

Comparing the Quality of Life of Patients and their Family Members with Dermatological and other Chronic Conditions, in The Bahamas

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Abstract

Background & Objectives:

Impact of dermatological and other chronic conditions not only affects the quality of life (QoL) of patients but also that of their family members. This pilot study aimed to compare the QoL impact of dermatological and other chronic conditions on patients with the QoL impact on their family members.

Methods:

A cross-sectional study using validated QoL questionnaires was conducted. In the dermatological group, patients (≥ 17 years) completed the Dermatology Life Quality Index (DLQI) questionnaire, while children (4-16 years) completed the Children's Dermatology Life Quality Index (CDLQI) questionnaire. Family members (≥ 18 years) completed both Family Reported Outcome Measure (FROM-16) and Family Dermatology Life Quality Index (FDLQI) questionnaires. In the other chronic conditions group, patients (≥ 17 years) completed the World Health Organization Quality of Life -BREF (WHOQoL-BREF) questionnaire and children (4-17 years) completed The Revised Children's Quality of Life Questionnaire (KINDL-r: Kiddy KINDL, Kid KINDL and Kiddo KINDL). Family members completed the FROM-16 questionnaire. Data were analysed using IBM SPSS™ statistical software.

Results:

Forty-four participants completed the study. In the dermatological group ($n=26$), there was a weak negative correlation between DLQI and FDLQI scores ($r = -0.23$, $p=0.55$) not between DLQI and FROM-16 ($r = -0.04$, $p=0.92$). There was a very strong positive relationship between both CDLQI and FDLQI ($r=0.83$, $p=0.17$) and CDLQI and FROM-16 ($r=0.82$, $p=0.18$). Although not statistically significant, there may be a correlation between the FROM-16 and FDLQI scores for family members of dermatology patients. In the chronic conditions group ($n=18$) the mean score of WHOQoL-BREF was 90.5 (SD=13) with a significant negative inverse relationship to FROM-16 ($r = -1.000$, $p < 0.001$). The KINDL-r scores (mean=66, SD =11) showed no significant correlation ($r = -0.24$, $p=0.61$) with FROM-16

scores (mean=9.6, SD=3.7).

Conclusion:

The impact of a patient's dermatological or other chronic condition can not only negatively affect the patient's QoL but also the QoL of their family members.

Keywords: "Quality of life", "Family", "Partner", "Impact", "Dermatology"

Introduction

Quality of life (QoL) is defined in terms of one's personal conception of life, achievements and goals and when QoL is impaired it can be physically and mentally challenging and difficult for a person to cope.⁽¹⁻³⁾ A family member's QoL may be negatively influenced by the ill health of the person they care for and little may be done to help support them through their difficulties. These "hidden patients", considered part of "The Greater Patient", often disregard their personal agendas to care for someone in the family with a health problem.⁽⁴⁻⁷⁾ However, there is a lack of knowledge about this area, and healthcare professionals may find it difficult to recognize and assist affected family members of patients with chronic conditions.

Whilst dermatological conditions do not generally have the same impact on overall physical health compared with other chronic conditions, they are usually more visible. Studies have demonstrated that dermatological diseases can have a negative impact on the patient's self-esteem and QoL.⁽⁸⁻¹⁰⁾ Therefore, this study intended to ascertain if there was a difference in the impact on the QoL of patients between these two groups of conditions. The Bahamas has a population of 402,825 people of which 49% are males and 51% are females. Sixty-nine percent of the population falls between the ages of 15 to 64 years. The predominant ethnicity is black and English is the main language. To the best of our knowledge there has been no study to date in cultural setting of The Bahamas which has investigated the impact of dermatological and other chronic conditions on a family member's QoL and compared this impact to that experienced by patients.

Pilot studies are considered an important stage in any research investigation.⁽¹¹⁾ A pilot study was therefore

conducted in the Bahamas to determine the feasibility amidst the COVID-19 pandemic of a joint larger scale cross-sectional project between Cardiff and New Providence.

The aim of this pilot study was to determine the feasibility of a larger study: firstly, assessing the extent of the correlation between the QoL of patients with a skin condition and the QoL of their family members within such households. Also, secondly, assessing the correlation between the QoL of patients with other chronic conditions and the QoL of their family members within such households. The secondary aim was to determine the correlation between the FROM-16 questionnaire scores and the FDLQI questionnaire scores in family members with dermatological conditions.

