The Leisure of Women Caring for People Harmfully Involved With Alcohol, Drugs, and Gambling

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Abstract

The health of family and friends affected by another person's substance use and/or gambling is an undervalued health issue. These relationships are rarely explored as caregiving. Research on caregivers suggests leisure is important for improving, maintaining, and protecting their health. Guided by feminist social constructionism, this article explores how women caring for people harmfully involved with alcohol, drugs and/or gambling experience leisure in Nova Scotia, Canada. Data were collected from ten women though semistructured interviews. Examples of caregiving are provided. Three themes demonstrate the results: loss of leisure, negotiation of leisure, and leisure as escape. Understanding the women's experience of leisure in this caregiving relationship has important implications for their health.

Keywords: Addiction, caregiving, family, leisure, women

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Introduction

Harmful involvement (HI) with alcohol, drugs and gambling has a wide range of health implications. The harms experienced by family and friends (concerned significant other(s) [CSO]) can be as significant as the harms experienced by the person(s) harmfully involved (PHI) (Suman & Nagalakshmi, 1996). Evidence suggests a CSO may greatly support the achievement of a loved one's recovery-related goals (Biegel, Katz-Saltzman, Meeks, Brown & Tracy, 2010; Biegel, Ishler, Katz, & Johnson, 2007; Copello, Velleman & Templeton, 2005). Most research and treatment focuses on the CSO's ability to support the PHI's recovery, prioritizing the health of PHI over the CSO (Csiernik, 2002). In Canada and elsewhere, the experience of the CSO has been overlooked by researchers and service providers alike (Csiernik, 2002; Orford, Velleman, Natera, Templeton & Copello, 2013). Explorations of the interactions between the PHI and CSO seldom recognize the caregiving within these messy, turbulent, and complicated relationships.

This study explored the leisure of women caring for PHI with alcohol, drugs, and gambling in Nova Scotia, Canada. Acts of caregiving within these relationships are compared to those caring for family and friends with other illnesses or disabilities. Important in this comparison is the women's ability to use leisure to cope with their caregiving roles, enhance self-actualization, and strengthen their relationships. Three themes represent the challenges and opportunities the women experienced in their leisure: Loss of leisure, negotiation of leisure, and leisure as escape.

Feminism is at a critical moment. Gains have been made, but new gaps emerge with each renegotiation of power. Although the ability to care is "a defining feature of human beings as important as [our] capacity for rationality" it is undervalued, oppressive, and viewed as women's work (Noddings, 1984 p. 3). This article highlights how the women and contextual factors (e.g., caregiving, HI, societal expectations) shape leisure and ultimately influence health.

Literature Review

Deconstructing Care

Understood as an emotion and an activity, the construct of care is a complex, shared, and reciprocal experience that influences the self-perception and social relationships of both caregiver and receiver (Armstrong & Armstrong, 2001; Graham, 1983; Ungerson, 1983). The act of caring for someone is often intertwined with social and/or relationship norms and expectations constructed through gender socialization; evidence clearly shows it influences how a person spends his or her time (Pearlin, Mullan, Semple & Skaff, 1990; Gahagan, Loppie, Rehman, MacLellan & Side, 2007; Ungerson, 1983). The influence of the experience of caring about is less understood. Giving support is often inaccurately assumed to be of little consequence to a caregiver's psychological health (Stranzdins & Broom, 2007), but even in the absence of physical care, caregiving can be a consuming, full-time experience. The inaccurate assumption of emotional caregiving as "natural, discretionary, effortless and without consequence" fails to recognize the labour involved and potential negative health implications (Stranzdins & Broom, 2004, p. 375). Caregiving has the potential to be problematic when established contextual relationship norms are altered and result in an unequal distribution of burden (Pearlin et al., 1990). Caregivers may simultaneously feel emotions that confuse and contradict (i.e., love, anger, resentment) and relinquish their own needs to fulfill the expectations of being a caregiver, thus changing how they act, think, value personal needs and spend their time.

From childhood, women are often socialized to define themselves in the context of both their human relationships and their ability to care (Gilligan, 1982). Reinforced over the life course, care

work offers women the opportunity to affirm their sense of self. But because it is undervalued and viewed as women's work, caregiving facilitates unequal relationships (Armstrong & Armstrong, 2001; Michelson & Tepperman, 2003; Waring, 2004; Zukewich, 2003). Many societies associate particular values, virtues, and traits (i.e., interdependence, community, connection, and sharing) with women (Tong, 2009). Although the social construction of romantic love or family responsibility may motivate care work, a physical, emotional, financial, and time commitment is still required (MacDonald, Phipps, & Lethbridge, 2005). The sometimes intimate and often emotional relationship between caregiver and receiver may contribute to its perception and normalization of being women's work (Zukewich, 2003; Stranzdins & Broom, 2004) and its devaluation relative to other types of work and as a contribution to the economy. Care work is underestimated, inaccurately measured, rarely recognized in policy and ignored as a contribution to the Gross National Product (Elson, 1999; Waring, 2004). The home is a physical and emotional workplace (Hochschild, 2008; Michelson & Tepperman, 2003). Emotional work becomes more complex when expected patterns of behaviors or anticipated social experiences are altered (Hochschild, 2008); this is often the norm within the context of HI. Women's increased participation in the paid workforce and continued performance of most household and child-rearing labor has led to a significant increase in women's responsibilities (Michelson & Tepperman). This complex combination positions caregiving to offer both burden and benefit.

