

1 Article

2 The spiritual journey of infertile couples: discussing 3 the opportunity for spiritual care

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13 Academic Editor: name

14 Received: date; Accepted: date; Published: date

15

16 **Abstract:** Infertility is a worldwide public health issue that exerts an in-depth impact on the
17 individual, couple, families and communities. This reproductive health condition, along with
18 fertility treatments, often forces couples to question and to find a new purpose and meaning in life,
19 and to begin a spiritual journey. Nursing and midwifery literature comprises the care of those
20 living with infertility, but often lacks a clear approach of the spiritual dimension, and diagnosis and
21 interventions may not be effectively addressed. In this paper, we present a discussion about
22 spirituality and the assessment of spiritual needs, such as hope, beliefs, meaning and satisfaction in
23 life. In addition, spiritual needs are defined, for both nurses and midwives, and spiritual
24 interventions are proposed in promoting couples' resilience and spiritual well-being. Spirituality
25 should be considered from the beginning to the end of life. It is necessary to translate this into the
26 development and implementation of specific policies regarding a spiritual approach, and also
27 advanced education and training programs for nurses and midwives who care for infertile couples.

28 **Keywords:** infertility; spirituality; spiritual care; nursing; midwifery.

29

30 1. Introduction

31 Infertility is a health problem that affects couples worldwide, regardless of their ethnicity,
32 society, culture or economic status [1–3]. The complex definition varies across disciplines [4], but is
33 mainly described as a condition manifested through the inability to conceive and to achieve a
34 successful clinical pregnancy after 12 months of regular and unprotected sexual intercourse [5]. Yet,
35 this generally accepted time frame is reduced to 6 months when individuals are over 35 years old
36 [4,6]. A primary and a secondary form of manifestation are recognised. Primary infertility happens
37 when there is the inability to achieve conception and to have a successful live birth without ever
38 having a child [7]. On the other hand, secondary infertility is the inability to achieve conception and
39 have a successful live birth when individuals have already had a previous biological child [7]. This
40 reproductive condition is silently experienced with deep and undeniable repercussions in the
41 essence of self, whether a man or a woman [8,9]. Moreover, being involuntarily childless can defy
42 the sense of one's completeness and wholeness due to the unfulfilled wish of parenthood [10–19].
43 Although infertility is identified, at first, as a physical problem, it is a broad and holistic experience
44 commonly associated with psychological, emotional and spiritual distress [15,20–23]. Being
45 diagnosed with infertility and receiving fertility treatment may induce an additional strain, not only

46 in marital relationships, but also in the societal roles individuals play [24]. Similar to other health
47 conditions, such as chronic illness [25–27], infertility is often described as a disease that can affect the
48 sense of well-being and life satisfaction [28]. As a result, a spiritual crisis may arise leading couples
49 to question their meaning and purpose in life [21,29]. Nevertheless, focus has remained on the
50 physiological and psychosocial aspects of involuntarily childlessness diagnosis and treatment
51 [9,24,29] rather than on the spiritual dimension of living with this condition [21]. Spirituality is often
52 described as a poorly explored dimension in nursing and midwifery practice [21], but attempts have
53 been made to overcome some barriers [30]. The significance of this life transition within a paradigm
54 of patient centeredness care reinforces the need for discussing the spiritual journey of infertile
55 couples [19,31]. This paper discusses the opportunities for nurses and midwives in providing an
56 effective holistic care based on relevant literature.
57

58 2. Living with Infertility

59
60 The complex nature of infertility is deeply experienced by most couples [32]. It's multi-systemic
61 impact affects the environmental and personal realms of each individual and for some this can
62 manifest as an extreme and traumatic event [32-33], in which couples may face questions concerning
63 the purpose and meaning of life [13]. Additionally, a person's perception of adulthood is closely
64 related to their social and cultural background, based on several expectations. Couples are mainly
65 expected to have children, take care of them and to preserve the bloodline inheritance [10]. This is a
66 societal expectation in many countries, and though there is ultimately more choice and diversity in
67 modern society, not being able to live up to perceived expectations or norms can affect the couple
68 psychologically and make them feel inadequate. Preconceptions related to becoming a father present
69 men with the implicit duty to generate a biological child in order to perpetuate the genetic heritage
70 [8,34]. Men and women's life satisfaction are, therefore, conditioned since early age by the ability to
71 fulfill the expected role of parenthood [14,18-19].

