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Perceived Barriers of Informal Caregivers of Children with Special Healthcare Needs

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PERCEIVED BARRIERS OF
CAREGIVERS OF CHILDREN WITH
SPECIAL HEALTHCARE NEEDS

By

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Introduction

Children with special health care needs (CSHCN) have or are at risk for chronic physical, mental, behavioral, or developmental disorders (Agostiniani, Nanni, & Langlano, 2014). They require more health-related services than needed by typically developing children. Approximately 36% of all children have one or more health condition and 18% are categorized as CSHCN. The number of children in this category are steadily increasing every year (NSCH, 2017). Of those that are categorized as CSHCN, 25% have one or more functional limitations, 12.9% have complex healthcare needs, and 40% have daily activities impacted by their conditions (NSCH, 2017). Children with one or more chronic conditions, with severe functional limitations, are medically fragile, and require specialized and considerable health care resources are further categorized as children with medical complexity (CMC) A majority of CSHCN and CMC are cared for at home by informal caregivers (i.e. parents, grandparents, siblings, family, and friends; Murphy, Christian, Caplin, & Young, 2006)

Background

Informal caregivers are those with no formal medical training, are not paid for their caregiving services, and are usually family members. The rate of informal caregivers of CSHCN and CMC are growing exponentially every year, which substantially impacts our healthcare system. Only, .4-.7% of all children are considered CMC; however, account for 15-33% of total healthcare spending, which is approximately \$50-110 billion annually (Berry et al., 2014). Informal caregivers have been shown to improve the wellbeing, quality of life, and health outcomes of their loved ones and reduce healthcare costs through decreased hospital readmissions and long-term care in the home (Levine, et al., 2010). Unlike caregivers with formal medical training, distress faced by informal caregivers is unique, in that they must learn

complex medical procedures to care for their loved one (MacDonald & Hastings, 2010; Murphy, et al., 2006; Weiss & Lunsky, 2011). Informal caregivers habitually neglect their own health and wellbeing, which can result in caregivers experiencing severe stress, illness, burnout, depression, and anxiety. When informal caregivers experience burnout, they experience increased work absenteeism, social isolation, and physical injury. Moreover, the person they care for is more likely to be repeatedly admitted to the hospital (MacDonald & Hastings, 2010; Murphy, et al., 2006; Weiss & Lunsky, 2011). Finally, the greater the caregiving demands are the more likely the caregiver is to experience significant distress, reduced coping, and have poorer physical and psychological health (Rodakowski, et. al, 2017).

Problem Statement

Current recommendations to improve informal caregiver wellbeing are respite care, the medical home, and other selfcare measures; however, there are significant barriers to these interventions (Berry, 2015; Sawatzky & Fowler-Kerry, 2003; Donelan, 2002; McNally, Ben-Shlomo, & Newman, 1999). Respite care is defined by the primary caregiver relinquishing care of their loved one for a short period of time, which is usually planned and may take place in a hospital, outpatient facility, or in the home (McNally, et al., 1999). The medical home is continuous, coordinated comprehensive, and compassionate family-centered health care. In the medical home model, the primary care physician acts as the “central hub” and coordinates all patient care (Berry, 2015). Selfcare activities include exercise, support groups, meditating, gardening, and adequate sleep. Respite care and/or a medical home are often not feasible for many families. Competent medical care, financial constraints, low health literacy, availability, and accessibility are major contributing factors that prevent informal caregivers from receiving respite care and/or a medical home. Furthermore, a decline in the care recipients'

health status during a respite period may cause a greater incidence of poor health and burnout in the informal caregiver and the effects of respite care are short-lived and that once care is resumed, informal caregivers begin to re- experience effects of caregiver burnout. Moreover, informal caregivers face significant barriers to selfcare measures, like time, guilt, and social isolation (Doig, McClennan, & Urichuk, 2008; Fedele, et al., 2014; McNally, et al., 1999; Rosen-Reynoso, et al., 2016; Toomey et al., 2013).

Purpose

The purpose of this project was to answer: What are the daily lived experiences and routines of informal caregivers of children with special healthcare needs and how does this affect their health and wellbeing? Our long-term goal based on these findings is to develop an intervention that fits the needs of this population to improve their overall health and wellbeing.

Aims.

We specifically aimed to answer:

- What do informal caregivers view as selfcare measures ?
- What do informal caregivers perceive as barriers to selfcare?
- How do they perceive the effects of caregiving on their health?
- What are challenges they experience as caregivers ?