Caregiving: Burden and Benefit

Caring for significant others with chronic, progressive conditions can virtually consume a relationship (Pearlin et al., 1990). Research shows caregivers providing emotional or physical care may experience a variety of mental, emotional, physical, and practical harms (Hjortsberg & Persson, 2010; Pinquart & Sörensen, 2007; Stranzdins & Broom, 2007). Examples include increased depressive symptoms (Biegel, et al., 2007; Biegel, et al., 2010; Chen & Lukens, 2011; Marks, Lambert & Lethbridge, 2002; Romero-Moreno, Márquez-González, Mausbach & Losada, 2012), increased hostility, decreased happiness, decreased opportunities for personal growth, decreased autonomy (Marks et al., 2002) increased personal and social life restrictions (Pinquart & Sörensen, 2003), increased hypertension, increased mortality risks, and increased cardiovascular disease (Lee, Colditz, Berkman & Kawachi, 2003; Shaw, Patterson, Ziegler, Dimsdale, Semple & Grant, 1999). Research also shows depressive symptoms increase for caregivers who listen to the worries of other people or soothe, intervene, or protect people who are sad, angry, or in conflict (Stranzdins & Broom, 2007). Financial burden, including loss of potential income (Hjortsberg & Persson, 2010) extends beyond caregivers and can impact care receivers and others of significant importance (Michelson & Tepperman, 2003). Higher age, lower levels of informal support, lower socioeconomic status, increased intensity of caregiving, and the amount of time spent caregiving are linked to increased harms and poorer caregiver health (Hirst, 2005; Pinquart & Sörensen, 2007). Adverse health effects may continue after caregiving has stopped (Hirst, 2005). The caregiving relationship may negatively impact a caregivers' leisure as it may be de-prioritized or altered as constraints intensify.

Despite its associated challenges, caregivers do report positive benefits from this work. Marks, et al. (2002) found caregivers reported increased purpose in life as a result of their roles. Chen and Lukens (2011) report parents and adult siblings caring for persons with severe and persistent mental illness, who found enjoyment and pleasure in their relationships, were more able to buffer the associated stresses. Building positive emotions in other people by showing closeness, warmth, and inclusion is associated with lower depressive symptoms.

Defining Caregiving

Zajdow (1995) argues women who care for PHI are not unlike women caregivers in other circumstances. Both groups of women provide unpaid emotional, physical, and financial care work. Yet the formers' situations have unique characteristics, including the relative absence of these women in caregiving literature, the dominant view that these women have chosen or contributed to their situation, particularly when caring for a partner (Hurcom, Copello, & Orford, 2000; Zajdow, 1995) and the extreme end of the caregiving spectrum at which some of these tasks are found (Zajdow). The stigmatized labeling of women as "enabling" and "codependent" taken from 12-Step culture has become embedded in popular culture (Cermak, 1986; Harkness & Cotrell, 1997; Hurcom et al., 2000; Uhle, 1994) and implies that "overzealous helping" supports the PHI's behavior (Harkness & Cotrell, 1997, p. 474). This research does not use these terms as they do not address the broader social and structural issues faced by women within the context of caregiving.

Labeling women as having "loved too much," the concept of codependency implies these women experience a personality disorder, which leads them to unconsciously select a partner who would then develop an addiction (Velleman et al., 1993). Although definitions of codependency continue to evolve, it is most often viewed as a psychological, emotional, or behavioral condition and/or preoccupation for controlling others (Harkness & Cotrell, 1997). This view blames women (Krestan & Bepko, 1990) and removes power by suggesting they self-identify as "powerless and diseased" (Harkness & Cotrell, 1997). We do not suggest these relationship dynamics are healthy, nor do we suggest all relationships between CSO and PHI involve caregiving (just as not all relationships between adult children and parents with dementia are caregiving relationships). What we do suggest is that these pathologized perceptions of women ignore the gendered and political nature of the socially constructed world.

Dupuis and Norris (1997) suggest a model to explore how women caregivers influence, and are influenced by, their environments and interactions as they shape their caregiving roles. It suggests the purpose and meaning recognized by the caregivers themselves define the caregiving role, not expectations and completed tasks. Role parameters are set by environmental and interpersonal interactions. Caregivers then interpret and respond as needed and meaning is given and made in the situation and interactions with systems (e.g., health care, social services). Policy, available supports, and interpersonal factors (e.g., family history, relationship quality) affect chosen roles and development over time. Thus, caregiving is individually constructed and reconstructed through experiences and contextual environments.

The Therapeutic Value of Leisure

Leisure has the potential to support health and emotional wellness by offering social support, coping, stress relief, buffering against the impact of life stress, and acting as a general protective factor to health (Bedini & Guinan, 1996; Caldwell, 2005; Coleman & Iso-Ahola, 1993; Iwasaki, 2003; Iwasaki, 2006; Iwasaki & Bartlett, 2006; Kleiber, Brock, Lee, Dattilo & Caldwell, 1995; Kleiber, Hutchinson & Williams, 2002; Klitzing, 2003). Research also shows the role and importance of women's leisure participation to their individual mental and emotional health and wellbeing (Fullugar, 2008; Gahagan et al., 2007; Hood, 2003; Pondé & Santana, 2000; Wearing, 1990). Evidence related to caregiving shows frequent leisure predicts decreases in levels of depression (Romero-Moreno et al., 2012) and leisure satisfaction may protect and positively impact cardiovascular health (Chattillion et al., 2012).