Methods

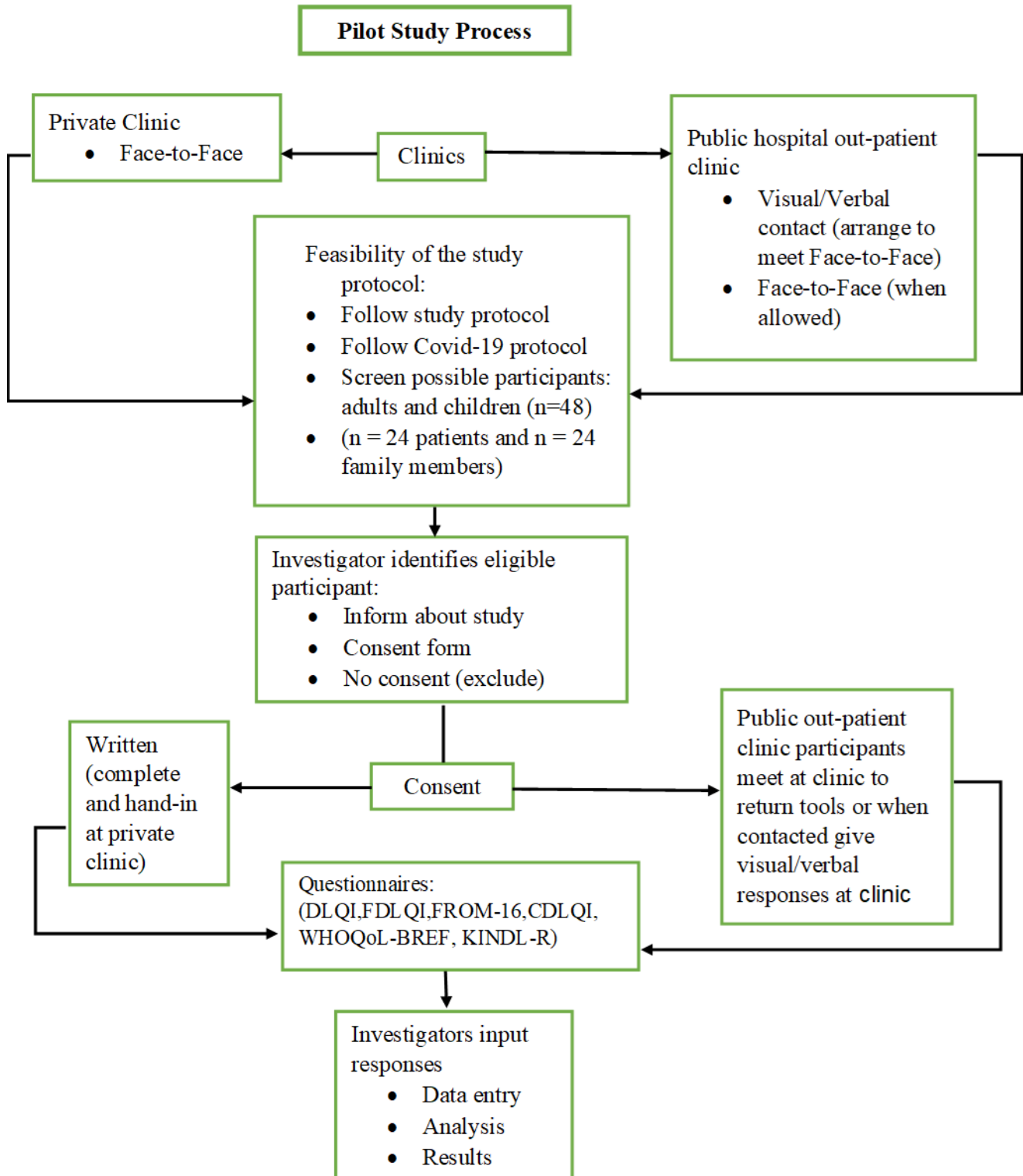
Ethics approval

Ethics approval was granted on May 4th, 2021 in The Bahamas (Ref No. PHA/31/1-B-2). The private clinic granted permission on May 13th, 2021 and on June 7th, 2021 the hospital granted permission to invite people attending public out-patient specialty clinics to participate in the study.

Study design

A prospective cross-sectional self-administered questionnaire study was carried out for three weeks, from June 8th, 2021 to June 30th, 2021 (Figure 1). Patients of any gender were included in the dermatological group if they had a formal diagnosis of psoriasis, acne, eczema, hidradenitis suppurativa and in the other chronic conditions group if they had a diagnosis of chronic kidney disease, rheumatoid arthritis or diabetes mellitus for more than six weeks. These conditions were chosen based on commonality, the chronicity of the disease and the possible effect on the QoL.^(4, 12-16) For the purposes of this pilot study, an ongoing medical condition lasting for more than 6 weeks is referred to as chronic. Patients were excluded if they had more than one chronic condition, if they had the above condition for less than six weeks, if they were involved in other clinical research and if they were less than four years of age as the two questionnaires used for the youngest age groups are validated from the age of

Figure 1. Pilot study process flow-chart



four. Family members were excluded if they were under the age of 18 years.

The validated QoL questionnaires in this study included the dermatology specific questionnaires: Dermatology Life Quality Index (DLQI)⁽¹⁷⁾ and Children's Dermatology Life Quality Index (CDLQI)⁽¹⁸⁾ for children, and the Family Dermatology Life Quality Index (FDLQI)⁽¹⁹⁾ for family members of patients with dermatological conditions. The generic health related quality of life (HRQoL) questionnaires included the Family Reported Outcome Measure-16 (FROM-16)⁽²⁰⁾, for family members of patients with dermatological and other chronic conditions. The patient specific questionnaires for the other chronic conditions group included World Health Quality of Life - BREF (WHOQoL-BREF)⁽²⁾ for adults and The Revised Children's Quality of Life Questionnaire (KINDL-r with the Kiddy, Kid and Kiddo versions) for children. Adult participants in both groups were also required to complete a demographic questionnaire.

Quality of Life assessment tools

Dermatology Life Quality Index

The DLQI is a dermatology-specific measuring tool created in 1994.⁽¹⁷⁾ The DLQI measures the perceived impact of a skin disease on the QoL of an adult patient.⁽²¹⁻²²⁾ The DLQI is a self-administered tool which can be used in a clinical setting to assist the clinician in the management of an affected patient.⁽¹⁷⁾ It comprises of a ten-item questionnaire with a one week recall period and can be completed in less than two minutes. The questions assess any impact caused by a skin disease on symptoms and feelings, daily activities, leisure, work/school, personal relationships and treatment.⁽¹⁷⁾ There are four responses to questions: "Not at all", "A little", "A lot", and "Very much".⁽²³⁾ The score band used is: 0-1 no effect, 2-5 small effect, 6-10 moderate effect, 11-20 very large effect and 21-30 extremely large effect. The maximum score obtainable is 30 with each question score ranging from 0-3. The higher the score the poorer the QoL and the lower the score the better the QoL. The DLQI has proven validity, has been found to be reliable and is one of the most frequently used QoL tools in clinical research.^(15,22,24,25)

