Author/s:
Dolgoy, ND;Krishnasamy, M;McNeely, ML

Title:
Uncertainty and sense-of-self as targets for intervention for cancer-related fatigue

Date:
2019-07-01

Citation:
Dolgoy, N. D., Krishnasamy, M. & McNeely, M. L. (2019). Uncertainty and sense-of-self as targets for intervention for cancer-related fatigue. European Journal of Cancer Care, 28 (4), https://doi.org/10.1111/ecc.13048.

Persistent Link:
https://hdl.handle.net/11343/285753

Uncertainty and Sense-of-Self as Targets for Intervention for Cancer Related Fatigue

Naomi D. Dolgoy, MOT, PhD Candidate, University of Alberta, Primary Author/Researcher

250 Corbett Hall University of Alberta Edmonton Alberta Canada T6G 2G4

Telephone: 780-492-6007

Correspondence: dolgoy@ualberta.ca

Mei Krishnasamy, BA, RGN, Dip N, MSc, PhD, Professor, Department of Nursing, University of Melbourne and Victorian Comprehensive Cancer Centre, Melbourne Author/Researcher

University of Melbourne, 305 Grattan Street, Parkville, Victoria, Australia, 3000

Margaret L. McNeely, PT, PhD, Associate Professor, University of Alberta and Cross Cancer Institute

250 Corbett Hall University of Alberta Edmonton Alberta Canada T6G 2G4

This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1111/ECC.13048

Disclosure: The authors have no disclosures nor any potential sources of conflict of interest, financial or otherwise, to claim or declare.

Ethical Approval Statement: This ”real world” study was deemed to be research of negligible risk, using non-identifiable data, and was exempt from a need for further ethical review.

The study was carried out with the permission of cancer centre and rehabilitation clinic managers and the support group lead. No member of the study team approached any contributor, and data collection relied solely on individuals' interest in contributing to, or motivation to provide, descriptors of Cancer Related Fatigue.

MS. NAOMI DANIELE DOLGOY (Orcid ID : 0000-0001-5699-2844)

Article type : Original Article

ABSTRACT

Background. Cancer related fatigue (CRF) can be a devastating consequence of cancer and cancer treatments, negatively impacting 50-90% of cancer patients regardless of age, sex, or diagnosis. Limited evidence and research exists to inform effective patient-centred interventions. To target symptom management, there must first be a broader understanding of the symptoms and the lived experience of the persons experiencing CRF and those caring for them, from a supportive as well as a healthcare perspective. **Objective**. This study set out to consider whether components of the language used or descriptors reported by patients, family members, or healthcare professionals, may provide new insights for potential targets for intervention development. **Methods.** Descriptors from 84 responses (n=84) from cancer survivors, family members, and healthcare professionals, were analysed for content. **Findings.** The descriptors reiterate the physical, emotional and functional consequences of CRF, but also reflect two new potential targets for intervention to mitigate the impacts of CRF: uncertainty and sense-of-self.

Keywords: cancer, fatigue, survivorship, quality of life, rehabilitation

INTRODUCTION

Background/Rationale

Cancer related fatigue (CRF) can be a devastating consequence of cancer and cancer treatments, negatively impacting 50-90% of cancer patients regardless of age, sex, or diagnosis (Campos et al, 2011). CRF is defined as a subjective sense of tiredness that interferes with emotional, physical, functional, social, and existential domains of life (National Comprehensive Cancer Network [NCCN], 2018). Despite almost two decades of investment in the development of standardized screening tools,

assessment measures, and almost 500 published manuscripts on pharmacological and non-pharmacological interventions to minimize or ameliorate its impact on multidimensional domains of quality of life, robust evidence to inform effective patient-centred interventions for CRF remains limited (Pearson et al, 2016; Bower et al, 2014; Howell et al, 2013). Where evidence does exist, such as exercise or psycho-educational approaches, its translation to usual care has been sparse (Weis & Horneber, 2015; Berger et al, 2011).

