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# Reassessing the goals of musical activities for people living with dementia: Supporting joint agency, selfhood and couplehood with an embodied and relational approach

Justin Christensen\*, Renee Timmers, Jennifer MacRitchie

Department of Music & Healthy Lifespan Institute, University of Sheffield, Sheffield, United Kingdom

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#### ABSTRACT

A risk present in medically informed psychosocial interventions for dementia, including musical interventions, is the potential to overly prioritise the reduction of cognitive decline, which can inadvertently emphasise deterioration and loss of skills and capacities. This focus can lead to disempowering people living with dementia rather than supporting and building on the skills that remain. In this paper, we present approaches linked with a more positive outlook on dementia, examining the strengths that continue in people living with dementia, as evidenced by how they engage in musical activities. We pay specific attention to how people living with dementia use embodied and relational ways of being and interacting with others, as well as the benefits that musical engagement can provide to selfhood, couplehood and agency in a context of change and adaptation due to the development of the condition. We propose a shift in perspective that takes advantage of music's affordances for embodied communication and connection, recognising people living with dementia as active agents with strengths in habituated ways of acting. With this shift we examine how couples can scaffold each other's abilities to reach towards a balanced sense of reciprocity. To further support this balanced reciprocity through embodied and relational aspects of musical participation, we make a proposal for the design of assistive music technologies that will support notions of we-perspective, joint agency and joint action, with each of these providing wellbeing benefits for people living with dementia and their carers. Drawing on the potential effects that embodiment and relationality have on agency, selfhood and couplehood in musical engagement, we present a case for reassessing the goals and design of musical activities and the technologies to support them.

# Introduction

Musical activities are increasingly being recognised as a means of supporting the wellbeing of people living with dementia, whilst also having additional potential benefits related to cognition, emotion, communication and social connection (Meadows & McLennan, 2022). In the research underpinning this increasing use of music in dementia care, however, there is a disconnect between the focus of study outcomes (typically individual behaviour and cognitive performance, Hydén & Forsblad, 2018) and the wishes of people living with dementia and their carers (typically centred around meaningfulness, relationships and communication, Reilly et al., 2020). The majority of research in music and dementia care is also built around the deficit model, focused on countering the loss of abilities rather than providing tools for accessing the remaining strengths of people living with dementia. In this

perspective article, we propose a shift in research focus that explicitly builds on strengths that remain in people with dementia, allows people to act with agency, and offers what they and their carers most value. Drawing on recent developments in the literature, we outline the theoretical foundations for the development of future musical interventions and activities. We use this perspective review to critically examine how research evaluating musical activities and the goals of musical interventions can be better aligned with the needs and interaction strengths of people living with dementia. Activities can more relationally involve the person with dementia and relevant others, such as their spouses or (family) carers, supporting the relationship-building valued therein (McDermott et al., 2014). We conclude by outlining what this means for the design of musical interventions and how these may be supported using music technology.

One of the fundamental goals of dementia research is and has been to

<sup>\*</sup> Corresponding author at: Department of Music, University of Sheffield, Jessop Building, 34 Leavygreave Rd, Sheffield S3 7RD, United Kingdom. E-mail address: j.christensen@sheffield.ac.uk (J. Christensen).

find a cure through the improvement of diagnosis and understanding of disease pathophysiology (Wong & Knapp, 2020). While this medicalised approach has led to many significant advancements in understanding dementia pathology, it can also perpetuate deficit-model-based research that focuses on the skills lost by people living with dementia and what they are no longer able to achieve (Cuijpers & Van Lente, 2015; Dowlen & Fleetwood-Smith, 2023; Hydén & Antelius, 2017). This, combined with dementia also being widely negatively portrayed in popular culture as a condition characterised by loss of memory, mind, identity, agency, and selfhood, fuels public anxiety about the disease (Low & Purwaningrum, 2020). In this context, engagement with music runs the risk of being seen as an isolated phenomenon that remains relatively well preserved, allowing temporary relief for those with sufficient levels of skill in otherwise declining conditions.

The deficit model of cognition generally relies on a disembodied perspective of the mind. From this disembodied viewpoint, a loss of cognitive and communicative abilities is, to put it crudely, equivalent to an individual being left with a body that is an empty vessel (Hughes et al., 2006; Kontos, 2005). According to this viewpoint, since cognition is hardwired in the brain, deterioration of the brain is a deterioration of selfhood and agency (Folkmarson Käll, 2017; Miller & Boeve, 2009; Tewes, 2022). Such disembodied viewpoints of dementia disease progression are not supported by empirical evidence, which instead suggests that many abilities assigned to the cognitive or mental realm do not deteriorate throughout dementia disease progression (Baird, 2019; Hennelly, 2020; Kontos, 2004). This lack of evidence suggests that a shift in thinking is required to one that is more empirically supported.

An alternative viewpoint is that associative and behavioural learning (drawing on connections between brain, body, and environment) are in many respects spared, allowing more embodied types of abilities, learning, and selfhood to continue (Baird, 2019; Baird & Thompson, 2018a). This highlights the opportunity for interventions to support behaviours and modes of communication that utilise embodied abilities and learning, and help people living with dementia retain agency and selfhood (Cohen-Mansfield et al., 2006; van der Byl Williams & Zeilig, 2023). This is corroborated by the perspectives of people living with dementia, who indicate that despite problems, they feel like they are the same person, and they continue to have a strong sense of agency and self when given opportunities to do so (Mariani et al., 2016). While there can be exceptions to this-such as the inability to recognise loved ones, which people living with dementia rated as most detrimental to their sense of self (Harris et al., 2021)-this does not imply that recognition is a cognitive ability in and of itself. Rather, it functions as a tool to reestablish and support connections with others. Evidence similarly points towards the benefits of appreciating embodied and in-themoment encounters, with people living with dementia and their family carers placing more emphasis on finding enjoyment, resilience, love and support, humour, hope, identity and growth with their current abilities than on enhancing cognitive function (Wolverson & Clarke, 2016). Dementia severity is not a significant factor in determining quality of life, with people at all stages, including advanced stages, being able to experience a good quality of life (Millenaar et al., 2017). Instead, Millenaar and colleagues found it was depressive symptoms, a lack of disease awareness, and being confronted with their limitations with the resultant loss of autonomy that had the most detrimental impact to quality of life.