Children's Dermatology Life Quality Index

The CDLQI is a dermatology-specific health-related QoL

paediatric measuring tool.⁽¹⁸⁾ The purpose of the CDLQI is to measure the perceived impact of a skin disease on the QoL of a paediatric patient.⁽¹⁸⁾ The CDLQI is an easy, tool to be used in a clinical setting. It is a 10-item questionnaire with a one week recall period and can be completed in less than two minutes. The questions assess any impact caused by a skin disease on symptoms and feelings, leisure, school/holidays, personal relationships, sleep and treatment of the paediatric patient. The response choices to the CDLQI questions are: "Not at all", "Only a little", "Quite a lot", and "Very much". The score band used is: 0-1 no effect, 2-6 small effect, 7-12 moderate effect, 13-18 very large effect and 19-30 extremely large effect. Each question score ranges from 0-3: the maximum score achievable is 30 with a higher the score indicating a poorer QoL. The CDLQI has been proven valid and found reliable in its use in clinical research.^(18,26-28) There are two versions of the CDLQI, a text-only version and a text with cartoons version.

Text with cartoons CDLQI: The cartoon questionnaire version appeals to the younger age group of 4-12 years and can be completed in 90 seconds.⁽²⁹⁾

Text-only CDLQI: The text questionnaire version can be used across the complete age range of 4 – 16 years. The text version is also easy to complete, understandable and on average is completed in 120 seconds.⁽¹⁸⁾ The text and cartoon version of the CDLQI have the same questions, though in the cartoon version there is an additional response "Prevented school" to question seven "If school time: How much did your skin affect your school work".⁽¹⁸⁾

Family Dermatology Life Index

The FDLQI is a dermatology-specific health-related QoL measuring tool to measure the impact on the QoL of family member of a person with a skin disease.⁽³⁰⁾ The FDLQI is a self-administered tool that can be used in a clinical setting to assist the clinician in identifying the extent to which a family member's QoL is impacted. It is a ten-item questionnaire with a one-month recall period and can be completed in less than three minutes. The questions assess any impact of the patient's skin disease on the family member's emotions, physical well-being, relationships, people's reaction, social life, leisure activities, burden of care, extra work, job/study and extra expenditure. The FDLQI has four responses to each

question: "Not at all/Not relevant", "A little", "A lot", and "Very much". The maximum score possible is 30, representing the greatest impact on QoL, with each question score ranging from 0-3. The FDLQI has been proven valid and found reliable in its use in clinical research.^(15,31-34)

Family Reported Outcome Measure -16

The FROM-16 is a QoL tool used to identify those areas of QoL of family members that are impacted by a patient's disease and to identify those areas in need of further support FROM-16 measures the impact of any disease of an adult family member of a patient with a chronic disease condition.⁽²⁰⁾ The FROM-16 is easy and quick to complete, with a completion time of approximately two minutes. The FROM-16 is a 16-item questionnaire with a present-day recall period. It is composed of two domains: 'Emotional' and 'Personal and Social life'.⁽²⁰⁾ The response choices for each question are: "Not at all", "A little", and "A lot". The score band used is: 0-1 no effect, 2-8 small effect, 9-16 moderate effect, 17-25 very large effect and 26-32 extremely large effect. The FROM-Emotional consists of six items, the score of each ranging from 0-2 and the FROM-Personal consists of ten items also with each score ranging from 0-2. The maximum scores achieved are 12 and 20 respectively. The higher the score the worse the QoL. The FROM-16 has several aspects of demonstrated validity and has been found to be reliable in research studies.^(35,26)

World Health Organization Quality of Life

The WHOQoL-BREF is a multidimensional health-related QoL questionnaire developed on behalf of the World Health Organization.⁽¹⁾ The WHOQoL-BREF assesses the perceived impact of disease on an affected adult patient. The WHOQoL-BREF is the short version of the WHOQoL-100.⁽³⁶⁾ The long version measures the QoL as it is perceived by the adult patient of any chronic disease condition. Similarly, the WHOQoL-BREF assesses the perceived impact of disease on the patient's daily activities, behaviour, health and disability/functional status.⁽³⁶⁾ The WHOQoL-BREF is a 26-item questionnaire with a one-month recall period. The WHOQoL-BREF has four domains: physical health (seven items), psychological/mental (six items), social relationships (three items) and environment (eight items).⁽¹⁾ The

maximum transformed score achievable is 100 with each question score ranging from 1-5 or 5-1 with a high score indicating better QoL. The WHOQoL-BREF has been found to be good with respect to reliability in its use in clinical research.⁽³⁶⁾

The Revised Children's Quality of Life Questionnaire (The Revised Children's Quality of Life Questionnaire)

The KINDL-r is a QoL evaluation questionnaire used to assess QoL and the effects of health conditions on children's everyday living.⁽³⁷⁾ The purpose of the KINDL-r is to measure the perceived impact of a chronic disease on the QoL of a paediatric patient aged 4-16 years. The KINDL-r tool is simple to use in a clinical setting.^(38,39) All of the KINDL-r questionnaires includes six questions with a one week recall period and is on average completed in less than fifteen minutes.^(37,40) The questions assess any impact on a child resulting from chronic disease or disturbed general health on any of its six dimensions: "physical", "emotional", "self-esteem", "family", "friends" and "school". The KINDL-r has been proven valid and found reliable in clinical research.^(38,39) The KINDL-r has three versions each considering the changes on quality of life of children and adolescents:

Kiddy-KINDL-r Interview: The text questionnaire version has been designed for the younger age group, 4-6 years. The Kiddy-KINDL-r is a six-item questionnaire each containing two parts totalling 12 questions. The Kiddy-KINDL-r has three responses to each question: "never", "sometimes" and "very often", each scored from 1-3.