The Impact of Harmful Involvement on Concerned Significant Others

HI has long been labeled and understood as a family issue (Rouhbakhsh, Lewis, & Allen-Byrd, 2004). Even with increased examination of the impact of HI on CSO (Hurcom et al., 2000), little is known of its impact, particularly on those providing informal care (Velleman et al., 1993). HI is known to impact the entire family (Gruber & Taylor, 2006), and its impact can be just as significant for caregivers as it is for the PHI (Suman & Nagalakshmi, 1996). Existing evidence highlights the adverse social, psychological, and physiological implications HI has on those close to the PHI. Examples include isolation; restricted social life; public embarrassment; relationship dissatisfaction; unsatisfactory sex life; adverse family outcomes (i.e., disrupted routines and family celebrations; restricted family life; reduced family standards of living); anger/resentment, shame, depression, responsibility, or guilt; psychological distress; poorer psychological and physical health; increased use of medical services; physical violence; burden of multiple, changing, or inappropriate family roles; financial instability; and dissatisfaction with current formal/informal supports (Biegel et al., 2007; Biegel et al., 2010; Gaudia, 1987; Hodgins, et al., 2007; Kahler, et al., 2003; Kirby, Dugosh, Benishek, & Harrington, 2005; Lennox, Scott-Lennox, & Holder, 1992; Lorenz & Yaffee, 1989; Suman & Nagalakshmi, 1996; Velleman, et al., 1993). Adult children of PHI report increased parentification (assuming parenting roles before being emotionally or developmentally ready) and physical and emotional caregiving compared to adults whose parents were not harmfully involved (Kelley et al., 2006). Parentification has been linked to challenges experiencing fun and play (Woititz, 1990). Although most of these known implications relate to leisure, the impact of HI on the CSO is relatively unexplored within leisure research. Finding its foundation in feminist theory, this article 1) recognizes and reframes the undervalued, stigmatized, and pathologized care work done by women CSO, and 2) explores their leisure experience and its influence on health. Doing so challenges the oppressive social requirements that shape the lives of women and makes visible the work done by women involved in this care.

Methods

Consistent with feminist research and methodologies, this study focused on exploring ways to improve the lives of women and the requirements for change to occur (Epstein Jayaratne & Stewart, 2008). Challenging "natural" assumptions about women, this research recognized gendered norms are influenced by many social factors and areas of inequality (Jagger, 2008b). This study was approached from a constructionist epistemology and feminist theoretical perspective, with specific emphasis on feminist social constructionism (FSC). FSC suggests gender is a constant part of our identity that influences our treatment by others and societal standing (Lorber, 2010). Sources of gender inequity are found in the "practices and processes of gendering in everyday life," particularly within gendered the division of family labor (Lorber, p. 243). For most adults, challenging gendered beliefs, actions, ways of arranging work and family life, and by extension reorganizing the balance of power and what is valued is "literally unthinkable" (p. 244). We acknowledge that the making and meaning of these results are informed by our subjective understanding of the caregiving and CSO experience. Incorporating lived experience and emotions into the research process is an important aspect of feminist methodologies (Jagger, 2008a; Neuman, 1997) and is a necessary component of qualitative leisure research (Dupuis, 1999).

Recruitment

Participants were recruited over four months using posters in community settings (e.g., libraries, coffee shops, shopping areas, recreation centers), word of mouth, media (e.g., radio and newspaper interviews, grant funder's press release) and electronic distribution (e.g., online community board e-mail lists, websites). Recruitment material asked for women who cared for a person(s) harmfully involved (PHI) with alcohol, drugs, and/or gambling. Recruitment initially focused broadly on women caring for PHI with alcohol, drugs, and gambling, but screens

showed women caring for PHI with gambling were either not forthcoming or unaware of the study. Recruitment then focused solely on these women. Ten women aged 18-71 participated in semistructured qualitative interviews. Eligible participants spoke English and at the time of the interview self-identified as a woman, aged 18 years or older, living in Nova Scotia who provided unpaid care for one or more family members or friends who they considered to be harmfully involved with alcohol, drugs, and/or gambling. Each participant received a \$20 honorarium.

Data Collection

Data collection decisions recognized the power relations between the researchers and participants (Jagger, 2008b). Data were collected through a semistructured, digitally recorded, face-to-face interview and self-completed, sociodemographic questionnaire. Interviews ranged from 30 to 120 minutes. Twelve questions with prompts were used to explore the women's relationships, caregiving, and leisure. For example: How does your relationship with (PHI) affect your leisure? What do you think of when you hear the word caregiver? How do you cope with your loved one's harmful involvement? Nine interviews occurred in a private office at the authors' workplace. One occurred privately at a women's centre new to both interviewer and participant.