72 Being a mother has not only an implicit connotation within society but is also associated to the
73 belief in the sacred nature of motherhood [11,18]. Motherhood has been defined as a transcendental
74 state [17,37]. The transitional process to maternity is reached through conceiving, carrying a
75 pregnancy and giving birth, and this is compared to an expected spiritual journey [10,17]. A review
76 over 20 years of cross-cultural phenomenological research found childbearing has the ultimate
77 achievement of a holistic existence [17]. Pregnancy and labor are considered significant rites of
78 passage capable of inducing a meaning and a spiritual transformation, regardless of whether women
79 are committed or not to a religious belief [17,38].

80 Some infertile women have manifested craving not only for the purpose of childbearing and its
81 implicit self-growth, but also being able to connect to other women [16,39]. Sharing similar
82 experience of birth seems a way to perceive the wholeness of the events, and to develop a new
83 meaning to what women have similarly experienced in their transition to motherhood [40]. The
84 inability of going through this expected transitional process has lead authors to describe? infertility
85 as a "non-event transition" [27] and an existential crisis [36].

86 Although both genders are affected by this reproductive health condition, evidence reveals that
87 the focus on women is more evident when compared to men [41]. Nevertheless, sparse research has
88 acknowledged the equal significance of this phenomenon to men [8,14,24,34]. Not being able to
89 follow the natural course of conceiving leads to disconnection with self-identity and a diminished
90 sense of self, which is manifested by depreciative descriptions of being dysfunctional [10], defective
91 [37], sterile [37], helpless [37], impotent [18], incomplete [10], incapable [18], less of a woman [16],
92 not a woman [11], half a man [14], low self-esteem [16,33], useless [10-11,13,18] , ugly [10], not pretty
93 [42] and a failure [15,19,43]. Self-guilt in some cases is expressed in association with delayed
94 motherhood, particularly in cases of advanced maternal age and when career accomplishments have
95 occurred before trying to conceive [19,37,44].

96 Going through the process of an infertility diagnosis often means needing Assisted
97 Reproductive Technologies [ART] as a therapeutic strategy to have a biological child [45]. Women
98 generally assume the main role in engaging with fertility treatment and care [12,14] however a
99 negotiation also has to be made with the partner and in some cultures with the extended family in
100 order to be able to access professional health assistance and treatment [16]. Men take on generally a
101 more passive role in any related medical treatments and in the decision-making process [15,19]. This
102 behaviour may not be always appreciated by the woman concerned [12,14,37].

103 Involuntarily childlessness may dominate the couple's lives to such an extent that it leads them
104 to delay other personal projects over fertility treatments [15,19,33]. Individuals are forced to break
105 routines and to face several changes in a turmoil of emotions [37,46] and in induced psychological
106 distress [24]. Nevertheless, it is important to put their own emotional responses aside in order to
107 endure critical drug administration, hormonal level checks [19,47], and invasive procedures with
108 recognised physical effects [12,15,19,26,37,42,44,47-48]. The treatments are hard [10,15,18-19,37,44]
109 and characterized by contradictory feelings of hope and despair [12,33,48-49]. Hope arises every
110 time a new treatment starts or with the positive result of a pregnancy test, but is replaced by grief
111 and mourning with failed procedures or miscarriage [22,37,50]. A sense of loss of control over
112 medical procedures, rigorous routines, and failed pregnancy attempts appear to go against all the
113 achievements couples had so long struggled to attain in their lives [19,46]. Spiritual suffering is
114 therefore triggered and constantly manifested through a mix of emotions most commonly
115 recognised as pain [11,15-16,37,42-44,46], stress [33,37,42-43,48], anxiety [10,15,37,44,49], hurt
116 [12,14,16,37,43], upset [10,19,37,46,51], frustration [37,43,48,52], anger [14,22,33,51], depression
117 [33,37,42,48], emptiness [10,14,22], fear [11,44,48], giving up [15,22,43], isolation [33,42,47], loneliness
118 [11,46,52], being lost [11,22,37], sadness [19,33,44], and being scared [16,37,42].