When examining the design of musical activities and interventions in dementia care, one can see an implicit focus on addressing cognitive decline and its challenges to quality of life. For example, meta-analyses and summative reviews of music therapy for people living with dementia focus on its effect on cognitive function (Fusar-Poli et al., 2018) or a combination of mood, cognition (Baird & Samson, 2015) and quality of life (Moreno-Morales et al., 2020). Additionally, in the pursuit of generally applicable solutions, musical activities have been binarized into receptive and active extremes (these classifications now going against their original purpose of helping design and deliver

individualised music therapy sessions; Bruscia, 1998). Irrespective of such binarization, music has not been found to deliver benefits to people living with dementia universally, demonstrating strong individual differences in how they respond to musical activities (Tsoi et al., 2018). It has been proposed that musical activities would be more beneficial to individuals if they were tailored to individual needs and wishes (Clements-Cortés et al., 2021). Adopting an embodied and contextualised perspective on the implications of cognitive function loss, with its impacts to selfhood and agency, may help improve our understanding of the affordances of musical engagement and the processes that contribute to music therapy's observed positive outcomes. Moreover, a greater exploration of the interaction complexities and opportunities presented in both receptive and active musical engagements (as well as in activities where these distinctions are blurred) could provide the benefit of increased tailoring to individual wishes and needs.

When individuals living with dementia are unaware that social groups can afford them forms of engagement that they can still prosper from, they tend to withdraw from these activities such as choirs or other musical groups following diagnosis (Clark et al., 2018; Harris & Caporella, 2014). It has been suggested that this occurs both due to changes in cognitive ability and the stigma associated with a diagnosis that can undermine a person's sense of worth, agency, and self (Clarke & Wolverson, 2016; Mitchell et al., 2013). According to Huber et al. (2011), the ability to fulfil one's obligations, the ability to maintain some degree of independence, and the ability to participate in social activities are critical to retaining agency and a strong sense of self. Social groups with appropriate challenge levels can still provide opportunities for people living with dementia by encouraging them to maintain a dynamic balance between their abilities and limitations (Huber et al., 2011). Therefore, a shift in focus towards the capacities and potentials of people living with dementia without underplaying their limitations is urgently required to help us learn which aspects of activities may provide the greatest benefit and what environmental stressors are most taxing (Dröes et al., 2016; Vernooij-Dassen & Jeon, 2016).

Solutions are therefore needed to overcome barriers of access and increase the rewards enjoyed, and we present a case for using music technologies to achieve this goal. For example, in group music-making activities, people living with dementia often lose their ability to read and follow music notation, which can lead them to become lost or feel excluded. Generally, there seem to be two solutions to this. First, people with dementia have a person and/or technology that supports them in overcoming these barriers. The second is for them to become involved in a more participatory style of music-making (Turino, 2008), which is more open and allows easy access to music-making and listening. Some participatory activities can be overly simplistic, and so there is also a role for technology to better allow people to feel like they are significantly contributing to the musical whole. This equity of skill and challenge is an important but often overlooked aspect in affording rewarding musical engagement in dementia care (MacRitchie, Breaden, Taylor, & Milne, 2022). There is an opportunity for technology to facilitate more equitable group musical interactions that can better allow people with different experiences and abilities to succeed together (see for example, group music-making in Taylor, Milne, & Macritchie, 2023; Favilla & Pedell, 2013; music-making in pairs in Houben et al., 2020). As much as the success of these technologies depends on the level of support and expertise required to operate them (Nicol, Loehr, Christensen, Lang, & Peacock, 2024), the perception of materials, sensors and controls can also guide how a device will be used (Pigrem, MacRitchie, & McPherson, 2023).

In short, the aim of this paper is to theoretically investigate the implications and opportunities offered by the adoption of an embodied and relational perspective for the design of musical interventions and the development of music technology to support dementia-friendly group musical engagement. Central to this investigation is the hypothesis that an embodied and relational approach better suits not only an individual's continuation of skills, but also the needs and wishes of people

with dementia and their carers in supporting a sense of agency, self-hood and couplehood. The paper first discusses embodiment (Section 0), followed by relationality (Section 0), before considering implications for the design of musical interventions supported by technology (Section 0).

#### Embodied perspectives on dementia and music

Embodied theories propose that cognition emerges from processes distributed across the brain, body, and environment, emphasising the important role of the active, situated, living body (Gallagher, 2017; van der Schyff et al., 2022). To think of selfhood in an embodied way, Thompson (2017) proposes that we consider selfhood as a continually constructive process of "I-ing" that arises from and is dependent on several different "I-making" processes. This process then enacts an "I" that is identical to the I-ing process itself (Thompson, 2017). Both Zahavi (2017) and Kontos (2004, 2005) have proposed that selfhood and agency can be enacted as a sense of "perspectival ownership" or for-meness of experiences, with us engaging with things not only as they are in themselves but also in the actions that they afford us. For instance, as people advance further along their dementia journey, meaning-making and I-making often become more deeply rooted in their past actions and interactions with others, and are increasingly played out through actions as well (Isene et al., 2022). This is because dementia can reduce people's ability to engage with the world through the use of narrative and linguistic resources, requiring an increased reliance on intuitive, embodied ways of engaging (Hydén, 2018a; Summa & Fuchs, 2015). With these changes, the world can appear new and unfamiliar, as many of the ways they have habitually come to rely on for making sense of the world are no longer reliable. To continue to make sense of their changing environment, they need to recalibrate what is both important to them and available with their current abilities so that they can adapt to or establish new behavioural routines, all while being confronted with a world that they can no longer trust as an impartial point of reference (Folkmarson Käll, 2017). For trust and a sense of agency to be possible, it is important that the environment is responsive in appropriate ways and available for interaction for people living with dementia. Whilst a retreat into past life events may offer feelings of safety, the continuation of an acting self is also within reach. An embodied approach to providing music in a dementia context highlights the challenges that people living with dementia face when interacting with an environment that is subjectively changing, whilst also emphasising opportunities to support agency and trust if an accessible environment is offered.