Data Analysis

Interviews were transcribed verbatim by the interviewer. Pseudonyms were assigned to replace identifying information and protect the confidentiality and anonymity of participants and other persons identified. Data were managed using the qualitative software ATLAS.ti. Data analysis was an iterative process. Inductive coding and thematic analysis supported the development of conceptual categories. The participants' words and phrases were examined for reoccurring ideas and concepts. Codes were assigned to help describe, organize and interpret the participants' responses. This subjective process led to the development of conceptual categories from which themes emerged to represent the women's experiences (Neuman, 1997). Themes were sorted and compared using constant comparison (Corbin & Strauss, 2008). Consistent with feminist methodologies, data were reviewed to explore other possible interpretations consistent with the findings (Epstein Jayaratne & Stewart, 2008). Our subjective understanding of topics and information that emerged from the data mutually informed the results.

Participant Demographics

The women were diverse in terms of age, household income, education, relationship to PHI, and the PHI's type of HI (see Table 1: Participant Demographics). Missing were racially diverse women (all identified as white/Caucasian) and women caring for same-sex partners. Other paid and unpaid caregiving was reported. Seven women cared for one PHI; three cared for two. Of the PHI referenced, six used alcohol, three used alcohol and drugs (illicit and/or prescription), two gambled, and two used alcohol and gambled. When asked what motivated their study participation, nearly all the women reported a desire to influence change, a few reported a desire to help the researchers, one reported the financial compensation and one saw it as a potential leisure experience.

I'm always looking [to] volunteer. I thought that sounds interesting, that will be fun. A nice leisure thing to do. Sit and talk with somebody [and] get paid on top of that. That's pretty good.—Anna

Table 1Participant Demographics

Name	Age	Education	Household Income	Relationship to PHI (Self-Identified)	Type of HI A=Alcohol, D=Drugs G= Gambling	Other Caregiving Responsibilities	Occupation
Alexis	37	Some College/ Technical/Trades	< 10K	Partner	A, G	None identified	Caregiver (P/T)
Anna	61	Some College/ Technical/Trades	10K-29,999	Girlfriend	А	Grandson	Retired, Caregiver (P/T)
Elisabeth	71	Some College/ Technical/Trades	30K-49,999	Mother Wife	G A	Adult Daughter	Caregiver (F/T)
Genevieve	70	High School/ GED	30K-49,999	Wife	Α	Husband	Retired
Gwen	64	Completed University	10K-29,999	Mother	A, D	None identified	Retired Caregiver (P/T)
Kate	20	Grade 9	Not identified	Daughter Girlfriend	G A	Daughter	Maternity Leave
Kelli	18	Some University	< 10K	Friend	A, D	None identified	Student (on leave)
Melanie	52	Some University	50K-69,999	Mother	А	Parents, Aunt, Husband (H)	Student (F/T)
Sarah	32	Completed University	50K-69,999	Daughter	Α	None identified	Health Professions (F/T)
Teresa	67	Some University	10K-29,999	Wife Mother	A, G A, D	None identified	Student (F/T)

Findings

The complex and consuming nature of the women's relationships with the PHI was evident, particularly its impact on the women's health. Descriptions of anxiety, stress, worry, anger, depression, guilt, loss, and abuse (emotional, verbal, and physical) emerged strongly from our analysis. Lonely and isolated, the women struggled to balance independence, dependence, and control. Trust was challenged. This shaped the women's perceptions of their relationships, identities, and caregiving. Unhealthy relationship dynamics, and turbulent, unstable environments led them to contemplate and experiment with leaving the situation physically and emotionally. The themes that emerged around the women's leisure include loss of leisure, negotiation of leisure, and leisure as escape. Prior to presenting the themes, we offer examples of caregiving within their relationships.

Caregiving within their Relationships

Descriptions of the women's caregiving illustrated relationships that were both personally satisfying and emotionally, mentally, and physically damaging. Past experiences with the PHI influenced the women's perceptions of caregiving. Most connected caregiving to overstepping boundaries and referenced concepts evident in 12-Step program narratives (e.g., codependency and enabling). All except one woman reported their caregiving resulted from their loved one's HI. For Genevieve, the caregiving resulted from other chronic health conditions.

[When] I think of a caregiver, I think of someone who does too much for someone else. Probably does more than they need to...In a positive way, someone who cares, someone who wants to help, be involved. All my life I've always been around and did things for [my mother] that really weren't for me to do. If she didn't have an addiction, she would have done them on her own. —Sarah

Caretaker. People pleaser. Not giving someone the opportunity to do it for themselves. How far do you go? I mean if somebody's really drunk and they fall on the floor, are you supposed to pick them up and pretend it didn't happen? Or do you just let it be? I don't know.—Gwen

Many of the women recognized the gendered component of their care work. Supporting Lorber's (2010) argument, some of the women even described it as "natural" to take on this level of care and discussed how women develop meaning through caregiving and feel pressured to care for others. Guilt and responsibility were often described as catalysts to their caregiving. Not all their care work was well received. Some women grew to resent the PHI and many also described resentment from the PHI toward them. These oppressive relationship dynamics combined with caregiving's ability to affirm their sense of self resulted in high levels of stress for the women.

From the data emerged a spectrum from hands-on to physically/emotionally distanced caregiving. This included financial support (money management, bill/rent payment, lending money, negotiation of overdue bills/repayment plans), emotional support (counseling, problem solving), physical support (activities of daily living, personal care), spiritual support, protection (physical harm; emotional harm; reconnection of utilities; discussions with police, fire, and adult protection about the PHI's living conditions), health advocacy (attending medical appointments, calling treatment centres), transportation (appointments, groceries, errands) and in one situation, the assumption of the PHI's caregiving responsibilities.