119 Financial and economic constraints emerge due to the expensive charges of unsuccessful
120 treatment cycles and to an intensive pursuit of parenthood at all cost [49,52]. The couple's
121 commitment to this common goal usually makes couples more supportive of each other [10,12-
122 15,37,42,46,51]. However sexual intercourse may be considered more as a task other than a natural
123 interaction [12,42,46]. A couple's relationship is not always reinforced and reassured, and in some
124 situations has led to manifestations of domestic abuse towards women [11-13], affairs by both
125 genders [13,14,53] and divorce [11-14,42,44,53].

126 In extreme cases extended family may voice depreciative judgments, insults and aggressive
127 behavior targeting infertile women [10-11,13,14,37,44,53] leading to the exclusion from social
128 gatherings [11] or a self-withdrawal from these [12,37,46,51]. Infertile couples have often reported as
129 not being able to match expectations or to be fully understood by others [10,12,13,15,42,44,46,47].
130 Connection to friends therefore becomes more sparse or absent [13,33,47]. In addition, contact with
131 pregnant women and children are perceived by these couples as a proof of others' fertility and the
132 recall of one's own inability to conceive [10,12,51]. This situation may lead to social interaction
133 barriers and to isolation [14].

134 When pregnancy is finally reached, couples cautiously celebrate [37]. Nevertheless, the fear of
135 something going wrong is still deep-rooted and can prevent men and women from recognising
136 themselves as parents and engaging in normal preparation for their child's arrival [37]. With
137 successful parenthood comes constant anxiety related to the remaining time to take care and to
138 watch over the growth of their child [44].

139 In many cases, couples' resilience is triggered by the infertility experience that is lived as an
140 opportunity for inner transformation and positive spiritual growth [14,15,42,46,51]. After a long time
141 in medical procedures with no child, the burden of treatment leads couples to cease their unfruitful
142 quest and to reach other forms of fulfilling their lives [54]. Focusing in their relationship, career,
143 educational projects [15,16,51] or other possibilities such as adoption [10,12,15-16,33,37,42,52] or
144 activities that provide close contact with children [12,52] were seen as realistic goals [51] and
145 acknowledged by some as new purposes in life.

146

147 2.1. Epidemiological aspects of infertility

148 Infertility is both an intimate reproductive health condition and a worldwide growing health
149 problem [3]. In 2010, a total of 48,5 million couples around the globe were dealing with this health
150 problem [3], and researchers believe that these numbers do not totally address the extent of its
151 prevalence due to different definitions across disciplines [4]. Inaccurate data has also been associated
152 with the fact that not all individuals with this health concern perceive themselves as infertile, and
153 this may compromise the full assessment [3,24]. Moreover, constraints related to the sensitive nature
154 of this phenomenon might compromise couples' infertility reports [3]. Despite that, this is
155 acknowledged as a public health priority [1].

156 Findings from a World Health Organization [WHO] study conducted in a diversified social and
157 cultural sample of 190 countries revealed that 1.9% women experienced primary infertility while
158 10.5% reported to manifest a secondary type of reproductive health condition [3]. This resulted in
159 19.2 million couples not being able to have a first-born and 29.3 million couples unable to have
160 another child [3].