To take a more positive outlook on dementia, we need to build on the strengths that people still have. For instance, researchers have found that the embodied processes involved in gestural communication and creative activities are more resistant to neurodegeneration, suggesting that people with dementia can still stay connected to social and personal meanings through movement and actions (Bomilcar et al., 2021). Persistence in creativity has been found in people who continue to draw (Utermohlen et al., 2015; van Buren et al., 2013), continue to actively engage with music by playing a musical instrument or singing (Baird et al., 2017; Cowles et al., 2003; Kontos & Grigorovich, 2018), continue to receive enjoyment from attending museums (Camic et al., 2019), and continue to dance even into the later stages of dementia (Dupuis et al., 2012; Kontos et al., 2021). According to Philpott and Kane (2016), the creative process of making persists because sensation, memory, and perception become entangled in this process, relying more on an embodied way of sensing and thinking. Positive continuations of associations with the environment can also be observed in the use of familiar music to help people living with dementia more easily adjust to a setting by providing a sense of familiarity (Son et al., 2002) whilst reducing agitation and anxiety more generally (Brancatisano & Thompson, 2020; Ridder et al., 2013). Building on existing strengths may mean developing everyday habits that accumulate on top of one another to form individualised ways of engaging with the world, expressing a self that persists in the body and in its movements (Hydén, 2018a).

Leman (2013) proposed that musical interactions are put into practice through actions and gestures with an active, individualised body and are embedded and enacted within a relational environment. Research has shown that our motor system influences how we perceive and experience music, suggesting that music is processed in ways relevant to our ability to act (Timmers et al., 2020; Dell'Anna et al., 2021; Maes et al., 2014). This motor repertoire of musical actions is not only related to performing a musical instrument that we may have played before, but includes everyday musical actions (Schiavio et al., 2017) and simple musical roles, such as synchronising, taking turns, starting and stopping, and moving upwards or downwards in pitch. Such actions can be part of defining a sense of self and relating to others in the way defined above as 'I-ing' (Thompson, 2017). Furthermore, according to DeNora (2016), music affords a means of meaning-making because it enacts an aesthetic context in which cultural and individual identities can be formed and dismantled. Continuing to engage with music as dementia progresses can therefore mean continuing to act as a musical agent. This includes active uses of music in everyday life, such as liking and disliking music, becoming familiar with new music and songs that have sufficient points of entry for active engagement, using music to support social interaction, physical activity, celebration or loss, etcetera. In these ways, motor repertoires of musical actions developed over a lifetime, supported or newly developed can offer people living with dementia opportunities to actively connect with others, their own self, and their environment. Emotional responses to music and emotion regulation are widely acknowledged as central motivations to engage with music (Saarikallio, 2011). An embodied (4E) definition of emotions presents them as patterns of adaptive sense-making behaviour related to shifts in the relations between brain, body, and environment, giving salience to elements of experience through emotional motivation (van der Schyff et al., 2022). Up to 90 % of people living with dementia will develop behavioural and psychological symptoms of dementia (BPSD), which are often correlated with distress in people living with dementia and family carers and can potentially lead to long-term hospitalisation (Cerejeira et al., 2012). Music has been reported to significantly reduce the BPSD symptoms of depression, apathy, anxiety, and irritability, although there is a high degree of heterogeneity even among findings across review papers (Abraha et al., 2017; Letrondo et al., 2023; van der Steen et al., 2018; Zhang et al., 2017). A better insight into the underpinning processes is required to understand the role of music in emotion regulation for people with dementia. Receptive interventions have been primarily focused on connecting people with music from their past in a calm environment to induce relaxation, whereas active interventions emphasise interpersonal relationships and opportunities to move along with the music and each other (Leggieri et al., 2019). When successful, active music programs may offer individualised motivations for engagement, such as a sense of accomplishment from taking part, feeling connected, having a sense of self affirmed, and feeling immersed in the moment (Dowlen et al., 2018). The differing emotional benefits of these activities may partly depend on how well they align with individual motivations for engagement (Dowlen et al., 2018). This suggests that the emotional benefits generated by music engagement do not only depend on the type of activity, but in considering the participants as active agents in this process and how they relate to the activity.

Music is considered a powerful resource to stimulate autobiographical memories in people living with Alzheimer's (El Haj et al., 2015; Kaiser & Berntsen, 2022), but may require repeated listenings to allow people with fronto-temporal dementia a similar effect (Baird et al., 2020). Music's effectiveness in evoking autobiographical memories (MEAMs) in people with Alzheimer's is suggested to be due to its involuntary nature, demanding less use of executive processes to activate the memories from associated modal-specific areas of the brain (Barsalou et al., 2003; El Haj et al., 2012). MEAMS are also found to evoke more positive memories than other means of memory evocation (Cuddy et al., 2017; Jakubowski & Ghosh, 2021), often including social themes like family, friends, and significant others (Jakubowski & Ghosh,

2021; Janata et al., 2007). Familiar music also shows an enhancement in social and communication functions in people with Alzheimer's (Cuddy et al., 2015; El Haj et al., 2013). It has been proposed that autobiographical memories and the sense of self have a reciprocal relationship, with autobiographical memories serving as a way of anchoring an individual's sense of self while their selfhood influences both the content and the organisation of their autobiographical memories (Conway & Pleydell-Pearce, 2000). DeNora (2016) has similarly suggested that engaging with music is a safe way to try out values, beliefs, viewpoints, ways of being, and ways of relating to others. In this way, music can act as a point of reference for people living with dementia to establish themselves and support new or evoke old ways of connecting. Music's ability to reawaken past experiences provides people access not only to earlier memories but also to prior ways of being and engaging with the world, offering a resource that is larger than the evoked memory and entails modes of agentic behaviour.