Kid-KINDL-r: The Kid-KINDL-r questionnaire version has been designed for the adolescent group 7-12 years. The questionnaire covers six domains, each containing four parts totalling 24 questions. There are five responses to each question: "never", "seldom", "sometimes", "often" and "all the time". Each question is scored from 1-5 points. The number of questions is the same for Kid-KINDL-r and Kiddo-KINDL-r but the questionnaires differ in various statements within questions 1, 2, 4, 5 and 6.

Kiddo-KINDL-r: The Kiddo-KINDL-r questionnaire version has been designed for the older age group, 13-17 years. The questionnaire is comprised of six domains, each containing four parts totalling 24 questions. The Kiddo-KINDL-r also has five responses to each question: "never", "seldom", "sometimes", "often" and "all the time". The maximum transformed score is 100. Each

question is scored from 1-5 points.

Participant recruitment

The recruitment of participants was carried out at one public and one private outpatient clinic. All patients with the diagnoses discussed in the study design section were recruited using convenience sampling and invited to participate in the study, to minimise selection bias. Recruitment was originally intended to be in face-to-face clinics, however, due to the COVID-19 pandemic the mode of recruitment had to be changed for the public hospital to comply with the hospital out-patient safety protocol. Paediatric patients with diabetes and their family members were recruited from the public clinic where patients attended via telemedicine or video conference. In this clinic, a booking list was provided to the researcher who contacted the patients with information on the study and participants were able to complete the questionnaire via the telephone/video conference. The pilot study therefore included patients and family members recruited via telemedicine/video conferencing as well as face-to-face consultations. Each participant was informed of the study procedure. All recruited individuals (or their parents in the case of children) were required to provide written or verbal informed consent for their participation.

In the other chronic conditions group, patients aged from 4-17 years completed the KINDL-r (children aged 7-12 years completed the Kid KINDL-r and children aged 13-17 years completed the Kiddo KINDL-r questionnaire, the kiddy KINDL-r was for children aged 4-6) and patients ≥ 17 years completed the WHOQoL-BREF questionnaire. Patients were excluded if they had more than one chronic condition. A family member ≥ 18 years of the patient completed the FROM-16 questionnaire.

Paediatric patients with diabetes at the public hospital out-patient clinic and their family member (a parent) were contacted via telemedicine/video conferencing for consent to enter into the pilot study. The paediatric participants and a family member, once consented, provided data for the specific instruments KINDL-r and FROM-16.

In the dermatological conditions group, children aged from 4-16 years completed the CDLQI, adult patients > 17 years completed the DLQI. Patients were excluded if they had more than one dermatological or other chronic

conditions while all family members ≥ 18 years completed the FROM-16 and FDLQI questionnaires. All adult participants in both groups completed a demographic survey. Each diagnosis and each participant were assigned unique codes for purposes of analysis.

Data Analysis

Data obtained from participants was entered into Microsoft Excel Workbook and transferred to IBM SPSS (v.28.0) software for further data management and analysis. The analysis was mainly descriptive, comparing DLQI/CDLQI with FDLQI and FROM-16 (dermatology family member), comparing WHOQoL-BREF/KINDL-r with FROM-16 (other chronic conditions family member), and comparing FROM-16 dermatology with FROM-16 other chronic conditions. Pearson's correlation was used. No subgroup, sampling strategy or sensitivity analysis was needed and there were no missing data.

Results

A total of 48 participants were screened (24 patients and 24 family members). 32 (66.7%) participants were recruited face-to-face and 16 (33.3%) were recruited via telemedicine/video conferencing. Forty-four recruited participants completed the questionnaires and four did not. Twelve (25%) patients/family members agreed to take and return the instruments within seven days from their recruitment. Eight (16.7%) of the 12 instruments were returned. Four participants (8.3%) (two patients and two family members) of the other chronic conditions group, did not complete the study. One patient and their family member did not return the completed questionnaire and could not be contacted. The other patient passed away and their patient and family member questionnaires were not returned. The total number of patients/family members who completed the was 44 (91.7%). Of the patients and family members who completed the study, 26 (54.2%) were dermatology participants (13 patients and 13 family members) and 18 (37.5%) participants (9 patients and 9 family members) had other chronic conditions Table 1. Two children aged 4 - 12 were able to complete the cartoon version of the CDLQI by themselves and two children 13-16 were able to complete the text CDLQI version. No children aged 4-6 were recruited in the other chronic conditions group. Two children aged 7-12 completed the Kid KINDL-r and five children aged 13-17 completed the Kiddo KINDL-r.

Table 1. Number of pilot study participants (family members and patients)

Family members	Dermatological	Other chronic conditions
Parent	9	7
Partner	3	1
Adult child	1	0
Sibling	0	1
Total	13	9
Patients	Dermatological	Other chronic conditions
Adults	9	2
Child	4	7
Total	13	9

Table 2. Demographics of pilot study participants for both groups (family members and patients)

Pilot study data		
Screened	48	
Responded	44	92%
Adults	33	69%
Children	11	23%
Male	12	25%
Female	32	67%
Distributed	12	25%
Returned	8	17%
No return	4	8%
Mean age (adult)	44	
Age range (adult)	18--77	
Age range (child)	4--16	

Each clinic participant took approximately 15 minutes, or less, to complete the instruments. The age range of the adult family member participants was 18-77 years (mean=44years), Table 2. The family members involved (n=22) were parents (n=16, 36.4%), partners (n=4, 9.1%), one adult child (2.3%) and one sibling (2.3%). The patient participants included 11 (50%) adults and 11 (50%) children aged four years and above.