Review of the Literature/Significance

There are multiple steps caregivers can take towards selfcare. Selfcare measures include, exercising, which produces stress-relieving hormones and helps increase energy levels, eating well and getting adequate sleep. Increasing fruit and vegetable consumption and decreasing processed foods are great steps towards healthy eating which improves overall health and wellbeing. Additionally, sleeping seven to nine hours per night and including

occasional 15 to 30-minute naps assists in energy level and brain function (“Taking Care of Yourself”, 2019). Moreover, getting support from others, either in the form of a support groups or from family and friends, are selfcare measure that greatly impacts caregivers’ wellbeing (“Practical solutions”, 2018). Finally, noting positive moments of each day and writing them down as they occur may help to create healthy mentality and thankfulness. Caregivers may accomplish these self-care measures by creating goals and clear action plans to reach each goal. Obtaining goals set by caregivers may improve their overall health and wellbeing. (“Taking care”, 2012).

When caregivers neglect themselves many negative outcomes may occur. Caregivers may experience headaches, low energy, and upset stomach due to lack of sleep and poor nutrition. Moreover, caregivers with poor selfcare may suffer from body aches, pains, and insomnia, which often coincide with stress and anxiety (“Taking Care of Yourself”, 2019). In addition, they may feel a loss of personal identity when selfcare is neglected. For example if caregivers must quit their jobs or other activities to accommodate their loved ones needs, they frequently do not replace the loss with any other form of activity which leads to loss of personal identity (Sawatzky & Fowler-Kerry, 2003).

However, caregivers endure many barriers to selfcare. One of the main barriers to selfcare they feel is guilt. The guilt that caregivers experience make it difficult for them to take attention and time from their loved ones and give it to themselves. They frequently perceive taking their own time as selfish (“Taking Care”, 2012). Another barrier to selfcare is that they are stuck in the mindset of needing to be a caregiver all the time. They are so used to tending to others that they do not consider themselves (“Taking Care of Yourself”, 2019). Additionally, many caregivers try to avoid asking others for help. They do not want to seem like they cannot

handle it on their own and see reaching out as a sign of weakness (“Practical solutions”, 2018). Another barrier to selfcare is the proximity of family and people to help. Some caregivers do not have anyone they trust that is nearby for assistance; therefore, they must solely rely on themselves (Donelan, et. al, 2002). Financial instability is also a barrier for caregivers selfcare. If they are not financially able to hire anyone to help or afford high quality care for their loved one, they take on that burden resulting in neglect of selfcare (Donelan, et al., 2002) Since the caregivers often have to perform specialized medical care to tend to their child, they lack time to tend to themselves. This can lead to higher levels of poverty, isolation, and sleep deprivation (Berry, et al. 2015). Occasionally, social isolation may also happen because it can be hard for caregivers to see other children meeting goals that their children has not. A coping strategy for this is often to remove themselves from those situations, which leads to less social interaction (Bradshaw, et al. 2019).

Methods

Methodology

To investigate experiences of informal caregivers, we chose to use a thematic analysis approach as our overall research structure to elucidate and examine characteristics from each interview. This method allows for detecting, evaluating, and deducing recurring topics or themes.

Sample

A convenience sample of informal caregivers of CSHCN were used in this study. Participants were recruited through flyers and past participation in research. Fifteen informal caregivers of CSHCN were recruited to participate in the study. Twelve agreed to participate;

however, one participant dropped out before the interview was conducted. No reason was given by the participant for not participating. Of the participants, eleven were female and one was male. All participants were informal caregivers of children categorized as medically complex in severity.

Data Collection

We conducted interviews via telephone. Participants were in a location of their choosing. An interview guide was developed based on findings from current research. Interviews were conducted by one researcher for continuity. Interviews consisted of ten semi-structured questions, that enabled informal caregivers to recount their experiences. The interviews were recorded, and later transcribed verbatim. Each interview lasted approximately 15 minutes. Researchers concluded that data saturation was achieved.

Data Analysis.

Transcriptions were read multiple times by two researchers and then independently coded as patterns emerged, researchers discussed the codes and came to a consensus. From the agreed upon codes, themes were developed and described. Use of thematic analysis permitted comparison of observed patterns between researchers throughout analysis. Through this process identified 11 subthemes and three predominant themes. The predominant themes were, daily life, selfcare, and caregiving.