This section has illustrated a number of ways in which music affords people living with dementia the opportunity to actively engage with their environment, which has implications not only for them as individuals but also for their interpersonal connections. For example, MEAMs retain their vividness for people living with dementia. Nevertheless, dementia can have an effect on how people tell stories about these MEAMs, which can impact the story itself as well as their sense of selfhood associated with it (Hydén, 2018a). For example, people living with dementia may increasingly use repetition, rely more on gestures, and find it challenging to connect all the elements of a story together (Hydén, 2013). Because they may regularly face disappointments of 'disencountering' others, people living with dementia place importance on being seen as capable (Hydén, 2018b). Stories may increasingly become co-constructed, with a spouse or family member often scaffolding the story. With some notable exceptions (Clark et al., 2018; Clark et al., 2020; Gardner, 1999; Lee et al., 2020; Macgregor, 2016; McMahon et al., 2022), music therapy and musical activities are often particularly targeted to the person with dementia on their own, with limited consideration for the role of carers and the broader ecosystem in which the musical activity takes place. In the following section, we will consider the role of relationality and how musical activities for people living with dementia can benefit from considering them as part of an ecosystem rather than on their own.

# Relational perspectives on dementia

The relationships that people living with dementia have with others, as well as the opportunities they have for interaction, play a critical role in maintaining or undermining their sense of self (Kitwood & Brooker, 2019). Despite this, selfhood and agency are mostly defined in terms of autonomy rather than solidarity or community. As such, a majority of the research done on people living with dementia examines their behaviour and performance on individual tasks (Hydén & Forsblad, 2018). However, this does not line up with what people living with dementia and carers want. Reilly et al. (2020) found that relationships, communication, and meaningful activities were the most often selected core values by people living with dementia. This may be because dementia frequently challenges relationship quality. Nevertheless, not all couples with dementia face the same level of difficulty in their relationship, and there are certain factors that impact relationship quality (Conway et al., 2018). Carers who are able to integrate care into their current roles and identities can sometimes enjoy greater relational closeness with their partner than before diagnosis (Ablitt et al., 2009), whereas those whose identity rests exclusively upon their care role frequently face relationship degradation (Boylstein & Hayes, 2012; Davies, 2011). When entirely focused on caregiving, carers feel they have little chance to focus on their own identity, and this contributes to feelings of depression (Litwin et al., 2014). The agency of a person living with dementia also suffers in these cases from the increased dependency on their carer (Davies, 2011). Furthermore, enforced togetherness can make people feel trapped in the relationship, another challenge that requires consideration (Wadham et al., 2016). This section focuses on dyadic relationships in couples with dementia, examining how selfhood and wellbeing of both members of a couple might be supported by them feeling part of a reciprocal relationship. Namely, we will discuss the potential roles of a we-perspective, experiencing self in terms of 'we', and joint agency, agency experienced on the level of the couple. Along with these concepts, we will discuss how some musical attributes make musical activities very well positioned to support couplehood.

Relationship continuity is a crucial factor in supporting selfhood in people living with dementia (Smebye & Kirkevold, 2013), increasing their ability to experience meaning and satisfaction in their lives (Dewitte et al., 2021). Furthermore, while there is an important emphasis placed on easing carer burden, the benefits that carers obtain from maintaining their relationship with their partner with dementia should not be overlooked (Peacock et al., 2010). Marino et al. (2017) suggest that carer benefits are undervalued because hedonic rewards (immediate pleasure) are frequently prioritised over eudaimonic rewards (personal growth). Assuming the burden placed on the carer is manageable and an appropriate support structure is in place, caregiving can stimulate personal growth, with it sustaining feelings of perceived self-mastery and increasing feelings of self-acceptance (Marino et al., 2017). Feelings of couplehood also increase a sense of accomplishment from providing care, and carers who more often view their relationship in terms of 'we' find caring to be less demanding and less stressful (Badr et al., 2007; Daley et al., 2017). Relationship continuity can reduce feelings of burden, entrapment, and isolation in carers (Riley et al., 2018), suggesting that developing ways to maintain relationship continuity benefits both the person living with dementia and their carer.

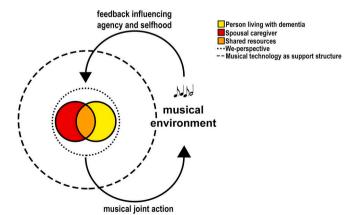
# We-perspective

Many couples experience feelings of togetherness, companionship, and reciprocity as part of being challenged together and working together as a team to meet the challenges of dementia, and this helps to maintain wellbeing for both of them (Bielsten, 2020; Swall et al., 2020). A strong sense of couplehood can also sustain feelings of warmth, love, and closeness (Hellström et al., 2007; Wadham et al., 2016). It facilitates open communication between spouses when one has dementia (Hellström et al., 2007), and it makes it easier for them to forgive each other and work through problems together (Daley et al., 2017; Wadham et al., 2016). A number of couples with dementia (generally one spouse with dementia and one acting as carer) report a sense of being one with each other, experiencing their lives from a we-perspective to share their successes and challenges with each other. Couples can also indicate that their couplehood is a core aspect of their selfhood, experiencing their sense of self as a 'we', which is connected to improvements in resilience and quality of life (Ablitt et al., 2009; Conway et al., 2018; Hellström et al., 2005; Hellström & Torres, 2021; Stedje et al., 2023; Vikström et al., 2008). Wadham et al. (2016) suggest that a shared 'we' identity is important in helping couples maintain a sense of togetherness after dementia diagnosis. We propose that identifying approaches to support couples with dementia in working together as a team against the challenges of dementia can improve a sense of self experienced at both an individual and couple level (i.e., selfhood and couplehood). For this, we briefly discuss how music might support a we-perspective and the intricacies that a couple's shared history brings to this, suggesting the importance of adapting to each couple's needs and motivations in order to help them flourish.