Qualitative literature explores lived experiences. For cancer survivors managing CRF, qualitative research offers a lens through which to better understand the functional barriers, and the impact of CRF on participation in daily living. Individuals experiencing CRF often describe activities that were once manageable as being too difficult to complete. A systematic review of 154 qualitative research articles on CRF described dynamic differences between symptoms of tiredness versus fatigue, wherein participants reported their CRF symptoms were not eased by rest, and bore a heavy burden on their everyday lives (Scott et al, 2011).

Many of the uni- and multi-dimensional screening tools and assessment measures recommended for use in research and clinical settings, have been informed by qualitative studies where peoples' descriptions of living with CRF have influenced the choice of items and domains included (NCCN, 2013; Howell et al, 2013). Ways in which people describe experiencing or witnessing the impact of CRF such as, lack of energy, inability to concentrate, excessive sleepiness, or exacerbation of pain, nausea or depression in the presence of CRF, have influenced development of interventions, such as exercise, psycho-educational approaches, mindfulness, sleep, yoga, diet and symptom management (Minton et al, 2013; Barsevick et al, 2008).

Given the recognized impact of CRF on the emotional health and wellbeing of people affected by cancer, this study set out to consider whether components of the language used or descriptors reported by patients, family members, or healthcare professionals, may provide new insights for potential targets for intervention development. To target symptom management, there must first be a broader understanding of the symptoms and the lived experience of the persons experiencing CRF and those caring for them, from a supportive as well as a healthcare perspective.

As such, this "real world" study was undertaken to collect spontaneous descriptors of CRF which may offer new insight or perspective with which to develop patient-centred, multidisciplinary CRF rehabilitative interventions.

Aim/Objective

This study set out to explore how people affected by cancer (patients, family friends and health care professionals) spontaneously describe the nature and impact of CRF, in order to consider opportunity for novel targets for intervention.

Context: This study was undertaken across two cancer centres, a cancer rehabilitation clinic, and a community support group environment in Melbourne, Australia during February-April 2017. People participated from ambulatory clinics, wellbeing centres, staff rooms, and at educational and information sessions across the cancer centres, the clinic, and the community support group setting.

METHODS

This study used an exploratory, descriptive methodology drawing on social theory. Social theory is an action-oriented methodology, rooted in the examination of relationships and societal structures in context (Rozend et al, 2017). Utilizing social theory in healthcare research provides a basis for exploring conventional assumptions about practice, systems of care and relationships between people, problems and interventions directed to them, offering opportunity for change or innovation (Wilson-Thomas, 1995). The purpose of this study was to collect spontaneous, unprompted descriptors of CRF by patients, family/friends, and healthcare professionals in order to consider and explore opportunity for novel targets for intervention. As such, a social theory approach with its focus on understanding phenomena in context, from a spontaneous, real-life perspective was considered an appropriate methodological framework for the project.

A content analysis approach was employed to guide to data analysis. As a research method which systematically and objectively details and describes experiences, content analysis offers a means of exploring both qualitative and quantitative phenomena (Viasmoradi et al, 2016). Exploring the descriptors in terms of commonalities, and drawing on recurring participant perspectives, allows for the development of themes derived directly from the words, phrases, and experiences described in the data. Content analysis offers opportunity to quantify and qualify the data generated into descriptors and themes, thereby making this information easily understandable and relevant to a broader audience, both from clinical and research scopes.

Sample and recruitment

Three distinct groups of people were targeted for the study: 1) cancer patients/survivors currently undergoing or post-treatment; 2) family members or friends (including people in the patient/survivor's support network), and 3) oncology healthcare professionals, present in any of the project data collection environments.

As the study was set up to collect spontaneous descriptors of CRF, a decision was made not to establish a formal consent process whereby people would be asked to take part in a research study, as this would direct their thinking about CRF in a focused or "constructed" way. As such, no attempt was made to collect any disease or demographic data about any contributor. There was no attempt to request any information that might identify contributors; rather, individuals were simply invited to record, on a piece of paper provided, the first words that came to mind when asked to describe CRF ("The words used to describe any tiredness or fatigue you experience(d) or observe(d) because of cancer or its treatment").