Results

Themes

Through analysis three main themes were found: daily life, selfcare, and caregiving. Each of these main themes included specific subthemes (Table 1).

Daily Life

The theme of daily life was divided into three sub-themes: typical days, sentiment of experience, and COVID-19 related changes.

Typical Days.

Typical days are the normal routine that the caregivers followed. Some caregivers reported their day, where others stated their day and their child's day. Often, these were intertwined and there were large overlaps between the caregivers' days and their child's day. Some of the caregivers were employed and others were stay at home parents. This often depended on the complexity of their child's healthcare needs and the spouses or support available to the caregivers.

Sentiment of Experience.

Sentiment of experience was the caregivers' feelings around everyday activities and their overall life experiences. Many participants felt as if it was their normal, and something they must do. One participant stated, "So for me, it's my kind of normal" and another stated "I've succumbed to the fact that is my role right now in life is a caregiver." It was not often that the caregivers stated feeling bad for themselves or had a "poor me" attitude. Another participant

stated, “I just push through it” when referring to life as a caregiver. For many of the caregivers they had accepted their roles as parent and caregiver.

COVID-19 Related Changes.

The last sub-theme was COVID-19 related changes and referred to impacts on caregivers’ daily routines because of COVID-19. A major part of this was that their children now were always at home, and they may also be working from home. This has required them to take on other roles such as, trying to teach their children in addition to caretaking. One caregiver said, “So now, I am mom, chef, therapist, all of it.” For others, COVID-19 had not had much affect. These caregivers were ones that were already a stay at home parents, had children that were not yet school age, or were home schooled.

Selfcare:

The theme of selfcare was divided into three subthemes: measures employed, barriers to selfcare, overcoming barriers to selfcare, and impact of selfcare

Measures Employed.

Measures employed were specific selfcare measures that caregivers have implemented into their lives. This could be anything from exercise to listening to music in the car. One caregiver stated this as their selfcare measure “And so I dance and I exercise and I blare music at the top of my car's capacity.” The most often stated selfcare measure was exercise, including walking and hiking. Caregiver said things such as “working out pretty regularly” and “I get to like go for a walk or exercise in the morning” when asked the selfcare measures they

implement. Many participants said one way they practice selfcare is being outdoors, in nature. Others liked methods of treating themselves with getting their nails done or a small trip.

Barriers to Selfcare.

Barriers to selfcare were physical or psychological circumstances that prevent caregivers from including selfcare activities into their daily lives. The main barriers we found were time and lack of energy. For example, one caregiver said, “There's really no time for anything”. In addition, a prominent barrier was lack of childcare. For some this was related to money constraints, for others it was the area they lived in. One caregiver said, “If could afford to be a stay at home mom like I probably could have more time to least fit in an hour or two a week to do that.” Some children with medical complexities require special care knowledge on how to take care of them. This is knowledge that must be learned, and the average babysitter is not capable of caring for such a child, this makes hiring someone for childcare more difficult. Another problem was the inability to commit set hours for assistance with childcare. Many people who do have the training and ability to care for medically complex children want specific hours and a weekly schedule, not being able to give that makes finding someone difficult.

Overcoming Barriers to Selfcare.

Overcoming barriers to selfcare was tools the individual needs or believes they need to overcome receiving or implementing selfcare activities into their lives. The most common pattern participants reported to overcome barriers were money and someone capable of caring for their child. Lack of sufficient funds is often impossible for caregivers. For example, one caregiver stated, “I don't have the money to just go and get a massage.” Another barrier reported was the age of the child and this is overcome as the child ages. Some caregivers did state that

their child had made progress as they had gotten older and that barriers lessened as the child aged.

Impact of Selfcare.

Impact of selfcare was specific psychological and physical effects that selfcare measures have when they are implemented. Most reported improvement in mentality and personality. One caregiver stated, “when I don't do it, I tend to be quicker to temper and less forgiving”, another said, “I feel more stable” when asked about the impacts of selfcare. Many participants stated they were less stressed and happier when they implemented selfcare activities. Some stated they were able to think or concentrate better when they implemented selfcare into their lives. Others stated they were better caregiver when they do make time for selfcare, because if they cannot take care of themselves, they cannot do their best job taking care of anyone else. One caregiver specifically stated, “I can definitely tell the difference, when I'm taking care of my own mental health, because I'm a lot more calmer” and another said, “If I can't take care of myself, I also can't take care of everyone else.”