Adopting a we-perspective can encourage participation among people living with dementia through its emphasis on group responsibility over individual responsibility, reducing the potential for the person living with dementia to lose face (Nilsson, 2018). Many musical activities already support a sense of we-perspective or group responsibility over the music as a whole, rather than considering the individual parts for soloistic affordances, as a way to encourage participation (Turino,

2008, p. 33). This shared responsibility in music-making can give a sense of being immersed in the group, with one's actions blending with those of others to form a meaningful whole (Loehr, 2022). McMahon et al. (2022) found that couples with dementia experienced shared musical activities both individually and collectively (as me and we). The shared enjoyment of music-making can foster active participation and a sense of togetherness, allowing couples to briefly forget their roles as carer and cared for and see each other as spouses again (Dowlen, 2019). From this, music can provide people living with dementia a sense of belonging and security, and when they contribute actively to the music-making process it fosters feelings of empathy and inclusion (Clark et al., 2020). All of this suggests a potential feedback loop in which musical engagement can be leveraged to encourage a we-perspective that can lead to an increased sense of participation, which then in turn can foster a sense of togetherness and couplehood. This feedback loop is explored again later and can be seen in Fig. 1 below.

A couple's shared history can play a role in sustaining a sense of couplehood by drawing on their years of experience engaging with each other's embodied practices, which scaffolds the mutually interpretive activity of interacting with each other (Hydén, 2011). At the same time, it can add to each spouse's challenges in adapting to their changing roles in the relationship as a result of the changing abilities of the person living with dementia. Returning to ideas from the previous section, people living with dementia may need to rely more on embodied habits and routines that have become sedimented over time. Furthermore, spouses negotiate and develop an intricate and complex web of relationships with one another over time, which becomes emotionally charged as a result of their loyalty to one another (Hydén & Nilsson, 2015). Because of these sedimented relationships and behavioural patterns, the ongoing process of re-evaluating and re-positioning habits and routines is hard work. To make the adaptation process to new roles easier, it is crucial to find ways to encourage and support couples to gradually develop new interaction strategies to fit their changing needs and abilities. As music offers a safe way to try out ways of being and relating to others, group musical activities afford opportunities to play around with interaction strategies while enjoying time with one another. Group music-making also allows people living with dementia a way to interact with others through musical and non-verbal forms of communication, giving the caregiving spouse a new perspective on the communicative abilities of their partner with dementia, and providing alternative ways for them to interact with each other (Macgregor, 2016; Schafer et al., 2022). Many of the scaffolds that couples have developed over years of engaging with one another will likely need to be altered rather than replaced (Hydén & Nilsson, 2015), and music may provide an opportunity to try out more embodied ways of interacting, increasing



**Fig. 1.** Couples with dementia engaging with music, having shared resources as part of their we-perspective, collaborating through making a joint action on the music. These joint actions, supported by technology, can promote selfhood and couplehood.

trust in their mutual communication and connection with one another (McMahon et al., 2022).

For musical activities to provide meaningful support to couples, they should take into consideration the complex and shifting relationship dynamics of couples with particular relational strengths and weaknesses. A special instance of relational dynamics is evident in joint action and the experience of joint agency, which occurs when people collaborate and coordinate closely with each other to accomplish a shared goal.

Joint agency

While the we-perspective of couplehood is frequently studied in couples with dementia, and maintaining agency for a person with dementia is a major concern, joint agency, or agency on the level of the couple, is far less discussed for this cohort. This is unexpected, considering that several studies suggest that people living with dementia do much better at everyday tasks when they collaborate with others, and these joint actions allow them a way to maintain an active role in their daily lives (Hyden, 2014; Vikström et al., 2008). In joint actions, a sense of joint agency can arise from the blurring of the connection between the consequences of an action and the action itself, because the action is cocreated by the mutual coordination of one's actions with others rather than being produced exclusively by one's own or another's actions (van der Wel et al., 2012). For instance, because joint actions are made up of individual contributions (e.g., playing your own musical part) that have to be coordinated to achieve a collective goal (e.g., playing a musical duet), people participating in a joint action can feel agency not only at the individual level ("I played my part"), but also at the group level ("We played the duet together") (Loehr, 2022). This feeling of agency over the music as a whole is typically linked to feelings of togetherness and could play a role in helping to maintain relationship continuity.

People living with dementia regularly take part in many types of joint actions. These joint actions are often seen in couples with dementia in everyday activities that would be commonly undertaken by one person but are now being done as a shared task (Roth & Reichertz, 2020). Examples of this are joint eating and joint managing of personal hygiene (Hydén et al., 2022; Roth & Reichertz, 2020). Joint actions also give opportunities for people living with dementia to take part in quite complex activities, often by making use of the linguistic and/or cognitive resources of their partner, such as in cooking together or making music together (Hyden, 2014; Majlesi & Ekström, 2016; McMahon et al., 2022). Though maybe not immediately apparent, these are precisely coordinated actions not simply achieved by one person following the instructions of another, but rather involve a back and forth of anticipating and adjusting to each other's actions (Roth & Reichertz, 2020). Examining these actions from a joint action perspective provides us with tools to recognise that, while there are asymmetries present in these actions and the sharing is not always experienced as positive, they are not actions done by an active carer to aid a passive partner living with dementia. We briefly discuss reciprocal scaffolding, how music may afford balanced reciprocity critical for people living with dementia, and how people can form meaningful connections with others through music by employing their own habituated ways of acting.