With the permission of cancer centre and rehabilitation clinic managers and the support group lead, a glass jar, pens, papers, an invitation to take part and instructions for participation in the CRF study were set out in a prominent place in each data collection environment. People interested in taking part were asked to write the first word or words that came to mind on the pieces of paper provided, when they thought of CRF. They were asked to return the piece of paper with their words/descriptors into the glass jar. Participants were asked to identify only whether they were a patient/survivor, family member/friend, or a healthcare professional, on the piece of paper with their words All data were gathered voluntarily. No member of the study team approached any contributor, and data collection relied solely on individuals' interest in contributing to, or motivation to provide, descriptors of CRF.

This "real world" study was deemed to be research of negligible risk, using non-identifiable data, and was exempt from a need for further ethical review.

Analysis

A content analysis approach was used, and a combination of quantitative (how many times the same word or words appeared), and qualitative approaches (how people described causes or consequences of CRF), were used to analyse the data provided.

The data were initially analysed independently (ND) and then in collaboration by two reviewers (ND, MK), both experienced cancer clinicians and familiar with CRF, and content analysis. Data were categorized into descriptors and emergent themes. Themes were generated through a process of analysis whereby similar words or phrases were allocated to broad groups of responses, such as physical or functional, until all data had been allocated.

Words used to describe CRF were counted more than once per respondent if the words of phrases were used to indicate different consequences. For example, if a patient wrote, "It's exhausting, it stops me from being able to work" and "It's exhausting, it makes me feel like a different person" the term exhausting would be counted twice, linked to different consequences (described below).

RESULTS

Respondents

Eighty-seven people provided descriptors from across each of the data collection environments (Table 1). A total of 84 responses were considered during data analysis. The three other responses were excluded because the content did not address CRF, rather these responses discussed either the overworking of nursing staff due to the time demands of nursing shifts (2), or pain and disease issues surrounding cancer progression from the perspective of a family member (1). The majority of respondents were patients/survivors (46/55%), followed by healthcare professionals (28/33%), and family/friends (10/12%).

[TABLE 1 - Respondents]

Words and descriptors

The words and descriptors provided by all respondents were analysed for common terms. The most frequently reported words are reported in Table 2.

[TABLE 2 - Frequently occurring words by respondent group]

The words "tiredness" and "energy" were the most commonly reported across all respondent groups followed by "frustration" and 'lethargy". When considered in the context of descriptors (described more fully below), participants referred to a never-ending tiredness, "waking up tired" and being "bone tired", despite resting or sleeping. These words and the text within which they were reported by some individuals (that is, the descriptors), indicated that for some people, CRF had a profound impact on sense-of-self. This is considered more fully below. Descriptors that included reference to frustration, largely related to functional capacity, having to rely on others, and uncertainty about the ongoing and fluctuating nature of CRF.

Themes

data analysis resulted in the generation of six key themes, common across patient/survivor, family/friends, and healthcare professional groups (Table 3). Four of the six themes referred to the consequences of CRF: 1) emotional consequence; 2) physical consequence; 3) cognitive consequence, and 4) functional consequence; and two themes related to the losses associated with those consequences: 1) impact on sense-of-self; 2) uncertainty.

[TABLE 3 -Themes]

In Table 4, the number of times descriptors were reported by respondents across each of the six themes is described.

[TABLE 4 – Descriptors and Respondents]

Descriptors by respondent group

When considered quantitatively, a greater proportion of health care professionals provided emotional (54%) and physical consequence descriptors (71%) than did patients/survivors (35% and 43% respectively) or family and friends (20% and 20% respectively). In both the healthcare professional and patient/survivor groups, physical consequence descriptors were the most commonly provided. In the patient/survivor group, functional and emotional consequence descriptors and descriptors of CRF related uncertainty, were similar in proportion (30%, 35%, and 30% respectively). Family and friends most often provided descriptors relating to functional consequences and uncertainty (30% and 40% respectively). Interestingly, despite published evidence of its impact on cognitive capacity, there were few descriptors from any of the groups that referred to cognition and CRF (Hampson et al, 2015). Reasons for these responses are considered below.

