), HbA1c levels (diabetes control) and personal stressors. Furthermore, Maytum, Heiman and Garwick[21] considered personal factors as coping strategies linked to burnout and CF. This current study aims to consider the relationship between personal factors and the development of CF and CS; in that the presence of personal stressors moderate the effects of work factors or there is no effect between the two variables.

Research Questions

1. Is compassion fatigue prevalent in paediatric diabetes teams?
2. What factors are associated with the development of compassion fatigue and compassion satisfaction?

3. Do personal stressors moderate the effects of work factors (e.g. profession, caseload size, HbA1c level, complexity, years experience) on compassion satisfaction and compassion fatigue?

Method

Design

The study adopted a cross sectional quantitative design where data were collected via an online survey to establish what factors may be linked to CF and CS in paediatric diabetes professionals.

Participants

148 Participants were recruited from professional diabetes networks across the UK between August 2019 and January 2020. Participants were recruited via email invitation which was distributed by the field supervisor in addition to word of mouth at professional meetings and forums. All participants were sent an online survey.

The inclusion criteria were as follows; must work in a paediatric diabetes team currently, must not have worked in diabetes teams for less than 3 months, must be in a permanent position.

The exclusion criteria were as follows; must not be a locum worker.

148 participants completed the whole survey, and therefore participated in the study. Figure 3 shows participant recruitment numbers. 14 participants were removed for analysis as they did not complete every question with a suitable answer for example: answered with “I don’t know”

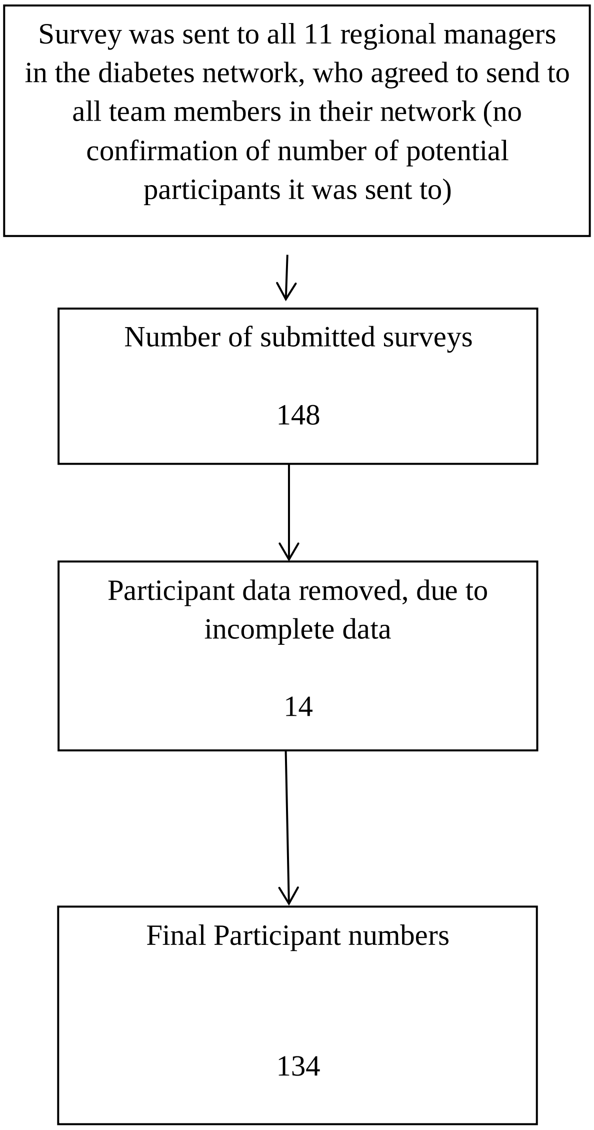

Figure 3: *Flow chart to show participant recruitment.*

Measures

Demographics and professional information

Information about the participants' were collected including: profession, time worked with diabetes in a professional capacity, size of caseload, percentage of caseload classed as complex (safeguarding, engagement issues, learning difficulties, CAMHS involvement, parent mental health difficulties etc.), percentage of caseload with HbA1c levels over 69mmol/mol and whether they have any personal stressors currently (the following question was used: do you currently have any personal stressors in your life such as: bereavement, mental health difficulties, financial stressors, parenting stress, marital stress etc.?). For analysis the personal stressors question was scored 0 for no personal stressors and 1 for personal stressors.

Professional Quality of Life Scale (ProQol Version 5.)[17]

The Professional Quality of Life Scale consists of 30 statements which ask the participant about their experiences as a helper in their current work situation. They are asked to rate from 1-5 (Never, rarely, sometimes, often and very often) how frequently they experienced the statement over the last 30 days.

The ProQol Manual[28] describes good construct validity, it is reported that the CF scale is distinct. Reliability was researched by Heritage, Rees and Hegney.[29] They found the following alpha reliabilities: burnout (.80), CF (Secondary traumatic stress) (.84) and CS (.90). This measure is therefore considered to be effective at measuring CF and CS. There is shared variance between the Burnout and STS scales, but they measure different constructs.[28] On the other hand, Heritage, Rees and Hegney[29] found that validity is better when burnout and CF (STS) scales are combined on the ProQol. The scores will be combined for the following research. See Figure 4 below from the ProQol Manual.

For each component the question scores were added together, for example: for compassion satisfaction scores for the following questions were added together: questions 3, 6, 12, 16, 18, 20, 22, 24, 27 and 30 (maximum score 50). For CF (burnout and secondary traumatic stress), the following questions were added together: questions 1*, 4*, 8, 10, 15*, 17*, 19, 21, 26, 29*, 2, 5, 7, 9, 11, 13, 14, 23, 25 and 28 (maximum combined score: 100). Those with * symbol were reverse scored so if the participant put 5 they scored 1, if they put 2 they scored 4 etc. This follows the self-score approach as detailed in the ProQol scale.

Table 1 shows the score categories this paper will be based upon. The ProQol website states that there are no cut off scores for the measure specifically. Raw scores were used for analysis, and the following cut off scores were used for categorisation. The scores for burnout and secondary traumatic stress from the self-score ProQol were added together to create the cut off scores below, following the theoretical model in Figure 4. The scores for burnout and secondary traumatic stress were taken from the self-score ProQol available online.

Table 1: *Showing the cut off scores for combined compassion fatigue scores.*

Compassion Fatigue (combined STS and burnout score)	Compassion Satisfaction	Categorisation
44 or less	22 or less	Low
45-83	23-41	Moderate
84 or above	42 or more	High

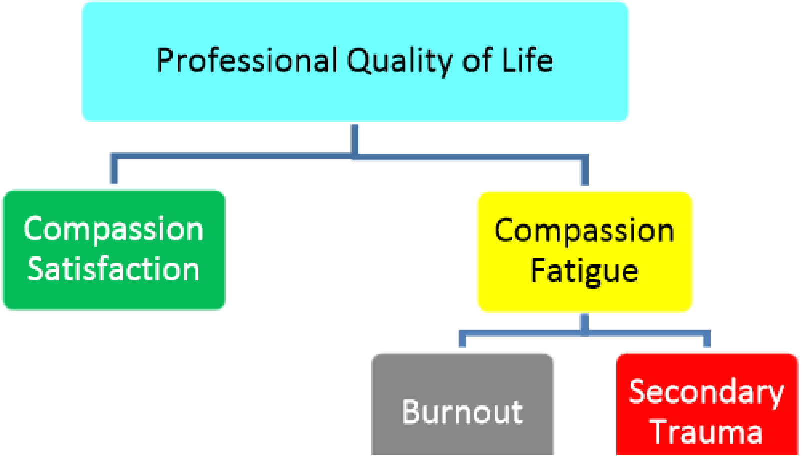

Figure 4: *Image taken from Professional Quality of Life Scale Manual*[28] *Retrieved from: https://proqol.org/uploads/ProQOLManual.pdf*

Procedure

Participants were asked the demographic/profession questions first then the ProQol. The final page contained a debrief (See Appendix F) and information on where they could access support if required. Participants were able to drop out at any time, but if they continued to the end all questions were compulsory. The survey was created in order to take roughly 10-15 minutes in one sitting.

Data Analysis

The results were analysed using a general linear regression model. The independent variables were profession, caseload size, HbA1c level, complexity, years experience and personal stressors. The dependent variables are compassion satisfaction and compassion fatigue. To test for moderation, interactions between each of profession, caseload size, HbA1c level, complexity, years of experience and personal stressors were added to the general linear model fitted to answer research question 2 for compassion satisfaction and compassion fatigue. A power calculation was completed which detailed that using a 5% significance level and assuming a medium effect size of 0.1 for moderation, 135 participants were required to achieve 80% power for testing moderation.

Results

148 participants responded to the survey online. Incomplete data or incorrect values e.g. “I don’t know” were removed before analysis. The same rules were used for each variable – for example if someone had written ‘I don’t know’ or ‘I do not have that information’ on one of their answers; they were fully removed from the analysis. If people had written ‘about 25 years’ or ‘about half’ then the numbers were used (’25 years’ and ‘50%’). For those who had provided a range e.g. ‘10-15%’, the average was used ’12.5%’.

Analysis below is based on 134 participants as 14 participants had one or more items of incorrect or incomplete data and were removed.

Research Question 1: Are compassion fatigue and compassion satisfaction prevalent in paediatric diabetes teams?

Table 2 details the profession distribution with Nursing being the highest represented and Dietitians being the lowest represented. There is no data available to know if this matches the composition of professionals within paediatric diabetes teams. This table also includes the mean and standard deviation of years worked in diabetes, mean caseload sizes and the mean percentage of the caseload with a HbA1c level above 69 mmol/mol, CF and CS scores.

Table 2: *Characteristics of data collected by factor grouped by profession.*

Variable	Psychologist	Nurse	Paediatrician	Dietitian	Total
Percentage included within the sample	29.9 (40/134)	39.6 (53/134)	18.7 (25/134)	11.9 (16/134)	100 (134/134)
Years worked in diabetes: Mean (SD)	5.78 (4.09)	10.57 (7.02)	13.04 (8.08)	9.38 (8.94)	9.46 (7.21)
Caseload Size Mean (SD)	42.9 (55.53)	63.55 (29.89)	125.08 (75.38)	201.25 (150.00)	85.31 (86.38)
Percentage of caseload rated as complex Mean (SD)	40.85 (28.24)	31.26 (20.42)	24.92 (13.27)	26.75 (18.56)	32.40 (22.45)
Percentage of caseload with HbA1c above 69 mmol/mol Mean (SD)	54 (28.34)	30.73 (20.26)	31.34 (15.39)	29.66 (18.45)	37.66 (24.33)
Compassion Satisfaction Mean (SD)	36.95 (5.86)	37.02 (5.49)	37.36 (4.25)	38.44 (5.39)	37.23 (5.35)
Compassion Fatigue Mean (SD)	43.38 (8.27)	47.79 (10.31)	45.88 (8.55)	43.44 (7.47)	45.60 (9.22)

Using the cut offs mentioned above the following percentages of participants fell into each category for compassion fatigue.

Table 3: *Showing the cut off scores for combined compassion fatigue score and percentage of participants in each category.*

Category	**Score cut offs**	**Percentage of participants in this category**
Low	44 or less	48.5
Moderate	45-83	51.5
High	84 or above	0

This therefore suggests that approximately half of the participants involved in the survey were experiencing low (65 participants) and half of the participants were experiencing moderate (69 participants) compassion fatigue. Whereas no participants in the survey were in the highest category for CF.

Table 4: *Showing the cut off scores for compassion satisfaction scores, and percentage of participants in each category.*

Category	**Score cut offs**	**Percentage of participants in this category**
Low	22 or less	0.75
Moderate	23-41	79.1
High	42 or more	20.1

Table 4 suggests that the majority of participants were in the moderate category for compassion satisfaction (79.1%; 106 participants), 20.1% (27 participants) were in the high category and one participant was in the low category.