Reciprocal scaffolding is a key feature that is highlighted when examining situations through a joint action perspective. The spouse who does not have dementia may need to contribute more to the joint action by taking on greater responsibility for overall planning, being responsive in doing ongoing repair work, and keeping track of what has already been completed (Hyden, 2014). Roth and Reichertz (2020) presented a husband being assisted to shave, with him making head movements to guide his wife on what to do next or to help achieve the proper amount of skin tension with the shaver. In this case, she made many of the larger actions and planning decisions for reaching the goal of shaving his face, but his small guiding actions were still important to the process and gave him agency in this action. In this way, he provided a scaffold for his

wife's actions while she scaffolded his ability to be shaved, creating a reciprocal scaffolding process that is key in joint actions (Roth & Reichertz, 2020). Caregiving is frequently regarded as something done for a person living with dementia, but it needs to more often be thought of as something done with them, facilitated by their collaborative acts (Majlesi & Ekström, 2016). This is because while scaffolding actions can enable, taking over actions can disempower, leading to loss of autonomy and increasing dementia disease progression (Clarke & Wolverson, 2016). As part of this, it can be useful to consider joint actions on the group level and to break the assumption that capabilities are the property of a single individual. Roth and Reichertz (2020) argued that the couple jointly shaving was a single unit, a "we", possibly displaying the strongest form of joint agency, 'we-agency' or united agency, which occurs when people perceive themselves to be acting as a single unit (Loehr, 2022). From this, we propose that the attunement and responsiveness involved in we-agency or the we-perspective could be useful in asymmetrical joint actions, allowing the actions of the person living with dementia to be actively considered, regardless of how small they are within the asymmetry of these actions.

For couples with dementia, maintaining equal degrees of reciprocity is challenging due to differences in abilities, even if people living with dementia consider reciprocity to be an important aspect of their relationships (Davies, 2011). Balanced reciprocity is a significant contributor to feelings of agency in joint actions in the general public (Le Bars et al., 2020), and musical activities that give people living with dementia opportunities for balanced reciprocity show them flourishing (Dowlen, 2019). McMahon et al. (2022) proposed that musicking can be a leveller that supports the strengths and abilities of people living with dementia to the point where it is difficult to determine at that moment who has Alzheimer's and who does not. For these reasons, aiming to set up musical interactions in a way that enables everyone to feel they are contributing equally could be crucial in helping to support the feelings of agency and selfhood of a person living with dementia.

Music's capacity to allow people living with dementia to interact on a level playing field may be related to the fact that musicking occurs primarily through habituated ways of acting together without needing to explicitly discuss the goal or strategy (Keller et al., 2014; Zeiler, 2014). At the same time, music can be set up so that people can engage with it in a highly communicative manner that does not rely on words, allowing couples to connect with each other through the music and enhancing their communication after musicking together (Baird & Thompson, 2018b; Elliott et al., 2020; Elliott & Gardner, 2018; Unadkat et al., 2017). People living with dementia can often move to the beat of the music, expressing their enjoyment and their musical preferences through these movements, also using movements to engage with embodied memories from past experiences of the music (Dowlen, 2019). People living with dementia synchronising both to the musical beat and with others can gain opportunities for meaningful connections with others, as moving in synchrony with others has been shown to increase a sense of joint agency and togetherness (Fu et al., 2021; Loehr, 2022). Music also contains open-ended structures that can scaffold creativity and playfulness, while enabling a sense of agency through the ability to modify its structures s (Motta-Ochoa et al., 2022). This openness sets up a space where co-creativity can occur—a sharing of cognitive, creative, and linguistic resources to nurture inclusion and participation that generates feelings of joint agency and the reinforcement of a self as grounded and belonging (Zeilig et al., 2018). When considered, these properties of music can give it rich if not unique abilities to support continued couplehood in the context of dementia.

Considering joint agency and the we-perspective can help us to understand how the cognitive, linguistic, social, and material resources may need to be prepared and shared among the collaborators involved in the activity in order for it to be performed in a way that is tailored to the person living with dementia and their carer's capabilities. This can then allow the collaboration to be structured in such a way that it compensates for the abilities lost by the person with dementia and gives

them opportunities to further develop their strengths. Focusing on the group level should also provide a clearer understanding of where support structures could be used to benefit the couple as a whole, allowing either the person with dementia or their spouse, or both, to use technology to support their interactions. Invisible planning work, work that sets up the activity in a way that allows the person with dementia to shine, requires extra time and energy that a carer typically does not have, suggesting that technology could also be used as a support structure in these invisible tasks to facilitate the best interaction possible. A reorganisation of the contributions and the use of support structures have been found to not only raise the chances of achieving a joint action, but it also offers the person with dementia more opportunities for agency and to support their sense of self (Hyden, 2014). As reciprocal relationships, communication and meaningful activities are regarded as core values for people living with dementia, considering technology as a means of enhancing these values will be extremely beneficial. In the final section, we examine how the insights so far play out in the context of group musical activities, focusing on how we can improve musical interactions by employing embodied and relational approaches to support joint agency, selfhood and couplehood.

#### Music, technology, selfhood and dementia

As we have discussed, dementia can negatively impact experiences of selfhood and identity due to changes in memory, linguistic resources and planning abilities, affecting the ability to interact with others and the environment. This can also have further consequences, affecting relationships, quality of life, and mental wellbeing. We have emphasised supporting a sense of self through an increased reliance on embodied and shared relational resources (rather than linguistic resources most commonly relied upon). Despite the many changes and adjustments that occur as a result of a dementia diagnosis, focusing on continued strengths will help to develop a more positive perspective that supports positive experiences of selfhood and will aid in sustaining meaningful relationships with others. It is in this context that we see musical participation to be at its most powerful.