The two themes associated with loss (uncertainty, and sense-of-self) are important, new insights generated by this study. Patient/survivor (30%) and friends and family (40%) groups described more concerns with the uncertainty caused by CRF, compared to healthcare professionals (11%). The content of these responses from patients/survivors and family and friends described the challenge of managing the uncertainty of CRF, specifically its onset and duration, as well as its impact on planning and managing daily routines or productive (primarily work related,) activities. The uncertainty descriptors relate to questions about the future, unknown challenges of dealing with symptoms, uncertainty experienced by friends and family with regard to planning for the future. In Table 5, examples of uncertainty descriptors are provided.

[TABLE 5 – Uncertainty Descriptor Examples]

There was a similarity of language across the three respondent groups with regard to the impact of CRF on sense-of-self. Although there were only a few descriptors about sense-of-self, individual responses from the patient group reflected powerful experiences regarding the burden of living with CRF. The following descriptors from six different participant responses relate to sense-of-self: “Relying on other people”; “Independence loss”; “All pervading; takes over”; “Draining life out of me”; “Takes everything out of you”; “Lifeless.”

The descriptors and themes generated in this study, are closely aligned with the language and domains included in best-practice uni- and multidimensional CRF measures– that is, emotional, physical, cognitive, and daily functioning domains (Howell et al, 2013; Bower et al, 2015). There was considerable similarity between words and phrases used by patients, family/friends, and healthcare professionals to describe their experience of CRF. When the words and phrases generated by respondents were de-identified for group allocation, it was not possible to distinguish between them, suggesting a commonality of experience whether lived or observed.

DISCUSSION

Consistent with previous research regarding CRF all three groups of respondents in this "real world" study reported descriptors of emotional, physical, and functional components to their fatigue experiences. Importantly, the study also provided insight into aspects of CRF- not routinely captured in CRF screening or assessment: uncertainty and sense-of-self.

Emotional considerations. Across all three groups the descriptors used by participants to describe CRF reflected its potential for profound emotional impact. These findings support data presented in other studies where the negative impact of fatigue on emotional wellbeing has repeatedly been demonstrated (Minton et al, 2013). In discussing emotional considerations regarding CRF with patients, research suggests that early education and awareness is more beneficial to patients/survivors and their support networks (Corbett et al, 2013). Our data suggest that attending to the emotional impact of fatigue may offer a key target for therapeutic intervention, and that aspects of these interventions should address the uncertainty and lack of sense of self engendered by CRF.

Physical considerations. Symptoms of CRF are known to impact physical performance, activity tolerance, and endurance (McNeely et al, 2016). Limitations in physical function featured prominently across descriptors of all groups in this study, reflective of the considerable body of evidence that described the impact of CRF on peoples' lives (Bower et al, 2014). Findings from our study indicate that interventions to minimise or obviate CRF, notably the growing body of evidence for exercise as medicine in cancer, continue to be an important target for therapeutic benefit (McNeely et al, 2016).

Functional considerations. Many patients/survivors in this study described their experiences of CRF in terms of loss of function; this is a commonly reported finding from studies of CRF, suggesting that interventions specifically targeting functional capability require ongoing attention (Scott et al, 2011). However in the context of our data, the link between function, uncertainty and loss of self may offer a

new lens on an established problem. In addressing the functional impacts of CRF, attention to the "downstream" effects on certainty and sense of self may offer novel approaches to enhancing patient perception or experience of functional impairment.

Cognitive considerations. Despite considerable evidence linking cognitive impairment and CRF, few responses or descriptors from any of the groups in this study referred to cognitive concerns (Hampson et al, 2015). It may be that people did not necessarily associate cognitive issues with CRF or that our convenience sample had few issues with cognitive impairment.

