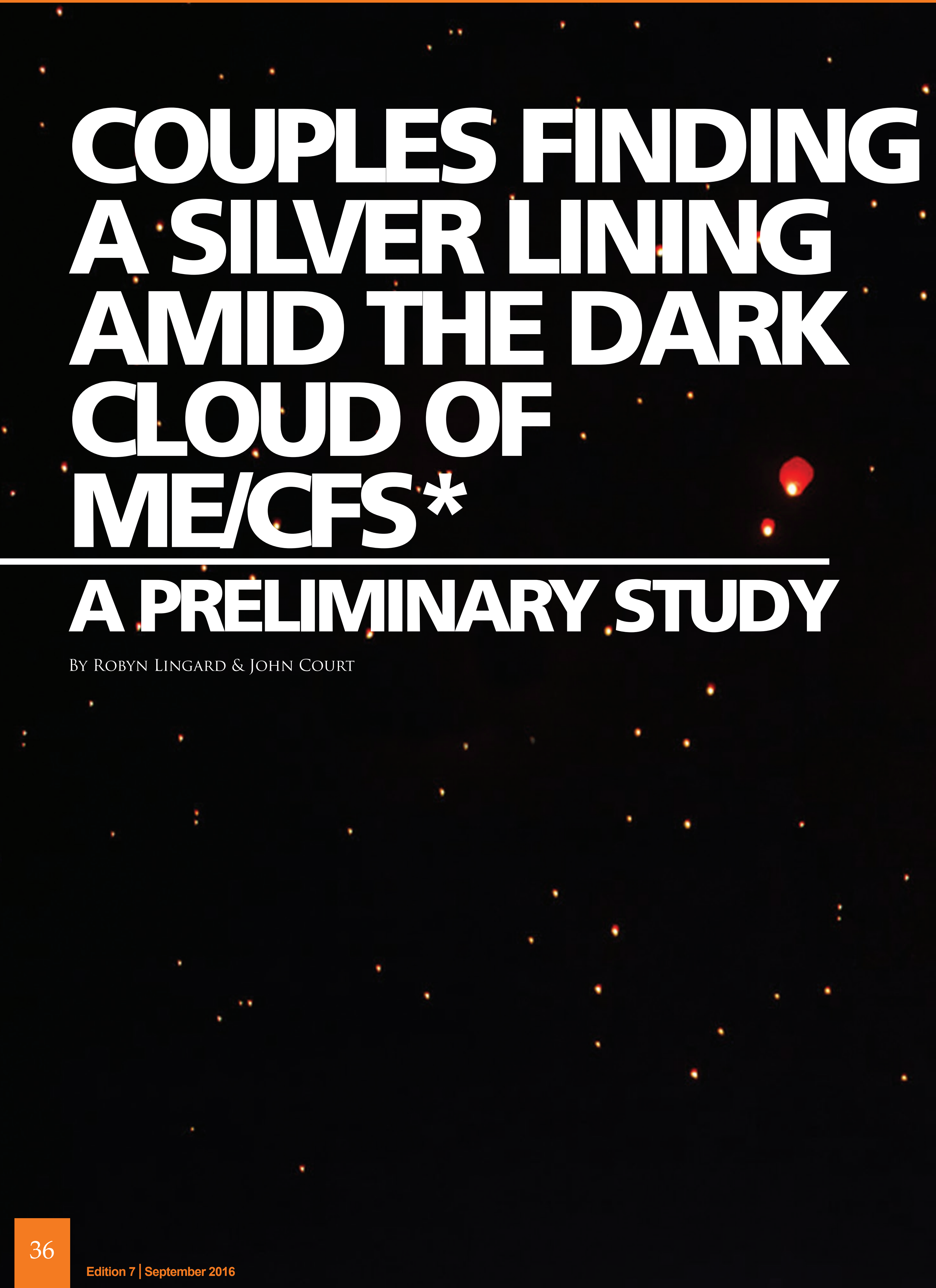

COUPLES FINDING A SILVER LINING AMID THE DARK CLOUD OF ME/CFS*

A PRELIMINARY STUDY

By Robyn Lingard & John Court

ABSTRACT

Sustaining a long-term committed couple relationship is often challenging. When the dark cloud of chronic illness descends upon a couple, remaining together can become even more daunting – or so it is commonly assumed. Current literature is highlighting a silver lining phenomenon known as positive reframing or benefit-finding as a reaction to the dark cloud of chronic illness. These studies focus upon the experience of the individual yet little research has been conducted into the experience of couple relationships.