I take care of things for him, emotional, physically, spiritually, but I'm not compensated for the work and time I put in to paying [the bills], making sure everything is organized and [cleaning] the house. —Alexis

[Because of his health] when he does [go to the bar] I usually take him. I don't want him driving the car. I enable him. I will not, not help him. It will serve no purpose. He would take the car, which is going to endanger other people. We can forget what it's going to do to him. The penalty to be paid would fall back on me and my children. ... So for the remainder of the years that he has left I will do what I can to keep him comfortable even though it angers me. —Genevieve

[I see] resentment coming at me. I'm controlling the purse strings. Whether he goes and gets a drink [or] plays the machines. He does buy lotto tickets. I allow that. You become the mother, the boss, the whatever. There's a certain amount of resentment, bitterness towards you. —Teresa

The women identified acts of caregiving that in retrospect were absurd, but in the moment seemed rational and even normal. They went to great lengths to protect the PHI. One described her actions as "obsessed." The control these women sought was an attempt to create stability in a volatile, unpredictable relationship. Many described how the PHI neglected his/her own personal safety and well-being, hygiene, and living environment and this influenced the care they provided.

She was defecating and urinating on the floor. I'd come in, look down and [ask] what's that on the floor? Is that shit? And she'd be like yeah. I'd say are you going to leave it there Mom? She's like yeah, so I would clean it up and not even think about it. —Sarah

His job [drug dealer] was harmful to the both of us. When you're in that kind of a profession, if you can call it that, you have thousands of dollars in your pocket. He'd go on a binge, and if I didn't take money out of his pocket and hide it in my bra, it would be gone. I protected him from a lot of stuff like that, making sure that he didn't go in over his head. —Kate

Financial decisions often impacted the women's relationships. Balancing the need to ensure their loved one had the necessary resources required to maintain personal and household well-being while not contributing to the HI was difficult. The women avoided giving money to the PHI, yet exceptions were made (e.g., a place to live, food). This was done out of concern for the PHI and to protect themselves from the potential impact of not helping (i.e., keep their own apartment to avoid having the PHI move in). Such actions were often hidden from other family members.

I'd give her money to pay her rent, but I was feeding her [gambling]. I did know in a way, but I was hoping that she would come to her senses and stop. She has to have [money] to survive. She can't be without her apartment. It's a really hard thing to do giving the caregiving. —Elisabeth

If she loses her house, where is she going to go? I felt so responsible. I probably would have taken her in, which would have been devastating. She was telling the doctors and nurses that she was going to come live with me, and I'm like, that's not going to happen. They were really rude to me. But they just see her coming in; they don't know the history. —Sarah

Financial responsibility and burden has been linked to caregiving (e.g., costs associated and loss of potential future earnings). In addition to day-to-day financial support, the women described selling a business, settling extensive gambling debts (thousands of dollars), taking unpaid leave from work, and paying for private rehabilitation services. Although financial responsibility is associated with caregiving, the dynamics of financial protection and management within these relationships is different. Influenced by feelings of responsibility and guilt, the women were often manipulated by the PHI. Here Kate describes a betrayal by her mother for whom she cared.

[I] dropped out of school in grade nine. I got a job and I had saved up quite a bit of money, like just for the future I guess, about \$1,500. My bank card went missing. For about two weeks she watched me live off of my tips. The whole time she had my bank card and she blew almost \$2,000 of my money. It [had] gotten to the point where I was either going to move out or it needed to stop because I couldn't live in my own house and not trust the people in it. —Kate

Personal connection between those giving and receiving care greatly increased the complexity of the caregiving. The women found it difficult to separate emotionally from the PHI when making decisions. Many reported that they felt someone outside the relationship (e.g., a paid worker) would be a more appropriate caregiver given the ability to separate themselves from the situation.

I see [caregiving and enabling] together. He is becoming more dependent on me. I will go out and get him his booze [and] take him to [the local pool hall]. You wouldn't do that if you were his caregiver because you're not related. You're not living with him and you would say there is no way I am going to enable you. I guess I am finding it hard to separate the two. —Genevieve

Most described changing their own behavior or tactics to try to influence the PHI to change (e.g., ask nicely, threaten, plead, remove or restrict access to the substance or gambling of choice). But, as Sarah explained, emptying bottles down the drain did not change the result.

Growing up [I] engrained [the] notion [that] if I am good enough, do the right thing, or get involved enough somehow that will stop her. ... I was always thinking how could I phrase it to her differently? Yell this time as opposed to cry? Wait until she's in a good mood? [I was] always trying to control and find the right answer so she will see what I see. —Sarah

When the women changed behaviors for personal benefit, most experienced backlash. Attempts to renegotiate their position and power within the relationship led to being criticized and verbally degraded. This feeling could also be uncomfortable for the women. For example, when a partner decided not to live with her PHI or share financial responsibilities, this created new boundaries, but the women also felt it made the relationship incomplete, lacking or, as one said, not "real."