Uncertainty. Uncertainty relating to onset, duration, impact, and management of CRF was evident in the words and descriptors of patients/survivors and family/friends, Frustration regarding and its impact on being able to plan from one day to the next characterised the responses. The impact of the unpredictability of CRF is not currently captured in CRF screening or assessment tools. Focusing on uncertainty as a novel target for CRF to minimize its emotional impact requires further exploration.

Sense-of-self. Respondents from each of the study groups described how CRF impacted sense-of-self. Descriptors provided presented a construct that has potential to overwhelm an individual's sense-of-self, such that the individual who experiences fatigue becomes a fatigued person (Krishnasamy, 2000). This distinction between experiencing the functional impact of a symptom versus being defined or characterised by its limitations may help explain how chronic health considerations can shift and alter identity constructs over time (Krishnasamy, 2000). In healthcare, the current focus of CRF management relies heavily on its physical and tangible symptom manifestations (Minton et al, 2013). However sense-of-self, a salient aspect of psychosocial wellbeing, is challenging to describe, understand and manage (NCCN, 2018). Attention to altered sense-of-self may offer a new target for CRF screening assessments and interventions.

Recommendations for future research and practice

Integrating a focus on uncertainty and sense-of-self into the care and support of people affected by CRF will require healthcare professionals to develop skills to elicit and respond to uncertainty and altered sense-of-self (Howell et al, 2014). Our findings offer novel, patient and family informed insight to address CRF, that has largely remained intractable to most interventions.

Limitations

This project is limited by small number of respondents (n<100), and the descriptive, convenience sample. This project did not collect identifying information from respondents, and therefore cannot analyse impacts of CRF based on cancer-diagnosis, treatments, or disease-related outcomes.

Conclusion

Data from this study have reiterated the physical, emotional and functional consequences of CRF. Importantly it has proposed two new potential targets for intervention to mitigate the impacts of CRF: uncertainty and sense-of-self. Further research is required to explore and better understand the potential of targeting uncertainty and sense-of-self as opportunities to reduce the multifaceted impacts of CRF.

References

Barsevick AM, Newhall T, & Brown S. (2008). Management of Cancer-Related Fatigue. Clinical Journal of Oncology Nursing, 12(5 Suppl), 21–25. http://doi.org/10.1188/08.CJON.S2.21-25

Berger AM, Abernethy AP, Atkinson A, Barsevick AM, et al. (2011). Cancer-related fatigue. NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines TM) Version 1.

Bower JE, Bak K, Berger A, & Breitbart W, et. al. (2014). Screening, Assessment, and Management of Fatigue in Adult Survivors of Cancer: An American Society of Clinical Oncology Clinical Practice Guideline Adaptation. Journal of Clinical Oncology, 32. doi:10.1200/JCO.2013.53.4495JCO.

Campos MPO, Hassan BJ, Riechelmann, & Del Giglio A. (2011). Cancer-related fatigue: a practical review. Annals of Oncology 22 (6), 1273-1279.DOI: https://doi.org/10.1093/annonc/mdq458

Corbett, T, Groarke A, Walsh JC, & McGuire BE. (2016). Cancer-related fatigue in post-treatment cancer survivors: application of the common sense model of illness representations. BMC cancer, 16(1), 919

Hampson JP, Zick SM, Khabir T, Wright BD, & Harris RE. (2015). Altered resting brain connectivity in persistent cancer related fatigue. NeuroImage: Clinical, 8, 305–313. http://doi.org/10.1016/j.nicl.2015.04.022

Howell D, Hack TF, Green E, Fitch M. (2014). Cancer distress screening data: translating knowledge into clinical action for a quality response. Palliative Support Care, 12(1) 39-51. doi:10.1017/s1478951513000382. PMID: 23942274.