Engagement with music takes many forms and is most often classified as receptive (typically listening to music alone or with others) or active (when the individual is engaged in some form of music-making), both of which can be supported by music technology (Agres et al., 2021; MacRitchie, Floridou, Christensen, Timmers, & de Witte, 2023). A weperspective can emerge in both receptive and active forms of engagement, examples being shared attention to the music, sharing of an emotional or enjoyable musical moment together, and joint participation in music. Joint action, on the other hand, is more likely to occur as a part of active engagement. In these cases we are not interested in technology attempting to replace social interaction, as is sometimes offered (Lazar et al., 2016). Instead, we see music technology as playing a supportive or enhancing role in exploring the possibilities of collaborative musical engagement and in levelling the playing field for both parties. We propose that technology can be developed to further encourage "active listening" specifically in dementia by allowing people to control aspects of their musical listening experience or environment, as well as by technologically enabling them to participate in partially automated musical performances. Active listening has been proposed as a way of allowing any listener (particularly non-musicians) to interactively modify the content of music in real-time (Camurri et al., 2007) and applications or devices exist: enabling control of orchestral sounds through mid-air gestures (Camurri et al., 2007), gamification of finding the "correct" sequencing of sections of pre-recorded music by moving across a floor projection (Mandanici et al., 2018), composing original music as a couple moving in space (Morreale et al., 2014), or encourage exploratory playing with sounds through a "hackable" physical interface (McPherson et al., 2016). Although a community of research exists around creating accessible digital music instruments (Frid, 2019), with the purpose of encouraging more inclusive music practice, very few

devices have been developed specifically for the dementia context (MacRitchie, Floridou, Christensen, Timmers, & de Witte, 2023; Creech, 2019) and these mainly relegate the role of the person living with dementia to the passive listener, or to a traditional form of music playing (e.g., on a light-up keyboard). Some exceptions to this are devices; that allow the control of a musical feature to be highlighted (e.g., musical speed and synchrony, Christensen et al., 2023; or musical balance and volume, Pigrem, MacRitchie, & McPherson, 2023; with other examples found in the scoping review by MacRitchie, Floridou, Christensen, Timmers, & de Witte, 2023). There is a range of opportunities for music to be tailored to specific individuals and their situated contexts, supporting the ability to share or be jointly engaged in the experience, which is further explored in the four musical scenario vignettes below. What the proposed scenarios have in common is depicted in Fig. 1 and relates to embodied opportunities for the person with dementia and their spousal carer to adopt a 'we-perspective' and for the joint engagement with music to afford feelings of agency and promote a sense of an embodied and relational self. Joint action, joint agency and selfhood are supported by technology in this model.

#### Scenario 1: sharing life history through music selection

Music is closely connected with selfhood and couplehood, particularly when couples with dementia listen to pieces of music that hold meaningful associations from their shared life history. Listening activities provide a platform for sharing both current experiences and past memories. Facilitated music selection in an appropriate and supportive context allows couples to take the time needed to relive special moments and memories together. Online technology may enable the remote involvement of participants and can allow couples to collaboratively generate new creative output through the act of sharing stories and music together (Lazar et al., 2014). Rather than focusing primarily on the person with dementia, musical selections are more likely to be related to shared histories of the couple that include their spouse and other key individuals (Harris et al., 2020). The current perspective article suggests a relevance for music technology to support actionable behaviours such as starting, stopping, skipping, selecting, sharing and saving, as well as a focus on the scaffolding of shared enjoyment with an aim to support agency, shared identity and couplehood.

# Scenario 2: enjoying music together

A facilitator, in collaboration with carers, presents either live or recorded music to a mixed group consisting of people with dementia, carers and/or family members. As barriers to communication increase, non-verbal communication—such as gentle touch, eye contact, music, and familiar voices-become crucial for providing comfort and maintaining connection (Clare et al., 2020). Individuals are encouraged to participate in whatever ways are accessible to them, whether by singing, humming, moving, swaying, dancing, clasping hands, or clapping (Morrissey et al., 2016; Rosseland & Culén, 2016). The opportunities to share enjoyment and engage in various forms of entrainment, such as mirroring the movement of the music and of others, may support a sense of belonging, active participation and engagement (Clark et al., 2020; Dowlen, 2019). Technology can play a supportive role by prompting actions, adjusting tempo, and facilitating the selection and playback of music. For instance, the CRDL device (Teunissen et al., 2017) translates physical touch into sound, adjusting the sound to reflect the intention behind the touch-such as ocean sounds for tickling and rainstorms for grabbing. This can stimulate physical connection and provide comfort when the escalating hurdles to communication make connecting increasingly challenging. This may help couples maintain their bond despite communication barriers, and enhance feelings of agency, particularly in the person living with dementia, by providing opportunities for their actions to be acknowledged and recognised. The joint participation and mutual enjoyment of the activity are important for

fostering a shared experience that contributes to relationship-building.

#### Scenario 3: creating music together

In this category, a wide range of activities can be developed and supported through the use of music technology (MacRitchie, Floridou, Christensen, Timmers, & de Witte, 2023). For people who have a background in performing music, adapting an instrument to their current abilities may provide them with an opportunity to reconnect with their past musical identity, especially if context is provided to make this an enjoyable experience. Creating music without a musical performance background can be supported as well, and may offer its own affordances if a meaningful context is provided. This approach can be an extension of scenario 2, fostering a greater sense of ownership and agency by offering individuals control over musical parts that can be combined together (Favilla & Pedell, 2014). It can also be an extension of active listening by allowing control over musical parameters, such as the foregrounding of different parts (e.g., in Pigrem, MacRitchie, & McPherson, 2023). These activities can take place as individual music-making in a group setting, or as group music-making in a more traditional sense, using instruments and materials that are accessible to the participants (Taylor, Milne, & Macritchie, 2023). These activities may be experienced as meaningful if they are shared with relevant others, incorporate elements of play and interaction, and use meaningful and enjoyable materials. If carefully considered, these types of activities can leverage music's openness to prepare a space where co-creativity can occur, offering people a safe way to explore their ways of being, acting and relating to others. This may offer a path for couples to strengthen their relationship's resilience in the face of changing roles and identities.