A preliminary study was conducted to research whether some couples experience an unexpected positivity when one partner has Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome. ME/CFS is a debilitating and mysterious disease of the immune, endocrine and central nervous systems. Positivity was measured by the Silver Lining Questionnaire for Couples (SLQFC) and explored further in an interview. Understanding how some couples experience this phenomenon can build resilient relationships and reduce the severity of symptoms for sufferers. The contribution of Christian faith in the lives of couples was also explored.

CASE STUDY

Sam and Ursula were drawn together through their shared Christian faith, interest in fitness, and passion for competitive sport. They expected their married life would involve continuing these interests and commencing overseas travel. However soon into their marriage, Sam underwent shoulder surgery to repair a sporting injury… and contracted ME/CFS. When beginning couples therapy, Sam had experienced five years of debilitating fatigue, headaches, and muscular pain. Instead of working out at the gym together, they now found themselves spending endless weekends watching DVDs. Their only travel together was an occasional trip to the supermarket and to medical appointments. As Christian counsellors, how may we assist couples such as Sam and Ursula grieving over their lost dreams and struggling to maintain their marriage and Christian faith amid the harsh reality of this debilitating and mysterious chronic illness?

INTRODUCTION

When chronic illness enters the life of the sufferer, its impact can be far reaching. Not only must sufferers live with the distress of their symptoms, they must adjust to unwelcome and unexpected lifestyle changes. For those sufferers in marriages, the arrival of a chronic disease often exacerbates unresolved issues in their relationship and brings them into contact with widely held societal pessimism regarding the impact of illness upon couple relationships. When sharing information about lifestyle adjustment to chronic illness, family, friends, health professionals, and illness support groups can unintentionally leave the couple feeling that there is little hope for the survival of their relationship.

On the other hand, the couple may also hear about a "superstar" couple whose description may tend toward the superhuman and epic. These accounts may provide a refreshing relief for struggling patients and couples, but seem so unreachable that they leave the average couple with little hope and confidence. These couples may believe they do not measure up to the exceptional ones and are more similar to the pathologically distressed couples. Rolland states that these contrasting experiences leave couples with a view of healthy adaptation that is "rarely achieved and perpetuates self-judgments of deficient performance, infused with blame, shame, and guilt. The inspirations of the exceptional and the warning signs of dysfunction need to be grounded by descriptions of typical experiences" (Walsh 2012, p 454).

In the light of these experiences, a pilot study was conducted regarding the journeys of couples who live with ME/CFS. The central hypothesis of this study was that there is a silver lining located within the stormy experience of couple relationships with CFS/ME. It also investigated the presence of common strategies used by these couples that can assist other marriages and partnerships. To this end, the Silver Lining Questionnaire (SLQ) which has already been utilized for similar purposes was selected and adapted for the present purpose (Sodergren & Hyland, 2000). The adapted tool was called the Silver Lining Questionnaire for Couples (SLQFC).

WHAT IS ME/CFS?

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a severe and debilitating illness that has no known cure, limited treatment, and little understanding among the medical and general community. The illness was first labelled as Myalgic Encephalomyelitis by the World Health Organisation in 1969 and renamed Chronic Fatigue Syndrome in 1994. Today the two terms are used (Carruthers et al., 2003). ME/CFS is a significant health problem that affects approx. 0.23% to 2.6% of the adult population depending upon which definition is used (White et al., 2011).

Symptoms include fatigue, pain, sleep disturbance, muscle aches, post–exertional malaise, and various neurological symptoms such as hypersensitivity to noise, short-term memory impairment, and impairment of information processing. Sufferers feel worse after exercise and usually require 24 hours or longer to recover. Diagnosis requires more than a 50% reduction of a patient's previous activity level (McCleary, 2011). ME/CFS typically requires a life time of adaptation to significant physical, social, psychological, and environmental changes in a manner similar to other chronic diseases such as multiple sclerosis, lupus, rheumatoid arthritis, heart disease (Nichols & Hunt, 2011). Medical treatments such as antidepressants sometimes help increase quality of sleep and relieve muscular pain. Counselling can assist sufferers and their families to learn stress management techniques (Lattie et al., 2013).