Research Question 2: What factors are associated with the development of compassion fatigue and compassion satisfaction?

Compassion Fatigue

A general linear regression model showed that all work related factors were not statistically significant, profession (*F(3, 125)* = 1.774, *p* = .155), years worked in diabetes (*F(1, 125)* = .266, *p* = .607), complexity (*F(1, 125)* = .125, *p* = .724), HbA1c (*F (1, 125)* = .083, *p* = .774) and caseload size (*F (1,125)* = 1.407, *p* = .238) apart from personal stressors (*F(1, 125)* = 12.188, *p* = .001) which was found to be statistically significant. If a participant did not report a personal stressor their CF scores were -5.492 points lower than those who did report a personal stressor.

***Table 5:** Parameter Estimates – Compassion Fatigue*

Parameter	**B (Std Error)**	**Confidence Intervals**
Psychologist	-4.469 (2.048)	(-8.523, -0.416)
Paediatrician	.124 (2.296)	(-4.420, 4.668)
Dietitian	-1.473 (3.054)	(-7.517, 4.571)
Nurse	0 (-)	-
Yes - Personal Stressors	0 (-)	-
No – Personal Stressors	**-5.492 (1.573)**	(-8.605, -2.378)
Years	.066 (.129)	(-0.188, 0.321)
Caseload Size	-.014 (.012)	(-0.038, 0.009)
Complexity	0.14 (.040)	(-0.065, 0.094)
HbA1c	-.012 (.042)	(-0.094, 0.070)

Compassion Satisfaction

A general linear regression model showed that all work related factors were not statistically significant, - profession (*F (3, 125)* = .504, *p* = .680), years worked in diabetes (*F (1, 125)* = .196, *p* = .659), complexity (*F (1,125)* = 1.675, *p* = .198), HbA1c (*F (1, 125)* = .009, *p* = .925) and caseload size (*F (1, 125)* = 1.838, *p* = .178). However, personal stressors (*F (1, 125)* = 8.72, *p* = .004) was found to be statistically significant. If a participant did not report a personal stressor their CS scores were 2.746 points higher than those who did report a personal stressor.

Normality testing

Normality tests were carried out, Shapiro Wilk revealed that the CF residuals were normally distributed (*p* = .082). No significant outliers were seen within scatter plots and histograms of the CF data. Parameter estimates for CF are displayed in Table 5. Normality tests were carried out, Shapiro Wilk revealed that the CS residuals were normally distributed (*p* = .320). No significant outliers were seen within scatter plots and histograms of the CS data. Parameter estimates for CS are displayed in Table 6.

Personal Stressors

53.7% of participants reported that they currently had a personal stressor that may have been affecting them at work.

***Table 6**: Parameter Estimates – Compassion Satisfaction*

Parameter	**B (Std Error)**	**Confidence Intervals**
Psychologist	.748 (1.210)	(-1.647, 3.144)
Paediatrician	-.1.140 (1.357)	(-3.826, 1.546)
Dietitian	-.400 (1.805)	(-3.972, 3.173)
Nurse		
Yes - Personal Stressors		
No – Personal Stressors	2.746 (.930)	(0.906, 4.586)
Years	.034 (.076)	(-0.117, 0.184)
Caseload Size	.010 (.007)	(-0.004, 0.023)
Complexity	-.031 (.024)	(-0.078, 0.016)
HbA1c	-.002 (.025)	(-.051, 0.046)

Research Question 3: Do personal stressors moderate the effects of work factors (e.g. profession, caseload size, HbA1c level, complexity, years experience) on compassion fatigue and compassion satisfaction?

For the compassion satisfaction model the overall model was found to be not statistically significant ($R^2 = .169$, *F* (1, 15) = 1.602, *p* = .083). The following were also found to be not statistically significant - profession*personal stressors (*F*(3, 118) = .421, *p* = .739); personal stressors*years (*F*(1, 118) = .008, *p* = .930); personal stressors*caseload size (*F*(1, 118) = 1.095, *p* = .297); personal stressors*complexity (*F*(1, 118) = 1.228, *p* = .270); personal stressors*HbA1cpercentage (*F*(2, 118) = .464, *p* = .630). Therefore, there is no evidence that personal stressors moderated the effect of the work factors for compassion satisfaction.

For the compassion fatigue model, the overall model was found not to be statistically significant ($R^2 = .150$, *F* (1, 15) = 1.390, *p* = .163), the following were also found not to be statistically significant - profession*personal stressors (*F*(3, 118) = .017, *p* = .997); personal stressors*years (*F*(1, 118) = .372, *p* = .543); personal stressors*caseload size (*F*(1, 118) = .678, *p* = .412); personal stressors*complexity (*F*(1, 118) = .566, *p* = .454); personal stressors*HbA1cpercentage (*F*(1, 118) = .350, *p* = .555). Therefore, there is no evidence that personal stressors moderated the effect of the work factors for compassion fatigue.

Discussion

This research paper aimed to investigate compassion fatigue and compassion satisfaction in paediatric diabetes professionals. The first research question is 'Is compassion fatigue prevalent in paediatric diabetes teams?' One hundred and thirty four participants from paediatric diabetes teams across the UK completed the ProQol and their data was included in the analysis. This identified that overall professionals did not display scores that were in the high range for CF, but did display scores in the low-moderate range. Roughly half were in the low range and half in the moderate range; this suggests that there was a reasonably good spread of participants. However, there were no participants who had high compassion fatigue. This may be due to how it has been measured as a screening measure. As mentioned above some caution has to be made in making conclusions because the cut off scores are not validated but give us some idea of the prevalence of CF scores in this population. Furthermore, it may be that the professionals have the highest compassion fatigue are no longer working in the profession or are off work sick. This paper was a preliminary research paper, as we did not know what to expect in terms of compassion fatigue for this population. From previous research[3] it could be expected that professionals simultaneously experience CF and CS, which appears the case in the current study. This paper found the majority of participants had moderate levels of compassion satisfaction.

For the second research question 'What factors are associated with the development of compassion fatigue and compassion satisfaction?' A general linear regression model was created with all work factors and they were found not to be statistically significantly apart from personal stressors when related to CF or CS scores. This appears in contrast with some research described in the introduction including: Green, Albanese, Shapiro and Aarons[19] who found that organisational factors accounted for most of the variance in burnout scores. This may be because they investigated a wider range of organisational factors including factors beyond the individual clinician (for example: cooperation with co-workers; role overload). It may be that professionals individual caseload factors do not link to the development of compassion fatigue but the multitude of demands including organisational factors does impact the development. In addition, Maytum, Heiman and Garwick[21] found that nurses can recognise triggers for CF for themselves, which included both work and personal factors. Within this paper, a question about personal stressors was included as a screening question, to account for individual differences. However, it appears that as this was the only factor which was significant it may be that this should be further explored within this population.

For the final research question, ‘Do personal stressors moderate the effects of work factors (e.g. profession, caseload size, HbA1c level, complexity, years experience) on compassion satisfaction and compassion fatigue?’ Moderation in a general linear regression model was created with all factors and the interactions were also found to not be statistically significant suggesting that there are no statistical relationships between the factors researched and the CS and CF scores when moderating for personal stressors. This therefore suggests that the concepts researched within this paper are not statistically related to CS and CF. It may be that there are other factors related to CF and CS scores, and that this needs to be further explored. It may also be how the personal stressors were measured - with a simple screening question. The primary aim of this paper was to understand whether CF is prevalent in the paediatric diabetes professional group, and to see if any factors were related to this. It is interesting that this came out statistically significant given the majority of the research focusses on work related factors and compassion fatigue. This may be because professionals do not discuss personal stressors or the impact of these at work. This will be further explored in the clinical implications below.

It is interesting given that previous research has found interactions or effects between work and personal factors and CF. It suggests that within this professional group, there is not a link between work factors and the development of CF/CS. There were some statistically significant results with the personal stressors being related to the CF and CS scores. If a participant reported no personal stressors their CS scores were higher, and CF scores were lower. This can be linked to Weber and Jaekel-Reinhard's[15] model in which multiple stress factors were included to increase psychosocial stress and higher burnout risk. It may be that further research needs to be done to disentangle the personal stressors effect on paediatric diabetes professionals. This is further explored in the limitations section below.

Strengths and limitations

For the current research, there are strengths in that it looks at paediatric diabetes professionals across the country, and therefore could be applicable for all diabetes teams in the UK. It is a subsection of these professionals, and is preliminary data to look into what factors are related to CF and CS in this group. However, there is a possible risk of sampling bias, in which the professionals with the highest fatigue may not have participated in the research as they may be off work sick. It may be that the sample is those who feel able to take on an extra demand, and have time at work/personally to take part in this. Furthermore, as it is preliminary research, it took an overview of factors on the development of CF and CS. This did not allow for in depth analysis into the factors, which may have been useful considering how to conceptualise a personal stressor – perhaps by rating the impact of the personal stressor on the person as well. For example: Do you currently have any personal stressors in your life such as: bereavement, mental health difficulties, financial stressors, parenting stress, marital stress etc.? and On a scale of 1-10, how much does this impact your daily life? It is assumed that a lot of people may have one of the stressors listed or a personal stressor, but the question used assumed that these will all have the same impact on the participant, which will not be the case.

In addition, there were a high proportion of psychologists (29.9%) who participated in the survey. This may have skewed the results given that psychologists generally have some form of clinical supervision which is advised above as a way to mitigate the effects of individual stressors on the development of compassion fatigue. This could also have been a limitation of the current study, as perhaps this could have also been moderated for (for example: clinical supervision time/discussion of personal stressors at work).

A further limitation of the current research is that workplace factors were not measured. Figure 2 shows a model of the development of burnout, within this workplace factors were important including: increased work complexity, job uncertainty, mobility/flexibility etc.[15] Further research also measured organisational factors including role conflict, role overload, growth and advancement, role clarity and cooperation, they found that organisational factors accounted for the majority of the reported burnout.[19] This may explain why individual and work factors researched in the current research did not link to the development of compassion fatigue. It may be that within paediatric diabetes professionals organisational factors are linked to the development of CF. It may be that a combination of organisational factors e.g. broader system issues[21] and individual factors (as researched in the current research) contribute to the development of compassion fatigue.

Future research recommendations

As mentioned further research could look into the impact of personal stressors, perhaps looking at different personal stressors, and the impact on working environments. In the current study personal stressors did not moderate work factors but did appear to predict CF and CS scores. This may be worth researching further through qualitative interviews and further questions regarding the impact of personal lives on the development of work-related CF and CS. It would also be important to consider organisational factors in future research, this may include: measuring or asking qualitative questions about how people perceive their organisation e.g. role conflict, chances to advance and grow in the organisation. One such scale that could be used as used in Green, Albanese, Shapiro and Aarons[19] is the Organisational social context measure.[30]

Clinical implications

Although these results are preliminary findings, it may be useful to think about this in the clinical environment. One way this could be done, is incorporating discussions regarding personal stressors into managerial and clinical supervision, considering the impacts that personal stressors have on working life. Considering this and potentially mediating these effects for example allowing health care professionals time off or flexible working to manage the impact a personal stressor may have. Furthermore, it would be important that healthcare professionals feel able to discuss their personal circumstances at work, so managers and teams should attempt to make environments in which staff feel comfortable to discuss this. This may be completed through different types of supervision. In many healthcare settings professionals have managerial supervision, where they can discuss the impact of work factors on themselves as well as their productivity. Some professions for example psychologists have clinical supervision whereby other factors can be discussed including the impact of personal stressors, the emotional impact of the work on the professional and how these affect the ability to work in a particular area. It may be important to think about how this is established within supervisory relationships for example: not discussing personal stressors alike to personal therapy and considering when a personal stressor is something which should be discussed with an Occupational Health professional. This may include: reflecting on the impact of the personal stressor and practical strategies to support the professional.