I was a real enabler. I realized that wasn't healthy. I had to stop. That was very difficult because then you become the bitch. You're not the nice person you used to be. But that's okay. I certainly didn't know that in the beginning. That's a big hard lesson to learn. When you're doing it, you don't see that you are doing wrong you know. It just seems to be the natural thing to do. —Teresa

For these women, caregiving for the PHI was as much about their own protection as the PHI's. From mental anguish (worry, embarrassment) to financial consequences (as a result of the PHI's actions), the women strove to protect themselves and those around them from the results of the PHI's actions. In the short term, their actions made sense as a pragmatic self-preservation strategy. The result facilitated the sacrifice of things of personal importance, including leisure.

The Loss of Leisure

Culturally we're driven [as] women that we have to be doing something for someone else other than you, every second of every day. If you take any time for you then you're self-ish. —Sarah

Loss of leisure was reflected in many ways: loss of leisure connections/relationships, loss of time for leisure, and changes in the experience of leisure. Often a lack of mental energy, required resources, and/or financial limitations (e.g., ability to cover costs, find transportation, or obtain child care) prevented the women's participation in meaningful leisure experiences, not disinterest.

There's lots of things I would like to do if I had the money to do them. —Alexis

Financial restraint is a big factor, not being able to do a lot of leisure things. ...Sometimes I don't have the gas money to drive...to hang out with friends and stuff. —Kate

The PHI's actions and behaviors often disrupted, constrained, or eliminated participation. For the women who lived with the PHI, their home was rarely a place of psychological and/or physical safety. Riding a range of emotions (i.e., anxiety, anger, frustration, and depression) the women described their experience living in a volatile environment as "walking on pins and needles," "riding a roller coaster" and "waiting for the bomb to explode." Unexpected social visits were feared. These conditions intensified the challenge to find opportunities for meaningful leisure.

I was with my brother and mother...it was Thanksgiving...My mother was drunk out of her mind, on the floor, really pitiful...[My brother] took off and she as on the floor and the turkey was in the oven and I can remember thinking now this, this is too much. I gotta get out of here...I was standing at the table with this big turkey in front of me. It was a joke. —Gwen

I really grew up fast because of [my mom's gambling]. ...I cut myself off from a lot of my friends. ... Problems that are really big to them seem totally ridiculous to you and you just lose the ability to be a good friend anyway, so there was no point. —Kate

Leisure activities were particularly constrained in social situations where alcohol was involved. This included the home. Each woman described at least one socially humiliating situation from the PHI's use and tended to avoid activities were alcohol was served. While some chose to eliminate home entertaining altogether, others used it to monitor the PHI. This left the women unable to relax and constantly providing care while prioritizing the needs of others.

I hate going out in public with my boyfriend if there is going to be alcohol around. That sucks, because I love him so much. He's a really good guy, but I hate feeling embarrassed sitting there getting that horrible feeling in my gut thinking, 'please don't get drunk.' At the same time, I don't want to be the nagging bitchy girlfriend that's like 'don't do it, just one [drink]'.—Kate

He's done embarrassing things at my apartment. He's gotten so drunk, sat on my grandson's girlfriend's knees and acted so embarrassing that they all left and went home. One night he was really loaded. He was walking around with chaps with nothing underneath outside in the yard. I know there were people looking out the window. He was making so much noise. He feels regret, but then he will turn around and do it again. —Anna

Other examples of the PHI's inappropriate social behavior included smoking in non-smoking buildings, passing out while preparing family meals, dancing inappropriately with others, leaving one participant physically stranded and urinating in a friend's refrigerator. The women described feeling disrespected and embarrassed and the results increased their isolation. Many reported invitations to social gatherings decreased and/or ended. When invitations were extended, attending social gatherings alone was common. This was usually because the PHI was not invited or too involved in his or her use to attend. By far, most of the women described avoiding social situations altogether, which was preferable to explaining, or avoid explaining, the PHI's absence. While not participating decreased the potential for embarrassment, it increased the women's isolation, limited their support networks, and intensified the burden of care they experienced.

The women identified leisure as a place to rejuvenate and restore; the loss of leisure resulted in the loss of associated benefits (e.g., relaxation, skill building, escape, self-improvement). For most, the biggest losses were social connections established through leisure, including those with friends, family, and the PHI. But for a few women, leisure was not a priority. The older women told of feeling guilty or selfish when prioritizing their needs, including leisure. Multitasking to maximize productivity in leisure (e.g., knitting while watching television) was also described.

There isn't [anything I do for me]. I guess there never really has been so that is who I am. The way that I am. All my life I've looked after people. I do not get out of bed and say

today you will go for your walk. I'm [not] going to kick up my feet and do nothing but read my book until it's gone. That does not happen. My days are involved with looking after [my husband]. —Genevieve

The women's well-being was significantly impacted by the loss of leisure. Leisure that was negotiated shows the power and oppression resulting from their relationships and responsibilities.

Negotiation of Leisure

[Leisure] is important. Some days you just accept you're probably not going to get it. I mean some days it is important, especially when you feel you've reached your ropes end, which is a lot. But yeah, it's important to be able to have at least one or twenty minutes a day to myself. —Kate

The women's leisure descriptions identified a range of activities. This included screen time (television, movies, computer), crafts, word and mind puzzles, card games, reading, taking a bath, listening to music, a quiet cup of tea, painting nails, meditation, physical fitness (going for a walk or to the gym) driving, and being in nature. These activities were relatively low cost, required little skill and energy expenditure, were easily started and stopped, and done close to home. The women referred to these activities as simple or basic. They were also interruptible and negotiable. When actively caregiving, their leisure opportunities required little set up, were easily started, could be done at relatively any time of the day with little disruption to others, and were quickly stopped if the situation changed (e.g., PHI using, mood swings by the PHI, emergency situation). The women often reported being tired and, not surprisingly, these activities required little energy. At times, even "simple" or "basic" activities were too much.