#### Scenario 4: duo performance

A special case of dyadic relationships may be developed as part of a technology-supported duo performance. Dementia can challenge one's ability to find harmony in communication and interaction with a loved one. Duo music performance may offer an outlet for expression, synchronisation and joint musical play if appropriately supported. The characteristics of this support through technology are one of the questions that we and our colleagues are addressing in our research on music technology for people with dementia (Taylor, Milne, & Macritchie, 2023; MacRitchie, Breaden, Taylor, & Milne, 2022). Reciprocal relationships and coordination are some of the key characteristics of duo performance (D'Amario et al., 2022; Loehr et al., 2013). Carefully designed technologies may enable the continuation of bidirectional adjustments where there is not a clear distinction between a leader and follower despite differences in ability and control. This approach has the potential to highlight in the users a sense of reciprocal scaffolding, as well as a balanced reciprocity that draws on habituated ways of acting, so that everyone can feel like they are contributing towards a larger musical goal.

#### Limitations and future directions

There is often a danger of a positivity bias in research on musical activities with people living with dementia or other groups, based on the assumption that music has very limited negative effects and, as such, can primarily work positively. Indeed, in the current perspective article, positive opportunities of technology and joint action were foregrounded over potential challenges and negative influences. However, positive outcomes are neither guaranteed nor always the case. Musical activities can be excluding as well as inclusive (Camlin, 2022; Dowlen & Fleetwood-Smith, 2023), memories evoked by music can be painful or confrontational as well as pleasurable, and engaging with music can be boring or unmeaningful as well as engaging. How musical activities are experienced is subjective and depends on the people involved. The tools offered in this perspective review are intended to facilitate reflection on

potentially negative and personalised effects as well as the positive affordances of offering music activities. This allows adjustments to be made and positive experiences and outcomes to be better achieved. These outcomes may or may not be in the realm of improvements in cognitive function, quality of life, or wellbeing. We have argued against an approach that emphasises countering loss due to dementia whilst arguing in favour of approaches that put a whole self at the centre, a self that is agentic, embodied and relational. With this in mind, musical activities can be enhanced in ways that support this relational, embodied and agentic self. In other words, a central question of this research should not be whether engagement with music improves cognitive functions, but how participation in musical activities can be designed and supported to offer a meaningful and inclusive experience for people with dementia to act in agentic and authentic manners in a positive relational and embodied manner with others. This way of acting and interacting builds on the known strengths of musical participation, and as such, facilitating participation and engagement with the musical task may be sufficient as a goal in itself.

#### Conclusion

Dementia can present many challenges for both the person with dementia and the people who interact with and care for them on a daily basis, particularly as the dementia progresses along with the contexts of potential comorbidities and its influences on mood and personality. Participation in musical activities is not a cure, but it frequently appears to offer a temporary, pleasurable and beneficial experience for those involved. As practices evolve to tailor such musical activities in ways that are supportive of the people involved and adaptable to musical tastes, such as their preferences for musical engagement, their needs and requirements, and the circumstances of activity delivery, it is important to consider where the core strengths of music may lie in relation to the needs and desires of the participants involved. Previous research has highlighted the importance of maintaining positive relationships, communication and engagement in meaningful activities for people living with dementia. It has further highlighted music's ability to support an increased continuity in the sense of agency experienced when their agentic actions are supported from a we-perspective and enabled through joint action and an experience of joint agency. Music-making and music listening are known to afford a sense of togetherness in music, increasing experiences of togetherness between people and offering them ample opportunities for shared perspectives, joint actions and synchronised responses. Nevertheless, few of the currently developed musical technologies for people living with dementia seem to be oriented towards enabling joint actions or promoting a sense of joint agency (MacRitchie, Floridou, Christensen, Timmers, & de Witte, 2023). Duet-oriented music boxes have started to address this gap (Pigrem et al., 2024), but only offer one example of what is possible. The discussed scenarios indicate some of the various directions where this can be further developed. We have also argued that taking an embodied approach to music cognition and musical participation offers advantages when it comes to how musical activities can support people living with dementia and their carers. This approach showcases the ways in which musical participation is a form of embodied communication, where self and others relate in embodied, nonverbal ways. It shifts the emphasis away from verbal communication and mental or cognitive-oriented processes and towards embodied ways of interacting and being that show resilience in the context of dementia. Thus, it provides opportunities for positive relationality-communication, connection and joint participation in shared activities. Whilst this offers guidance for the design of musical activities and technologies to support them, it also offers insight into what the important goals of musical interventions may be. Memory recall, cognitive functioning, mood improvement and participation in conversation may be among these outcomes. However, closer to the heart of it are processes related to agency, whether as part of individual or joint action: embodied communication, shared

attention, shared enjoyment, and complementary or coordinated actions that can be done in enhanced ways through appropriate supportive technology. The power of music lies in its situated ability to enable embodied actions and interactions that may use lyrics but otherwise have a limited reliance on verbal communication. The core affordances remain related to music as composed or improvised sonic structure with rhythms, pitches and harmonies that can be jointly appreciated and enacted through movement, mimicry, emotion, feeling, and the assigning of cultural and individual meaning.

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# CRediT authorship contribution statement

**Justin Christensen:** Writing – review & editing, Writing – original draft, Visualization, Conceptualization. **Renee Timmers:** Writing – review & editing, Writing – original draft, Conceptualization. **Jennifer MacRitchie:** Writing – review & editing, Project administration, Funding acquisition.

#### Declaration of competing interest

We have no known competing interests to disclose.

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# Data availability

No data was used for the research described in the article.

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