Research has found clinical supervision to be effective for reducing stress, compassion fatigue and burnout and increasing compassion satisfaction in a group of nurses and doctors who did not previously have clinical supervision[31]. Schwartz Rounds have also been rated positively in paediatric settings including a children's hospital[32] and paediatrics within a general hospital setting[33] (p20) with staff reporting that "Schwartz Rounds help to alleviate Compassion Fatigue by giving people a way to vent and discuss frustrations". It may be that the addition of these within a paediatric diabetes professional group could support the staff both individually and as a team to reduce compassion fatigue.

Conclusion

In conclusion, this empirical paper has explored predictors of the development of compassion fatigue and compassion satisfaction in paediatric diabetes professionals. No statistically significant effects were found for work factors (profession, time worked with diabetes in a professional capacity, size of caseload, percentage of caseload classed as complex and percentage of caseload with HbA1c levels over 69mmol/mol) but statistically significant effects were found for personal stressors and CF and CS. This paper was a preliminary analysis into whether professionals in this group experience compassion fatigue and what may be linked to this, it has suggested areas for future research e.g. into personal stressors and their effect on development of compassion fatigue and compassion satisfaction, which may be useful especially given the potential clinical and managerial implications in the workplace. Future research should look into organisational factors as well as further exploring individual personal stressors. This may include further exploring broader system issues[21], organisational factors[15], as well as more detailed exploration into personal stressors e.g. by rating the impact of the personal stressor or through qualitative analysis in how this personal stressor affects them at work, as this was a limitation within the current research project.

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Part 3 Appendices

Appendix A: Epistemological Statement

An individual’s approach to research depends on their understanding of how to gain knowledge. For this empirical project presented in this paper a post-positivist critical realist stance was taken. This is the view that all research can contain error and we cannot measure things accurately and with certainty. Trochim and Donnelly (2001) describe that post positivist critical realist’s recognise that observation is fallible and has error and all theory is revisable.

The researcher is critical that we can know the reality of the level of compassion fatigue within a population with certainty. This is because we only have the participants that participate in the research from certain areas in the United Kingdom. The research findings in this paper give us some idea of the prevalence of compassion fatigue and satisfaction and what could affect that. This is true for this time in 2019-2020, with the participants who submitted a survey; this may not be transferable to other professionals or years. This is reflected in the clinical implications which are vague and idiosyncratic to each individual professional. Furthermore, the measures used for compassion fatigue may not accurately measure the experiences of professionals in these teams, the researcher felt torn between using measures which reduce a person’s experience to a number or qualitative interviews which capture only a few individual’s experiences. Quantitative methodology was chosen as this explores the issue wider and enables more professionals to be involved in the research project. As suggested in the future research recommendations section, there is still a value of qualitative research in exploring individual’s experiences.

Whilst completing this research, the researcher was aware of the position they were taking but did feel some pull when analysing the results to want to explore further the experiences of the professionals. This may come from being from a clinical psychology background and wanting to explore and speak with participants. Having this awareness enabled me to complete my Systematic Literature Review which included both quantitative and qualitative research papers, exploring the experiences in the therapeutic relationship for children, adolescents, families, and health care professionals. Trochim and Donnelly (2001) suggest that multiple measures and observations are important within post-positivist critical realist research; therefore, further research is required to begin to understand the experiences of paediatric diabetes professionals.

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Appendix B: Reflective Statement

Empirical paper

From the beginning of the doctorate I knew I was interested in staff wellbeing but also in diabetes. Therefore, it made sense that this was something I researched. I had two field supervisors who met with me to talk through our ideas for my research project. It was really good to work with people in the field who knew the day to day activities of a staff group in this area. It was particularly useful in the development of the research and survey as they could inform me of the main things they felt were difficulties for the professionals in this area.

From the beginning of recruitment participant numbers steadily increased; this was a real strength and a high point for me in the research. It felt like I was capturing people's stories through my survey, and hoped to provide well-needed data to support professionals. Throughout this recruitment, I and my field supervisor received some emails explaining that people wanted to complete the research but could not as there were not options for this. In one way, this made me feel saddened that I was unable to capture their experiences, but understood that through the scope of this project the aim was to understand the core members who are in all teams. This limited our ability to expand the number of professions we could include within the project. Furthermore, potential participants commented that although it was important research, they could not complete it as they did not have a named caseload for themselves; this would have been hard to include and compare the results in a quantitative research project amongst participants who do have a named caseload. This potentially would be important to consider in terms of group level burnout.

Once the data was collected, the analysis process began. It was difficult as some data had to be removed because participants had answered with "I don't know" or other alternatives. On reflection I should have listed the information needed at the beginning of the survey, and restricted the answers in the boxes so only correct digits could be submitted, this would have ensured every participant who took the time to submit a survey was included in the analysis.

I have enjoyed the research process, but writing up the research was difficult given we were in isolation in COVID-19 pandemic. The support we would have previously had with study groups with other trainees and face to face meetings had to be held online, this affected my motivation to the write up of the project. However, I was dedicated to complete it on time, and felt it was important to write up data from surveys that the participants had taken time to complete.

Systematic Literature Review (SLR)

My motivation towards the SLR was slightly lower than towards my empirical project. It took me a long time to decide on a question and complete the initial searches. It just seemed like a huge mountain to climb when I saw thousands of papers coming back after each search.

I wanted to capture some element of my empirical in my SLR, with considering what may happen to a therapeutic relationship if a professional is experiencing compassion fatigue. I think through completing the SLR my perfectionism started to shine through with me attempting to ensure I found the exact correct search and all papers, but sometimes this stopped me working as again the tasks seemed so huge.

When I began to cut the SLR down into sections, this is where the hard work and similar dedication came in. I finally felt able to tackle the SLR!

I cut the SLR down into sections and completed a few small tasks a day; the SLR finally began shaping up. I overcame my perfectionism and sent my supervisor imperfect drafts to get comments and support on, and this finally helped me to write and write and write. When I was reaching the end of the SLR, I had a really positive moment. Seeing my Venn diagram of factors, it felt like I had captured the voices of many participants and researchers and this felt as valuable as my empirical project. I hope this will support professionals in developing a positive therapeutic relationship with children and adolescents with type 1 diabetes.

Summary

I saw this project as a huge mountain to climb and at the start I couldn't see the top but I've managed it. Dare I say I actually enjoyed most parts of it and I am looking forward to completing research in the future.

Appendix C: Mixed Methods Appraisal Tool (Hong et al, 2018)

Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?				
	S2. Do the collected data allow to address the research questions?				
	Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?				
	1.2. Are the qualitative data collection methods adequate to address the research question?				
	1.3. Are the findings adequately derived from the data?				
	1.4. Is the interpretation of results sufficiently substantiated by data?				
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?				
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed?				
	2.2. Are the groups comparable at baseline?				
	2.3. Are there complete outcome data?				
	2.4. Are outcome assessors blinded to the intervention provided?				

	2.5 Did the participants adhere to the assigned intervention?				
3. Quantitative nonrandomized	3.1. Are the participants representative of the target population?				
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?				
	3.3. Are there complete outcome data?				
	3.4. Are the confounders accounted for in the design and analysis?				
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?				
	4.2. Is the sample representative of the target population?				
	4.3. Are the measurements appropriate?				
	4.4. Is the risk of nonresponse bias low?				
	4.5. Is the statistical analysis appropriate to answer the research question?				
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?				
	5.2. Are the different components of the study effectively integrated to answer the research question?				
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?				

	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?				
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?				

Mixed Methods Appraisal Tool (MMAT), version 2018

Appendix D: Information Sheet

Information Sheet for Participants

Title of Study: Factors relating to Burnout and Compassion Fatigue in professionals working in Paediatric Diabetes Health teams

I would like to invite you to participate in a research project which forms part of my Clinical Psychology Doctorate research. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please contact me before completing the survey if there is anything which is not clear or if you would like more information.

What is the purpose of the study?

This study will look at the development of burnout and compassion fatigue in professionals working within paediatric diabetes teams. Past research has looked at what factors affect the development of burnout and compassion fatigue within different groups of professionals (mental health, neonatal intensive care, oncology). The current research will consider what factors affect the development or protection against the development of burnout and compassion fatigue.

Why have I been invited to take part?

You are being invited to take part as you are a professional working within a paediatric diabetes team. The information sheet has been sent to all professionals who are part of the diabetes network; and all professionals will be asked to take part. Unfortunately, those who are Locum workers, and those who have been working within the profession for less than 3 months will not be able to take part.

What will happen if I take part?

If you agree to take part you will be asked to follow the link in the email and at the bottom of the information sheet. This link will provide the survey and the consent forms you are asked to complete. The survey should take about 10 minutes to complete, which would preferably be completed in one sitting. All data submitted is anonymous and kept confidential on an encrypted NHS laptop.

Do I have to take part?

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in any way. Once you have read this information sheet you are able to contact me with any questions that will help you make a decision about taking part. If you decide to take part you should click the link provided, read the consent form, once you click next and submit your answers you have given consent to take part in the survey.

What are the possible risks of taking part?

Participating in the study will require 10 minutes of your time and this may be inconvenient for you. Some people may experience emotional distress when they complete a survey regarding burnout and compassion fatigue. At the end of the survey there is information regarding support you can access if you feel it is required. This includes professional regulatory bodies, psychology within your team, and occupational health within the NHS.

What are the possible benefits of taking part?

There will be no direct benefits from taking part in the study. However, it is hoped that the information you give us will help us to understand more about the development of burnout and compassion fatigue in paediatric diabetes professionals. It is hoped that this information can help to provide information on how to support professionals in these teams.

Data handling and confidentiality

Your data will be processed in accordance with General Data Protection Regulation 2018 (GDPR).

No personal information is collected from you. The questionnaire includes collecting information about your profession, caseload, time spent working within diabetes care, personal stressors, and the Professional Quality of Life Scale (B. Hudnall Stamm, 2009. *Professional Quality of Life: Compassion Satisfaction and Fatigue Version 5 (ProQOL)*.

/www.isu.edu/~bhstamm or www.proqol.org). You will not be identifiable by the data you provide.

Data Protection Statement

The data controller for this project will be the University of Hull. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under GDPR is a ‘task in the public interest’ You can provide your consent for the use of your personal data in this study by completing the consent form that has been provided to you at the beginning of the online survey**.**

What if I change my mind about taking part?

You are free withdraw at any point of the study, without having to give a reason. Withdrawing from the study will not affect you in any way. You are able to withdraw your data from the study up until you have submitted your survey, at that point the data will be anonymised and will be part of a larger data set, and you will be unable to withdraw your data.

What will happen to the results of the study?

The results of the study will be summarized in a written thesis as part of a Doctorate in Clinical Psychology. The thesis will be available on the University of Hull's on-line repository https://hydra.hull.ac.uk/ The research may also be published in academic journals or presented at conferences.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact me using the following contact details:

Charlotte Adams

Clinical Psychology

Aire Building

The University of Hull

Cottingham Road

Hull

HU6 7RX

E-mail: C.adams@2017.hull.ac.uk

What if I have further questions, or if something goes wrong?

If you wish to make a complaint about the conduct of the study, you can contact the University of Hull using the research supervisor’s details below for further advice and information:

Dr Emma Lewis

Clinical Psychology

Aire Building

The University of Hull

Cottingham Road

Hull

HU6 7RX

Tel: 01482464617

Email address: e.lewis@hull.ac.uk

Thank you for reading this information sheet and for considering taking part in this research.

Appendix E: Consent Form

Factors relating to Burnout and Compassion Fatigue in professionals working in Pediatrics Diabetes Health teams.

Consent – By clicking next you consent to:

- Taking part in this study
- Having read the information sheet
- Considered the information, asked any questions you may have and have had these answered satisfactorily.
- You are participating voluntarily and can freely withdraw until point of submission. Once the survey has been submitted the data is anonymised; and cannot be withdrawn as it is part of a larger data set.

Appendix F: Debrief Sheet

The results of the study will be summarized in a written thesis as part of a Doctorate in Clinical Psychology. The thesis will be available on the University of Hull's on-line repository https://hydra.hull.ac.uk/ The research may also be published in academic journals or presented at conferences.