I'll have a bath or watch TV or talk to a friend. Or even sometimes I just sit and listen to soft music. Sometimes go out for coffee, movies, like very basic types of things. —Sarah

When I go to bed I can't read, because I'm really tired and I want to sleep. —Elisabeth

I've given up trying to find an hour [for leisure]...I call them five-minute vacations. Wherever I can, I take a five-minute vacation. And that's what it comes down to. —Melanie

The women identified leisure's contribution to their mental and (to a lesser extent) physical health. Reported mental health benefits included healthy coping, decreased stress and increased happiness, energy, and social connection. Reported physical health benefits included improved cardiovascular health, strength, flexibility, and mobility. Mental and physical health problems were often linked (e.g., ulcers and migraines from stress). Although most did not regularly exercise, their caregiving kept them physically active. Many identified leisure's potential to keep them productive and working though challenges resulting from their demanding roles. When asked about leisure's negative effects, some said too much leisure was problematic, a response likely rooted in their gendered socialization and the consequences of problematic leisure as witnessed through the PHI.

For a few women, negotiating leisure was about renegotiating power in their relationships. Research on leisure as resistance highlights the political nature of leisure (Shaw, 2001). Leisure as resistance to societal roles and expectations has explored women's participation in activities traditionally unavailable to them (Delamere & Shaw, 2008; Roster, 2007). This study found leisure as resistance described as an experience, context or ideal and allowed them to challenge how they viewed themselves (Fullagar, 2008; Wearing, 1990).

Leisure time is doing what I've want to do without a man telling me what to do. Or having to put up with their foolishness, their drinking. It's nice to know I can go out with a friend, go shopping, or spend a day with my daughters and not have to really answer to anybody for that. —Anna

Leisure for me would be if I could get out of bed in the morning, just for a day, I wouldn't like to do it very often, and really have nothing to do. That would be leisure. —Genevieve

The restrictions are there because of the drinking...I understand, I appreciate it. It's just I like to dance...I feel that maybe I should be doing that without him. And that may be wrong on my part but it...seems I've given up everything I've ever wanted to do because of my partner, [that is] nuts. They don't give up their hobbies for you, that's for sure.— Teresa

Leisure as Escape

Temporary escape through leisure (literal and metaphorical, short term and long term) was a strategy the women used to cope. Done alone and with leisure partners, it offered relief and removed focus from their roles, relationships, and commitments. Some described this opportunity as a distraction from the trauma and a time to let go of the "agenda" of stopping the PHI's use. Although leisure was rare, the women were well aware of its benefits (relaxation, rejuvenation and strengthening/nurturing themselves). It was seen as something positive to anticipate, sustain them through difficult times and put themselves "back on track" during a crisis. Descriptions of ideal leisure focused on vacations, eliminating caregiving responsibilities and being invisible to others.

[Leisure is] a detour from the norm to get your mind off you, life, your problems, off everything, and just concentrate on poking the needle or playing the card or whatever. To detour yourself to somewhere else, to some other place, some other way of thinking for an hour or two. —Teresa

Overall, the women identified leisure as a healthy outlet that helped rather than hurt them. But the women's leisure participation had the potential to be problematic. Descriptions of harms from overeating, shopping, alcohol use, and/or drug use were described as their own leisure escape.

[Through leisure] I'm way more able to cope with what I have to do every day, especially in relation with him. I have all these supports, I have all these ways that I know how to nurture myself. I'm not hurting myself which I would do before.—Alexis

Long-term benefits were also noticed by the women, including the impact on their overall health, well-being, and personality. It was also described as an alternative option to pharmaceutical stress reduction and sleep aids.

[Leisure is] very important. There have been lots of times I have just put [my work] down and flipped on the television to unwind. If I don't, the brain is still thinking [and] I suffer cause I don't sleep. I end up having to get up and get something to help me sleep. —Teresa

The women were realistic about leisure's coping potential. Although it helped on a day-to-day basis, during times of crisis, it was not always enough to help them find temporary relief. It was also not enough to change the overall oppressive context of their lives.

Right now [leisure] is not helping me. I can't get my mind off of this, but normally it would allow me to just get a second breath again. —Melanie (referring to her son's recent overdose on cocaine).

Discussion and Conclusion

Feminist work has long struggled to illuminate the value and range of work done by women (Armstrong & Armstrong, 2001; Waring, 2004). Our study presents an overlooked element of the undervalued role of caregiving and offers an exploratory view of the leisure experience of women balancing caregiving and CSO roles. Identifying this as care work is critical for supporting the needs, realities, constraints, and possibilities for these women, particularly around leisure.