The sociodemographic data for the patient participants and family members are given in table 3 of this pilot study for the dermatology and other chronic conditions group. There were no correlations or impact found between any of the sociodemographic areas on QoL in this pilot study.

The number of patients for each diagnosis in the dermatological group was: psoriasis (n=2), acne (n=1), hidradenitis suppurativa (n=1), eczema (n=9). On In the other conditions group, the number of patients for each diagnosis was: chronic kidney disease (n=1) and diabetes mellitus (n=8). No patients with rheumatoid arthritis were recruited (Figure 2).

Thirty-two (66.7%) of the questionnaires were distributed to one private clinic which recruited patients from the dermatology and general medical clinic. The remaining 16 (33.3%) were recruited from the public clinic in which 14 (29.2%) participants (7 paediatric patients and 7 family member) were involved and data was collected, with the consent of a family member.

Table 3 Sociodemographic for patients and family members of both groups

Sociodemographics	Dermatology		Other chronic condition	
	Patients	Family members	Patients	Family members
Family member (total)	9	13	2	9
Gender				
Female	8	7	1	9
Male	1	6	1	0
Ethnicity				
Black	6	7	2	9
White	2	5	0	0
Other	1	1	0	0
Marital status				
Never married	5	3	1	4
Married	4	10	1	4
Widowed	0	0	0	1
Employment status				
Full time	4	11	1	5
Part time	0	1	0	0
Unemployed	5	1	1	4
Education				
None	0	2	0	2
GCSE's	5	3	2	5
AS, A level or equivalent	0	0	0	0
NVQ or equivalent	0	1	0	0
Other	4	7	0	2
Income				
\$10,000 or less	2	1	1	2
\$10,000 - \$20,000	0	1	1	2
\$21,000 - \$30,000	2	2	0	1
\$31,000 - \$40,000	1	3	0	2
\$41,000 - \$50,000	1	2	0	0
\$51,000 - \$60,000	1	2	0	0
\$61,000 or more	0	2	0	0
N/A	2	0	0	2

Figure 2. Participants involved

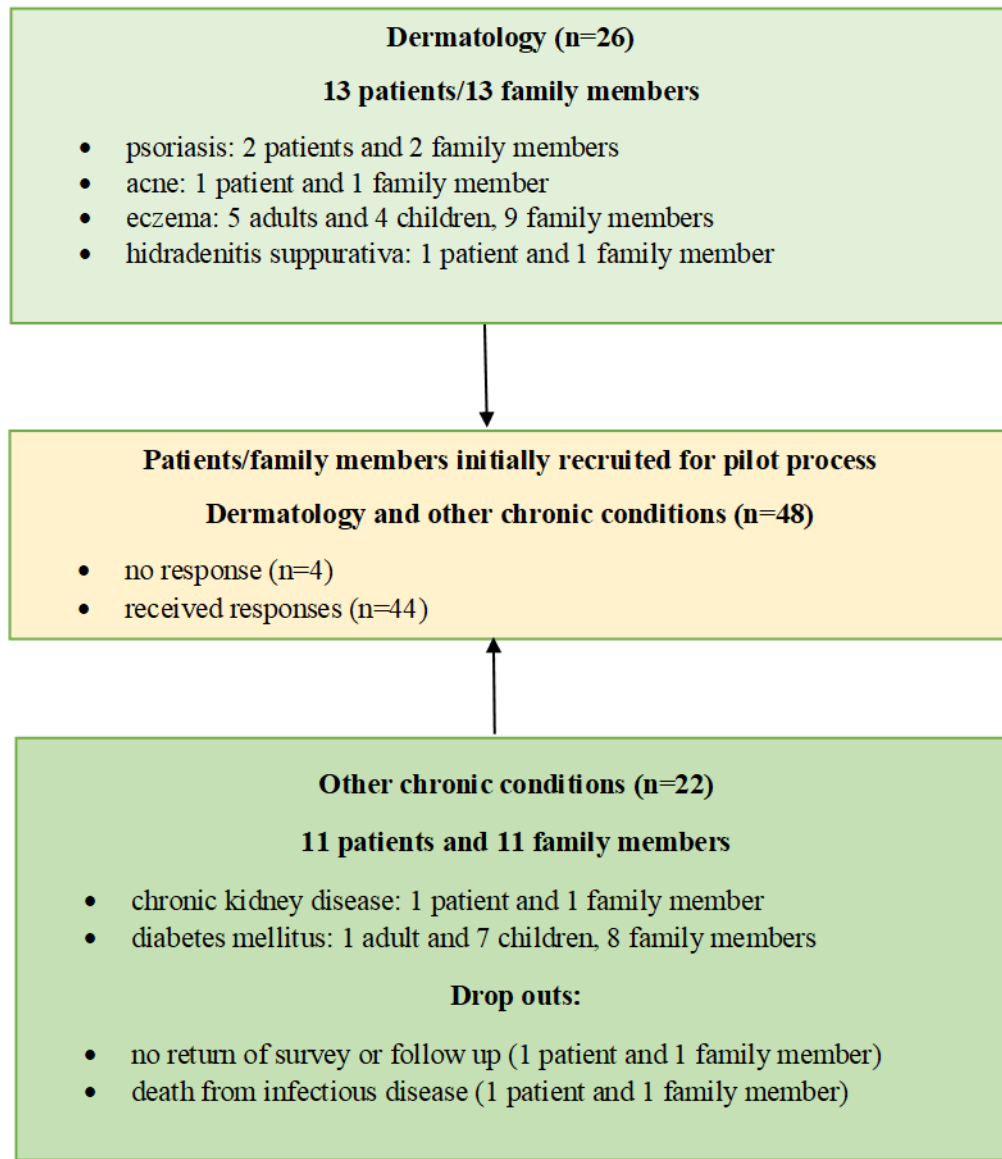
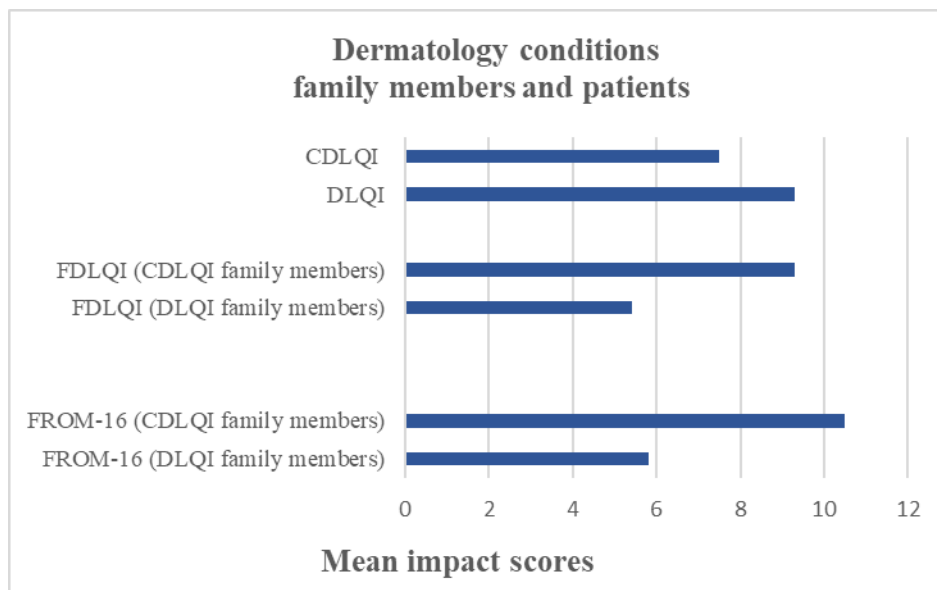