161 Several environmental, occupational, genetic and infectious diseases have been identified as the
162 causes of impaired reproduction [1]. Both genders are affected in 40% but the most common reasons
163 for reproductive issues are related to gynecologic and other conditions, such as ovulatory disorders
164 [25%], fallopian tubal damage [20%], and uterine or peritoneal abnormalities [10%]. Also, in 30% of
165 cases of infertility, causes are unknown [55]. This health condition is not only related to physical
166 impairment, but also results from current societal trends [24]. For instance, child-seeking behaviour
167 was reported to have decreased between 1990 and 2010 [3]. Additionally, the need to reach
168 economic stability, financial independency, a career, and educational goals lead men and women
169 to delay conception [19,37,44]. All those factors are reflected in the increasing age of people that get
170 married [56] and in the delay in having the first child, which occurs between 25 and 49 years [3]. The
171 advanced age of couples engaging parenthood is an important aspect in fertility, as it is related to the
172 decreasing physical ability of having a child [57]. Concerns towards the unknown future of the
173 world's next generation are raised not only because of the aging population, but also due to the
174 rapid decrease in fertility rates [58], with an estimated reduction of children per women in the years
175 to come [58].
176

177 *2.2. Nursing and midwifery in this specific context of care*

178 Scientific advances in recent years lead to the development of a variety of health services in
179 addressing infertility as a global problem, and in helping couples to achieve their fullest
180 reproductive health potential [45]. An urge to conceive lead to the demand not only for medical and
181 surgical treatments, but also for advanced reproduction techniques. Regardless of the growing
182 success of these methods of conceiving, a positive outcome is not guaranteed in all cases, resulting
183 in the pursuit of recurrent treatment cycles [45]. These procedures are regulated by specific
184 reproductive protocols and policies in each country [39]. But, in 2007, the United Nations
185 implemented protective measures for women's reproductive health [59]. Infertility care was
186 therefore included in the Fifth Millennium Development Goal, which was far from being fully
187 accomplished in 2015. The need to improve sexual and reproductive health inequities remains [60].
188 The development of such programs generated the need for an integrated interdisciplinary approach
189 in the fertility care setting. Examples are found in the guidelines released by the National Institute
190 for Health and Care Excellence [55].

191 Studies conducted with samples of infertile people have commonly focused on the
192 bio-psycho-social and cultural dimensions of living with this health condition [29,32,50,61–64].
193 Although sparse, nursing and midwifery literature addressing impaired reproduction is growing,
194 revealing an increasing attention towards care provision, specifically in the ART settings. Advances
195 have been achieved through protocols that are specifically designed to address psychosocial needs
196 [65]. Recently, a positive relationship was found between the psychological status, the couple's
197 relationship, the child-carrying rates, and psychosocial nursing interventions [64]. Scholars attention
198 seems to keep focusing the emotional dimension of this unanticipated life and health event [66,67],

199 even comprising multicultural samples and socio-economic diversified environments, in both
200 qualitative and quantitative research [24].

201 A person centered approach has been underlined as playing a determinant role in the
202 implementation of policies which comprise an holistic approach, as those including spiritual needs
203 [19,21,31,55]. Even with evidence of spiritual needs, such as hope [43] and meaning and satisfaction
204 in life [28], a consistent and clear spiritual approach is missing in the infertility care context [21,68].
205 Previous studies reported that women engaging in religious practices have a coping mechanism in
206 transcending spiritual distress [69]. These findings reveal the current trend to address spirituality
207 through the lens of religion and religiosity [21,35], but other attributes of spirituality should be taken
208 into account, such as connectedness, transcendence and meaning in life [70]. Spiritual needs are
209 known to be influenced by social and cultural aspects, and to be determined by family values, which
210 might influence the choices of treatment [35]. Yet, disturbed connectedness to self, to others (to
211 husband or wife, relatives, friends and healthcare professionals), and to a higher power are
212 commonly described in infertile people [24]. Early studies have concluded that nurses and midwives
213 should receive specific training regarding spiritual assessment and interventions [71], to support
214 couples through all stages of the journey of living with infertility, from the diagnosis to the
215 treatments, and beyond [35,43,54]. In fact, spiritual distress may occur in infertile couples [21], and
216 this is a nursing diagnosis listed in NANDA International, since 1978 [72], and no validation was
217 found in infertile couples, but was, for example, in cancer patients [73]. When nurses and midwives
218 diagnose they are confirming their autonomy in clinical reasoning, which pervades the assessment,
219 the planning and the interventions, based on a person-centered paradigm. Infertility is a specific,
220 vulnerable condition and has a specific context of care, which requires a particular approach, such as
221 that of the Patient Centered Infertility Care (PCIC) [19]. This is a specific relational model based on
222 provision of holistic and supportive care capable of connecting all intervening actors (patient,
223 couples, family, and health care professionals) and environments or contexts (fertility clinic's
224 organization, protocols, policies , communities and countries) to help each in the transition to
225 healing and perceiving well-being [19].