The struggle to care both *for* and *about* the PHI was evident. Our results reinforce caregiving as "both love and labor, both identity and activity, with the nature of the demands being shaped by the social relations of the wider society" (Graham, 1983, pp. 13-14). All caregivers are not looked upon equally, and the experience of caregiving varies. Although other stigmatized contexts may exist (e.g., caring for family members with mental illness) those caregivers are not pathologized or labeled as having contributed or causing the illness. Our results support that the care work performed by these women is not unlike other care work and that most of this care work exists on the extreme end of the spectrum (Zadjow, 1995). We argue that the extreme nature is not necessarily derived from the acts of care, but from the shame, stigmatized and secret context where the care occurs and the lack of cultural and economic value afforded to women's emotional labor.

The social positioning and powerlessness women experience relative to men has little to do with female biology; rather it is a result of the social construction of femininity (Tong, 2009). Gendered socialization and family structures reinforce women's identity as caregivers. The women's descriptions of their roles, responsibilities, and relationship dynamics support the notion that women define and affirm themselves within the context ability to care (Armstrong & Armstrong, 2001; Gilligan, 1982; Graham, 1983). Dupuis and Norris' (1997) model offers an important lens for understanding the making and meaning of the role of caregiving for women in this context.

Defining one's self in the context of putting others first often leads women to suppress their needs, in particular leisure needs. With self-interest internalized as selfishness, women are not taught to value or prioritize personal time (outside of perhaps superficial physical beauty). Maintaining (at least the façade of) a well-kept home, feeding your family, and dressing and presenting them as clean and happy are markers of a good woman (Lorber, 2010). When placed in the context of HI, the struggle to maintain these markers of a good woman is intensified. This often pragmatic self-protection or cleaning up the messy, turbulent, and complicated consequences was an attempt to demonstrate to themselves and those around them that they were capable of meeting society's expectations of what a good woman does. This gendered division of labor has great benefits for society and the economy despite the obvious negative consequences on the women who care. Although the health care, social services, and legal systems all benefit from this undervalued work, rarely is it recognized contribution to the economy. Reinforcing evidence by Waring (2004), women's invisibility within these systems (and what we argue was pathologized visibility) remove power, value and respect for this work.

The women's lives were never free from obligation nor were they truly free to choose the types of activities in which they wanted to participate. Leisure definitions based on the masculine model that suggest leisure as high individualized time after paid work is complete, done at the discretion of the individual when his/her mind is guilt free and able to focus on nothing else fails to recognize women's lived experience (Waring, 2004). Balancing personal preference and gendered expectations, it could be argued the women sacrificed personally meaningful activities to protect themselves and those around them. Losing this opportunity to relax, rejuvenate, and restore challenged the women's ability to use leisure as a tool to cope with the context of their lives. Navon & Weinblatt (1996) offer a different perspective. They suggest the reduction in leisure activities, self-isolation, disregard for personal needs, and the types of duties taken on are not the cost of caregiving, but rather part of the caregiver's coping mechanism that allowed the caregivers to experience a sense of control over the situation.

Research shows women caregivers view respite care services as "luxurious self-indulgences" and may be reluctant to use them (Strang, 2001, p. 79). Maintaining the (perceived) secrecy of HI is often a family priority. Asking for help may enhance and expose feelings of shame and guilt. Although the stigma associated with HI may increase resistance to accessing supportive care, a more important consideration is whether respite care is even possible.

Leisure needs to be seen as a necessity as opposed to an indulgence. It offers women opportunities to resist societal expectations, challenge unequal power distributions in relationships, and demonstrate personal agency (Wearing, 1990). Leisure constraints will always exist, but the right to rest and leisure is a human right that needs to be protected and equitably supported for all (United Nations, n.d). Women need strategies to navigate constraints and the social and physical supports to do so. Policies and practices need to recognize the unique needs of these women.

For the women in this study, leisure under the right circumstances may offer opportunities for respite, escape, relaxation, and rejuvenation; decrease feelings of isolation and loneliness; and increase connection and social support. Glover and Parry's (2008) exploration of friendships developed post a stressful life event offers insight into the experiences of women in this study. They suggest although the emotional support and resources that result from friendships may be important to health and well-being, the norms and effective sanctions associated with friendships can be burdensome. Furthermore, Stranzdins & Broom's (2007) research suggests women in this situation may have limited capacity to provide others with emotional resources. This is problematic when most available help is found within self-help and mutual aid type programming. The struggle with social connection and isolation (which at times was self-induced) described by women in this study demonstrates the complexity of friendships and social support. Women caring for PHI may need additional support and strategies for negotiating physical and social leisure constraints influencing leisure access. Beyond using recreation and leisure as a coping strategy, some women in this study used it as a tool to gain a sense of control and power in their lives, contributing to their sense of self outside of caregiving roles. In safe environments, leisure can facilitate (re)building trust and relationships that have been impacted by HI

The way we conceptualize, negotiate, and distribute care remains problematic. Caring, and a women's capacity for care, is an essential element of our society and human identity and should be celebrated as a human strength, not weakness (Tong, 2009). The needs of caregivers have not been regularly or consistently addressed by service providers in substance and gambling treatment (Biegel et al., 2010). The blame-laden lens framing the caregiving done by women for PHI needs to shift and recognize the work, expertise, and skill these women offer. Their actions and acts of caregiving are their best effort to manage situations within the limits of their resources. The role

of unpaid caregiving is overlooked in policy on the financial impact to individuals and health care systems alike. Interventions need to assist caregivers in learning coping strategies, including thorough leisure. This research offers a modest beginning to a more informed response to the realities of lives of women in this context.

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