Howell D, Keller-Olaman S, Oliver TK, Hack TF, et al. (2013). A pan-Canadian practice guideline and algorithm: screening, assessment, and supportive care of adults with cancer-related fatigue. Curr Oncol 20(3):e233–e246. doi:10.3747/co.20.1302

Krishnasamy M. (2000). Fatigue in advanced cancer -- meaning before measurement? Int J Nurs Stud, 37(5), 401-14.

McNeely ML, Dolgoy N, Onazi M, & Suderman K. (2016). The Interdisciplinary Rehabilitation Care Team and the Role of Physical Therapy in Survivor Exercise. Clinical Journal of Oncology Nursing, 20, S8-S16. Doi: 10.1188/16.CJON.S2.8-16.

Minton O, Berger A, Barsevick A, Cramp F, Goedendorp M, et al. (2013). Cancer-related fatigue and its impact on functioning. Journal of Cancer, 119(Suppl 11), 2124–30. doi: 10.1002/cncr.28058.

National Comprehensive Cancer Network [NCCN]. (2018). Cancer-related fatigue version2. Accessed June 2018, http://www.nccn.org/professionals/physician_gls/pdf/fatigue.pdf

Oyserman D. (2015). Identity-Based Motivation. Emerging Trends in the Social and Behavioral Sciences: An Interdisciplinary, Searchable, and Linkable Resource. 1–11.

Pearson EJM, Morris ME, di Stefano M, & McKinstry CE. (2016). Interventions for cancer-related fatigue: a scoping review. European Journal of Cancer Care, 27:1. Doi: 10.1111/ecc.12516.

Pilarska A. (2015). Contextualized self-views and sense of identity. Personality and Individual Differences, 86, 326-331.

Rozend CA, Salntos Salas A, & Cameron B. (2017). A critical review
of social and health inequalities in the nursing curriculum. Nurse Education Today, 50, 62-71
Scott JA, Lasch KE, Barsevick AM, & Piault-Louis E. (2011). Patients' Experiences With Cancer-Related Fatigue: A Review and Synthesis of Qualitative Research. Oncology Nursing Forum, 38. 191-203. 10.1188/11.ONF.E191-E203.

Vaismoradi M, Jones J, Turunen H, & Snelgrove S. (2016). Theme development in qualitative content analysis and thematic analysis. Journal of Nursing Education and Practice, 6: 100-110. 10.5430/jnep.v6n5p100.

Weis J, & Horneber M. (2015). Definition and Prevalence of Cancer-Related Fatigue. In Cancer-Related Fatigue 1-10.

Wilson-Thomas L. (1995). Applying critical social theory in nursing education to bridge the gap between theory, research and practice. Journal of Advanced Nursing, 21: 568–575. doi:10.1111/j.1365-2648.1995.tb02742.x

Table 1: Respondents (n=84)

Group	Number of descriptors provided by responder group	Location of data collection environment
Patients/survivors (n=46)	78	outpatient clinic (11); rehabilitation clinic (6); community-based support group (28); wellness centre (25)
Family/friends (n=10)	14	outpatient clinic (1); community-based wellness centre (13)
Health professionals (n=28)	52	outpatient clinic (5); healthcare meeting or break room (46); wellness centre (1)
Total number of descriptors across all responders (n=84)	144	

Table 2: Frequently occurring words by respondent group

Words/phrases	Respondent Groups			
	Patient/survivor (n=46)	Family member/friend (n=10)	Healthcare professional (n=28)	Total Respondents (n=84/100%)†

Frustrat[ion/ed]	4 (9%)		4 (14%)	8
Tired[ness]	18 (40%)	3 (30%)	9 (32%)	30
Weak[ness]	1 (2%)	1 (10%)	4 (14%)	5
Letharg[y/ic]	3 (7%)		4 (14%)	7
Motivation	1 (2%)		3 (11%)	4
Energy	7 (15%)	1 (10%)	7 (25%)	15

†The total number of terms exceed the numbers of participants as individual respondents provided multiple terms in their responses.