Caregiving The subthemes of caregiving are caregiving challenges, negative physical and psychological perceptions and effects of caregiving, support, and effect on other children and family members.

Caregiving Challenges

Caregiving challenges and those that caregivers face due to caring for a child with medical complexity. Money and lack of understanding/societally pressure were two main responses, one caregiver stated, “I mean, societally, you know, you're looked down upon for being a stay at home mom.” In addition, the intense pressure of having to keep the child alive

without help was included as a caregiving challenge. A caregiver said “there’s a lack of understanding about that level of pressure” in reference to the difficulty of having to keep their child alive 24/7. Another challenge was lack of answers on their child’s condition. Some caregivers do not have a full diagnosis, which led to reported increased stress. Having childcare can be helpful for the caregivers but it can also add stress too. Their child might have a condition which makes their behavior more unpredictable which could make the caregiver anxious to leave them with someone else who may not know the best way to handle their behavior.

Negative Physical and Psychological Impacts

The negative physical and psychological impacts for caring for a child with medical complexity include feelings of exhaustion, lack of sleep, and stress. Caregivers stated, “just utter exhaustion”, “it is very debilitating”, and “it could be lack of sleep”. Caregivers also reported mourning the loss of activities their child will never participate in. A caregiver said, “emotional, they're just tenfold. You know, I mean, you just feel awful for someone you just wish you could have conversation with and your heartbreaks for him, you wish he could do Cub Scouts. He's never going to get married. He never owned a pair of underwear. I mean, it's just really, it's just a tough thing to go through.” This was mentally draining and led to feelings of sadness. In addition, exhaustion can make caregivers more emotional which increased reported feelings of anxiety, a caregiver stated, “I'm more anxious, like I, never used to have anxiety issues.”

Support

The subtheme of support was the effects of support and lack of support impact caregivers of CSHCN. Participants reported that they have no one else to care for their child,

and that it is very difficult to ever get a break. For example, one caregiver said, “Well my son is difficult to take care of. So there's really no one, you know, to take care of him.” In one instance, the child was getting too heavy that only the father could lift him anymore. This is a constraint because then the father needs to be present whenever the child must be moved. The caregiver said, “My relatives aren't able to care for him anymore.” Some caregivers have outside family members that were able to help. However, in these cases they might only be capable for a short period of time and/or it needs to be set up in advance.

Effects on other Children and Family Members

The effect on other children and family members was the emotional strain put on caregivers to give attention or time to other members of the family. These encompassed feelings of guilt and worry about others, often because circumstances prevented them from doing things for other children and family members that they want to or think they should be doing. One caregiver stated, “our youngest would love to go to Disney. I can't do that with my son.” One term that came up was “mom guilt”, feeling like they were not doing enough for all their children. This caregiver said, “my youngest is something she would love to do and I've never done that with her. So I kind of kind of like mom guilt, I guess. And I guess it can be stressful thinking, Man, you know, I would love to do this for her.” For many of the caregivers their children with medically complexities was not their only child, they had other children to worry about as well.

Table 1

Theme	Subtheme	Definition	Example
Daily Life	Typical Days	The average routine of a caregiver with at least one child with special healthcare needs	“I have to school to go to school every day for lunch. I take him lunch from home”, “she gets up about 645 so wake up, go to the bathroom, get dressed...We do showers around 730 and then read books around 830 and do medicine at 9 she goes to bed around 915 or 930.” “Which changing him is literally probably about a 10 to 15-minute ordeal because of he's just not very ambulatory or mobile. So, it takes a while and then we'll go wait for the bus”
	Sentiment of Experience	Feelings around the everyday experiences and life as a whole of the caregivers	“I just push through it” “it’s just something you do” “So for me, it’s my kind of normal.” “I’ve kind of succumb to the fact that my role right now in life is a caregiver”
	Covid-19 related changes	Changes due to COVID-19 that have impacted the caregiver’s daily routine	“So now, I am mom, chef, therapist, all of it.” “So, understanding it’s been rough” “not understanding why you know, hey dads not coming in and hugging me” “it’s totally turned it upside down” “he gets really upset and angry” “actually I have anxiety, like I think it just