If you have any questions or require more information about this study, please contact me using the following contact details:

Charlotte Adams
Clinical Psychology
Aire Building
The University of Hull
Cottingham Road
Hull
HU6 7RX
E-mail: C.adams@2017.hull.ac.uk

If you feel that you need support after completing this survey please utilise the following: the team psychologist, Unite, Nursing and Midwifery Council, your professional union and NHS Occupational Health.

Appendix G: Ethics approval and first amendment

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Removed for digital archiving

Appendix H: Survey

1. What is your profession?
    a. Nurse
    b. Paediatrician
    c. Dietitian
    d. Psychologist
2. How long have you worked with diabetes in a professional capacity? (In years and months) Please type your answer in the following format: e.g. 6 years 5 months
3. What size is your caseload? e.g. the total number of people you are responsible for individually, not the total team's caseload.
4. What percentage of your caseload would you class as complex? I.e. has other factors affecting the patient/family, such as safeguarding issues (Whether open to social care or not), engagement issues, learning difficulties, CAMHS involvement, parent mental health difficulties etc.
5. What percentage of your caseload have HbA1c levels of over 69 mmol/mol?
6. Do you currently have any personal stressors in your life such as: bereavement, mental health difficulties, financial stressors, parenting stress, marital stress etc.?
    a. Yes
    b. No
7. Professional Quality of Life Scale - When you help people you have direct contact with their lives. As you may have found, your compassion for those you help can affect you in positive and negative ways. Below are some questions about your experiences, both positive and negative, as a helper.

Consider each of the following questions about you and **your current work situation**. Select the number that honestly reflects **how frequently you experienced these things in the last 30 days.**

8. I am happy
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Very Often
9. I am preoccupied with more than one person I help
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Very Often
10. I get satisfaction from being able to help people
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Very Often
11. I feel connected to others
    a. Never
    b. Rarely
    c. Sometimes

    d. Often
    e. Very Often

12. I jump or am startled by unexpected sounds
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Very Often
13. I feel invigorated after working with those I help.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Very Often
14. I find it difficult to separate my personal life from my life as a helper.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Very Often
15. I am not as productive at work because I am losing sleep over traumatic experiences of a person I help.
    a. Never
    b. Rarely
    c. Sometimes

d. Often
e. Very Often

16. I think that I might have been affected by the traumatic stress of those I help.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Very Often
17. I feel trapped by my job as a helper.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Very Often
18. Because of my helping, I have felt "on edge" about various things.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Very Often
19. I like my work as a helper.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often

    e. Very Often

20. I feel depressed because of the traumatic experiences of the people I help
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Very Often
21. I feel as though I am experiencing the trauma of someone I have helped.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Very Often
22. I have beliefs that sustain me.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Very Often
23. I am pleased with how I am able to keep up with helping techniques and protocols.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often

e. Very Often

24. I am the person I always wanted to be.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Very Often
25. My work makes me feel satisfied.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Very Often
26. I feel worn out because of my work as a helper.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Very Often
27. I have happy thoughts and feelings about those I help and how I could help them.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often

    e. Very Often

28. I feel overwhelmed because my case work load seems endless.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Very Often
29. I believe I can make a difference through my work.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Very Often
30. I avoid certain activities or situations because they remind me of frightening experiences of the people I help.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Very Often
31. I am proud of what I can do to help.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often

   e. Very Often

32. As a result of my helping, I have intrusive, frightening thoughts.

   a. Never
   b. Rarely
   c. Sometimes
   d. Often
   e. Very Often

33. I feel "bogged down" by the system.

   a. Never
   b. Rarely
   c. Sometimes
   d. Often
   e. Very Often

34. I have thoughts that I am a "success" as a helper.

   a. Never
   b. Rarely
   c. Sometimes
   d. Often
   e. Very Often

35. I can't recall important parts of my work with trauma victims.

   a. Never
   b. Rarely
   c. Sometimes
   d. Often
   e. Very Often

36. I am a very caring person.

   a. Never
   b. Rarely
   c. Sometimes
   d. Often
   e. Very Often

37. I am happy that I chose to do this work.

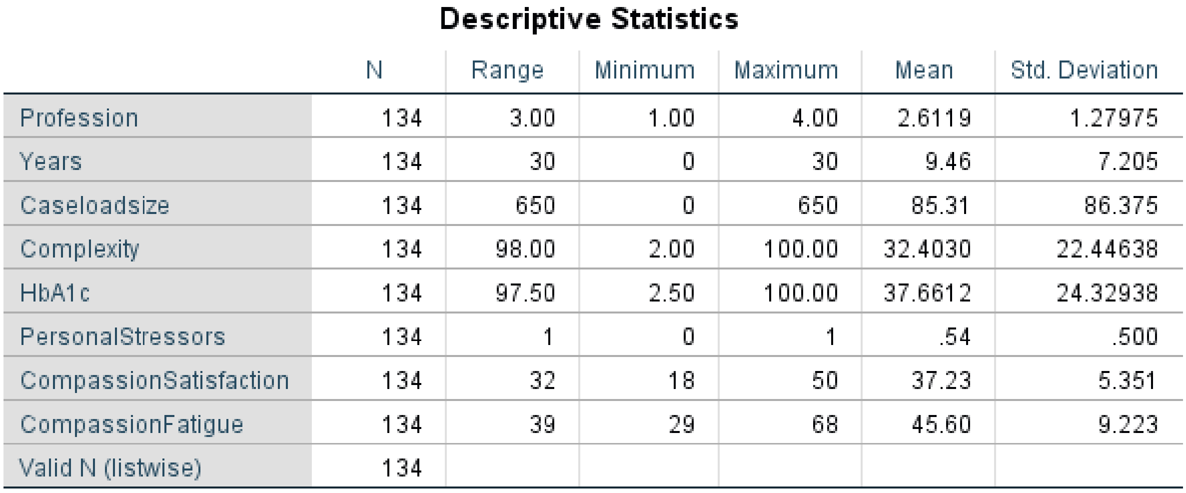
   a. Never
   b. Rarely
   c. Sometimes
   d. Often
   e. Very Often

Appendix I: Cossette, Cote, Pepin, Ricard & D’Aoust, 2006

1. Clinical Care
    a. Giving treatments
    b. Operating equipment
    c. Medication management
    d. Monitoring health condition
2. Relational Care
    a. Helped me look for a balance in my life
    b. Explore what is important in my life
    c. Explore the meaning of my health condition
    d. Try to identify with me the consequences of my behaviour
3. Humanistic Care
    a. Considered me as a complete individual
    b. Encouraged me to be hopeful when appropriate
    c. Emphasised my efforts
    d. Did not have an attitude of disapproval
4. Comforting Care
    a. Respected my privacy
    b. Took my basic needs into account
    c. Did treatments/medications at the scheduled time.

Appendix J: SPSS Outputs.

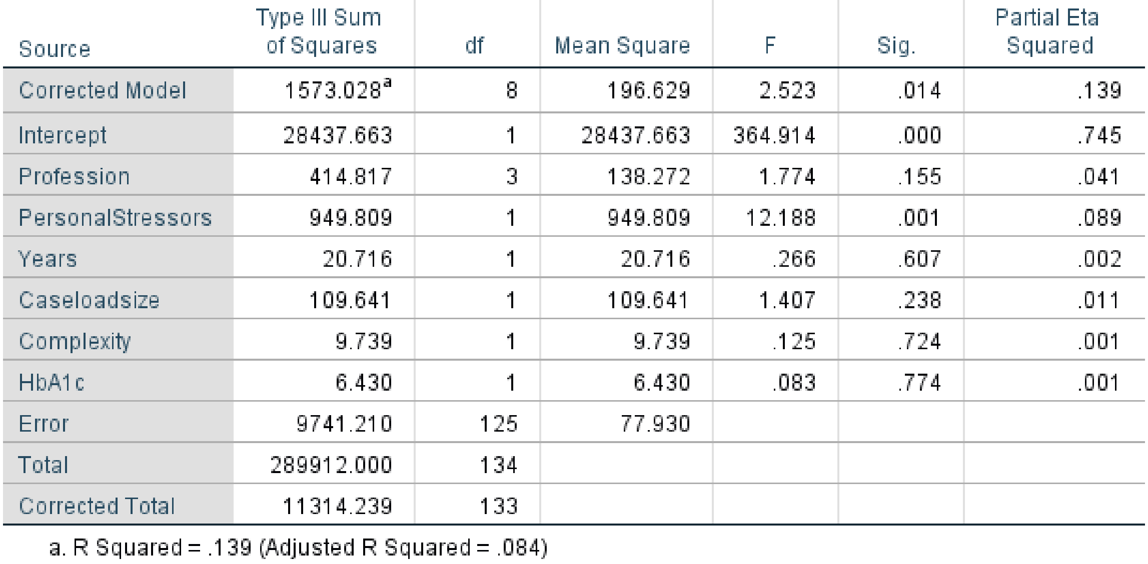
Descriptive Statistics



Descriptive Statistics

	N	Range	Minimum	Maximum	Mean	Std. Deviation
Profession	134	3.00	1.00	4.00	2.6119	1.27975
Years	134	30	0	30	9.46	7.205
Caseloadsize	134	650	0	650	85.31	86.375
Complexity	134	98.00	2.00	100.00	32.4030	22.44638
HbA1c	134	97.50	2.50	100.00	37.6612	24.32938
PersonalStressors	134	1	0	1	.54	.500
CompassionSatisfaction	134	32	18	50	37.23	5.351
CompassionFatigue	134	39	29	68	45.60	9.223
Valid N (listwise)	134					

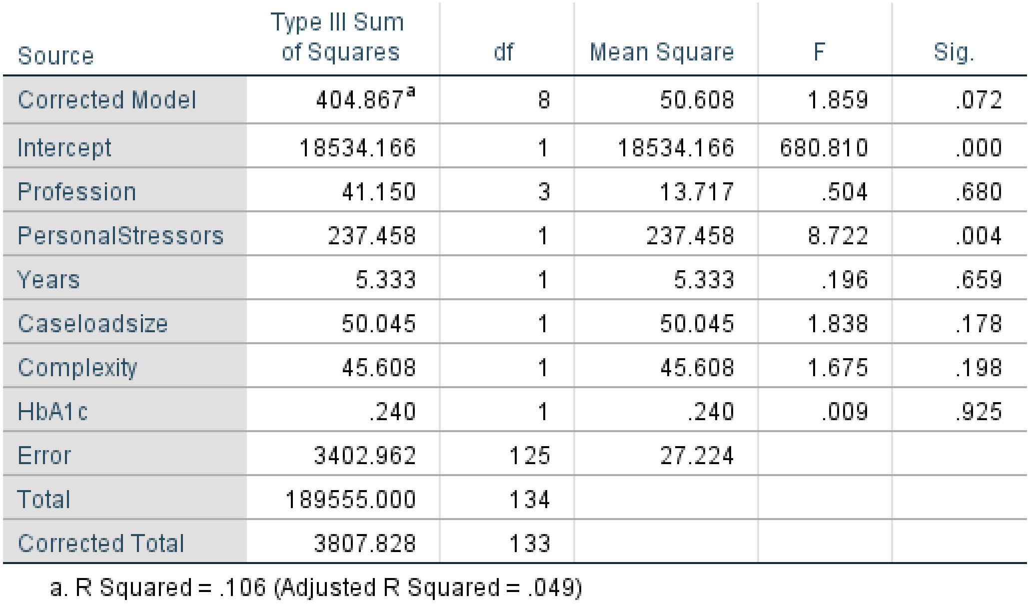
General Linear Regression Model - Compassion Fatigue



Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	1573.028[a]	8	196.629	2.523	.014	.139
Intercept	28437.663	1	28437.663	364.914	.000	.745
Profession	414.817	3	138.272	1.774	.155	.041
PersonalStressors	949.809	1	949.809	12.188	.001	.089
Years	20.716	1	20.716	.266	.607	.002
Caseloadsize	109.641	1	109.641	1.407	.238	.011
Complexity	9.739	1	9.739	.125	.724	.001
HbA1c	6.430	1	6.430	.083	.774	.001
Error	9741.210	125	77.930			
Total	289912.000	134				
Corrected Total	11314.239	133				

a. R Squared = .139 (Adjusted R Squared = .084)

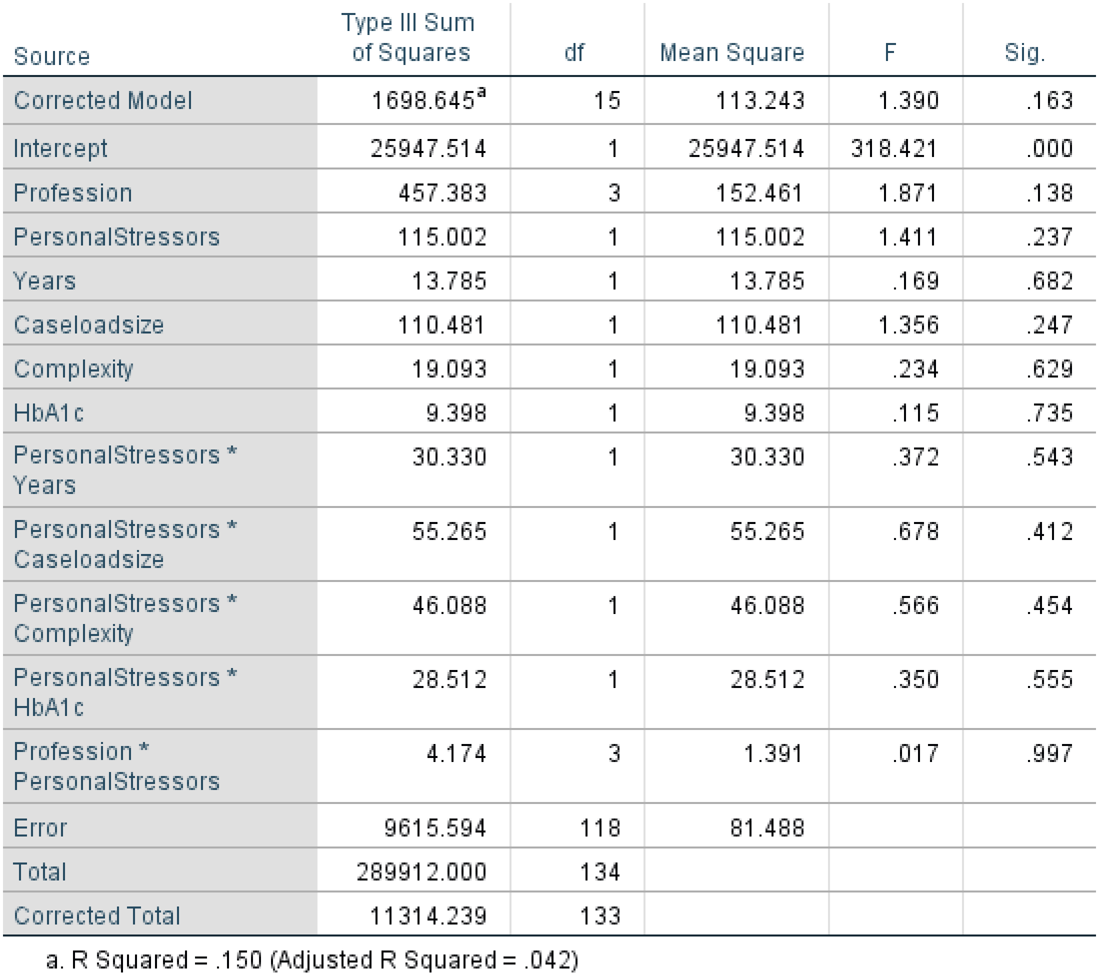
General Linear Regression Model – Compassion Satisfaction



Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	404.867[a]	8	50.608	1.859	.072
Intercept	18534.166	1	18534.166	680.810	.000
Profession	41.150	3	13.717	.504	.680
PersonalStressors	237.458	1	237.458	8.722	.004
Years	5.333	1	5.333	.196	.659
Caseloadsize	50.045	1	50.045	1.838	.178
Complexity	45.608	1	45.608	1.675	.198
HbA1c	.240	1	.240	.009	.925
Error	3402.962	125	27.224		
Total	189555.000	134			
Corrected Total	3807.828	133			

a. R Squared = .106 (Adjusted R Squared = .049)

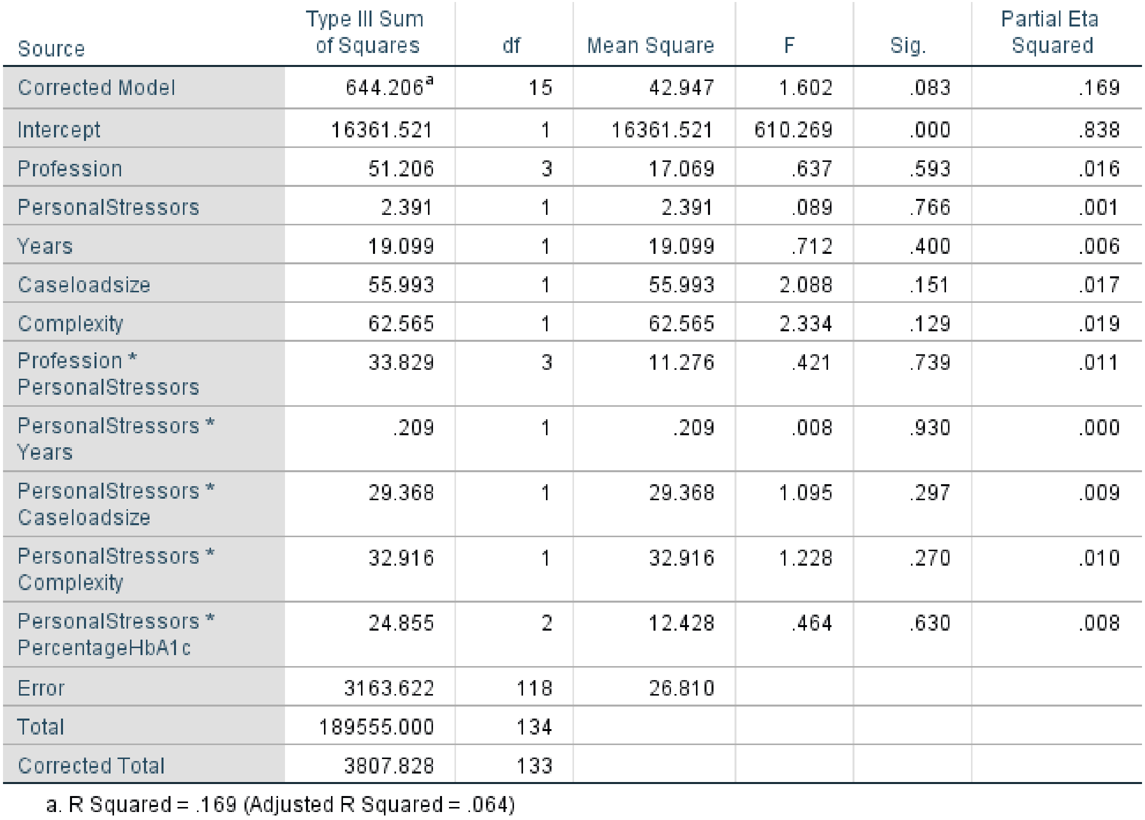
Moderation output - Compassion Fatigue



Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	1698.645[a]	15	113.243	1.390	.163
Intercept	25947.514	1	25947.514	318.421	.000
Profession	457.383	3	152.461	1.871	.138
PersonalStressors	115.002	1	115.002	1.411	.237
Years	13.785	1	13.785	.169	.682
Caseloadsize	110.481	1	110.481	1.356	.247
Complexity	19.093	1	19.093	.234	.629
HbA1c	9.398	1	9.398	.115	.735
PersonalStressors * Years	30.330	1	30.330	.372	.543
PersonalStressors * Caseloadsize	55.265	1	55.265	.678	.412
PersonalStressors * Complexity	46.088	1	46.088	.566	.454
PersonalStressors * HbA1c	28.512	1	28.512	.350	.555
Profession * PersonalStressors	4.174	3	1.391	.017	.997
Error	9615.594	118	81.488		
Total	289912.000	134			
Corrected Total	11314.239	133			

a. R Squared = .150 (Adjusted R Squared = .042)

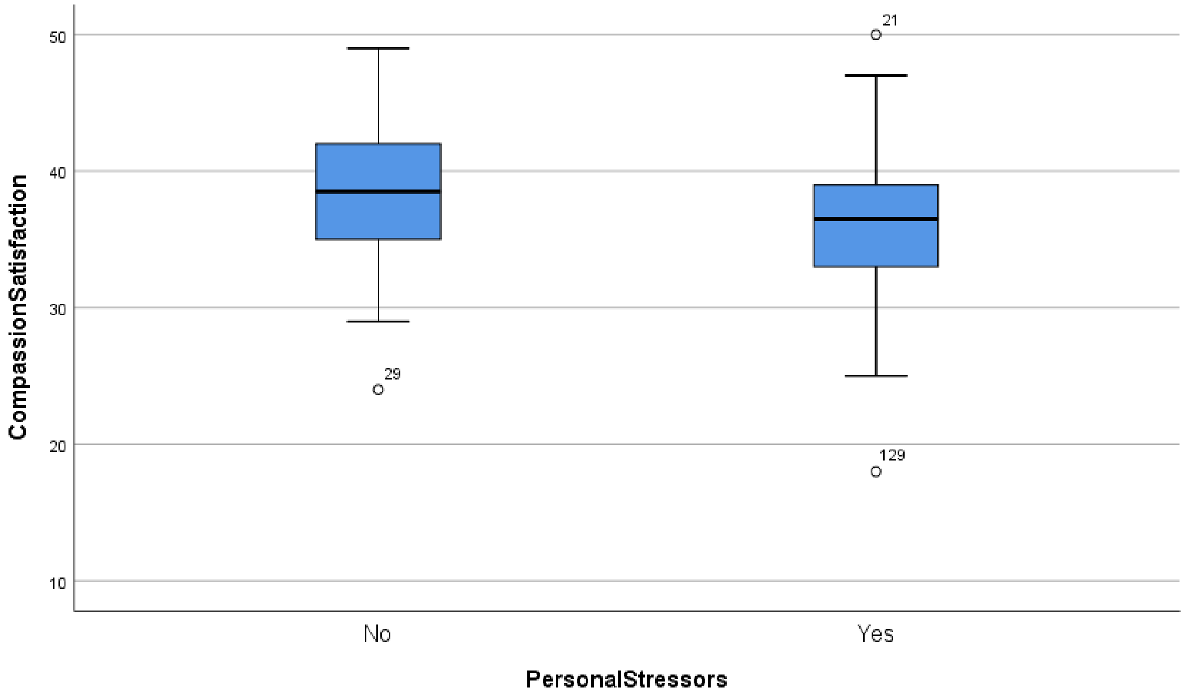
Moderation output – Compassion Satisfaction