Figure 3. Dermatology group scores



In the dermatology conditions group (n=26) all patients (adults ≥ 18 and children 4-16 years) were able to complete the validated QoL questionnaires. The mean DLQI score for adults was 9.3 (SD=4.1) and for children the mean CDLQI score was 7.5 (SD=6.4). The mean FROM-16 score was 5.8 (SD=5.7) for family members of adults and the mean FROM-16 score was 10.5 (SD=11.8) for the family members of children. The mean FDLQI score was 5.4 (SD=4.8) for family members of adults and mean FDLQI score was 9.3 (SD=7.3), for the family members of children, Figure 3. Of the 10 FDLQI items, the areas most affected were “emotional distress”, “times spent looking after the patient” and “increase in routine household expenditure.” The FROM-16 showed slightly more impact in the emotional domain (similar to that of the FDLQI). Of the FROM-16 items the areas most impaired were: “I feel worried and angry”, “I feel sad and I feel frustrated” “caring for my family is difficult”, “hard to find time for myself and family activities”, “my sex life is affected” and “increase in family expense”.

Inferential statistics on the dermatology conditions group showed that the DLQI had a weak negative relationship to (FDLQI) of family members of adult patients (r=-0.23, p=0.55, n=9) and no relationship to FROM-16 (r=-0.04, p=0.92, n=9). There was also a very strong positive relationship between the CDLQI and both FROM-16 (r=0.82, p=0.18, n=4) and FDLQI for family members of paediatric patients (r=0.83, p=0.17, n=4). Although not statistically significant, for adult patients, there was a very strong positive relationship between FDLQI and FROM-16 (r=0.74, p=0.03, n= 9) and for paediatric patients there was also a very strong positive relationship

between FDLQI and FROM-16 was (r=0.99, p=0.02, n=4).

The correlations within the dermatology group reveals that family members of adult patients experience more QoL impact “over the last month (FDLQI)” than “at the moment (FROM-16)” time period. Whereas, family members of paediatric patients experience an equal impact on their QoL be it “over the last month (FDLQI)” or “at the moment (FROM-16). Also, for family members of paediatric patients, findings may suggest that FROM-16 (at that moment) can indicate what the family member may experience over the last four weeks using the FDLQI questionnaire.

For family members of dermatology patients (n=13), the mean FROM 16 score was 7.2. The emotional domain mean score was 3.3. This domain consisted of six questions with a maximum score of 12. The mean personal and social domain score was 3.9. The personal and social domain consisted of 10 questions with a maximum score of 20. The mean FROM-16 score for family members of patients with other chronic conditions (n=9) was 9.5. The emotional domain mean score was 3.1 and the personal and social domain mean score was 6.4. (Figure 4).

In the other chronic conditions group the patients’ mean WHOQoL-BREF score was 90.5 (SD=13.4) and the mean KINDL-r score was 78.9 (SD=41.5). The family members’ mean FROM-16 score was 9.55 (SD=3.69), (Figure 4). Patient participants experienced a good QoL whilst their family members’ QoL was greatly impacted. There was a