Table 3. Themes and descriptors

Theme	Respondent group	Example of descriptors
Emotional	Patient/Survivor	"Frustrated by lack of energy."
	Family/Friend	"We encouraged him to exercise even though it feels impossible to move the body, but as hard [as] it is for patients, it is also hard [on] family members to encourage they don't feel like doing it."
	Healthcare professional	"Frustration; desire to engage more than able to."
Physical	Patient/Survivor	"Hit by a mac truck". So intense, […] greater than any other type of 'tiredness'."
	Family/Friend	"Drained. Listless."
	Healthcare professional	"Extreme tiredness where it's difficult to stay awake for any length of time."
Cognitive	Patient/Survivor	"Sinking sands. Mind boggy."
	Family/Friend	"Confusion through tiredness."
	Healthcare professional	"Poor concentration."
Functional	Patient	"Non-stop tiredness (doesn't go away); tired after sleep; can't do dinner - by afternoon too exhausted; too tired to walk after tea; must do shopping and exercise early in the day."; "Waking up tired; unable to do jobs."
	Family/Friend	"Sudden loss of energy"; Dad doesn't like to get

		dressed in the morning because he thinks he will just sleep before noontime."
	Healthcare professional	"Inability to complete tasks you want to do; requirement of rest throughout the day"
Sense-of-Self‡	Patient/Survivor	"Takes everything out of you. Completely worn; lifeless."
	Family/Friend	"Surprize at inability to do things that were in the past "just normal."
	Healthcare professional	"Reduced sense of purpose."
Uncertainty	Patient/Survivor	"How long does fatigue last? How bad does it get? I feel tired these days, but is it worth asking my nurse about?"
	Family/Friend	"It is very hard to plan out the day, because sometimes the fatigue is bad and sometimes it is better, but there is no routine about this fatigue."
	Healthcare professional	"I don't know how to explain fatigue save for extreme tiredness"

‡The theme "sense-of-self" was generated from descriptors that conveyed impact of CRF on identity and included references to a change or shift to a person's sense of who they are, and what they are capable of doing (Oyserman, 2015). [i]Research on sense-of-self suggests that identity is a fluid construct, shifting based on situational requirements; essentially, individuals prefer consistency between their perception of identity, ability and meaningfulness within the environment around them. When functional or emotional difficulty or distress are experienced an individual may change their sense-of-self or reduce their perceptions of self-worth, and in doing so, may grieve their former sense-of-self and may withdraw from previously important activities, believing they cannot or should not participate anymore (Pilarska, 2015).[ii]

Table 4. Themes, descriptors and respondents

Themes	Number of times the descriptors were reported per group, and numbers of respondents per group			
	Patient/survivor (n=46)	Family member/friend (n=10)	Healthcare professional (n=28)	Total n=84 (100%) Descriptors

				n=144§(100%)
Emotional consequence	16 (35%)	2 (20%)	15 (54%)	33
Physical consequence	20 (43%)	2 (20%)	20 (71%)	42
Cognitive consequence	5 (4%)	1 (10%)	2 (7%)	8
Functional consequence	14 (30%)	3 (30%)	7 (25%)	24
Sense-of-self	9 (20%)	2 (20%)	5 (18%)	16
Uncertainty	14 (30%)	4 (40%)	3 (11%)	21

§Total number of descriptors exceed the numbers of participants as individual respondents provided descriptors across several themes.

Table 5. Uncertainty Descriptor Examples

Group	Current Uncertainty Issues	Future Uncertainty Issues	Intervention Uncertainty
Family/friend	"Unsure how to help my husband with his fatigue. It comes and go and it is hard to guess how he will feel."		
Patient/survivor		"Where does it end?"	
Patient/survivor		"What will happen to me?"	
Patient/survivor	"Sometimes it is there, and sometimes it is there more, and sometimes it is there less - so I can't be sure what will happen in a day."		
Family/Friend			"How do I help him? I wish there were more answers."
Healthcare professional			"[It's] not always taken seriously – so how do we help people?"