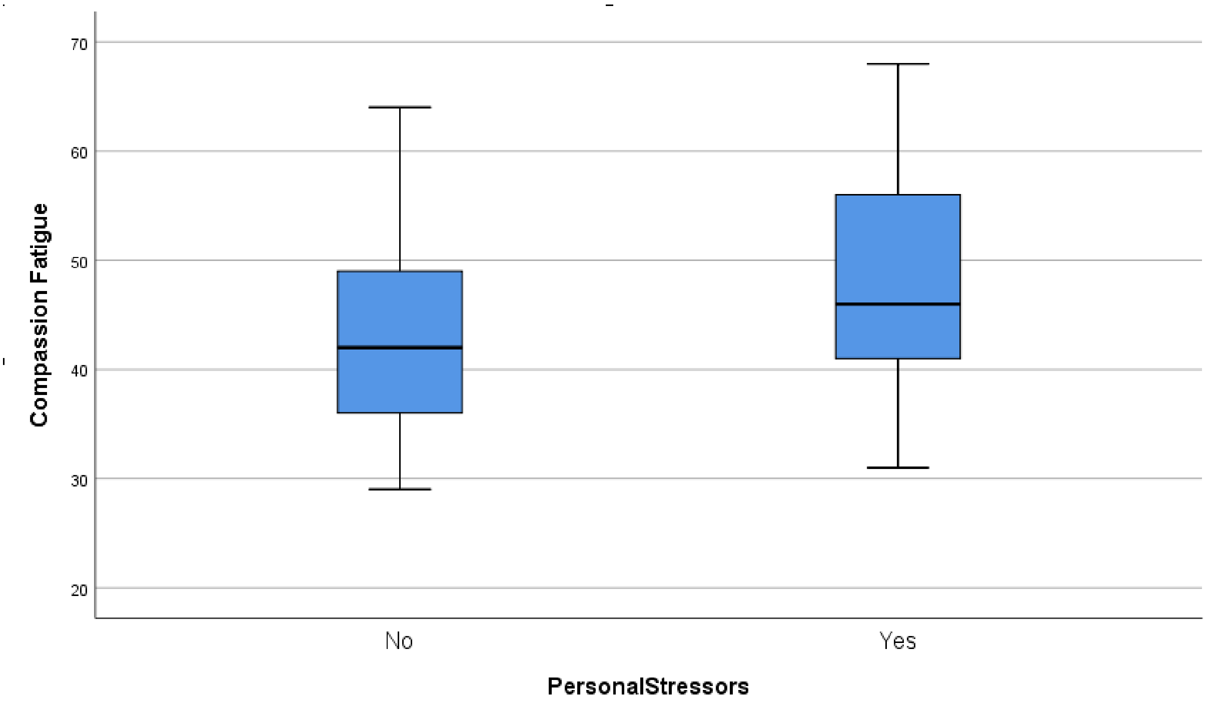
Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	644.206[a]	15	42.947	1.602	.083	.169
Intercept	16361.521	1	16361.521	610.269	.000	.838
Profession	51.206	3	17.069	.637	.593	.016
PersonalStressors	2.391	1	2.391	.089	.766	.001
Years	19.099	1	19.099	.712	.400	.006
Caseloadsize	55.993	1	55.993	2.088	.151	.017
Complexity	62.565	1	62.565	2.334	.129	.019
Profession * PersonalStressors	33.829	3	11.276	.421	.739	.011
PersonalStressors * Years	.209	1	.209	.008	.930	.000
PersonalStressors * Caseloadsize	29.368	1	29.368	1.095	.297	.009
PersonalStressors * Complexity	32.916	1	32.916	1.228	.270	.010
PersonalStressors * PercentageHbA1c	24.855	2	12.428	.464	.630	.008
Error	3163.622	118	26.810			
Total	189555.000	134				
Corrected Total	3807.828	133				

a. R Squared = .169 (Adjusted R Squared = .064)

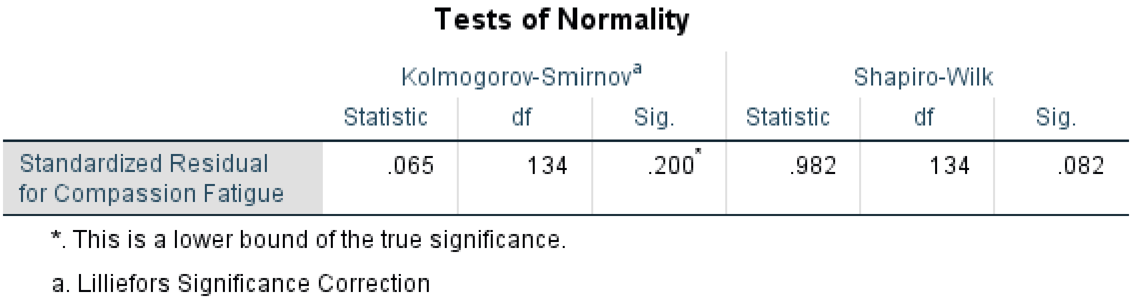
A box plot to show the distribution of the data in Compassion Satisfaction and personal stressors



A box plot to show the distribution of the data in Compassion fatigue and personal stressors



Normality Testing – Compassion Fatigue



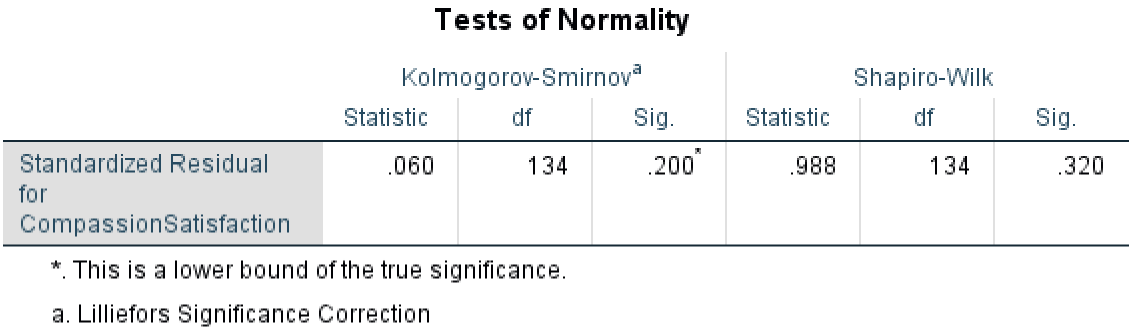
Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Standardized Residual for Compassion Fatigue	.065	134	.200*	.982	134	.082

*. This is a lower bound of the true significance.

a. Lilliefors Significance Correction

Normality Testing – Compassion Satisfaction



Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Standardized Residual for CompassionSatisfaction	.060	134	.200*	.988	134	.320

*. This is a lower bound of the true significance.

a. Lilliefors Significance Correction

Appendix K – Author Guidelines for Systematic Literature Review – Journal of Clinical Nursing

1. SUBMISSION

Thank you for your interest in the *Journal of Clinical Nursing*. Note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium. See Cover letter in Section 4 Preparing Your Submission for further details.

Once you have prepared your submission in accordance with the Guidelines, manuscripts should be submitted online at https://mc.manuscriptcentral.com/jcnur

The submission system will prompt you to use an ORCID iD (a unique author identifier) to help distinguish your work from that of other researchers. Click here to find out more.

Click here for more details on how to use ScholarOne

For help with submissions, please contact: JCN@wiley.com

We look forward to your submission.

Data Protection

By submitting a manuscript to or reviewing for this publication, your name, email address, and affiliation, and other contact details the publication might require, will be used for the regular operations of the publication, including, when necessary, sharing with the publisher (Wiley) and partners for production and publication. The publication and the publisher recognize the importance of protecting the personal information collected from users in the operation of these services, and have practices in place to ensure that steps are taken to maintain the security, integrity, and privacy of the personal data collected and processed. You can learn more here ...

Preprint Policy

The Journal of Clinical Nursing (JCN) will consider for review articles previously available as preprints. Authors may also post the submitted version of a manuscript to a preprint server at any time. Authors are requested to update any pre-publication versions with a link to the final published article.

2. AIMS AND SCOPE

The Journal of Clinical Nursing (JCN) is an international, peer reviewed, scientific journal that seeks to promote the development and exchange of knowledge that is directly relevant to all spheres of nursing practice. The primary aim is to promote a high standard of clinically related scholarship which advances and supports the practice and discipline of nursing. The Journal also aims to promote the international exchange of ideas and experience that draws from the different cultures in which practice takes place. Further, JCN seeks to enrich insight into clinical need and the implications for nursing intervention and models of service delivery. Emphasis is placed on promoting critical debate on the art and science of nursing practice.

JCN is essential reading for anyone involved in nursing practice, whether clinicians, researchers, educators, managers, policy makers, or students. The development of clinical practice and the changing patterns of inter-professional working are also central to JCN's scope of interest. Contributions are welcomed from other health professionals on issues that have a direct impact on nursing practice.

We publish high quality papers from across the methodological spectrum that make an important and novel contribution to the field of clinical nursing (regardless of where care is provided), and which demonstrate clinical application and international relevance.

Topics include but are not limited to:

- Development of clinical research, evaluation, evidence-based practice and scientific enquiry;
- Patient and family experiences of health and health care; illness and recovery;
- Nursing research to enhance patient safety and reduce harm to patients;
- The nature of nursing need, intervention, social interaction and models of service delivery;
- Clinical nursing leadership;
- Examination of clinical decision-making;
- Exploration of organisational or systemic factors that enhance or impede the provision of effective, high-quality nursing care;
- Application and dissemination of clinical knowledge and theory;
- Role development and inter-disciplinary working, exploring the scope and changing boundaries of clinical nursing; and
- Cultural comparisons and evaluations of nursing practice in different health sectors, social and geographical settings.

Useful Resources

Nurse Author & Editor is a valuable resource for authors, editors and reviewers involved or wanting to become involved in nursing journals and the free Nurse Author & Editor newsletter contains useful articles including the Writing for Publication booklet which you may find helpful.

*If you are presenting a paper from a study from which publications have already been drawn, or are planned, please carefully read our **guidance pertaining to multiple publications from a single study.***

3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

i. Original Articles

Pilot studies are not suitable for publication as original articles.
Word limit: 8,000 words maximum (quotations are included in the overall word count of articles, and abstract, references, tables and figures are excluded).

Abstract: 300 words maximum, no abbreviations. Structured under the sub-headings: Aims and objectives; Background (stating what is already known about this topic); Design; Methods (for both qualitative and quantitative studies state n); Results (do not report p values, confidence intervals and other statistical parameters); Conclusions (stating what this study adds to the topic); Relevance to clinical practice. Trial registration details (if required).

Main text structure: Introduction (putting the paper in context - policy, practice or research); Background (literature); Methods (design, data collection and analysis); Results; Discussion; Conclusion; Relevance to clinical practice.

References: 50 maximum; all references must be available in English
Impact Statement: should contain 2-3 bullet points under the heading 'What does this paper contribute to the wider global clinical community?'

Research Reporting Checklist: May be required. Please see Section 5.

ii. Review Articles

Literature reviews on any area of research relevant to clinical nursing are welcomed.
Word limit: 8,000 words maximum (quotations are included in the overall word count of articles, and abstract, references, tables and figures are excluded).

Main text structure: Review Articles should be structures, under the sub-headings: Introduction, Aims, Methods, Results, Discussion, Conclusion, and Relevance to Clinical Practice.

References: 50 maximum; all references must be available in English.

Research Reporting Checklist: Required. Please see Section 5.

iii. Discursive Articles

Word limit: 8,000 words maximum.
Main text structure: Aims; Background; Design (stating that it is a position paper or critical review, for example); Method (how the issues were approached); Conclusions, Relevance to clinical practice.

iv. Special Issue Articles

Authors interested in submitting a paper for a forthcoming Special Issue must contact the

Editorial Office to discuss and agree submission of the paper with the designated Special Issue Guest Editor before submission to the journal takes place. Upon submission, Authors must indicate that the paper is to be considered for a Special Issue.

v. Registered Report

Journal of Clinical Nursing is now considering submissions of Registered Reports. Registered Reports are a new form of empirical article in which the methods and proposed analyses are pre-registered and reviewed prior to research being conducted. For more information please refer to our Registered Reports guidelines.

4. PREPARING YOUR SUBMISSION

Cover Letters

All manuscripts submitted to Journal of Clinical Nursing should include a covering letter stating on behalf of all the authors that the work has not been published and is not being considered for publication elsewhere. Any previous submission of the work, in any form, must be declared. If the study that is being submitted is similar in any way to another study previously submitted/published or is part of multiple studies on the same topic, a brief sentence explaining how the manuscript differs and that there is no identical material should be stated in the cover letter upon submission. Manuscripts undergo a similarity check when submitted and your article may be returned to you, if the above has not been adhered to.