226

227

228 3. The imperative of a holistic and multidisciplinary approach

229 An attempt has been made to understand the wholeness of the couple in this context, but the
230 physical, emotional, psychological, social and spiritual dimensions have been often addressed
231 individually. Researchers have mainly focused on the psychological and social aspects of the lived
232 experience of infertility [24,29,74]. The perception about this reproductive issue is affected by both
233 interpersonal and intrapersonal factors [36], and several studies have been conducted in an attempt
234 to define a pattern of human response towards infertility. Examples are found in the established
235 relationship between a positive adjustment to infertility and age, high socioeconomic and
236 educational status, positive self-esteem and internal locus of control and the relationship between
237 distress and advanced age and low self-esteem [27]. Only sparse evidence has lifted the veil and
238 uncovered the presence of a spiritual realm in individuals living with this reproductive condition
239 [20-21]. Being a religious woman and having a supportive family was associated with positive
240 coping and with finding meaning in infertile women [36]. A full understanding of the phenomenon,
241 as lived by the couple, would not be possible without a holistic view of the interconnection between
242 body, mind, soul and spirit [75]. In contrast to the biomedical model, each person is perceived to
243 own specific needs and capable of affecting and being affected by the environment, in a particular
244 and individual way [75]. These assumptions based on Florence Nightingale's standards are
245 fundamentals of the nursing and health care [76]. The ground for holistic nursing care [75] has been
246 established and endorsed by organizations, such as the American Holistic Nurses Association
247 (AHNA) [77]. All commonly embrace a person's health as a dynamic process and as a result of the
248 relationship between the individual and the environment, between the subjective and the objective
249 aspects of the life experience [76]. Individuals are seen in their own contextualized life [75] and in a

250 constant balance with internal and external factors [76]. A disruption in the balanced interaction of
251 all dimensions may compromise the individual's ability to adapt and to deal with life's stressors
252 [75]. Disturbance in the sense of well-being may arise and induce a change on health status towards
253 illness [78]. Complex interactions between all of those realms determine the individual meaning,
254 well-being and quality of life [75]. This seems to go along with the WHO's established health
255 concept as a state of well-being (physical, mental and social) and not merely the reductionist absence
256 of disease or infirmity [79]. Additionally, empirical evidence have demonstrated that the
257 individual's perception of infertility is influenced by the meaning each individual attributes to that
258 reproductive health condition [24]. A state of well-being is therefore defied when the expected and
259 desired goal of parenthood is compromised by the diagnosis of infertility [28,36]. The subjection to
260 painful procedures, the lack of control over treatment outcomes, the social pressure from partners,
261 friends, family and community, are described as stressors which may be manifested in mental health
262 conditions such as depression [62,80]. Emphasis is therefore placed on an integrated approach [76]
263 provided by holistic nursing or midwifery care, based not only in a scientific knowledge-based, but
264 also in a sensitive and intuitive therapeutic relationship [81]. Thus, seems important the practice of
265 conventional and complementary therapies in a collaborative effort to provide multi-systemic and
266 multidimensional care capable of regaining and maintaining health and preventing illness [75,76,78].
267 A fragmented approach to caring for couples who present with fertility concerns/challenges? is
268 evident in the literature along with the need to invest in a holistic health approach [38]. The answer
269 to complexity is only possible and continuously reaffirmed by close collaboration among different
270 disciplines [78], as well as an integrated and interdisciplinary approach between all members of the
271 health care team [75,78]. The WHO [82] and The Lancet Commissions report [83] provide useful
272 guidelines for interprofessional education as a path to collaborative practice and to reach the
273 transdisciplinary health approach.
274