Figure 4. FROM-16 mean scores

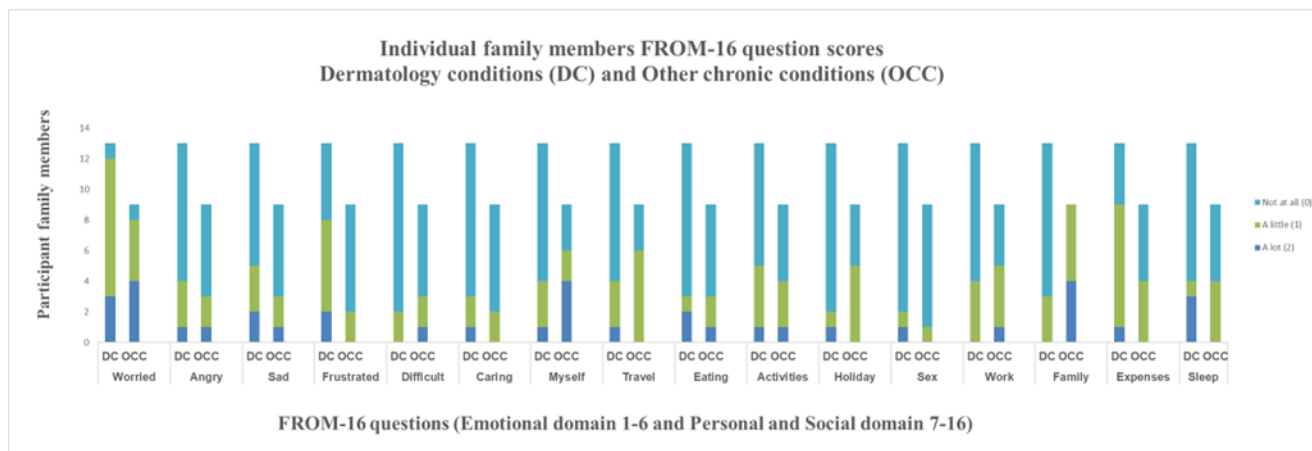
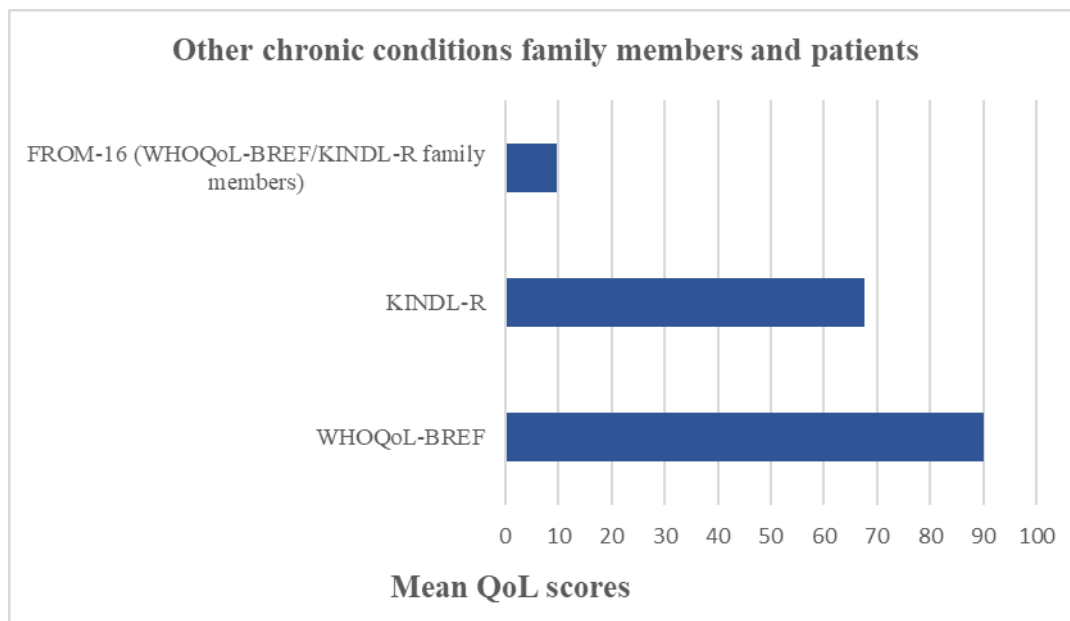


Figure 5. Other chronic conditions group scores



weak insignificant inverse relationship between KINDL-r and FROM-16 scores ($r=-0.236$, $p=0.610$, $n=7$)

The correlation within the other chronic conditions group reveals that family members of adult/paediatric patients experience little impact “at the moment (FROM-16)” on their QoL.

Discussion

Family members experience a variety of QoL impacts from having a family member with a health condition, including having their own QoL influenced by the QoL impact experienced by the patient.⁽⁴¹⁾ Skin and other health conditions affect the QoL of patients, and also family members, however information about QoL impact between dermatology and a chronic medical condition has not been gathered using validated QoL questionnaires (DLQI, CDLQI, WHOQoL-BREF, KINDL-r, FDLQI and FROM-16) in the Caribbean.

This pilot study provides initial data suggesting that the QoL impact of a patient with a dermatological or with other chronic conditions can negatively affect the QoL of their family member.⁽⁴²⁾ Shah et al recognised a large impact on the QoL of family members of patients with chronic health conditions.⁽⁷⁾ Our findings demonstrate that a family member of a paediatric patient with a dermatologic condition may experience a large impact on their QoL compared to family members of adult patients with dermatologic conditions. In keeping with our results,

several other studies have demonstrated a significant impact on the QoL of family members of paediatric patients.^(8,43,44) Kelly et al reported a notable strain on family members, highlighting the feelings of anxiety, stress and depression of caregivers of children with eczema, and psoriasis. In contrast, the participants’ FDLQI and FROM-16 scores indicated a small impairment of the QoL of the family members of adult patients.⁽⁴⁵⁾ Our findings may indicate that the additional demand on family members of children with chronic dermatology conditions are higher than on family members of adults with chronic dermatology conditions; thus, impairing their quality of life even more.

The FDLQI items impacted were the same as for the family members of adult patients. Similar impairment was revealed by the FROM-16 data in the emotional domain in areas of “worry” and “frustration”. In addition, there were similar impacts in the personal and social life domain with impacts on “family activities” and “increased family expense” and also impairment of “sleep”. The correlation between FROM-16 and FDLQI in family members of dermatology patients is positive (as one increases so does the other).