Parts of the Manuscript

The manuscript should be submitted in separate files: title page; main text file; figures.

Title Page:

The title page should be submitted separately to the main file and contain:

i. A short informative title that contains the major key words. The title should not contain abbreviations (see Wiley's best practice SEO tips).
ii. A short running title of less than 40 characters
iii. The full names of the authors
iv. The authors' institutional affiliations at which the work was carried out
v. Corresponding author's contact email address and telephone number
vi. Acknowledgements.
vii. Conflict of Interest Statement
viii. Funding or sources of support in the form of grants, equipment, drugs etc.

The present address of any author, if different from that where the work was carried out, should be supplied in a footnote.

Authorship

For details on eligibility for author listing, please refer to the journal's Authorship policy outlined in the Editorial Policies and Ethical Considerations section.

Acknowledgments

Contributions from individuals who do not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

Conflict of Interest Statement

Authors will be asked to provide a conflict of interest statement during the submission process. See ‘Conflict of Interest’ section in Editorial Policies and Ethical Considerations for details on what to include in this section. Authors should ensure they liaise with all co-authors to confirm agreement with the final statement.

Main Text File and Figures

The main text file should be presented in the following order:

i. Title, abstract and key words;
ii. Main text;
iii. References;
iv. Tables (each table complete with title and footnotes);
v. Figure legends;
vi. Appendices (if relevant).

Figures and supporting information should be supplied as separate files.

Title

The title must contain both a descriptive and concise title of the paper. Country names are only to be included in titles where it is made clear the content is being compared and contrasted to the International arena.

Keywords

Please provide up to 10 keywords When selecting keywords, Authors should consider how readers will search for their articles. Keywords should be taken from those recommended by the US National Library of Medicine's Medical Subject Headings (MeSH) browser list at https://www.nlm.nih.gov/mesh/.

Main Text

- As papers are double-blind peer reviewed, the main text file should not include any information that might identify the authors.
- All articles must be relevant to an international audience. Authors should explain policies, practices and terms that are specific to a particular country or region; outline the relevance of the paper to the subject field internationally and also its transferability into other care settings, cultures or nursing specialities; placed discussions within an international context any papers exploring focussed cultural or other specific issues, and that clinical issues are put into context to other geographical regions and cultural settings.
- The journal uses British/US spelling; however, authors may submit using either option, as spelling of accepted papers is converted during the production process.
- Footnotes to the text are not allowed and any such material should be incorporated into the text as parenthetical matter.

References

APA Style

References should be prepared according to the Wiley APA Manual Style. Detailed guide and examples can be found here: https://authorservices.wiley.com/author-resources/Journal-Authors/Prepare/manuscript-preparation-guidelines.html/index.html

Tables

Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

Figure Legends

Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

Figures

Although we encourage authors to send us the highest-quality figures possible, for peer-review purposes we are happy to accept a wide variety of formats, sizes, and resolutions. Click here for the basic figure requirements for figures submitted with manuscripts for initial peer review, as well as the more detailed post-acceptance figure requirements.

Figures submitted in colour will be reproduced in colour online free of charge. Please note, however, that it is preferable that line figures (e.g. graphs and charts) are supplied in black and white so that they are legible if printed by a reader in black and white. If an author would prefer to have figures printed in colour in hard copies of the journal, a fee will be charged by the Publisher.

Guidelines for Cover Submissions

If you would like to send suggestions for artwork related to your manuscript to be considered to appear on the cover of the journal, please follow these general guidelines: **https://authorservices.wiley.com/author-resources/Journal-Authors/Promotion/journal-cover-image.html**

Additional Files

Appendices

Appendices will be published after the references. For submission they should be supplied as separate files but referred to in the text.

Supporting Information

Supporting information is information that is not essential to the article but that provides greater depth and background. It is hosted online, and appears without editing or typesetting. It may include tables, figures, videos, datasets, etc. Click here for Wiley's FAQs on supporting information. Note, if data, scripts or other artefacts used to generate the analyses presented in the paper are available via a publicly available data repository, authors should include a reference to the location of the material within their paper.

General Style Points

The following points provide general advice on formatting and style.

- **Abbreviations:** In general, terms should not be abbreviated unless they are used repeatedly and the abbreviation is helpful to the reader. Initially, use the word in full, followed by the abbreviation in parentheses. Thereafter use the abbreviation only.
- **Units of measurement:** Measurements should be given in SI or SI-derived units. Visit the Bureau International des Poids et Mesures (BIPM) website at www.bipm.fr for more information about SI units.
- **Numbers:** numbers under 10 are spelt out, except for: measurements with a unit (8mmol/l); age (6 weeks old), or lists with other numbers (11 dogs, 9 cats, 4 gerbils).
- **Trade Names:** Chemical substances should be referred to by the generic name only. Trade names should not be used. Drugs should be referred to by their generic names. If proprietary drugs have been used in the study, refer to these by their generic name, mentioning the proprietary name and the name and location of the manufacturer in parentheses.

Wiley Author Resources

Manuscript Preparation Tips

Wiley has a range of resources for authors preparing manuscripts for submission available here. In particular, authors may benefit from referring to Wiley's best practice tips on Writing for Search Engine Optimization.

Article Preparation Supports

Wiley Editing Services offers expert help with English Language Editing, as well as translation, manuscript formatting, figure illustration, figure formatting, and graphical abstract design – so you can submit your manuscript with confidence. Also, check out our resources for Preparing Your Article for general guidance about writing and preparing your manuscript.

5. EDITORIAL POLICIES AND ETHICAL CONSIDERATIONS

Editorial Review and Acceptance

The acceptance criteria for all papers are the quality and originality of the research and its significance to our readership. Except where otherwise stated, manuscripts are double-blind peer reviewed. Papers will only be sent to review if the Editor-in-Chief determines that the paper meets the appropriate quality and relevance requirements. Wiley's policy on confidentiality of the review process is available here.

Decision Appeals

Appeals should be filed within 28 days of notification of the decision. The appeal should be

in the form of a letter addressed and submitted to the *Journal of Clinical Nursing* Editorial Office. The letter should include clear and concise grounds for the appeal, including specific points of concern. The appeal will then be assessed by the *Journal of Clinical Nursing* management team, led by the Editorial Office, and informed by the subsequent editorial communications.
You will be informed of the outcome of the appeal in writing, normally within 28 days. The decision will be final.

Data storage and documentation
Journal of Clinical Nursing encourages data sharing wherever possible, unless this is prevented by ethical, privacy or confidentiality matters. Authors publishing in the journal are therefore encouraged to make their data, scripts and other artefacts used to generate the analyses presented in the paper available via a publicly available data repository, however this is not mandatory. If the study includes original data, at least one author must confirm that he or she had full access to all the data in the study, and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Authors can consult the global registry of research data repositories to help them identify registered and certified repositories relevant to their subject areas.

Data Citation
In recognition of the significance of data as an output of research effort, Wiley has endorsed the FORCE11 Data Citation Principles, and is implementing a mandatory data citation policy. Journal policies should require data to be cited in the same way as article, book, and web citations and authors are required to include data citations as part of their reference list. Data citation is appropriate for data held within institutional, subject focused, or more general data repositories. It is not intended to take the place of community standards such as in-line citation of GenBank accession codes.

When citing or making claims based on data, authors must refer to the data at the relevant place in the manuscript text and in addition provide a formal citation in the reference list. We recommend the format proposed by the Joint Declaration of Data Citation Principles:
Authors; Year; Dataset title; Data repository or archive; Version (if any); Persistent identifier (e.g. DOI)

Human Studies and Subjects
For manuscripts reporting medical studies involving human participants, we require a statement identifying the ethics committee that approved the study, and that the study conforms to recognized standards, for example: Declaration of Helsinki; US Federal Policy for the Protection of Human Subjects; or European Medicines Agency Guidelines for Good Clinical Practice.
Images and information from individual participants will only be published where the authors have obtained the individual's free prior informed consent. Authors do not need to provide a copy of the consent form to the publisher, however in signing the author license to publish authors are required to confirm that consent has been obtained. Wiley has a standard patient consent form available for use.

Clinical Trial Registration
The journal requires that clinical trials are prospectively registered in a publicly accessible database such as http://clinicaltrials.gov/ and clinical trial registration numbers should be

included in all papers that report their results. Authors are asked to include the name of the trial register and the clinical trial registration number at the end of the abstract. If the trial is not registered, or was registered retrospectively, the reasons for this should be explained.

The ICMJE defines a clinical trial as any research project that prospectively assigns people or a group of people to an intervention, with or without concurrent comparison or control groups, to study the relationship between a health-related intervention and a health outcome. Health-related interventions are those used to modify a biomedical or health-related outcome; examples include drugs, surgical procedures, devices, behavioural treatments, educational programs, dietary interventions, quality improvement interventions, and process-of-care changes. Health outcomes are any biomedical or health-related measures obtained in patients or participants, including pharmacokinetic measures and adverse events. The ICMJE does not define the timing of first participant enrollment, but best practice dictates registration by the time of first participant consent.

Research Reporting Guidelines

Accurate and complete reporting enables readers to fully appraise research, replicate it, and use it. For Original Articles, Review Articles and Sepcial Issue submissions, we require authors to adhere to the relevant EQUATOR research reporting checklist.

For each item in the checklist, please state the manuscript page number on which this aspect of the guidelines has been addressed. Should your manuscript be accepted for publication, your completed checklist will be published alongside the manuscript as a supporting information file; when preparing your manuscript draft please therefore include the checklist as a “supporting file for review and online publication”. Please state in your manuscript abstract which checklist you have used using the short title (eg. CONSORT), where available, and cite the checklist as a supporting file in the Methods section using the full title (eg. Guidelines for reporting parallel group randomised trials (Supplementary File 1)).

EQUATOR checklists include:

- ***CONSORT*** checklist for reports of randomised trials and cluster randomised trials
- ***TREND*** checklist for non-randomised controlled trials
- ***PRISMA*** guidelines for systematic reviews and meta-analyses
- ***STROBE*** checklist for observational research
- ***COREQ*** checklist for qualitative studies
- ***SQUIRE*** checklist for quality improvement
- ***TRIPOD*** checklist for prediction model development and/or validation
- ***CHEERS*** guidelines for economic evaluations
- ***SPIRIT*** checklist for study protocols
- ***AGREE*** checklist for clinical practice guidelines

You can find the full list of EQUATOR checklists here.

Note that case studies with CARE checklists are not suitable for submission to Journal of Clinical Nursing. Submitted Original Article and Review Article manuscripts without EQUATOR checklists or with incomplete checklists will be returned to the authors for their amendment

Appendix L – Author Guidelines for Empirical paper – Paediatric Diabetes

1. SUBMISSION

Authors should kindly note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

Once the submission materials have been prepared in accordance with the Author Guidelines, manuscripts should be submitted online at https://mc.manuscriptcentral.com/pdi

Click here for more details on how to use ScholarOne.

Data protection

By submitting a manuscript to or reviewing for this publication, your name, email address, and affiliation, and other contact details the publication might require, will be used for the regular operations of the publication, including, when necessary, sharing with the publisher (Wiley) and partners for production and publication. The publication and the publisher recognize the importance of protecting the personal information collected from users in the operation of these services, and have practices in place to ensure that steps are taken to maintain the security, integrity, and privacy of the personal data collected and processed. You can learn more at **https://authorservices.wiley.com/statements/data-protection-policy.html**.

Preprint policy

Please find the Wiley preprint policy here.

This journal accepts articles previously published on preprint servers.

Pediatric Diabetes will consider for review articles previously available as preprints. Authors may also post the submitted version of a manuscript to a preprint server at any time. Authors are requested to update any pre-publication versions with a link to the final published article.