275 *3.1. Moving beyond emotional aspects and understanding the spiritual dimension*

276 Scholars' concerns towards spirituality are mainly associated with holistic understanding of the
277 human being [84]. Studies have broadly addressed spirituality in settings of persons living in
278 different phases of the lifespan, such as childhood [85], adolescence [86] and adulthood [87-88], with
279 focus on specific situations of extreme vulnerability, such as chronic illness [73,85,87], intensive and
280 palliative care [88-90]. Extreme life events and death experiences are commonly found not only in
281 nursing, but also in midwifery literature. Religious practices frequently emerge in neonatal intensive
282 care units with the awakening of not only an individual's emotional response but also a spiritual
283 response [90]. Nevertheless an increasing body of evidence has raised interest in transitional events
284 like child-bearing, child-birth or parenthood experiences [38,40,91]. Those could be seen has
285 reminders that spirituality should be considered from the beginning to the end of life. Grieving,
286 spiritual self-growth, self-awareness, redefinition of self-identity and meaning emerges in every life
287 transition, such as in illness or in a life crisis.

288 Spirituality has a complex and multidimensional nature [70] and is considered to be a human
289 dimension, innate to existence [84,92], and difficult to strictly define. Spirituality is "a way of being
290 in the world in which a person feels a sense of connectedness to self, others, and/or a higher power
291 or nature; a sense of meaning in life; and transcendence beyond self, everyday living, and suffering"
292 [70]. Connectedness, transcendence and meaning in life were therefore identified as the main
293 attributes of spirituality, regardless a religious affiliation [70]. The need to apprehend the subjective
294 nature of this concept led researchers to develop instruments of measurement in specific
295 populations and settings [92].

296 Although recognised by several authors as an essential dimension in life and health, the WHO's
297 definition of health still lacks a full approach of spirituality [93]. This gap seems to be related to the
298 biomedical model and the poor development and implementation of policies towards effective
299 holistic care [93]. Spiritual well-being is considered by many as the missing fourth dimension of
300 health [94]. The way in which the dynamic relationship between personal (self), communal (with

301 others), environmental and transcendental domains occur is reflected in one's spiritual health and
302 spiritual well-being [92]. Emphasis in emotional status and psychological well-being has buried
303 spiritual well-being under the cognitive approach of the mind instead of an in-depth understanding
304 of the spirit [92]. Findings have proven that defective or absent harmonious relationships between
305 self, others, environment or higher power compromises the wholeness of one's spirit [84,92], and
306 impacts one's psychological health [95].

307 Similar to biological needs, hope, forgiveness, justice, love, creativity, peace, joy, trust, identity,
308 self-worth, adoration, harmonious relationships, meaning, purpose in life and religious practices are
309 expressions of spiritual needs [92]. Not meeting those spiritual needs can create a spiritual instability
310 and induce spiritual distress defined as "a state of suffering related to the impaired ability to
311 experience meaning in life through connectedness with self, others, world or a Superior Being" [89].
312 Therefore, the lack of a fundamental need such as meaning and purpose in life as perceived by
313 infertile people may induce spiritual distress in this population [15,18,20,22,37,42,46]. If not resilient
314 or capable of effectively coping with this adversity, then self-healing may be compromised and
315 suffering may be manifested through isolation [10–13,33,37,46,47,51], low-self-esteem [16,33],
316 anxiety [10,15,37,44,49] and depression [33,37,42,48]. Those with infertility have also reported using
317 rituals like prayer [10,16,20,37,42,48], meditation [37], attending church, sanctuaries and shrines
318 [16,46,48], in a spiritual path to transcend suffering and strengthen their hope in their parenthood
319 pursuit. Religious practices are commonly addressed as a way for couples to find meaning in life
320 and to prevent hopelessness [15,37]. But these are not the only spiritual resources they use. Other
321 non-religious coping strategies are described to help individuals regain some kind of spiritual
322 comfort [20] through becoming persistent and resilient [15] in facing failure and focusing on the
323 positive outcomes of this adverse event [22].