IMPACT UPON COUPLES

When ME/CFS strikes, both individual sufferers and their partners experience significant distress. A combination of no cure, delayed diagnosis, limited treatment, ongoing symptoms, lack of visible symptoms, medical scepticism, and uncertainty regarding diagnosis and prognosis is a challenge for any relationship. Social isolation and financial pressures follow from a decrease or withdrawal from employment. Major changes in roles impact the couple relationship as the well partner juggles full-time bread winning, household management, and increased care for any children. Pleasurable activities such as hobbies and sport are reduced. Sexual desire for the sufferer and at times the healthy partner is disrupted (Blasquez et al., 2008). It can also lead to a deep questioning of one's faith and even misjudgement and ostracism from well-intentioned but misguided fellow Christians (Lingard 2012, p. 73).

While there is limited research into the rates of divorce amongst couples with chronic illness, anecdotal reports indicate a higher than average rate of relationship breakdown. Typically the arrival of a chronic disease intensifies unresolved couple issues and introduces new stresses (Sperry, 2011). One poll amongst fibromyalgia sufferers found that more than a quarter of respondents said that their illness ended their relationship, and half of respondents indicated that the illness caused more marital strain than marital strengthening (Dellwoo, 2009). These results are consistent with statistics into other chronic illness groups. It is estimated 75% of marriages with a chronically unwell partner end in divorce compared to approximately 50% of marriages in general (Nakazawa, 2009).

A couple's approach to managing ME/ CFS

The literature regarding the management of ME/CFS mainly adopts an individual approach that focuses upon the sufferer with comparatively little emphasis on the couple relationship. This pattern is consistent with the medical community's approach to other chronic illnesses despite the well documented evidence that positive spouse support reduces symptom severity in sufferers. Susan MacDaniel from the University of Rochester states, "The medical community often neglects to help couples metabolize the toll that chronic illness takes on a marriage, even though we know that how well a husband and wife cope together has a direct impact on how well a patient will heal" (Nakazawa, 2009, p.7).

The few existing studies about ME/CFS and couple relationships suggest a stronger couple relationship reduces psychological distress in both partners which has the flow-on effect of lessening physical symptoms (Goodwin, 1997; Ax et al., 2002).

EXPLORING AN UNEXPECTED OUTCOME – POSITIVITY

While illness is commonly viewed as a purely negative experience, the literature regarding coping with chronic illness mentions a serendipitous phenomenon called positive reframing or benefit-finding as a response to chronic illness (Flasher et al., 2001). In other words, there can be a silver lining within the dark cloud of chronic illness. Chronic illnesses such as stroke, lupus, respiratory failure, and cancer can yield an unexpected silver lining for some individuals despite the dark cloud of profound disruption to their normal life (Gillen, 2005; McBride et al., 2008). Some reports of positivity in illness were reported in about 95% of patients with respiratory complaints such as asthma and chronic respiratory disease (Sodergren et al., 2004).

While positivity is highly varied amongst sufferers of ME/CFS, the experience of positivity is more common than typically assumed. Positivity is found to decrease mental fatigue but not physical fatigue and is more evident in those with spiritual/religious beliefs, openness to new experiences, and extraversion (Hyland et al., 2006). Participants report personal development through redefinition of priorities, self-improvement, greater appreciation of life, deepening spirituality, and an opportunity to become more like their ideal self (Sodergren & Hyland, 2000; Sodergren et al., 2002). Increased happiness during or after their illness can occur due to a greater awareness of being loved by their family.

Limited mention is made in the literature regarding the presence of benefit-finding amongst couples with ME/CFS. Benefits cited were the opportunity to develop a more resilient relationship and increased time to be together, which correlated with their reason for commencing the couple relationship (Ax et al., 2002). Christian faith and strong marital friendship have been mentioned as strengthening factors for relationships (Goodwin, 2000).

Method & Results

The present study had two stages. First, 15 couples completed the Silver Living Questionnaire for Couples (SLQFC) and then five of these couples were interviewed. While there was conceptual overlap between the SLQFC categories, each category aimed to gather information about the impact of the illness upon the quality of the couple relationship. The interviews aimed to identify common strategies that yielded this benefit-finding phenomenon. For further explanation of method and results, please see Appendix.