			stems from withImmune system being so depleted so much throughout his whole life."
Selfcare	Measures Employed	Specific self-care measures that have been implemented into caregivers' lives	"I get to like go for a walk or exercise in the morning", "when he's home I usually go for a walk", "working out pretty regularly" "And so I dance and I exercise and I blare music at the top of my car's capacity"
	Barriers to selfcare	The physical or psychological circumstances that prevent caregivers to including selfcare into their daily lives	"when it comes to exercise... no energy" "in this current time of not being able to work out it is just, it's awful" "too many things to do", "it just takes too long to finish", "sometimes I don't have time to do them", "And, you know, everybody's got their own excuse, but mine is literally when I'm at home, me or my wife is caring for our child. And we do not have the ability to just take an hour to go work out", "There's really no time for anything" "I think it's time and now it's going to be money too" "If could afford to be a stay at home mom like I probably could have more time to least fit in an hour or two a week to do that"
	Overcoming barriers to self-care	The tools the individual needs or believes they need to overcome receiving or implementing self-care into their life	"So if I was able to commit to somebody for regular hours every week then it would probably be better" "So it's

			probably you know, to me changing my attitude" "I don't have the money to just go and get a massage." "Maybe circumstances changing" "the older he gets; some things are just easier"
	Impact of selfcare	The specific psychological and physical effects that self-care measures have when they are implemented	"less stressed", "happier mom", "I can think better", "attitude with my kids is different", "shorter attention span and shorter fuse temper wise", "not as good concentration", "I'm not sleeping at night", "the harder it is for me to complete tasks because I can't concentrate", "I feel more stable", "I can definitely tell the difference, when I'm taking care of my own mental health, because I'm a lot more calmer", "I can tell you that it greatly affects my health and well-being", "when I don't do it, I tend to be quicker to temper and less forgiving", "If I can't take care of myself, I also can't take care of everyone else"
Caregiving	Caregiving Challenges	The challenges caregivers face due to caring for a child with medical complexity	"those with money can figure it out and pay for the help", "I think a lot of it is money", "of course money can be an issue as well when looking for someone to watch" "sometimes people don't understand", "I mean, societally,

			<p>you know, you're looked down upon for being a stay at home mom", "we still don't have answers" "it's really hard to have anybody watch" "there's not a lot of training and research on his condition", "finding good consistent help is really hard" "sometimes people don't understand", "I mean, societally, you know, you're looked down upon for being a stay at home mom", "we still don't have answers" "kids who literally have to be kept alive 24hrs a day", "there's a lack of understanding about that level of pressure"</p>
	<p>Negative physical and psychological perceptions and effects of caregiving</p>	<p>The physical and psychological impact of caring for a child with medical complexity</p>	<p>"just utter exhaustion", "it is very debilitating" "it could be lack of sleep" we do drink a lot. Which I know is not healthy" "I'm more anxious, like I, never used to have anxiety issues" "like mom guilt, I guess. And I guess it can be stressful" "emotional, they're just tenfold. You know, I mean, you just feels awful for someone you just wish you could have conversation with and your heartbreaks for him, you wish he could do Cub Scouts. He's never going to get married. He never owned a pair of underwear. I mean, it's just really, it's just a</p>

			tough thing to go through.” “I can definitely tell it’s taking a toll” (in reference to stress), “I think I’m getting an ulcer”
	Support	How support or lack of support affects caregivers with children with special healthcare needs	“people don't really think to offer help”, “My relatives aren't able to care for him anymore” Well my son is difficult to take care of. So there's really no one, you know, to take care of”, “it's all hands on deck”, “Well, we don't have a whole lot of support in the area, so babysitters or people who can help out with the kids and when they're stressful situations are pretty well, nonexistent” “like my parents has been a huge, huge blessing with that they can, you know, they're still physically they've been a big help with that and support to help me” “so occasionally I'll get some comments especially from, you know, to a lesser extent my grandmother and my mom, but my sister in law has her own opinions about how I do things that I can, you know, cause some strife. But my husband is very supportive of me”
	Effect on other children and family members	The emotional strain put on caregivers to give their attention or time to other members of the family	“I'm worried about my boys, you know, nobody being there for them and my, my younger two, you know, not getting as much

			attention because you know, I'm focused on her" "our youngest would love to go to Disney. I can't do that with my son" "my youngest is something she would love to do, and I've never done that with her. So, I kind of kind of like mom guilt, I guess. And I guess it can be stressful thinking, Man, you know, I would love to do this for her" "it is really hard for my whole family" "she's unpredictable and it can be embarrassing for them"
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Discussion