324 Developments made towards the linkage of healing, health and illness with spirituality are still
325 far from full understanding [70,92]. Many links keep unknown and several proposals for further
326 research are still emerging from current literature [93]. People dealing with infertility are still lacking
327 a spiritual and integrative health approach [21,68].
328

329 *3.2. Opportunities to provide spiritual care*

330 Spirituality is considered an essential aspect of providing holistic and person centered care [81].
331 A person centered approach, promotion of self-awareness and empowerment of each person are
332 advocated principles in assessing and caring for the human being [75-76,78]. Despite that, diagnosis
333 and interventions are not effectively addressed, and depreciative reports of infertile individuals
334 towards fertility services and health staff are commonly expressed [68]. An alarming absence of
335 connectedness with health professionals is reported, and the interactions are often described as
336 distant, dehumanized and lacking sensitivity [10,12,19,33,37,42,47,96]. Professionals' concerns
337 towards the biological causes of infertility and its cure makes them focus on the physical condition
338 and treatment procedures rather than on the wholeness of the infertile person or couple [19,42,47].
339 Consequently, a sense of mistrust and humiliation is described by patients along with the sense of
340 their emotional, psychological and spiritual needs being actively neglected [42]. Communication
341 [19,33], information [19,33,46,52,96], promotion of realistic hope [33,47], accessibility of care
342 [16,19,33,96], support [18-19,33,42,47], and empowerment [33,47,96] were identified as areas in need
343 for further improvement. These aspects are crucial in the relationship established between staff and
344 patients, and are affecting future interactions between people living with infertility and health
345 caregivers and the decision-making process. Distant interactions and defective communication
346 associated with the exhaustive treatment procedures have been pointed as one of the main reasons
347 to quit fertility treatment [54].

348 Nurses and midwives have been identified as having a main role in all In Vitro Fertilization [IVF]
349 processes [19,33]. In some cases, their intervention is negatively perceived and linked with the
350 enhancement of patient's sense of lost control [37,47], and in reinforcing the passive role of
351 individuals in the decision-making process [47,52]. Unappreciated comments and information

352 denials made infertile patients conscious of the poor availability of the team to answer to their
353 specific needs [42,52,96]. Unrealistic hope nurtured by the health care team is seen as unfruitful, as
354 the high expectations are normally shattered after a few attempts without positive conception results
355 [47].

356 Professionals' unawareness of the spiritual needs assessment, and the lack of organizational
357 environment conditions to provide spiritual care have induced lower levels of satisfaction in fertility
358 services [20]. The inability to cope with all involved, the clinical and the treatment procedures, lead
359 to burden and, consequently, to treatment withdrawals [54]. The high rates of burden in this
360 population may therefore reflect the existing gap in the provision of effective holistic care [20].
361 Mandatory interventions towards promoting hope and resilience are essential to empower and help
362 infertile individuals in achieving well-being [20]. Nurturing care, capable of transcending the
363 physical reality is grounded in the nursing spiritual care principles of a "healing presence,
364 therapeutic use of self, intuitive sense, exploration of the spiritual perspective, patient-centeredness,
365 meaning-centered therapeutic intervention and creation of a spiritual nursing environment" [91]. A
366 sensitive approach to care comprises the respect for values and beliefs regardless of a religious
367 affiliation [20]. Though workload [20] and lack of training to deal with patient's spiritual issues [68]
368 emerge in nursing and midwifery disciplines as barriers in bringing this dimension into practice
369 [30]. Nevertheless, efforts have been made to perceive this context of living with infertility as an
370 opportunity to provide spiritual care [20]. Advanced education and improving communication skills
371 to adequately assess distress have been reported as emergent in the provision of accurate
372 information to infertile couples and in enhancing empowerment in the decision-making regarding
373 fertility treatments [54].