Discussion

The SLQFC and interviews provided an understanding of the strengthening factors in couple relationships where one partner has ME/CFS. Broadly speaking, the scores were consistent with the existing literature that indicates considerable distress experienced by couples with ME/CFS. The scores are also consistent with the benefit-finding literature that indicates the presence of some positive outcomes from chronic illness. The qualitative data from the five interviews was interpreted according to the ten headings based on content analysis of the SLQFC.

The strengthening factors in order of importance were:

Spiritual Gains

The highest category identified within the SLQFC was a deepening of Spirituality. While participants were drawn from both general and Christian communities, each interviewed couple expressed their belief within a Christian faith based framework.

Male Sufferer: "We really involve God in our marriage and ask Him to remind us of the things that we need so that we can have the best marriage possible…"

During their experience of ME/CFS, interviewed couples stated that God had enabled them to positively reframe their many losses concerning health, finances, social and career opportunities and instead they had grasped a deeper meaning to life. Their faith helped them to reprioritize many of their values including their marriages and children, and to let go of seemingly less significant goals such as a tidy home and a busy social life. Their faith also helped them to develop values and character qualities such as hope, courage, patience, forgiveness, and compassion that strengthened their commitment to each other.

Couples identified a variety of strategies that developed their spirituality. One couple spoke about drawing inspiration from the model of Jesus to forgive their partner during times of conflict and chaos. They spoke about Jesus who, in His suffering, demonstrated unconditional forgiveness and compassion for His enemies irrespective of whether they deserved His mercy. Three couples described a willingness to talk about their problems with other Christians and/or helping professionals who had travelled similar paths of suffering with illness.

Greater Couple Resilience

Each couple expressed an awareness of their increased shared strength and determination to meet current and future challenges. They cited various strategies that helped them to build the resilience of their marriage such as laughing together, being committed to talking as friends not arguing about issues, and drawing inspiration from their wedding vows.

Greater Fondness & Admiration for each other

Each couple spoke of developing increased affection, respect and positive regard for one another because of the challenges of ME/CFS. The illness led to the discovery of new and deepening of known positive attributes in each other.

Male Spouse: "in the midst of the struggles with the symptoms and the medical appointments and the drugs and the regime and the lack of mobility and the pain, she has a really acute sense of other people that helps keep things in balance …this part of her I have always appreciated and appreciate even more".

Increased appreciation for Couple Relationship

Each couple interviewed expressed a greater appreciation and gratitude for their marriage because of the distress created by ME/CFS. One reason for this increased appreciation was that some couples felt that they needed each other's combined strength to endure the hardships.

Female Spouse: "We simply needed each other to get through"

Reappraisal of Relationship

Couples described how the impact of the illness led them to re-examine their relationship.

Male Spouse: "My commitment to her is literally through illness and health ….she has stuck by me through my ups and downs and it's no real burden to stick with her."

Discovering new Couple Relationship Strengths

Couples frequently reported new strengths that had developed because of the demands of the illness.

Female Spouse said: "After I helped you work through college, we kept working as a team. You share more housework; we have a routine going where we help each other."

More Sensitivity to Emotions of Self & Partner

Couples frequently commented that they are now more in touch with how their spouse's emotions because of their combined battle with the ME/CFS.

Female Spouse: "He was so driven and could work 80 hours/week. I hardly ever saw him. One nice thing about the CFS is that he has changed from being so task focused to more people focused, including me."

Confrontation of Current Concerns

Couples were frequently proactive about addressing problems within their marriage created by the ME/CFS in order to maximize their quality of life.

Male sufferer: "We want to deal with challenges then and there so it doesn't become an issue."

If mobility was a problem, it was time to buy a motorized scooter. If fatigue was limiting sexual intimacy, it was time to reprioritize energy expended on other activities to save energy for making love. While the ME/CFS was an ongoing perpetual problem largely beyond their control, the couples were proactive in controlling what they could control.

Self-improvement

Each couple identified varying aspects of personal growth, such as becoming less self-focused, more confident in making decisions, being more patient and compassionate for others. Self-improvement not only benefitted the individual but also the marriage. For example, one male partner had assumed more decision making responsibilities for their marriage, which resulted in him becoming an advocate and protector of his sick wife.