We identified three overarching themes: daily life, selfcare, and caregiving. In this research, we found specific ways caregivers of CSHCN implemented self-care into their lives. We also found barriers they face to implementing selfcare and what they believe would help them overcome those barriers. Key barriers many caregivers expressed were: “no time” or “no energy”. Past research has shown that sleeping 7-9 hours a night is essential to having adequate amount of energy (“Taking Care of Yourself”, 2019). Many participants stated that sleep was one area they lacked and likely do not get enough of. This could be a major factor in their lack of energy, which leads to not implementing selfcare, so the cycle continues. Seeing that two prominent barriers that emerged for caregivers were time and energy, it narrows down possible selfcare measures to suggest. For example, suggesting they take a 15 to 30-minute nap would not be helpful because even if it helps with the energy aspect, most of the caregivers would most likely say they do not have the time. Since we know these are both barriers, we can begin to find solutions that are attainable for the caregivers.

Obtaining support from others is another method selfcare could be implemented. One of the subthemes we identified was support, specifically lack of support. Past research has shown that support or joining support groups can help lighten caregivers stress load (Doig, McClennan, & Urichuk, 2008; Fedele, et al., 2014; McNally, et al., 1999; Rosen-Reynoso, et al., 2016; Toomey et al., 2013). However, with time being a challenge that many of the caregivers identified, most of them would likely say they do not have the time to go to a support group. Having an online support group that caregivers could access whenever they wanted to would be one way this could be combatted.

Those who stated one of their ways of selfcare is exercise, also said they have mood improvements after they exercise. These mood improvements not only affect themselves but everyone else around them, including their children. Previous research supports these findings, saying that setting specific goals can help, even if it is just going for a walk every day (“Practical Solutions for Caregiver Stress”, 2018). This shows that practicing individual selfcare cannot only enhance one’s own life but the lives of others as well.

We did not analyze how well one particular intervention worked but used a thematic analysis to look at individual approaches to selfcare. The adjustment for caregivers of CSNCN is different for everyone, some parents will adapt, where others will have on-going distress (Bradshaw, 2019). In this study, we interviewed caregivers in all stages of adjustment, some did not have full diagnosis yet. In these instance caregivers wanted to know what was wrong with their child, which likely led to increased stress and anxiety.

Implications

There are still many things to discover about CSNCN. Future researchers have many routes to explore because of the lack of current research. For example, to find out a selfcare measure that could be widely used and effective should be explored in the future. This research has shown where caregivers need help to achieve selfcare. Researchers should explore methods for aiding caregivers to overcome their barriers to selfcare. This population is very focused on caring for their children, they often do not try to take time for themselves. It is critical to show caregivers how important it is to implement selfcare into their daily lives. Additionally, caregivers should be shown how selfcare activities can improve their moods and psychological states and their physical well-being.

One limitation of the study was that the sample size was 11 participants. To get a wider range of experiences, there should be a larger sample of caregivers. In addition, these were people who live around the Tallahassee, FL area. Responses may differ depending on culture and where people are located. Selfcare measures are often unique to the individual, most people have a specific way they chose to practice selfcare. Overall, selfcare measures often reduce stress and anxiety. However, some caregivers do not have any way they practice selfcare and may not know how. For these instances, it would be ideal to have a uniform method for caregivers to implement selfcare into their daily lives that is proven to be effective.

There is some research that has been done about specific interventions, such as mindfulness-based interventions. In these studies, the participants are asked to implement a certain intervention into their lives for a specific amount of time. After the time is up the participants re-take whatever assessments were giving to them previous to the intervention. In these studies, often the results do not last through follow ups that are months later, especially if caregivers stop practicing techniques after completion of the study. The qualitative nature of this study allowed us to discover how they chose to implement selfcare and the specific barriers caregivers had to implementing selfcare. This gives a basis on what interventions may be most helpful for them.

Conclusion

This study can help guide future research on informal caregivers of CSHCN. Currently, this population is not widely studied, we have shown that there is much more to be learned. The burden that informal caregivers experience cannot only be harmful to themselves and can negatively affect those around them . Selfcare can attenuate these effects and it is important for informal caregivers to realize the importance of selfcare and how they can best achieve it. Stress

can lead to multiple physiological conditions; therefore, it is important to be aware of your own stress and combat it. The major themes of this thesis were daily life, selfcare, and caregiving. These themes break down into specific subthemes that focus on aspects of the daily lives and selfcare measures of the caregivers. These are all areas which can be looked in to further to expand our knowledge and find ways to best help caregivers of children with special healthcare needs.

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