374 A holistic approach to the care of infertile couples may be effective when a thorough assessment
375 of their physical, emotional, psychological, cultural, social and spiritual needs is implemented and
376 when interventions are taken towards experiences in and beyond the fertility clinic. Nurses and
377 midwives must be prepared, aware, present and supportive in keeping hope, healing, spiritual
378 well-being, psychological adaptation, life satisfaction and a state of well-being [35,81], within a
379 multidisciplinary healthcare team. Equally essential is to be respectful of each human singularity as
380 well as their personal values, religion and beliefs [20], in the context of living with infertility.

381 4. Conclusions

382 Dealing closely with situations of chronic illness and death experiences has awakened a broad
383 interest by health teams in the development of a spiritual approach in care, particularly in caring for
384 vulnerable people. Similarly, the intense life experience lived by infertile persons has deep
385 manifestations in the sense of self and meaning in life, and can also be considered an emergent
386 opportunity for spiritual care. Spirituality should be considered from the beginning to the end of life,
387 and couples express suffering when facing this situation, from the diagnosis of infertility to the
388 treatment and beyond. This dominates the individual's thoughts, feelings and purpose in every
389 aspect of their lives. This unanticipated event when associated with the inability in transitioning and
390 creating a new meaning in life may pose individuals to a crossroad between the decision of
391 continuing the pursuit of having a biological child and the decision to adopt a child. Although the
392 need for a theoretical integrated approach has been recognised in the fertility setting, the biomedical
393 approach still prevails and fragmented attention is still given to the patient with poor consideration
394 of spirituality. Infertility is not the merely absence of a desired state of parenthood instead it is a
395 more complex experience with several internal and external dimensions being affected by this
396 reproductive health condition. Hope and resilience are the main issues in the fertility healthcare
397 services, however the success is not guaranteed. Following interactions with staff are therefore
398 affected and sometimes with extreme reactions like withdrawal from treatment. The translation into
399 the development and implementation of specific policies regarding the spiritual approach is needed,
400 as infertility is a growing and wide ranging health problem. Equally essential is collaborative team
401 work and recognition of own discipline limitations in providing counselling and spiritual comfort.
402 An integrated approach respectful of the boundaries of each discipline's fields of intervention is the

403 answer to an increased quality in nursing and midwifery care and promotion of the patient's
404 well-being.

405 Future research is needed in adapting existing instruments for measuring spiritual well-being,
406 hope, resilience and life satisfaction in this population. Longitudinal and cross-cultural studies
407 should be implemented in order to understand how spiritual needs evolve through diagnosis,
408 treatment and beyond. The impact of this reproductive conditioning is usually addressed in small
409 samples and by gender which poses the need for a broaden understanding of this reality lived by
410 couples and the impact it exerts on a relationship. In addition, the effect that religious belief has in
411 patient's decision-making in engaging medical treatments for infertility and how faith in believers
412 and non-believers evolves through all phases of diagnosis, treatment and after ceasing ART.
413 Evidence related to the effectiveness of nursing and midwifery spiritual interventions are essential
414 to develop a more integrated and holistic approach to care not only in infertile individuals that
415 pursue ART but in those who experience this reproductive conditioning outside fertility clinics.

416 In conclusion, it is nursing and midwifery disciplines and professionals responsibility to
417 develop evidence-based knowledge and practice that guarantee a higher quality of care to people,
418 who endure the struggle of not having a biological child.

419
420

421 **Author Contributions:** J.R. and S.C. were responsible for the study design, collected the data, and draft the
422 manuscript; J.R., S.C., V.B., J.H., and F.T contributed in the critical reflection in the manuscript. The final
423 manuscript was approved by all authors.

424

425 **Conflicts of Interest:** The authors declare no conflict of interest.

426

427 **Abbreviations**

428 The following abbreviations are used in this manuscript:

429 AHNA American Holistic Nurses Association

430 ART Assisted Reproductive Technologies

431 IVF In Vitro Fertilization

432 PCIC Patient Centered Infertility Care

433 WHO World Health Organization

434

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