Improved Relationships with other People

This category contained the greatest variation in participant experiences. Most couples described increased social isolation and gave examples of friends and family not understanding. Those who reported positivity in this category mainly referred to family supports, such as parents or adult children.

Other results

Each couple spoke with energy and pleasure about joint hobbies and entertainment. Sometimes these activities had continued from their pre-ME/CFS life and were adjusted to accommodate the health constraints, such as sitting in the car by the beach as opposed to walking along the beach, and holidaying via cruises as opposed to international travel tours. Couples also spoke of developing new hobbies which could be enjoyed as a couple. One couple had begun collecting "The Beatles" memorabilia. The sufferer from another couple learned to play his teenager's video games which was a source of entertainment and laughter for them as a couple and their children.

While simply acquiring mutually enjoyable hobbies alone does not keep couples together, such joint activities do enable couples to enjoy each other's company and build their friendships. This ability to maintain the couple friendship is the most important ingredient in strengthening marriages (Gottman & Silver 1999). Each interviewed couple in the present study demonstrated a liking for each other and an ability to find enjoyment in each other's company. This tendency indicated their strong marital friendships.

LIMITATIONS OF THE STUDY

While the present study contributes to a greater understanding of coping strategies for couples managing ME/CFS, it does contain limitations. Future research could address a wider pool of participants and test the psychometric properties of the SLQFC since such tasks were beyond the scope of this research project.

IMPLICATIONS OF THE STUDY

This study can assist sufferers, their partners, health professionals, the church, and the wider community since it disputes the prevailing negative stereotype surrounding the impact of chronic illness upon couples. Instead, it provides some reassurance, hope and specific strategies regarding couples relationships surviving and strengthening amid chronic illness.

The study confirms that ME/CFS impacts not only the sufferer but also the partner. This illness is not a solo but a shared experience. Since partner support reduces severity of symptoms, an important but rarely considered avenue for treatment is to assist the sufferer with their couple relationship.

Since completing this research project in 2013, I (Robyn) have established my own private practice in Adelaide’s north east, where I am privileged to work with couples and individuals living with ME/CFS. These research findings have flowed into areas beyond ME/CFS, such as other chronic illness, mental illness, and grief; more broadly speaking, wherever clients face unwelcome and uninvited challenges in their lives.

This research project continues to inform a number of my therapeutic interventions, such as listening out for experiences of positivity expressed by unwell clients. I have noticed that such gains are usually only mentioned in passing, yet when explored more deeply, do build resilience. For clients with a Christian faith, this phenomenon helps them to experience the presence of Jesus in their life as the good Shepherd who has not abandoned them but is at work within their suffering to build their faith, character, and marriage. As written in the book of James chapter 1, trials can build faith since they require us to reach out to God for wisdom and to practise perseverance. Such concepts have assisted couples, such as Sam and Ursula, to gain a more positive perspective of their relationship and the journey upon which their illness has taken them.

Assisting clients to examine their assumptive world has also been important, namely that “young people don’t become sick”, “marriage shouldn’t have to be this hard”, “illness means our relationship will end”, and “my illness is robbing me of any quality of life”. Helping individuals and couples to use accurate, kind, helpful, and balanced thoughts assists stepping outside of despair and grief that is triggered by faulty core beliefs about how the world should be as opposed to how the world is. Illness and death are part of life and enters the life of the” deserving” and “undeserving”. Accepting this reality frees us to place our energy into flourishing in our current circumstance. Jesus reassured the disciples on the eve of His crucifixion, “In this world, you will have trouble. But take heart. I have overcome the world” (John 16:33). In seeking counselling, clients often hope for a fresh perspective on a long-term trouble. Looking for a silver lining is one way of “overcoming the world” since it builds hope and courage. As counsellors, may we also take heart as we journey with our clients and face our own fears amid the dark clouds that arise in a fallen world.

CONCLUSION

The present study contributes to four little-explored areas of research into living with ME/CFS. An existing measurement tool has been adapted from an individual to a couple focus. The positive couple experiences of sufferers and their spouses have been identified. The role of spirituality in strengthening couple relationships has been noted. Relationships where the sufferers are predominately male have been considered.