This pilot study also compared the impact on the QoL of family members from the dermatological conditions group to that of the family members in the other chronic conditions group using FROM-16. Our results have shown that both groups of family members experience similar

areas of impact. The impact experienced by the family members in the dermatology group showed a FROM-16 mean score of 7.3 whereas the FROM-16 mean score in the other chronic conditions group was 9.5. Using the FROM-16 score banding, the other chronic conditions mean score displayed a slightly higher result, scoring within the 9-16 range representing a moderate impact on the QoL.

Furthermore, even though dermatology conditions are different from other chronic conditions, the FROM-16 has been found to reliably measure the impact of disease on family members across all medical specialities, as demonstrated by Golics et al.⁽⁴⁶⁾ That study involved family members from 26 medical specialties of chronically ill patients all experiencing effects on their lives in areas of emotion, finance, relationships, work and social activity. Using the FROM-16 to measure the impact on the QoL of these two groups has proven important. Even though dermatological conditions are mainly visible and other chronic conditions are mainly internal, the areas which the patient or family experiences the impact can be similar.^(47,48)

Also, this pilot study showed that the adult and paediatric patients in the dermatology group experienced similar impact on their QoL. Adult patients' DLQI mean score was 9.3 and paediatric patients' CDLQI mean score was 7.5, both representing a moderate impact on QoL. These findings correspond with the impactful trends seen in the study by Geel et al on the QoL of psoriasis in patients, using DLQI and CDLQI questionnaires.⁽²⁵⁾ The similar findings in both groups reveal the extent to which skin conditions can sometime limit, debilitate or hinder the lifestyle of a patient regardless of their age or the severity of their skin condition.^(21,27,44,49)

In the other chronic conditions study group the FROM-16 scores of family members of adult patients indicated a moderate impairment of their QoL in the personal and social domain compared to the small impairment recorded by the dermatology family members (Figure 4). This could be because family members of patients with other chronic conditions may have experienced greater impact on daily tasks and other responsibilities for a longer period of time.⁽⁴⁶⁾ The impact experienced by the adults using WHOQoL- BREF and paediatric patients using KINDL-r (Kid and Kiddo) were found to be similar. Although the instruments are different, they both aim to

measure how the patient feels about their overall well-being, physical, mental, social and family QoL. Adult patients using WHOQoL-BREF scored 90.5 and paediatric patients using KINDL-r scored 78.9, both indicating a good QoL.

As the focus of this study was to measure the impact on QoL of a patient and a family member using the previously mentioned validated QoL questionnaires, the impact that COVID-19 may have placed on the patient or family member was not assessed.

Limitations and Strengths

The number of subjects was small and so the results may not be generalisable to The Bahamas. The dermatology group was larger with more adult patients, whereas the other chronic conditions group was smaller with more paediatric patients which may account for some of the differences in the results. Although the clinics used in The Bahamas for this pilot study are a modest representation of the clinic population, the small sample size can introduce bias. There is a high female to male ratio, the ethnicity predominance is black and the age range is between 18-77 years. Questionnaire anonymity may have been breached due to a patient and an accompanied family member seeing how each other may have responded. As a result, the patient/family member could have over or understated their responses. Although the method of recruiting participants (patient/family members) in the public hospital was different from the recruitment of participants in the private clinic, Erhart et al, using Kindl-r along with other questionnaires in a mixed method study using telephone interviews and mail-in questionnaires found differences in results between both methods to be small.⁽⁵⁰⁾

The major strength of this study is that this is the first pilot study of its kind to be conducted in the cultural setting of The Bahamas, shedding a light on the QoL impact of chronic conditions on patients and their family members. Inclusion of QoL of paediatric patients is another strength of this study. Questionnaires were easily distributed face-to-face to participants whilst adhering to Covid-19 protocols. It is possible that the COVID-19 pandemic may have impacted people's (patients and family members) QoL scores given that the pandemic likely impacted patients and families with chronic conditions worse than those who do not have any underlying health issues.

Conclusion

This pilot study indicates that the study protocol is feasible. This is the first study in The Bahamas to measure the QoL of family members as well as of adult and paediatric patients with dermatological and other chronic conditions using validated questionnaires. There is a correlation between the impact on the QoL of a patient and the impact on the QoL of a family member. Family members of paediatric patients experience a greater impairment on their QoL than family members of adult patients. This was a small questionnaire-based pilot study that revealed several study issues. Family members may have been caring for more than one patient, and this may have had an impact on their QoL scores. However, analysis of family members caring for multiple people (patients) and QoL impact between family members is an area that would warrant further research. The difference between the QoL of different family members such as parents versus siblings was not measured and this could be addressed in future research. This study also identified issues concerning how participants responded to questionnaires such as checking the correct boxes on the questionnaire, forgetting to fill out all required forms, exceeding the allotted completion time and the need for

assistance in completing the forms. Lessons learnt from solving these will inform the conduct of the planned larger study. This pilot study gives ample evidence to support a larger scale study to corroborate these findings.

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Author contribution

	Contributor 1 Chanta'l Clare-	Contributor 2 <u>Jui Vyas</u>	Contributor 3 <u>Flora Kiss</u>	Contributor 4 <u>Prof. Andrew Finlay</u>	Contributor 5 Morton Anthony
Concepts	X	X	X	X	X
Design	X	X	X	X	X
Definition of intellectual content	X	X	X	X	
Literature search	X				
Clinical studies	X				
Experimental studies					
Data acquisition	X				X
Data analysis	X				X
Statistical analysis	X				X
Manuscript preparation	X	X	X	X	
Manuscript editing	X	X	X	X	X
Manuscript review	X	X	X	X	X
Guarantor		X			

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