For help with submissions, please contact: James Cook, **pedi@wiley.com**

2. AIMS AND SCOPE

Pediatric Diabetes is a bi-monthly journal devoted to disseminating new knowledge relating to the epidemiology, etiology, pathogenesis, management, complications and prevention of diabetes in childhood and adolescence. The aim of the journal is to become the leading vehicle for international dissemination of research and practice relating to diabetes in youth. Papers are considered for publication based on the rigor of scientific approach, novelty, and importance for understanding mechanisms involved in the epidemiology and etiology of this disease, especially its molecular, biochemical and physiological aspects. Work relating to the clinical presentation, course, management and outcome of diabetes, including its physical and emotional sequelae, is considered. *In vitro* studies using animal or human tissues, whole animal and clinical studies in humans are also considered. The journal reviews full-length papers, preliminary communications with important new information, clinical reports, and reviews of major topics. Invited editorials, commentaries, and perspectives are a regular feature. The editors, based in the USA, Europe, and Australasia, maintain regular communications to assure rapid turnaround time of submitted manuscripts.

3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

Full-length Papers – 5000 word limit, including the main body of text and excluding abstract, references, figures and tables.

Brief Reports – Brief reports should not exceed 1,500 words and are limited to a maximum of 2 figures or 2 tables or 1 figure and 1 table and 20 references. A structured abstract (maximum 250 words) is required.

Clinical Case reports - 2000 word limit.

Invited reviews of major topics – 5000 word limit, including the main body of text and excluding abstract, references, figures and tables. We are not currently accepting unsolicited reviews.

Invited editorials and perspectives – 2000 word limit.

4. PREPARING THE SUBMISSION

Free Format submission

Pediatric Diabetes now offers Free Format submission for a simplified and streamlined submission process.

Before you submit, you will need:

- Your manuscript: this can be a single file including text, figures, and tables, or separate files – whichever you prefer. All required sections should be contained in your manuscript, including abstract, introduction, methods, results, and conclusions. Figures and tables should have legends. References may be submitted in any style or format, as long as it is consistent throughout the manuscript. If the manuscript, figures or tables are difficult for you to read, they will also be difficult for the editors and reviewers. If your manuscript is difficult to read, the editorial office may send it back to you for revision.
- The title page of the manuscript, including statements relating to our ethics and integrity policies:
    -
    - funding statement
    - conflict of interest disclosure
    - ethics approval statement
    - patient consent statement (if appropriate)
    - permission to reproduce material from other sources

(Why is this important? We need to uphold rigorous ethical standards for the research we consider for publication.)

- A separate Conflict of Interest form for each author. *(Why is this important? We need to uphold rigorous ethical standards for the research we consider for publication.)*
- Your co-author details, including affiliation and email address. *(Why is this important? We need to keep all co-authors informed of the outcome of the peer review process.)*
- An ORCID ID, freely available at https://orcid.org. *(Why is this important? Your article, if accepted and published, will be attached to your ORCID profile. Institutions and funders are increasingly requiring authors to have ORCID IDs.)*

To submit, login at **https://mc.manuscriptcentral.com/pdi** and create a new submission. Follow the submission steps as required and submit the manuscript.

If you are invited to revise your manuscript after peer review, the journal will also request the revised manuscript to be formatted according to journal requirements as described below.

Cover Letters

Cover letters are not mandatory; however, they may be supplied at the author's discretion.

Parts of the Manuscript

The manuscript should be submitted in separate files: main text file; figures.

Main Text File

The text file should be presented in the following order:

1. A short informative title that contains the major key words. The title should not contain abbreviations (see Wiley's best practice SEO tips);
2. A short running title of less than 40 characters;
3. The full names of the authors;
4. The author's institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;
5. Acknowledgments;
6. Author Contributions;
7. Abstract and keywords;
8. Main text;
9. References;
10. Tables (each table complete with title and footnotes);
11. Figure legends;
12. Appendices (if relevant).

Figures and supporting information should be supplied as separate files.

Authorship

Please refer to the journal's authorship policy the **Editorial Policies and Ethical Considerations section** for details on author listing eligibility.

The individual contributions of each author must be specified in the Author Contributions section. Please use authors' initials and state that all authors have read and approved the final manuscript. An example of a suitable statement is: "S.W., N.J., D.W. and S.S. performed the research. S.W., N.J., H.H. and T.L. designed the research study. H.H. and S.S. contributed essential reagents or tools. S.W., N.J. and D.W. analysed the data. S.W. and N.J. wrote the paper." Please see the 'Authorship' section in the **Editorial Policies and Ethical Considerations section** below for what constitutes authorship.

Acknowledgments

Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

Conflict of Interest Statement

Authors will be asked to provide a conflict of interest statement during the submission process. For details on what to include in this section, see the section 'Conflict of Interest' in the Editorial Policies and Ethical Considerations section below. Submitting authors should ensure they liaise with all co-authors to confirm agreement with the final statement.

Abstract

Please provide an abstract of no more than 250 words containing data on background, objective or hypothesis, subjects, methods or plan, results and conclusions. Please make sure that the data in the abstract accurately reflect the information provided in the body of the manuscript.

Keywords

Please provide up to five keywords. Keywords should be taken from those recommended by the US National Library of Medicine's Medical Subject Headings (MeSH) browser list at **www.nlm.nih.gov/mesh**.

Main Text

- The main text should include the following sections: Introduction; Methods; Results; Discussion.
- Introduction: The introduction should be succinct and should orient the reader to the state of knowledge in the specific area under investigation. The questions and hypotheses of the research should be clearly delineated.
- Methods: Methods should be described and referenced with sufficient detail to allow other researchers to reproduce the results. It is often quite useful to subdivide methods into sections such as subjects, measurements, protocol, and data analysis. Describe selection of patients or experimental animals, including controls; inclusion of a CONSORT diagram for clinical trials is recommended. Do not provide patients' names or any hospital ID numbers. Any complex data analysis should be reviewed by a statistician. Provide references and brief descriptions of methods that have been published. When using new methods, evaluate their advantages and limitations.

- Results: The results should be presented in the most appropriate form, in logical sequence in tables and illustrations. In the text, explain, emphasize or summarize the most important observations.
- Discussion: Do not repeat in detail data given in the Results section. Emphasize the new and important aspects of the study. The findings should be related to other relevant studies. On the basis of your findings (and others') discuss possible implications/conclusions, revealing any limitations of the study. When stating a new hypothesis, clearly label it as such.

References

All references should be numbered consecutively in order of appearance and should be as complete as possible. In text citations should cite references in consecutive order using Arabic superscript numerals. For more information about AMA reference style please consult the **AMA Manual of Style**

Sample references follow:

Journal article
1. King VM, Armstrong DM, Apps R, Trott JR. Numerical aspects of pontine, lateral reticular, and inferior olivary projections to two paravermal cortical zones of the cat cerebellum. J Comp Neurol 1998;390:537-551.

Book
2. Voet D, Voet JG. Biochemistry. New York: John Wiley & Sons; 1990. 1223 p.

Internet document
3. American Cancer Society. Cancer Facts & Figures 2003. http://www.cancer.org/downloads/STT/CAFF2003PWSecured.pdf Accessed March 3, 2003

Tables

Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

Figure Legends

Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

Figures

Although authors are encouraged to send the highest-quality figures possible, for peer-review purposes, a wide variety of formats, sizes, and resolutions are accepted.

Click here for the basic figure requirements for figures submitted with manuscripts for initial peer review, as well as the more detailed post-acceptance figure requirements.

Colour Figures. Figures submitted in colour may be reproduced in colour online free of charge. Please note, however, that it is preferable that line figures (e.g. graphs and charts) are supplied in black and white so that they are legible if printed by a reader in black and white.

Data Citation

Please review Wiley's data citation policy here.

Additional Files

Appendices

Appendices will be published after the references. For submission they should be supplied as separate files but referred to in the text.

Supporting Information

Supporting information is information that is not essential to the article, but provides greater depth and background. It is hosted online and appears without editing or typesetting. It may include tables, figures, videos, datasets, etc.

Click here for Wiley's FAQs on supporting information.

Note: if data, scripts, or other artefacts used to generate the analyses presented in the paper are available via a publicly available data repository, authors should include a reference to the location of the material within their paper.

General Style Points

The following points provide general advice on formatting and style.

- **Abbreviations:** In general, terms should not be abbreviated unless they are used repeatedly and the abbreviation is helpful to the reader. Initially, use the word in full, followed by the abbreviation in parentheses. Thereafter use the abbreviation only.
- **Units of measurement:** Measurements should be given in SI or SI-derived units. Visit the Bureau International des Poids et Mesures (BIPM) website for more information about SI units. Although not an SI unit, Celsius should be used for body temperature or for laboratory measurement temperatures in the physiologic range. If using conventional system measurements, these should be followed in parentheses by equivalent SI values. Submitted manuscripts are required to report HbA1c in both SI (IFCC) and NGSP/DCCT units.
- **Numbers:** numbers under 10 are spelt out, except for: measurements with a unit (8mmol/l); age (6 weeks old), or lists with other numbers (11 dogs, 9 cats, 4 gerbils).
- **Trade Names:** Chemical substances should be referred to by the generic name only. Trade names should not be used. Drugs should be referred to by their generic names. If proprietary chemicals, reagents or special pieces of apparatus have been used in the study, refer to these by their generic name, mentioning the proprietary name and the name and location of the manufacturer in parentheses.

Appendix M – Table detailing the quality score breakdown for each paper included within the Systematic Literature Review

Paper	Question 1: Are there clear research questions?	Question 2: Do the collected data allow to address the research questions?	Category of study design: 1 – Qualitative 2 – Quantitative Randomised Control Trials 3 – Quantitative nonrandomised 4 – Quantitative Descriptive 5 – Mixed Methods.				
Döger et al (2019)	Yes	Yes	3.1 – Yes	3.2 - Yes	3.3 – Yes	3.4 - No	3.5 - Yes
Howe, Ayala, Dumser, Buzby & Murphy (2012)	Yes	Yes	1.1 - Yes	1.2 - Yes	1.3 - Yes	1.4 - Yes	1.5 – Yes
Swedlund, Schumacher, Young & Cox (2012)	Yes	Yes	3.1 - Yes	3.2 - No	3.3 - Yes	3.4 – Can't tell	3.5 – Yes
Pyatak, Florindez & Weigensberg (2013)	Yes	Yes	1.1 - Yes	1.2 - Yes	1.3 - Yes	1.4 - Yes	1.5 – Yes
Zoni et al (2018)	Yes	Yes	3.1 - Yes	3.2 - Yes	3.3 - Yes	3.4 – Can't tell	N/A

Dovey – Pearcy, Hurrell, May, Walker & Doherty (2005)	Yes	Yes	1.1 - Yes	1.2 - Yes	1.3 - Yes	1.4 - Yes	1.5 – Yes
Ayala, Howe, Dumser, Buzby & Murphy (2014)	Yes	Yes	1.1 - Yes	1.2 - Yes	1.3 - Yes	1.4 - Yes	1.5 – Yes
Jones, Hammersly & Shepherd (2003)	Yes	Yes	1.1 - Yes	1.2 - Yes	1.3 - Yes	1.4 - Yes	1.5 – Yes
Coyne, Sheehan, Heery & While (2019)	Yes	Yes	1.1 - Yes	1.2 - Yes	1.3 - Yes	1.4 - Yes	1.5 – Yes
Ginsburg, Howe, Jawad, Buzby, Ayala, Tuttle, Murphy (2005)	Yes	Yes	5.1 - Yes	5.2 - Yes	5.3 - Yes	5.4 - Yes	5.5 - Yes
Hilliard et al (2019)	Yes	Yes	5.1 Yes	5.2 - Yes	5.3 - Yes	5.4 – No	5.5 - Yes

Hilliard et al 2014	Yes	Yes	5.1 Yes	5.2 - Yes	5.3 - No	5.4 – Can’t tell	5.5 - Yes