The keys to strengthening couple relationships with ME/CFS form an important area of research in order to understand how best to manage this chronic illness. The significant challenges associated with living with ME/CFS can erode the quality of the couple relationship. However stable and supportive couple relationships may decrease the severity of symptoms and provide an important source of support for sufferers. The five couples who completed the SLQFC and interview were not “superstars” but everyday people who described how together they endured their mutual distress. Their experiences of positivity in their marriages may provide an important source of information for other couples who seek to find a silver lining amidst the dark cloud of chronic illnesses, such as ME/CFS.

References

Ax, S., Gregg, V. & Jones, D. (2002). Caring for a relative with chronic fatigue syndrome: difficulties, cognition and acceptance over time. *The Journal of the Royal Society for the Promotion of Health*, March, 122, 35 – 42. doi: 10.1177/146642400212200113

Blazquez, A., Ruiz, E., Vazquez, A., Fernandez de Sevilla, T., Garcia-Quintana, A., Garcia-Quintana, J. & Alegre, J. (2008). Sexual dysfunction as related to severity of fatigue in women with CFS. *Journal of Sex & Marital Therapy*, *34*, 240-247. doi: 10.1080/00926230701866232

Carruthers, B., Jain, A., De Meirleir, K., Peterson, D., Klimas, N., Lerner, A., Bested, A., Flor-Henry, P., Joshi, P., Powles, A. & Sherkey, J. (2003). Myalgic encephalomyelitis/chronic fatigue syndrome: clinical working case definition, diagnostic and treatment Protocols. *Journal of Chronic Fatigue Syndrome*, *11*, 7-116.

Dellwoo, A. (2009). “Fibromyalgia, chronic fatigue syndrome and quality of marriage”, *Fibromyalgia & CFS Blog*.

Flasher, L. Cacciapaglia, H., & Nelson, S. (2001). The psychological impact of cancer and lupus: a cross validation study that extends the generality of “benefit finding” in patients with chronic disease. *Journal of Behavioural Medicine*, 24, 561-571. doi: 10.1023/A:1012939310459

Gillen, G. (2005). Brief Report - The positive consequences of surviving a stroke. *The American Journal of Occupational Therapy, 59*, 346-357.

Goodwin, S.S. (1997). The marital relationship & health in women with chronic fatigue and immune dysfunction syndrome: views of wives and husbands. *Nursing Research, 46,* 138-146. doi: 10.1097/00006199-199705000-00004

Goodwin, S.S. (2000). Couple’s perception of wives’ CFS symptoms, symptom change, and impact on the marital relationship. *Issues in Mental Health Nursing*, *21*, 347-363. doi: 10.1080/016128400247979

Gottman, J.M. & Silver, N. (1999). The Seven Principles for Making Marriage Work. Weidenfeld & Nicolson, London.

Hyland, M., Sodergren, S. & Lewith, G. (2006).The role of positivity to illness in chronic fatigue syndrome patients. Journal of Health Psychology, 11, 731- 74. doi: 10.1177/1359105306066628

Lattie, E., Antoni, M., Fletcher, M., Czaja, S., Perdomo, D., Sala, A., Nair, S., Fu, S., Penedo, F., & Klimas, N. (2013). Beyond Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) symptom severity: stress management skills are related to lower illness burden. doi: 10.1080/21641846.2013.843255

Lingard, R.J. (2012), Strengthening factors in couple relationships with Myalgic encephalomyelitis/chronic fatigue syndrome, Master's Thesis, Tabor College Library, Adelaide.

Lingard, R.J. & Court, J. (2014). Can couples find a silver lining amid the dark cloud of ME/CFS: a pilot study. The Family Journal: Counselling and Therapy for Couples and Families, 22, 3, 304-310. doi: 10.1177/1066480714533652 2014 22: 304

McBride O., Dunwoody, L., Lowe-Strong, A., & Kennedy, S. (2008). Examining adversarial growth in illness: the factor structure of the silver lining questionnaire (SLQ-38). Psychology & Health, 23, 661- 678. doi: 10.1080/08870440802108900

McCleary, K.K. (2011). International Consensus criteria published for Myalgic encephalomyelitis. Talking Point: Official Journal of ME/CFS Australia (SA) Inc 3, 7-9.

Nakazawa, D.J.(2009). "How a marriage survives when one partner gets sick", 1-9, from <http://www.more.com/2024/7563-how-a-marriage-survives-when-one-partner-gets-sick>.

"New study finds high prevalence of chronic fatigue syndrome" (2004). CFIDS Association of America e-newsletter, 13. <http://www.cfids.org/cfidslink/ncid-focus.asp>.

Nichols, L.M. & Hunt, B. (2011). The significance of spirituality for individuals with chronic illness: implications for mental health counseling, Journal of Mental Health Counseling. 33, 51-66.

Sodergren, S.C. & Hyland, M.E. (2000). What are the positive consequences of illness? Psychology & Health, 15, 85-97. doi:10.1080/08870440008400290

Sodergren, S.C., Hyland, M.E., Singh, S.J. & Sewell, L. (2002). The effects of rehabilitation of positive interpretations of illness. Psychology and Health, 17, 753-760. doi: 10.1080/0887044021000009674

Sodergren, S.C., Hyland, M.E., Crawford, A. & Partridge, M.R. (2004). Positivity in illness: self-delusion or existential growth? British Journal of Health Psychology, 9, 163-174. doi: 10.1348/135910704773891023

Sperry, L. (2012). Recognizing family dynamics in the treatment of Chronic Fatigue Syndrome. The Family Journal, 20, 79-85. doi: 10.1177/1066480711429426

Walsh, F. (2012). Normal Family processes 4th edn, New York: Guildford Press.

White, D., Goldsmith, K., Johnson, A., Potts, L., Walwyn, R., DeCesare, J., Baber, H., Burgess, M., Clark, L., Cox, D., Bavinton, J. Angus, B., Murphy, G., Murphy, M., O'Dowd, H., Wilks, D., McCrone, P., Chalder, T., & Sharpe, M. (2011). Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial. The Lancet, 377, 823-836. doi: 10.1016/S0140-6736(11)60096-2

APPENDIX

Method

Given the emotional and physical benefits to sufferers of various chronic illnesses when experiencing a supportive couple relationship, a study was conducted to determine whether positivity is experienced amongst ME/CFS sufferers. If so, the study aimed to identify those strategies that strengthened their couple relationship.

The present study had two stages. The Silver Lining Questionnaire for Couples was administered and selected respondents were contacted for a semi-structured interview.

1. SILVER LINING QUESTIONNAIRE FOR COUPLES

The Silver Lining Questionnaire (SLQ) is a published questionnaire developed to measure the phenomena of benefits finding amongst individual sufferers of chronic illness. The Silver Lining Questionnaire for Couples (SLQFC) is an adapted version of the Silver Lining Questionnaire (SLQ). Permission to adapt was granted by Hyland to focus specifically upon how chronic illness influences the couple relationship. Various scales that measure satisfaction within the marital relationship were considered. The SLQ was selected because it measured positivity in chronic illness, had been used amongst individual sufferers of ME/CFS and could be adapted from an individual focus to a couple relationship focus (Hyland et al., 2006). The SLQFC can be obtained from the first author.

Minimal changes were made to the SLQ items. The main adaptations involved reframing the questions from an individual focus about various aspects of life to a couple focus primarily about their relationship. This research project has rearranged an existing questionnaire and adapted it to a new purpose.

SLQFC Recruitment

Canvassing for participants was conducted through a collection of professional agencies, medical practices, and personal contacts. The criteria for participation were that participants were in a long-term committed couple relationship such as marriage or defacto partnership, both partners completed the questionnaire, one partner had ME/CFS, and their diagnosis had been made by a medical practitioner. At this stage, there was no reference to positivity but a general cohort was sought. Questionnaires were either emailed or sent via post depending upon the preference of the participants.

SLQFC Scoring

The SLQFC contains a Likert scale which gauges positivity to adversity responses according to "strongly agree" (2), "agree" (1), "unsure" (0), "disagree" (-1), and "strongly disagree" (-2).

SLQFC Analysis

Classifying the SLQFC data involved allocating the 38 items according to various headings or aspects of positivity within illness. The construction of the headings was based on SLQ headings, resiliency literature, John Gottman's couple relationship research, and my own analysis (Gottman & Silver, 1999). The SLQFC data was classified using ten headings in order to maintain similarity to the SLQ analysis. Changes were made to several of the SLQ headings although six out of ten SLQ headings were used with only minor adaptations.

The SLQFC categories are: Increased Appreciation for Couple Relationship, Greater Fondness & Admiration for Each Other, Self-improvement, Discovering New Couple Relationship Strengths, Greater Couple Resilience, Reappraisal of Relationship, Spiritual Gains, Confrontation of Current Concerns, More Sensitivity to Emotions of Self and Partner, and Improved Relationships with Other People.

2. SEMI-STRUCTURED INTERVIEW

The second stage of the study involved conducting semi-structured interviews. The key selection criteria were positivity about the influence of ME/CFS upon their couple relationship as demonstrated in the SLQFC, together with accessibility since some participants were too unwell to be interviewed.

Interviews ranged in duration from one to one and a quarter hours, with each couple choosing to be interviewed together. Two interviews were conducted in the participants' homes, two at the researcher's premises, and one via telephone as the participants lived interstate. All interviews were audio recorded with the permission of the participants.

After beginning with questions about illness history and the impact upon both sufferer and partner, the interview then proceeded to include the following exploration: What has ME/CFS meant to your marriage? How have you maintained your marriage amidst the challenges of the illness? What, if any, new qualities or surprises have you noticed in each other since the illness began? How do you cope as a couple with any seemingly unresolvable problems created by the illness? How have you as a couple tried to maintain a lighter side of life despite the challenges of the illness?

Analysis of interview data

Each interview was transcribed verbatim and analysed for couple statements about the influence of the illness upon their relationship. Statements were drawn from each of the five interviewed couples and included reflections from both sufferer and partner. The research focus was upon statements made about the relationships, with less attention given to individual reflections or experiences with other relationships, such as their children. These excerpts from the transcripts were categorized according to the most appropriate SLQFC heading.

In summary, while some adaptations have been made to the Silver Lining Questionnaire, the Silver Lining Questionnaire for Couples maintained the same structure and emphasis upon positivity within the context of chronic illness. The SLQFC aimed to locate couples experiencing positivity in their relationship, and semi-structured interviews were conducted to identify common strategies that yielded this benefit-finding phenomena.

RESULTS & DISCUSSION

Participants

In the study, 15 out of 19 married couples approached returned their SLQFC (79% return rate). Male sufferers comprised 60% of respondents in this study whereas they account for only 22% of sufferers of ME/CFS (New study finds high prevalence of chronic fatigue syndrome 2004). Existing studies typically have focused upon the experience of the female sufferer or have a higher proportion of female participants, for example Blasquez et al., 2008.

Is there any silver lining for couples with ME/CFS?

Positivity was measured for each couple who completed the SLQFC. Nine out of the 15 couples (60%) indicated positivity since their scores were higher than zero. The average score of all the couples was +13.3 out of a possible +152 points, indicating that on average couples did experience some positive influence of the illness upon their couple relationships. Sufferers' scores ranged between +46 and -61. Partners' scored ranged between +58 and -37.

How did couples obtain this silver lining?

An analysis of the SLQFC was then considered and this report analyses results from the five couples selected for interview. The average SLQFC gains indicated by the five couples were totalled to identify which factors were most significant in strengthening their relationship. Possible scores ranged between +2 to -2 for each item, with actual scores between +0.3 and +1.00. Broadly speaking, "Spiritual Gains" was the heading that scored the highest result. The Spiritual Gain factor stood out as most significant, while Improved Relationships with Other People factor scored the lowest result.

** A previous version of this paper first appeared in the July 2014 edition of The Family Journal: Counseling and Therapy for Couples and Families doi: 10.1177/1066480714533652 2014 22: 304*

It can also be found in SAGE Journals http://tfj.sagepub.com/content/22/3/304

Robyn Lingard: After completing a Bachelor of Social Work at University of Queensland, Robyn worked with Campus Crusade for Christ as a youth worker at Universities of Queensland and Sydney 1989-1995. Robyn worked as a school social worker at Tyndale Christian school 1998-2006. In 2008-2010, Robyn undertook her Master's counselling practicum and internship training at Tabor Adelaide, in a psychologist's private practice, and as a cross-cultural counsellor for Indian and Chinese adult students. Robyn commenced her own practice in 2010, consulting 3 days/week and is also actively involved in the SA Branch of the AASW.